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Diabetes Surveillance and Data Validity Among Children and Adolescents

by

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Abstract

Diabetes is a growing public health issue in Canada, and this concern is now extending to children and adolescents. Our goal was to conduct research projects aimed at pediatric diabetes surveillance in Alberta, Canada. To identify diabetes cases, we applied the National Diabetes Surveillance System (NDSS) case definition to retrospectively-collected, population-based datasets.

Our first objective was to assess the regional variation in diabetes incidence and prevalence across urban and rural areas between 1995-2007. After observing an unexpected decrease in diabetes incidence between 2002-2006, our second objective was to investigate a possible association with changes in physician remuneration through Alternate Relationship Plans (ARPs) that may have affected the number of diabetes cases identified from administrative data.

Our results indicated that there was no regional variation in diabetes incidence and prevalence over the period of study and that there was no association between ARPs and the observed decline in incident diabetes cases.

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List of Abbreviations

ADSS	Alberta Diabetes Surveillance System
AHCIP	Alberta Health Care Insurance Plan
AHW	Alberta Health and Wellness
ARP	Alternate Relationship Plan
CIHI	The Canadian Institute for Health Information
DCCT	Diabetes Control and Complications Trial
FFS	Fee-for-service
HRQOL	Health-related quality of life
ICD-9/10	International Classification of Disease and Health Related Problems, $9^{th}/10^{th}$ Revision
IDDM	Insulin-dependent diabetes mellitus
NDSS	National Diabetes Surveillance System

CHAPTER 1.0. INTRODUCTION

1.1. Background

1.1.1. Diabetes Among Children and Adolescents

Chronic diseases have become the leading causes of death in the world.[1] Among these, diabetes mellitus is a growing public health concern: estimates show that, soon, diabetes will affect almost one in twenty people worldwide.[2] In Canada, past estimates of direct costs of the burden of diabetes hospital costs alone have been $400 million per year.[3] The three most common forms of diabetes are: type 1, characterized by the destruction of the β-cells of the pancreas, limiting its production of insulin; type 2, characterized by an inability of the pancreas to produce enough insulin and/or insulin-resistance; and, Gestational, a transient condition affecting some women during pregnancy.[4,5]

In the adult population with diabetes, approximately 90-95% of cases are type 2 and 5-10% are type 1.[6] Among children, however, type 1 diabetes is the most common form of the disease and in those under the age of 10 is almost uniquely observed.[7] As a consequence, the majority of the existing literature addressing diabetes in children focuses on type 1. That said, rates of both type 1 and type 2 diabetes diagnoses among children are reportedly on the rise.[8-10] The exact cause of type 1 diabetes is unknown, but it is believed to result from a combination of genetic and environmental factors.[11] Development of type 2 diabetes has been associated with obesity and physical activity levels,[12] and it has been reported that type 2 diabetes accounts for 33% of new diagnoses among adolescents between the ages of 10 and 19.[13] Because these diseases have very different etiologies and approaches to prevention and treatment, it is essential for us to have accurate estimates of the prevalence of each disease to ensure its proper population health management.

1.1.2. Diabetes Surveillance in Canada

It is acknowledged that past estimates of diabetes prevalence in Canada have underestimated the true burden of the disease.[3] In 1999, the National Diabetes Surveillance System (NDSS) was piloted as part of the Canadian Diabetes Strategy to enhance diabetes surveillance through the use of administrative health data to improve our monitoring of the disease over previously-used sources, including: mortality data, self-reporting, and, hospital data.[14] The NDSS tracks the number of diabetes cases using a definition which identifies individuals with diabetes based on coding in physician claims and hospital discharge abstracts. The algorithm applied to this administrative data selects individuals having a hospitalization with a discharge diagnostic code of the International Classification of Disease and Health Related Problems, 10th revision (ICD-10) coded E10-E14 (or the corresponding ICD-9 code before 2001), or two physician claims within a two-year period with an ICD-9 code of 250 (diabetes mellitus).[15] Validation studies have shown this definition – "2 in 2 years" – to have a sensitivity between 74-86% and a specificity between 97-99%[16,17] and it is considered to be reasonably accurate measure.[18] The NDSS algorithm was validated for physician charts and hospital discharge abstracts using ICD-9 codes – ICD-10 was adopted for the NDSS definition in 2002 without formal evaluation.

Recently, Guttmann and colleagues validated several provisional algorithms for children and adolescents under the age of 19 years.[19] They found the "2 in 2 years" definition to have a high sensitivity (100%) and specificity (94.2%).[19]

Following national implementation of the NDSS, the Alberta Diabetes Surveillance System (ADSS) was established in 2006 in collaboration with Alberta Health and Wellness (AHW) and the Institute of Health Economics (IHE) with the aim of disseminating information about diabetes in the province.[15] To describe diabetes epidemiology in Alberta, the ADSS applies a modified version of the aforementioned NDSS algorithm to the health services claims records maintained by AHW. The ADSS algorithm searches the 3 primary fields of a patient's records for the appropriate diagnostic codes, while the NDSS uses the primary diagnostic field. The NDSS also excludes probable cases of gestational diabetes based on pregnancy and obstetric procedure codes whereas the ADSS does not exclude gestational diabetes.[15]

1.1.3. Disease Classification

The importance of systematic disease classification has been recognized since the nineteenth century, with the first International List of Causes of Death being accepted by the International Statistics Institute in 1893.[20] In the mid-twentieth century, the World Health Organization (WHO) took responsibility for the sixth revision of this list, called the International Classification of Disease and Health Related Problems (ICD).[20] The current revision, ICD-10, was approved in 1990[20] and implemented in Alberta starting in 2001.[21] In this nomenclature, diabetes is coded by the values E10-E14, which represent diabetes mellitus type 1, type 2, malnutrition-related, other specified and unspecified respectively.[22]

The Canadian Institute for Health Information (CIHI) received permission from the WHO to enhance the ICD-10 coding for Canadian use. CIHI created the ICD-10-CA/CCI (Canadian Classification of Health Interventions) system, replacing the former ICD-9/ICD-9-CM and Canadian Classification of Diagnostic, Therapeutic, and Surgical Procedures (CCP). These enhancements provide a "national standard" which will improve translation of results between provinces and territories.[23]

Currently, ICD-10-CA is used for coding discharge or death from hospitals, with ICD-9 coding still used by outpatient physicians.[24] It is important to note that the more detailed ICD-10-CA/CCI has 23 chapters, while ICD-9/-CM had only 17.[25] Furthermore, the number of codes has risen from under 20,000 in ICD-9/CCP and ICD-9-CM to over 30,000 under 1CD-10-CA.[25] Therefore, while ICD-10-CA may remain comparable to ICD-10, it is unclear whether the new coding structure will affect disease surveillance when compared to ICD-9. In 2001/02, ICD-10-CA coding was introduced in Alberta, replacing the former ICD-9 system. While Anderson and Rosenberg[26] found that ICD-10 changed the ranking of leading causes of death in the United States compared to ICD-9, Quan et al. found that coding validity was generally similar between dually-coded charts in Alberta, Canada for ICD-9-CM and ICD-10-CA.[27]

1.1.4. Policy Changes Relating to Diabetes Surveillance

In Canada, our publicly-funded health care system provides a rich source of health information to researchers. This system has typically reimbursed physicians on a fee-for-service (FFS) basis. Under this model, physicians must submit billing claims for each patient seen in order to receive remuneration. These service claims contribute to our knowledge of disease prevalence and distribution in Canada by comprehensively accounting for each visit a Canadian makes with their health provider. This FFS data has been the basis for the development of the NDSS, and currently for its expansion to surveillance of other chronic conditions.

Recently, several jurisdictions across the country have implemented alternative approaches to payment known as Alternative Payment Plans (APP) or, in Alberta, Alternate Relationship Plans (ARP). These ARPs were signed between the provincial government and pediatric endocrinologists in the Alberta in late 2002. The introduction of APPs across Canada has changed the way that many physicians are reimbursed. While they are contractually required to continue submitting billing claims, a practice known as "shadow billing", physicians are often not remunerated for the time spent doing this. In Alberta, just 10% of physicians were receiving some form of alternate payments in 2005-2006.[28] This represents the lowest proportion in Canada.[28] If shadow billing is not occurring at physician-patient encounters at the same rate as under the FFS model, then it may lower the case ascertainment under the NDSS and ADSS definition.

1.1.5. Geographic Variation in Diabetes

Incidence rates for type 1 diabetes among children fluctuate greatly depending on global geographic location,[8] ranging from 0.1/100,000 per year in parts of China to almost 41/100,000 per year in Finland.[29] In Canada, rates of diabetes incidence have been reported for children between 20.6-24.5/100,000 per year and represent some of the highest rates in the world.[29]

Previous within-country studies have examined whether place of residence is associated with the risk of developing diabetes among children, specifically between areas of high and low population density. Again, the focus has been on type 1 diabetes. When comparing incidence rates of type 1 diabetes among children between localities, the research has been divided: some studies have observed higher rates in urban settings,[30] and others have found higher rates in rural/remote areas.[11,31] For example, in Finland, where the incidence of type 1 diabetes is among the highest reported in the world, it was found that children living in rural/remote areas were at a higher risk of developing the disease.[11] This finding was not in agreement with a study from Western Australia where children living in urban areas were considered to be at higher risk for type 1 diabetes than those in remote regions.[30] Few have explored this relationship in North America. In Wisconsin, Allen et al. found that urban incidence rates of type 1 diabetes were higher among males compared to their rural counterparts; however, this conclusion did not hold for females.[32]

1.2. Significance of Diabetes Surveillance in Children and Adolescents

Clinical Significance

Diabetes is estimated to affect over 24,000 children and adolescents in Canada[33], with over 2500 currently residing in Alberta.[34] Chronic complications of diabetes among children and adolescents are very similar to those seen when diabetes is diagnosed in adults, but they tend to manifest earlier in life, related to a longer duration of disease.[35,36] These complications, including nephropathy, retinopathy, and neuropathy[37], are associated with metabolic control.[35] In Canadian children and adolescents with type 2 diabetes, Amed et al. reported that 37% had one or more comorbidities at diagnosis, including hypertension, dyslipidemia, and obesity.[38] Although type 1 diabetes survival has improved appreciably[39,40], Narayan et al. have estimated that children and adolescents diagnosed with diabetes at age 10 will lose, on average, 19.0 years of life due to this disease and its comorbidities.[41]

Encouraging results from the Diabetes Control and Complications Trial (DCCT) demonstrated that intensive glucose control reduced the incidence of microvascular complications and macrovascular risk factors among patients with insulin-dependent diabetes mellitus (IDDM).[42] While type 2 diabetes accounts for a relatively small proportion of cases among children and adolescents, this form of the disease is largely preventable – relating to controllable lifestyle factors, such as obesity. For example, the Diabetes Prevention Program (DPP) trial demonstrated that intensive lifestyle changes could decrease the incidence of type 2 diabetes by 58% among adult patients at high risk of developing diabetes.[43]

It is not only functional aspects of a child or adolescent's life that suffer as a result of this disease, but also social and psychological – features contributing to the health-related quality of life (HRQOL). HRQOL is a representation of an individual's functional ability relating to their health state and their perception of well-being.[44] Children and adolescents living with diabetes face distinct challenges from their healthy peers relating to social, functional and psychological aspects of their lives and disease management, and HRQOL should be an important consideration in the management of the disease.[35]

These clinical areas are important to recognize, as they provide the opportunity to introduce health promotion and illness prevention activities. Accurate data relating to the burden of diabetes is essential for effective evidence-based decision making to manage this disease in the young population.

Policy Significance

In 1994, the National Forum on Health was established "…to advise the federal government on innovative ways to improve Canada's health system and the health of Canadians".[45] The members of the forum highlighted the need for the best available evidence in health-care decision making in clinical, administrative, and policy settings. The increasing focus on population health within our health care system was one of the drivers of this objective. In addition, the increasing availability and development of health information systems called "…for a much greater capacity to produce integrated and linked information at the individual patient level."[46]

The NDSS is an example of a nationally-coordinated effort to link available data systems for longitudinal disease surveillance.[3] Having the most up-to-date information allows groups responsible for public health to react to changing levels and patterns of a disease in an informed and timely manner. In addition, surveillance activities identify areas of need for services and research, as well as identifying areas of public health priority.[47]

In light of these clinical and administrative considerations, it is important that we track the trends of diabetes for children and adolescents to ensure that the necessary health and human resources are in place to support affected individuals in their disease care and management. While diabetes among children and adolescents may not represent the bulk of the disease's burden, the incidence of both type 1 and type 2 in this population is reportedly rising.[8-10] Diabetes among children and adolescents represents a serious health problem as children under the age of twenty who have been diagnosed with diabetes are more likely to have family physician and specialist visits than those without diabetes.[18] Not only is this a problem for the patients and their families, but these increased interactions with the health system result in the consumption of more health care services. The examination of novel data sources and the continual monitoring of data validity will provide policy makers and researchers with enhanced resources for population health management of this disease.

1.3. Objectives

The goals of this proposed research are to evaluate data validity and examine epidemiologic trends for diabetes in children and adolescents under the age of twenty. These individuals will be identified using the NDSS case definition relying on physician billing claims and hospital discharge summaries. For this population, we have two specific objectives:

1) To compare urban-rural differences in diabetes incidence and prevalence in cases identified in Alberta; and,
2) To investigate and attempt to explain recent trends observed in incident cases identified in Alberta.

1.4. Summary of Research Projects

In support of these objectives, two research projects were conducted relying on the retrospective analysis of population-based data collected by Alberta Health and Wellness (AHW). While the data were provided at the individual level, the data were de-identified before analyses were performed.

In the second chapter, we examined the effect of location of residence on the incidence and prevalence of diabetes. In the third chapter, we critically assessed our surveillance methods to test whether policy changes in Alberta may have affected the validity of the way that data is collected in this jurisdiction.

This research was approved by the University of Alberta Health Research Ethics Board, Panel B as part of the Alberta Diabetes Surveillance System (ADSS) research activities.

1.5. References

1. Integrated chronic disease prevention and control [webpage on the Internet]. © World Health Organization 2010 [updated 2009 May 19; cited 2010 May 27]. Available from: http://www.who.int/chp/about/integrated_cd/en/index.html

2. Wild S, Roglic G, Green A, Sicree R, King H. Global prevalence of diabetes: Estimates for the year 2000 and projections for 2030. *Diabetes Care,* 2004;27(5):1047-53

3. Health Canada. Responding to the challenge of diabetes in Canada: First Report of the National Diabetes Surveillance System (NDSS) 2003. Ottawa (ON): Health Canada, 2003. Cat. N° H39-4/21-2003E

4. Health Canada. Center for Chronic Disease Prevention and Control. Population and Public Health Branch. Diabetes in Canada. Ottawa (ON): Health Canada; 2002. Cat. N° H49-121/2002E

5. Millar WJ, Young TK. Tracking Diabetes: Prevalence, incidence and risk factors. *Health Reports*, 2003;14(3):35-47. Statistics Canada Cat. N° 82-003

6. Centers for Disease Control and Prevention. National diabetes fact sheet: general information and national estimates on diabetes in the United States, 2007. Atlanta (GA): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention; 2008

7. National Institutes of Health. National Institute of Diabetes and Digestive and Kidney Diseases. National Diabetes Education Program. Overview of Diabetes in Children and Adolescents: A Fact Sheet From the National Diabetes Education Program [document on the Internet]. Bethesda (MD): NIDDK [updated 2008 Nov 25; cited 2009 Mar 20]. Available from: http://www.ndep.nih.gov/diabetes/youth/youth_FS.htm#Type1

8. Karvonen M, Viik-Kajander M, Moltchanova E, Libman I, LaPorte R, Tuomilehto J, for the Diabetes Mondiale (DiaMond) Project Group. Incidence of Childhood Type 1 Diabetes Worldwide. *Diabetes Care*, 2000;23(10):1516-26

9. Rosenbloom AL, Joe JR, Young RS, Winter WE. Emerging Epidemic of Type 2 Diabetes in Youth. *Diabetes Care*, 1999;22(2):345-54

10. Pinhas-Hamiel O, Zeitler P. The Global Spread of Type 2 Diabetes Mellitus in Children and Adolescents. *J Pediatr*, 2005;146(5):693-700

11. Rytkönen M, Moltchanova E, Ranta J, Taskinen O, Tuomilehto J, Karvonen M. The incidence of type 1 diabetes among children in Finland—rural–urban difference. *Health Place*, 2003;9(4):315-25

12. Bennett PH, Knowler WC. Chapter 19: Definition, Diagnosis, and Classification of Diabetes Mellitus and Glucose Homeostatis. In: Kahn CR, Weir GC, et al., editors. Joslin's Diabetes Mellitus. 14th ed. Philadelphia (PA): Lippincott Williams & Willkins; 2005. p. 331-39

13. Pinhas-Hamiel O, Dolan LM, Daniels SR, Standiford D, Khoury PR, Zeitler P. Increased incidence of non-insulin-dependent diabetes mellitus among adolescents. *J Pediatr*, 1996;128(5)Part 1:608-15

14. Clottey C, Mo F, LeBrun B, Mickelson P, Niles J, Robbins G. The Development of the National Diabetes Surveillance System (NDSS) in Canada. *Chronic Dis Can*, 2001;22(2):67-9

15. Johnson JA, Vermeulen SU, Hugel G. Chapter 1: Background and Methods. In: Johnson JA, editor, *Alberta Diabetes Atlas* 2007. Edmonton (AB): Institute of Health Economics; 2007:1-10

16. Van Til L. Prince Edward Island – Diabetes Validation Project: Interim Report [report to the National Diabetes Surveillance System]. Charlottetown (PE): Document Publishing Centre; 2001

17. Hux JE, Ivis F, Flintoft V, Bica A. Diabetes in Ontario: Determination of prevalence and incidence using a validated administrative data algorithm. *Diabetes Care*, 2002;25(3):512-16

18. Public Health Agency of Canada. Diabetes in Canada: Highlights from the National Diabetes Surveillance System, 2004-2005. Ottawa (ON); 2008. Cat. N° HP32-2/2005 | 978-0-662-05378-1

19. Guttmann A, Nakhla M, Henderson M, To T, Daneman D, Cauch-Dudek K, et al. Validation of a health administrative data algorithm for assessing the epidemiology of diabetes in Canadian children. *Pediatr Diabetes*, 2010;11(2):122-8

20. World Health Organization (WHO). International Classification of Diseases (ICD) [webpage on the Internet]. © World Health Organization 2010 [updated 2010 Jan 18; cited 2010 May 27]. Available from: http://www.who.int/classifications/icd/en/

21. Canadian Institute for Health Information. ICD-10-CA / CCI Implementation Schedule [webpage on the Internet]. © 1996-2009, Canadian Institute for Health Information (CIHI) [updated 2006 Aug 28; cited 2009 Jun 4]. Available from: http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=codingclass_icd10status_e

22. World Health Organization. ICD Version 2007: Chapter IV - Endocrine, nutritional and metabolic diseases (E00-E90), Diabetes Mellitus (E10-E14) [webpage on the Internet]. © WHO/DIMDI 1994/2006 [updated 2006 Nov 12; cited 30 Apr 2009]. Available from: http://www.who.int/classifications/apps/icd/icd10online/ge10.htm

23. Canadian Institute for Health Information. ICD-9/CCP and ICD-9-CM [webpage on the Internet]. © 1996-2009, Canadian Institute for Health Information (CIHI) [updated 2009 Jun 15; cited 2009 Jun 3]. Available from: http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=codingclass_icd9cm_e

24. Public Health Agency of Canada. Injury Surveillance Online – Glossary [webpage on the Internet]. Public Health Agency of Canada. [updated 2005 Jun 10; cited 2009 Jun 1]. Available from: http://dsol-smed.phac-aspc.gc.ca/dsol-smed/is-sb/glossa-eng.php

25. Canadian Institute for Health Information. ICD-10 Coding Structure [webpage on the Internet] © 1996-2009, Canadian Institute for Health Information (CIHI) [updated 2008 Oct 17; cited 2009 Jun 4]. Available from: http://secure.cihi.ca/cihiweb/dispPage.jsp?cw_page=codingclass_icd10struct_e

26. Anderson RN, Rosenberg HM. Disease classification: measuring the effect of the Tenth Revision of the International Classification of Diseases on cause-of-death data in the United States. *Stat Med*, 2003;22(9):1551-70

27. Quan H, Li B, Saunders LD, Parsons GA, et al. Assessing validity of ICD-9-CM and ICD-10 administrative data in recording clinical conditions in a unique dually coded database. *Health Serv Res*, 2008;43(4):1424-41

28. Canadian Institute for Health Information (CIHI). Physicians in Canada: The Status of Alternative Payment Programs, 2005-2006. Ottawa (ON): CIHI; 2008

29. Bessaoud K, Boudraa G, Molinero de Ropolo M, de Sereday M, Marti ML, Moser M, et al. (The DIAMOND Project Group). Incidence and trends of childhood Type 1 diabetes worldwide 1990-1999. *Diabet Med*, 2006;23(8):857-66

30. Haynes A, Bulsara MK, Bower C, Codde JP, Jones TW, Davis EA. Independent effects of socioeconomic status and place of residence on the incidence of childhood type 1 diabetes in Western Australia. *Pediatr Diabetes*, 2006;7(2):94-100

31. Cardwell CR, Carson DJ, Patterson CC. Higher incidence of childhood-onset type 1 diabetes mellitus in remote areas: a UK regional small-area analysis. *Diabetologia*, 2006;49(9):2074-77

32. Allen C, Palta M, D'Alessio DJ. Incidence and differences in urban-rural seasonal variation of type 1 (insulin-dependent) diabetes in Wisconsin. *Diabetologia*, 1986;29(9):629-33

33. Public Health Agency of Canada, Chronic Disease Surveillance Division, Centre for Chronic Disease Prevention and Control. Report from the National Diabetes Surveillance System: Diabetes in Canada, 2008. Ottawa (ON): Public Health Agency of Canada; 2009. Cat. N° HP32-2/1-2008

34. Johnson JA, Vanderloo SE, Marks SD, Couch RM, Pacaud D. Diabetes in Children and Adolescents. In: Johnson JA, editor; *Alberta Diabetes Atlas* 2009. Edmonton: Institute of Health Economics; 2009: 33-42

35. Polak M, Czernichow P. Diabetes in childhood and adolescence. In: Pickup JC & Williams G, editors. Textbook of Diabetes 2. 3rd Edition. MA, USA: Blackwell Science Ltd; 2003. p. 66.1-66.25

36. Orchard TJ, Dorman JS, Maser RE, Becker DJ, Drash AL, Ellis D. Prevalence of complications in IDDM by sex and duration. Pittsburgh Epidemiology of Diabetes Complications Study II. *Diabetes*, 1990;39(9):1116-24.

37. Daneman D. Type 1 diabetes. *Lancet*, 2006;367(9513):847-58

38. Amed S, Dean HJ, Panagiotopoulos C, Sellers EA, Hadjiyannakis S, Laubscher TA, et al. Type 2 diabetes, medication-induced diabetes, and monogenic diabetes in Canadian children: a prospective national surveillance study. *Diabetes Care*, 2010;33(4):786-91

39. Nishimura R, LaPorte RE, Dorman JS, Tajima N, Becker D, Orchard TJ. Mortality trends in type 1 diabetes. The Allegheny County (Pennsylvania) Registry 1965-1999. *Diabetes Care*, 2001;24(5):823-7

40. Bi P, Parton KA, Donald K. Secular trends in mortality rates for diabetes in Australia, 1907-1998. *Diabetes Res Clin Pract*, 2005;70(3):270-7

41. Narayan KM, Boyle JP, Thompson TJ, Sorensen SW, Williamson DF. Lifetime risk for diabetes mellitus in the United States. *JAMA*, 2003;290(14):1884-90

42. The Diabetes Control and Complications Trial Research Group. The Effect of Intensive Treatment of Diabetes on the Development and Progression of Long-Term Complications in Insulin-Dependent Diabetes Mellitus. *N Engl J Med*, 1993;329(14):977-86

43. Knowler WC, Barrett-Connor E, Fowler SE, Hamman RF, Lachin JM, Walker EA, et al.; Diabetes Prevention Program Research Group. Reduction in the incidence of type 2 diabetes with lifestyle intervention or metformin. *N Engl J Med*, 2002;346(6):393-403

44. Hays RD, Anderson R, Revicki D. Psychometric considerations in evaluating health-related quality of life measures. *Quality Life Res* 1993;2(6):441-9.

45. Health Canada. Canada's Health Infrastructure – National Forum on Health. [webpage on the Internet] Health Canada [updated 2004 Oct 1; cited 2010 Aug 4]. Available from: http://www.hc-sc.gc.ca/hcs-sss/ehealth-esante/infostructure/nfoh_nfss-eng.php

46. Creating a Culture of Evidence-Based Decision Making. In: Canada Health Action: Building on the Legacy – Volume II: Synthesis Reports and Issue Papers. National Forum on Health, 1997. © Minister of Public Works and Government Services. Cat N° H21-126/5-2-1997E

47. Thacker SB. Historical Development. In: Teutsch SM & Churchill RE, editors. Principles and Practice of Public Health Surveillance. Second Edition. NY, USA: Oxford University Press, Inc.; 2000. p.1-16

CHAPTER 2.0. DIABETES TRENDS AMONG URBAN AND RURAL CHILDREN AND ADOLESCENTS IN ALBERTA, CANADA

2.1. Background

Among the pediatric population, type 1 diabetes is the most common form of the disease and, as a consequence, the majority of the existing literature addressing diabetes in children focuses on type 1. Global surveillance of diabetes in children and adolescents has indicated that the incidence of type 1 diabetes varies greatly depending on geographic location. Results of the World Health Organization's (WHO) DiaMond project highlight the range of global variation in the incidence of this disease: from 0.1 – 40.9 per 100,000/year in children aged 14 years and younger.[1] Reports from this study indicated that Canada has some of the highest incidence rates in the world of type 1 diabetes, at approximately 20.6 – 24.5 per 100,000/year.[1,2] More recently, incidence rates for diabetes amongst Canadian children and adolescents have been reported as approximately 40 out of 100,000/year.[3]

Several within-country studies have further investigated the regional variation of diabetes among children and adolescents. Some have shown an increased incidence of type 1 diabetes for those living in rural or remote areas,[4,5] while others have found that higher rates of incidence of diabetes were found in urban areas.[6,7] That said, studies from Sardinia and Colorado found no differences in the incidence of insulin-dependent diabetes mellitus across geographic locations.[8,9]

From these diverse results, it is apparent that further evidence is required to inform our knowledge of the geographic distribution of diabetes among children and adolescents, especially from a North American perspective. Thus, the objective of the present research is to compare urban and rural differences in diabetes incidence and prevalence among children and adolescents aged 1 to 19 years living in Alberta, a province in western Canada, for the period 1995-2007.

2.2. Research Design and Methods

Study Population

Employing a retrospective cohort design, we collected data on all children and adolescents between the ages of 1 and 19 years from the Alberta Health and Wellness (AHW) provincial administrative databases, which include: the Alberta Physician Claims Database, which contains information on fee-for-service (FFS) claims, information of healthcare recipients and providers, and services; the Alberta Discharge Abstract Database (DAD) of the Canadian Institute for Health Information (CIHI), which contains information on discharged inpatients, including diagnoses and procedures based on ICD-9-CM and ICD-10-CA/CCI coding; and the linked Alberta Health Care Insurance Plan Central Stakeholder Registry File (AHCIP), which summarizes demographic and geographic information.[10] Data were collected from January 1, 1995 to December 31, 2007, inclusively. Information on date of birth, gender, physician billing claims, hospitalizations, Aboriginal status, and subjects' postal codes were included in this data. For confidentiality reasons, only the first three characters of the study subjects' postal codes were provided. These three characters represent the

Forward Sortation Area (FSA), which corresponds to areas within large geographic zones, such as provinces.[11]

Study subjects with diabetes were identified according to the Canadian National Diabetes Surveillance System (NDSS) case definition: two physician claims with an ICD-9 code 250 (diabetes mellitus) over two years; or, one hospital discharge diagnostic code of ICD-10-CA, codes E10-E14 (type 1, type 2, malnutrition-related, other specified, and unspecified diabetes mellitus, respectively), or, the equivalent ICD-9 code for discharges before the years 2001/02 when ICD-10-CA codes were introduced in the province.[12] This case definition has been validated in the pediatric population.[13] We included all subjects who were between the ages of 1 to 19 years on the date they met the NDSS definition. As per the Alberta Diabetes Surveillance System (ADSS) methodology, we did not exclude possible cases of gestational diabetes mellitus.[12] Also, we only looked at the primary diagnosis field codes. This definition does not distinguish between type of diabetes because the ICD-9 coding used in physician billing claims and in hospital discharges prior to 2001/02 did not differentiate between certain forms of diabetes.[14]

Prevalent cases of diabetes were defined as the sum of the new cases in a calendar year and the existing cases, divided by the total population of children and adolescents between the ages of 1 to 19 years registered with the Alberta Health Care Insurance Plan (AHCIP). Incident cases were defined as the number of new cases, divided by the population at risk, that is, the total population minus the number of prevalent diabetes cases. To identify incident cases, we ensured that subjects did not meet the NDSS case definition for a minimum two-year period prior to identification.

Urban and rural locations of residence were determined by the Canadian Postal Code classification, as described by du Plessis et al.[11,15] If the second character of the postal code was “0”, we coded the location of residence as “rural”. Otherwise, we coded the location of residence as “urban”.

Statistical Analyses

Our primary outcomes of interest were rates for diabetes prevalence and incidence, as described by the NDSS case definition. To calculate the changes in prevalence and incidence over our period of study, we took the difference of the most recent and oldest values, divided by the oldest values, and multiplied by 100. Using Poisson regression analysis, we tested the interaction of calendar year and location of residence to assess the differences in prevalence and incidence between urban and rural areas over time. We controlled for the following covariates: location of residence (urban/rural), age (broken into four groups: 1-4, 5-9, 10-14, 15-19 years), year meeting the diabetes case definition, gender, and whether or not the subject was identified as Status Aboriginal. Our population denominator was all Albertans between the ages of 1 and 19 years who were registered with the AHCIP. For point estimates, we calculated the exact 95% Poisson rate confidence intervals.

Statistical analyses were performed using Stata™ Version 10.0 for Macintosh (StataCorp, College Station, TX, USA). Ethics approval for this research was obtained from the Health Research Ethics Board, Panel B, at the University of Alberta.

2.3. Results

Prevalence

In 2007, there were 2589 prevalent cases of diabetes identified among those aged 1 to 19 years in Alberta across urban (n=2067) and rural areas (n=522). In urban areas, the crude annual prevalence (95% confidence interval, per 100) of diabetes increased between 1995-2007 by 65%, from 0.183 (0.172-0.194) to 0.302 (0.289-0.315) (**Figure 2.1.**). Among cases identified in children and adolescents living in rural areas over the same time period, the crude annual prevalence increased from 0.198 (0.179-0.217) to 0.310 (0.284-0.338), or 57% (**Figure 2.1.**). When we compared the differences in these trends by testing the interaction of calendar year with location of residence by Poisson regression analysis, we found no significant difference between the prevalence of diabetes identified in urban areas and the rate among children and adolescents living in rural areas (p=0.947).

These increasing trends were consistent across all age groups. The highest crude prevalence was observed among the oldest age group (15-19 year olds) (**Table 2.1.**); however, the largest increase in prevalence was observed among the youngest age group (1-4 year olds), with an increase of 213% for those living in rural areas, and a 99% increase for those living in urban locations (**Table 2.1.**).

Incidence

Over the period of study, 3467 incident cases of diabetes among children and adolescents were identified across urban (n=2691) and rural (n=776) locations. Parallel to our observations of prevalence, we observed an overall increase in the annual incidence (per 1,000) of diabetes for children and adolescents living in both urban and rural areas. In urban areas, the annual incidence increased from 0.209 (0.173-0.251) to 0.477 (0.427-0.532) (128%) (**Figure 2.2.**). The annual incidence of diabetes among children and adolescents living in rural areas increased from 0.251 (0.190-0.328) to 0.571 (0.463-0.698), or by 127% (**Figure 2.2.**). Again, we observed no significant difference in the trend of increase in the incidence rate of diabetes among children and adolescents between those living in urban and rural areas of Alberta when comparing the two groups by Poisson regression analysis (p=0.149). Incidence, by age and location of residence, is presented in **Table 2.2.**

2.4. Discussion and Conclusions

In the surveillance of diabetes among children and adolescents living in Alberta, Canada, we found no apparent difference in the rates of prevalent and incident cases identified between urban and rural geographic areas. Distressingly, both the prevalence and incidence of diabetes increased for those aged 1-19 years between 1995-2007, independent of location of residence.

By age, the largest increases in prevalence were seen among children between the ages of 1-4 for both geographic areas. Increases in incidence and prevalence were observed across all age groups and locations. As diabetes in children under the age of 10 is almost exclusively type 1,[16] incident cases in this group may represent an important increase in the number of new diagnoses of type 1 diabetes in the province. This observation is consistent with reports of increasing incidence of type 1 diabetes in children.[17,18]

An important limitation to our study is that our case definition does not distinguish between type 1 and type 2 diabetes. While type 1 diabetes has traditionally represented the majority of cases among children and adolescents, increased reports of the diagnoses of type 2 diabetes in this age group have been emerging, parallel to increasing trends in childhood obesity.[19] Some studies from the United States suggest that the proportion of new cases that are diagnosed as type 2 could range from 8-46%[20] or even as high as 86% among certain minorities.[21] This may, in part, explain why our results differ from those in Northern Ireland, Finland, Western Australia and Italy,[4-7] which found differences in the distribution of incidence of type 1 diabetes only among children and adolescents between urban and rural areas.

In our observation of no differences in the trends between geographic locations, there may be potential for a surveillance bias between the children and adolescents living in rural areas compared to urban. Number and type of visits to health care professionals may vary between urban and rural areas.[22] Because our case definition relies on two visits to a general practitioner or one hospitalization within two years, persons living in urban areas may meet the definition more often if they have easier access to medical care than those in rural areas. This disparity may be especially true for youth living in remote areas of Alberta.

The reason for the plateau in the diabetes incidence rates from 2002 to 2006 and the spike in 2007 is not clear. The plateau appeared to be more evident for the adolescents (ages 10-19). During that time period, there were two health care policy changes that occurred within Alberta: the introduction of ICD-10 coding for hospital discharge abstracts and the introduction of alternative reimbursement plans for academic specialist physicians where fee-for-service (FFS) billing was replaced by salaried income. As our diabetes case definition is based on administrative records for hospital and FFS billing, these policy changes may have had an impact on the surveillance data.

Another limitation of this research is that the definition used to distinguish urban and rural participants varies from the existing literature; however, the previous studies have not maintained consistent urban and rural classifications. The definition applied was chosen for its simplicity and for the purpose of intra-provincial comparability with trends in the adult population.[23] One weakness to our definition is that the postal code at diagnosis may not be the same as the postal code of residence for the majority of the exposure time or development of the disease.

The strengths of this study are that our analyses rely upon a large population-based dataset that should accurately reflect the true population of Alberta, based on Albertans seeking health care in the province who must be registered with the AHCIP. Such population-based datasets provide helpful resources in the surveillance of chronic disease. Guttmann et al. in Ontario validated several potential case definitions for children and adolescents using administrative data in that province.[13] The authors found that the NDSS definition had a high sensitivity and specificity for those aged less than 19 years. Due to a lower specificity, it is possible that we have overestimated the true number of diabetes cases in the province; however, this error should be consistent across geographic areas and should not affect our analyses.

While these data indicate that the incidence and prevalence of diabetes among children and adolescents do not differ between urban and rural locations in Alberta, they do provide important information for policy- and decision-makers. Children and adolescents diagnosed with diabetes are more likely to visit their family physician or a specialist than those living without diabetes,[24] and the increased interaction with the health care system is not only a burden on patients and their families, but also results in the consumption of more health care resources. With the incidence of both type 1 and type 2 diabetes reportedly rising,[17,21] we can strive to improve how this disease is managed by accurate reporting of its trends and distribution by providing appropriately enhanced resources for population health management.

Figure 2.1. – Prevalence of diabetes cases identified by the NDSS definition for children and adolescents aged 1-19 years (1995-2007).

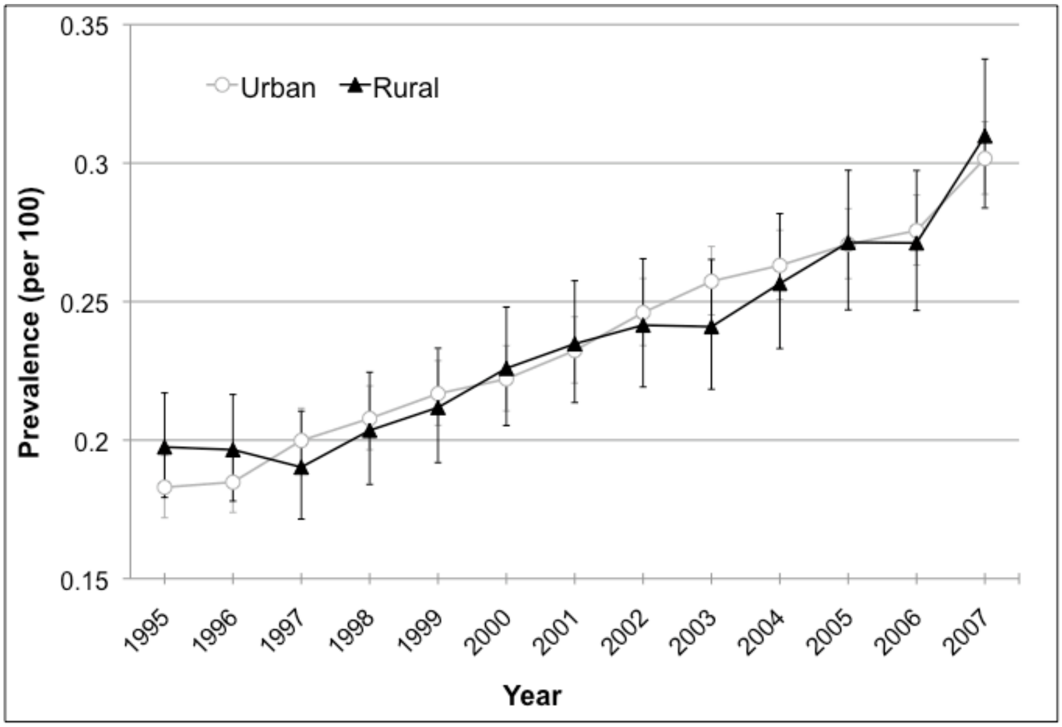

Figure 2.2. – Incidence of diabetes cases identified by the NDSS definition for children and adolescents aged 1-19 years (1995-2007).

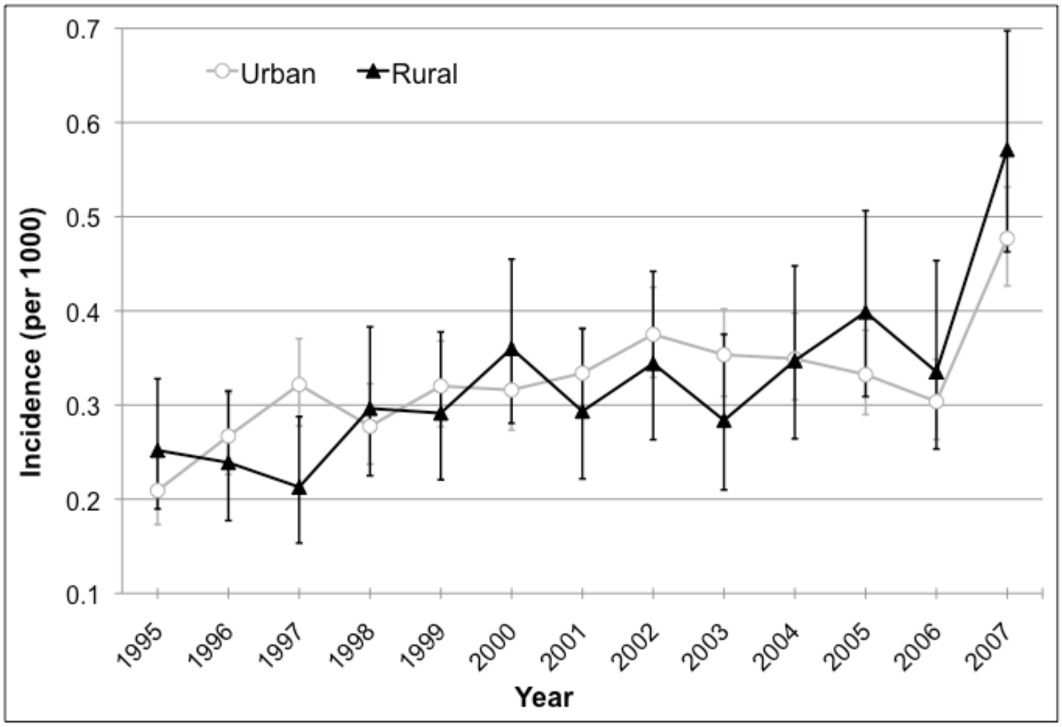

Table 2.1. – Prevalence per 100 (95% confidence interval) of diabetes cases identified by the NDSS definition for children and adolescents aged 1-19 years (1995-2007), by age and location of residence.

Year	1-4 Years	5-9 Years	10-14 Years	15-19 Years
1995				
U	0.040 (0.029 - 0.053)	0.112 (0.096 - 0.130)	0.244 (0.219 - 0.270)	0.322 (0.293 - 0.353)
R	0.041 (0.024 - 0.064)	0.145 (0.116 - 0.178)	0.210 (0.175 - 0.249)	0.372 (0.322 - 0.427)
1996				
U	0.047 (0.035 - 0.061)	0.116 (0.100 - 0.134)	0.251 (0.227 - 0.277)	0.304 (0.276 - 0.334)
R	0.036 (0.020 - 0.060)	0.126 (0.099 - 0.159)	0.235 (0.198 - 0.278)	0.356 (0.307 - 0.411)
1997				
U	0.055 (0.043 - 0.070)	0.135 (0.118 - 0.154)	0.251 (0.227 - 0.277)	0.331 (0.303 - 0.362)
R	0.039 (0.022 - 0.065)	0.121 (0.094 - 0.155)	0.242 (0.203 - 0.287)	0.321 (0.273 - 0.374)
1998				
U	0.046 (0.035 - 0.060)	0.133 (0.116 - 0.151)	0.262 (0.237 - 0.287)	0.355 (0.326 - 0.386)
R	0.027 (0.013 - 0.049)	0.117 (0.090 - 0.150)	0.262 (0.221 - 0.308)	0.361 (0.311 - 0.417)
1999				
U	0.049 (0.037 - 0.063)	0.146 (0.128 - 0.165)	0.254 (0.231 - 0.279)	0.375 (0.346 - 0.405)
R	0.043 (0.025 - 0.070)	0.130 (0.101 - 0.165)	0.260 (0.219 - 0.306)	0.364 (0.314 - 0.419)
2000				
U	0.058 (0.045 - 0.073)	0.142 (0.124 - 0.161)	0.269 (0.245 - 0.294)	0.369 (0.341 - 0.400)
R	0.047 (0.027 - 0.075)	0.143 (0.112 - 0.180)	0.286 (0.243 - 0.334)	0.368 (0.318 - 0.424)
2001				
U	0.055 (0.043 - 0.070)	0.158 (0.140 - 0.179)	0.282 (0.257 - 0.308)	0.375 (0.347 - 0.405)
R	0.043 (0.024 - 0.070)	0.140 (0.109 - 0.177)	0.276 (0.234 - 0.324)	0.411 (0.358 - 0.470)
2002				
U	0.058 (0.046 - 0.073)	0.178 (0.158 - 0.199)	0.303 (0.278 - 0.330)	0.379 (0.351 - 0.408)
R	0.058 (0.035 - 0.091)	0.109 (0.081 - 0.144)	0.300 (0.254 - 0.352)	0.428 (0.372 - 0.489)
2003				
U	0.059 (0.046 - 0.074)	0.180 (0.161 - 0.202)	0.313 (0.287 - 0.339)	0.405 (0.377 - 0.435)
R	0.054 (0.031 - 0.086)	0.144 (0.111 - 0.184)	0.298 (0.252 - 0.351)	0.397 (0.342 - 0.457)
2004				
U	0.072 (0.058 - 0.088)	0.187 (0.166 - 0.209)	0.323 (0.297 - 0.350)	0.401 (0.372 - 0.430)
R	0.054 (0.032 - 0.087)	0.145 (0.111 - 0.185)	0.327 (0.278 - 0.383)	0.421 (0.364 - 0.483)
2005				
U	0.067 (0.054 - 0.083)	0.193 (0.172 - 0.216)	0.328 (0.302 - 0.356)	0.421 (0.392 - 0.451)
R	0.074 (0.047 - 0.110)	0.148 (0.114 - 0.189)	0.342 (0.291 - 0.399)	0.442 (0.384 - 0.506)
2006				
U	0.073 (0.060 - 0.089)	0.188 (0.168 - 0.210)	0.337 (0.311 - 0.365)	0.434 (0.405 - 0.465)
R	0.095 (0.064 - 0.135)	0.165 (0.128 - 0.208)	0.326 (0.276 - 0.382)	0.429 (0.372 - 0.493)
2007				
U	0.079 (0.065 - 0.095)	0.216 (0.195 - 0.240)	0.381 (0.353 - 0.410)	0.462 (0.433 - 0.493)
R	0.127 (0.092 - 0.172)	0.194 (0.154 - 0.241)	0.327 (0.276 - 0.383)	0.521 (0.458 - 0.590)

U = urban
R = rural

Table 2.2. – Incidence per 1,000 (95% confidence interval) of diabetes cases identified by the NDSS definition for children and adolescents aged 1-19 years (1995-2007), by age and location of residence.

Year	1-4 Years	5-9 Years	10-14 Years	15-19 Years
1995				
U	0.157 (0.095 - 0.246)	0.187 (0.125 - 0.268)	0.240 (0.168 - 0.332)	0.247 (0.171 - 0.346)
R	0.136 (0.050 - 0.295)	0.250 (0.140 - 0.412)	0.248 (0.139 - 0.409)	0.354 (0.213 - 0.553)
1996				
U	0.208 (0.135 - 0.307)	0.247 (0.175 - 0.337)	0.328 (0.244 - 0.431)	0.273 (0.194 - 0.373)
R	0.072 (0.015 - 0.211)	0.228 (0.122 - 0.390)	0.359 (0.222 - 0.549)	0.249 (0.132 - 0.425)
1997				
U	0.255 (0.173 - 0.362)	0.326 (0.244 - 0.426)	0.389 (0.299 - 0.497)	0.299 (0.218 - 0.400)
R	0.261 (0.125 - 0.480)	0.131 (0.053 - 0.270)	0.254 (0.139 - 0.426)	0.218 (0.109 - 0.391)
1998				
U	0.107 (0.057 - 0.183)	0.267 (0.194 - 0.358)	0.340 (0.257 - 0.441)	0.356 (0.269 - 0.462)
R	0.053 (0.006 - 0.192)	0.265 (0.145 - 0.445)	0.312 (0.182 - 0.499)	0.492 (0.318 - 0.726)
1999				
U	0.189 (0.120 - 0.284)	0.339 (0.256 - 0.440)	0.369 (0.283 - 0.473)	0.348 (0.264 - 0.451)
R	0.216 (0.093 - 0.425)	0.288 (0.161 - 0.474)	0.367 (0.224 - 0.566)	0.270 (0.148 - 0.454)
2000				
U	0.266 (0.182 - 0.375)	0.263 (0.190 - 0.354)	0.369 (0.283 - 0.472)	0.350 (0.266 - 0.451)
R	0.165 (0.060 - 0.358)	0.393 (0.240 - 0.606)	0.404 (0.253 - 0.612)	0.419 (0.262 - 0.634)
2001				
U	0.224 (0.147 - 0.325)	0.361 (0.275 - 0.466)	0.404 (0.315 - 0.510)	0.315 (0.238 - 0.410)
R	0.085 (0.018 - 0.249)	0.261 (0.139 - 0.446)	0.356 (0.214 - 0.555)	0.401 (0.248 - 0.614)
2002				
U	0.218 (0.144 - 0.318)	0.447 (0.351 - 0.561)	0.407 (0.319 - 0.512)	0.384 (0.300 - 0.486)
R	0.214 (0.086 - 0.441)	0.328 (0.183 - 0.540)	0.482 (0.309 - 0.716)	0.307 (0.172 - 0.506)
2003				
U	0.283 (0.197 - 0.393)	0.352 (0.267 - 0.455)	0.420 (0.331 - 0.525)	0.338 (0.259 - 0.433)
R	0.190 (0.070 - 0.413)	0.382 (0.223 - 0.612)	0.266 (0.142 - 0.455)	0.272 (0.145 - 0.466)
2004				
U	0.304 (0.215 - 0.417)	0.414 (0.322 - 0.525)	0.393 (0.307 - 0.496)	0.280 (0.209 - 0.367)
R	0.192 (0.070 - 0.418)	0.207 (0.095 - 0.393)	0.481 (0.305 - 0.722)	0.443 (0.275 - 0.678)
2005				
U	0.290 (0.204 - 0.399)	0.342 (0.258 - 0.444)	0.358 (0.276 - 0.457)	0.329 (0.252 - 0.422)
R	0.384 (0.199 - 0.671)	0.306 (0.163 - 0.523)	0.448 (0.277 - 0.684)	0.444 (0.275 - 0.678)
2006				
U	0.225 (0.152 - 0.321)	0.376 (0.289 - 0.483)	0.312 (0.236 - 0.406)	0.288 (0.217 - 0.375)
R	0.380 (0.196 - 0.663)	0.215 (0.098 - 0.408)	0.474 (0.297 - 0.717)	0.276 (0.147 - 0.472)
2007				
U	0.284 (0.203 - 0.387)	0.488 (0.388 - 0.606)	0.622 (0.512 - 0.748)	0.472 (0.381 - 0.579)
R	0.334 (0.167 - 0.597)	0.503 (0.312 - 0.769)	0.655 (0.442 - 0.935)	0.714 (0.495 - 0.998)

U = urban
R = rural

2.5. References

1. Bessaoud K, Boudraa G, Molinero de Ropolo M, de Sereday M, Marti ML, Moser M, et al. (The DIAMOND Project Group). Incidence and trends of childhood Type 1 diabetes worldwide 1990-1999. *Diabet Med*, 2006;23(8):857-66

2. Toth EL, Lee KC, Couch RM, Martin LF. High incidence of IDDM over 6 years in Edmonton, Alberta, Canada. *Diabetes Care*, 1997;20(3):311-3

3. Public Health Agency of Canada, Chronic Disease Surveillance Division, Centre for Chronic Disease Prevention and Control. Report from the National Diabetes Surveillance System: Diabetes in Canada, 2008. Ottawa (ON): Public Health Agency of Canada; 2009. Cat. N° HP32-2/1-2008

4. Cardwell CR, Carson DJ, Patterson CC. Higher incidence of childhood-onset type 1 diabetes mellitus in remote areas: a UK regional small-area analysis. *Diabetologia,* 2006;49(9):2074-77

5. Rytkönen M, Moltchanova E, Ranta J, Taskinen O, Tuomilehto J, Karvonen M. The incidence of type 1 diabetes among children in Finland—rural–urban difference. *Health Place*, 2003;9(4):315-25

6. Haynes A, Bulsara MK, Bower C, Codde JP, Jones TW, Davis EA. Independent effects of socioeconomic status and place of residence on the incidence of childhood type 1 diabetes in Western Australia. *Pediatr Diabetes*, 2006;7(2):94-100

7. Cherubini V, Carle F, Gesuita R, Iannilli A, Tuomilehto J, Prisco F, et al. Large incidence variation of Type I diabetes in central-southern Italy 1990-1995: lower risk in rural areas. *Diabetologia*, 1999; 42(7):789-92

8. Casu A, Pascutto C, Bernardinelli L, Songini M, The Sardinian IDDM Epidemiology Study Group. Type 1 Diabetes Among Sardinian Children is Increasing: The Sardinian diabetes register for children aged 0-14. *Diabetes Care*, 2004;27(7):1623-29

9. Hamman RF, Gay EC, Cruickshanks KJ, Cook M, Lezotte DC, Klingensmith GJ, et al. Colorado IDDM Registry. Incidence and validation of IDDM in children aged 0-17 yr. *Diabetes Care*, 1990;13(5):499-506

10. Alberta Health and Wellness, Information Analysis Branch. Overview of Administrative Health Databases [document on the Internet]. Government of Alberta [updated 2010 Mar; cited 2010 Jul 30]. Available from: http://www.health.alberta.ca/documents/Research-Health-Databases.pdf

11. Canada Post. Postal Code[OM]. In: Addressing Guidelines [webpage on the Internet]. © Canada Post Corporation [cited 2010 Mar 4] Available from: http://www.canadapost.ca/tools/pg/manual/PGaddress-e.asp#1383055

12. Johnson JA, Balko SU, Hugel G. Chapter 1: Background and Methods. In Johnson JA, editor; *Alberta Diabetes Atlas* 2009. Edmonton (AB): Institute of Health Economics; 2009:1-10

13. Guttmann A, Nakhla M, Henderson M, To T, Daneman D, Cauch-Dudek K, et al. Validation of a health administrative data algorithm for assessing the epidemiology of diabetes in Canadian children. *Pediatr Diabetes*, 2010;11(2):122-8

14. Centers for Disease Control and Prevention. Classification of Diseases, Functioning, and Disability – International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) [document on the Internet] Centers for Disease Control and Prevention [updated 2009 Sep 10; cited 2010 Aug 3]. Available from: ftp://ftp.cdc.gov/pub/Health_Statistics/NCHS/Publications/ICD9-CM/2001/DTAB02.ZIP

15. du Plessis V, Beshiri R, Bollman RD, Clemenson H. Definitions of Rural. *Rural and Small Town Canada Analysis Bulletin*. Ottawa (ON): Statistics Canada; 2001. Cat. N° 21-006-XIE

16. National Institutes of Health. National Institute of Diabetes and Digestive and Kidney Diseases. National Diabetes Education Program. Overview of Diabetes in Children and Adolescents: A Fact Sheet From the National Diabetes Education Program [document on the Internet]. Bethesda (MD): NIDDK [updated 2008 Nov 25; cited 2010 Mar 6]. Available from: http://www.ndep.nih.gov/media/Youth_FactSheet.pdf

17. Harjutsalo V, Sjöberg L, Tuomilehto J. Time trends in the incidence of type 1 diabetes in Finnish children: a cohort study. *Lancet*, 2008;371(9626):1777-82

18. Ehehalt S, Blumenstock G, Willasch AM, Hub R, Ranke MB and Neu A, DIARY-study Group Baden-Württemberg. Continuous rise in incidence of childhood Type 1 diabetes in Germany. *Diabet Med*, 2008;25(6):755-57

19. Wang Y, Lobstein T. Worldwide trends in childhood overweight and obesity. *Int J Pediatr Obes*, 2006;1(1):11-25

20. Fagot-Campagna A, Pettitt DJ, Engelgau MM, Burrows NR, Geiss LS, Valdez R, et al. Type 2 diabetes among North American children and adolescents: An epidemiologic review and a public health perspective. *J Pediatr*, 2000;136(5):664-72

21. Dabelea D, Bell RA, D'Agostino RB Jr, Imperatore G, Johansen JM, Linder B, et al., The Writing Group for the SEARCH for Diabetes in Youth Study Group. Incidence of diabetes in youth in the United States. *JAMA*, 2007;297(24):2716-24

22. Yawn BP, Mainous AG, Love MM, Hueston W. Do Rural and Urban Children Have Comparable Asthma Care Utilization? *J Rural Health*, 2001;17(1):32-9

23. Johnson JA, Balko SU, Hugel G, Low C, Svenson LW. Increasing incidence and prevalence with limited survival gains among rural Albertans with Diabetes: a retrospective cohort study, 1995-2006. *Diabet Med*, 2009;26(10):989-95

24. Public Health Agency of Canada. Diabetes in Canada: Highlights from the National Diabetes Surveillance System, 2004-2005. Ottawa (ON); 2008. Cat. N° HP32-2/2005 | 978-0-662-05378-1

CHAPTER 3.0. DATA VALIDITY AND THE ALBERTA DIABETES SURVEILLANCE SYSTEM

3.1. Background

Accurate reporting and tracking of chronic illness trends in the population is important for how well the health system addresses the burden of disease. As a part of the Canadian Diabetes Strategy, the National Diabetes Surveillance System (NDSS) was established to inform Canadians about the magnitude of diabetes in Canada.[1] The NDSS originally focused on epidemiologic trends of diabetes in the adult population, but recently extended the scope of its diabetes case definition to include children and adolescents aged less than 20 years. This extension of surveillance is important, as incidence reports suggest that the number of new diabetes cases identified worldwide among children and adolescents has been steadily increasing.[2,3]

This trend has also been observed in Alberta, a province in western Canada, from data collected through the Alberta Diabetes Surveillance System (ADSS). Using the similar methods to the NDSS, the ADSS identifies diabetes cases from administrative physician billing and hospital discharge data. From 1995 and 2007, incidence rates of diabetes in the under 20 population appear to have increased[4]; however, between 2002 and 2006, incidence rates appeared to decline or plateau for older children and adolescents (**Figure 3.1.**). This decrease is not in keeping with historical trends, nor the international patterns for diabetes among children and adolescents. Furthermore, there is a seeming 'rebound' of incidence in 2007 to the expected level. Taken together, these anomalies in incidence trends suggest possible data quality concerns that should be explored.

One possible explanation for the puzzling decline in incidence could be an association with specific policy changes that may have affected the quality of the ADSS' administrative data. In this report, we hypothesize that changes made to the way that physicians are reimbursed relate to these data quality concerns. In particular, we consider the establishment of Alternate Relationship Plan (ARP) contracts with pediatric endocrinologists in Alberta in the Fall of 2002.

The introduction of ARPs across Canada has changed the way that many physicians are reimbursed. Under traditional remuneration models, physicians would submit a billing claim to the provincial health ministry for each service rendered in a 'fee-for-service' (FFS). Under new funding models in Alberta, certain physicians have been given the option to be compensated based on either contractual, sessional, or capitation models.[5] While they are contractually required to continue submitting billing claims, a practice known as 'shadow billing', physicians are not remunerated for the time spent doing this.

In 2005-2006 in Alberta, just 10% of physicians were receiving some form of alternate payments.[6] This represents the lowest proportion of physicians in Canada receiving alternate payments.[6] If shadow billing is not occurring at physician-patient encounters at the same rate as under the former FFS model, it may lower the case ascertainment under the NDSS and ADSS definition. To address this potential weakness in the ADSS' diabetes identification, our objective is to examine the effect of ARPs on incident diabetes cases identified in Alberta.

3.2. Research Design and Methods

Population

Incident diabetes cases among children and adolescents were identified in Alberta between 1995-2007 from the provincial health ministry, Alberta Health and Wellness (AHW), administrative databases. Individuals aged less than 20 years on case date were identified and defined according to the NDSS definition: either two physician claims with a diagnostic code of ICD-9 250 (diabetes mellitus) or one hospitalization with a discharge code of ICD-9 (prior to 2001) or, more recently, ICD-10-CA, codes E10-E14 (type 1, type 2, malnutrition-related, other specified, and unspecified, respectively).[7] This definition has recently undergone validation in children and adolescents under the age of 20, and has shown high sensitivity and specificity.[8] Cases were not excluded if they were likely gestational diabetes – that is, having diagnostic or procedural codes for pregnancy and obstetrics.[9]

Analysis

Our first step was to examine the proportion of cases identified from physician claims relative to the total number of identified cases from claims and hospitalizations. If shadow billing under ARPs did not account for the same number of medical service encounters as FFS, it was hypothesized that the proportion of cases identified through physician claims would have dropped following the implementation of these contracts. We tested this possibility by comparing the trend of the proportion of diabetes cases identified by physician claims before and after ARP signing, in the Fall of 2002.

Second, we compared the proportion of diabetes incidence cases identified by physician claims between urban and rural locations of residence. Blancquaert et al. found that urban physicians were more likely to refer patients to tertiary care, while rural physicians more often assumed a larger role in the management of chronic conditions among children.[10] It was hypothesized that more rural cases would be captured from general practitioners and that urban children and adolescents would more often be referred to pediatric endocrinologists in urban tertiary care centres, who were under the ARP; thus, we expected a drop in physician claim-identified cases in urban settings after the implementation of the ARP. We tested this possibility by comparing the interaction of location of residence (urban or rural) with time – before and after the ARP policy change. Location of residence was defined based on the Canadian Postal Code classification, described in du Plessis et al.[11,12]

Statistical Approach

To assess whether there was a statistically significant change in the proportion of diabetes cases identified by physician claims following ARP signing, we compared the change in this proportion with time periods before and after autumn 2002. Data were reported at six-month intervals and adjusted for age (by four groups: 1-4, 5-9, 10-14, and 15-19 years), location of residence (urban or rural), gender, diabetes case date, and whether the subject was a Status

Aboriginal. The trends were analysed by a generalized linear model with a logit link function, using a linear spline with the marginal command, with a knot at the beginning of ARP implementation. These analyses were completed with Stata™ Version 10.0 for Macintosh (StataCorp, College Station, TX, USA). The change in the proportion of cases identified by physician claims was calculated by dividing the difference between the oldest and most recent values by the oldest value. This research was approved by the University of Alberta, Health Research Ethics Board, Panel B.

3.3. Results

Before the signing of the ARP contracts with pediatric endocrinologists in the Fall of 2002, the proportion of cases identified by physician claims had increased by 4.0% from 1995. Following the adoption of ARPs in 2002, the proportion of diabetes cases identified by physician claims grew by 0.8% by the end of 2007. Overall, there was a 1.7% increase in the proportion of diabetes cases identified by physician claims for children and adolescents living in Alberta between 1995-2007 (**Figure 3.2.**). Relative to the trend in the source of cases prior to the second half of 2002, the change in the proportion of cases identified by physician claims following ARP signing was not statistically significant (p-value=0.435; **Table 3.1.**). In addition, a higher variability in the proportion of cases identified by physician claims was observed in the period preceding the ARP contracts with a range of 9%, compared to 4% in the period that followed (**Figure 3.2.**).

The proportion of diabetes cases identified by physician claims was higher for children and adolescents living in urban areas than for those living in rural regions of the province overall (p=0.003; **Table 3.1.**). However, the proportion of cases identified from physician claims in each region was not significantly different across time – either before, or after, the introduction of ARPs (p-values: 0.327 and 0.159, respectively).

There were also age and sex differences for the proportion of cases identified by physician claims. Overall, children were more likely than adolescents to be identified by physician claims (p=<0.002) and females were more likely than males to meet the ADSS definition from outpatient encounters (p=0.014).

3.4. Discussion and Conclusions

In our investigation of the apparent changes in diabetes incidence among children and adolescents in Alberta, we found that the implementation of an alternate funding arrangement among pediatric endocrinologists was not associated with a change in the proportion of cases identified from physician billing claims.

We found that the relative amount of cases identified by physician claims increased overall between 1995-2007, and that the relative proportion of cases meeting the ADSS definition through physician claims remained high – over 90% in most instances. This may reflect changing patterns of care whereby newly diagnosed patients are less often admitted to hospital, but rather supported in the management of their disease in the home setting.[13] This recent shift may also explain why we observed less variation in case source towards the end of our study period.

Results from the Future of Pediatric Education II survey indicate that almost all pediatric endocrinologists are employed in urban centres.[14] This likely has an effect on the way that rural-dwelling patients are able to access subspecialty care. In this study, we observed that the proportion of cases identified by physician claims was significantly lower for children and adolescents living in rural areas versus those living in urban centres, and that this relationship did not change over time. It is possible that rural children and adolescents are more frequently admitted to hospital care to manage their diabetes in the absence of easily accessible subspecialty care.

The main strength of this study was the availability of a population-based dataset through the provincial ministry of health databases, AHW. From this source, the diabetes cases identified should exhibit limited selection bias. The main limitation of this study was that we are unable to infer a causal relationship from our results. Thus, while we observed no significant decline in the proportion of cases identified by physician claims occurring at the same time as a decline in the incidence of identified diabetes among children and adolescents, the drop in incidence may have been due to other factors, including a true reduction in the number of diagnoses made in the province.

Through this study, we were unable to provide a possible explanation for the curious decline or levelling in diabetes incidence observed in Alberta between

2002-2006. However, due to the perplexing jump in diabetes incidence in 2007, we should not necessarily abandon questions relating to the validity of our data. Though Guttmann and colleagues did provide strong evidence for the validity of our diabetes case definition[8], they relied upon data from Ontario. A future strategy could be to perform a validation of the NDSS diabetes case definition against a clinical dataset in Alberta to support our case identification methodology.

Under FFS models, remuneration follows a strict coding structure that typically results in rewarding physicians for the volume of patients seen. Therefore, improving the efficiency of patient encounters corresponds to an increased output. However, this strategy may fail for patients with more complex chronic conditions who have difficulty communicating their symptoms or who require more effort to elicit understanding – such as in a pediatric population. This may be especially true among younger patients. Indeed, evidence shows that pediatricians who are reimbursed under a pre-specified compensation scheme spend more time with patients during visits than those compensated under fee-for-service.[15] The ability to recruit specialists in pediatric care reflects the availability of alternate payment models that appreciate such unique challenges faced in pediatric care. For example, at the start of the last decade, there were two pediatric endocrinologists affiliated with the University of Alberta hospital in Edmonton. Following the period that included the introduction of ARPs, that number has grown to five. While these developments will likely represent an improvement in patient health-related quality of life outcomes, we must continue to examine their impact on the data which researchers and policy makers rely on for disease surveillance and population health planning.

Figure 3.1. – Diabetes incidence rates per 1,000 children and adolescents, by age, identified through the Alberta Diabetes Surveillance System: 1995-2007.

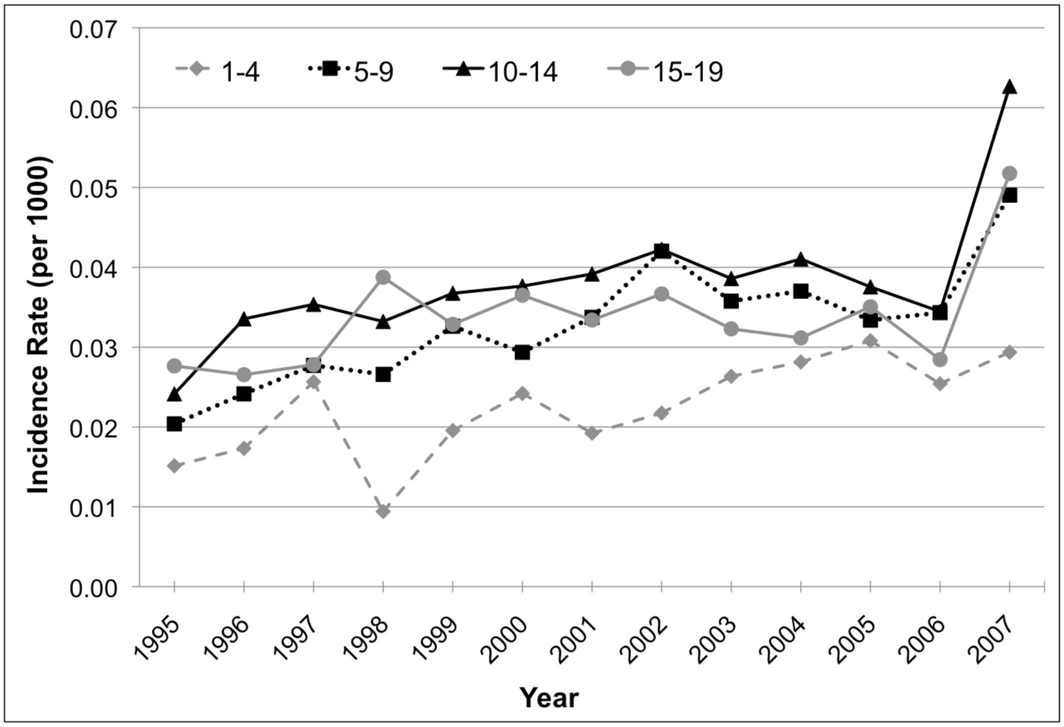

Figure 3.2. – Proportion of Cases Identified by Physician Claims Relative to Total Number of Cases Identified, by six-month period: 1995-2007.

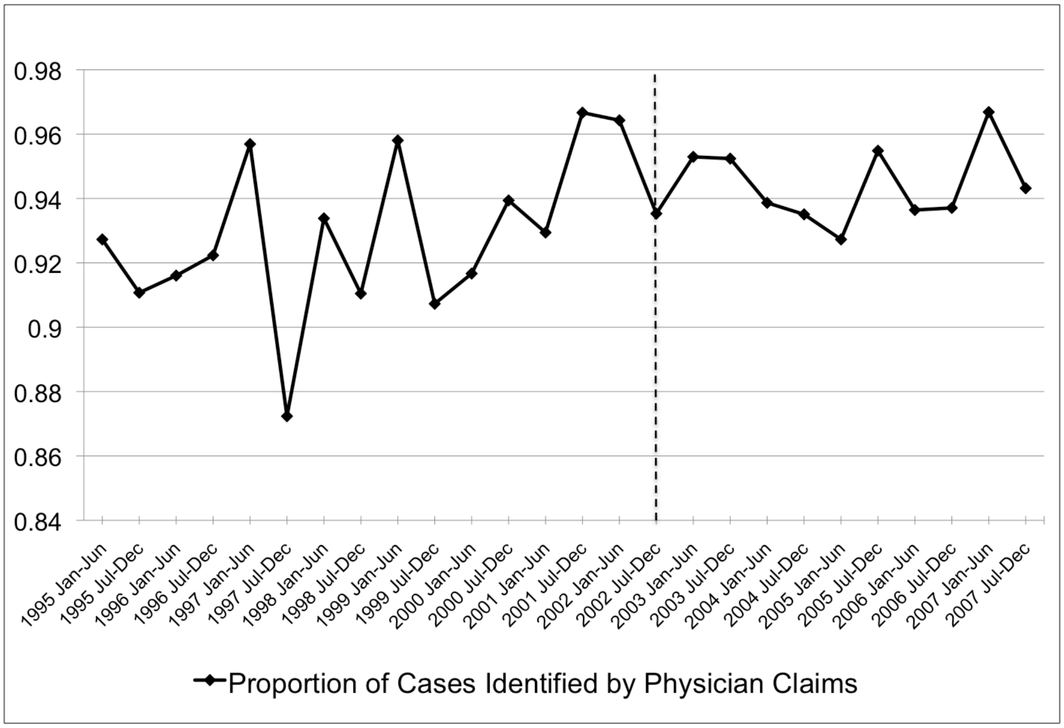

Table 3.1. – Multivariable logistic regression for identification by physician claims relative to total number of cases identified, 1995-2007.

	Odds Ratio	Standard Error	p-value	95% CI
Time (Jan 1995 – Dec 2007)	1.04	0.021	0.041	1.00 – 1.09
Post-ARP Implementation (Jul 2002 – Dec 2007)	0.97	0.037	0.435	0.90 – 1.05
Intervention*	0.87	0.231	0.608	0.52 – 1.47
Age (reference: 15-19 yrs)				
10-14 yrs	1.32	0.208	0.083	0.97 – 1.80
5-9 yrs	1.76	0.327	0.002	1.23 – 2.54
1-4 yrs	2.19	0.532	0.001	1.36 – 3.52
Sex (reference: Male) Female	0.72	0.096	0.014	0.55 – 0.94
Status Aboriginal	0.42	0.084	<0.001	0.29 – 0.62
Residence (reference: Urban)				
Rural	0.65	0.096	0.003	0.49 – 0.87
Residence*Time†:				
Jan 1995 – Jun 2002	1.04	0.044	0.327	0.96 – 1.13
Jul 2002 – Dec 2007	0.90	0.064	0.159	0.79 – 1.03

* The intervention term represents the change in the intercept, or level, of the trend after the ARP implementation.
† The interaction term between location of residence and time was calculated using two separate models representing the time before ARP implementation and the time after ARP implementation.

3.5. References

1. Clottey C, Mo F, LeBrun B, Mickelson P, Niles J, Robbins G. The Development of the National Diabetes Surveillance System (NDSS) in Canada. *Chronic Dis Can*, 2001;22(2):67-9

2. Bessaoud K, Boudraa G, Molinero de Ropolo M, de Sereday M, Marti ML, Moser M, et al. (The DIAMOND Project Group). Incidence and trends of childhood Type 1 diabetes worldwide 1990-1999. *Diabet Med*, 2006;23(8):857-66

3. Harjutsalo V, Sjöberg L, Tuomilehto J. Time trends in the incidence of type 1 diabetes in Finnish children: a cohort study. *Lancet*, 2008;371(9626):1777-82

4. Johnson JA, Vanderloo SE, Marks SD, Couch RM, Pacaud D. Chapter 3: Diabetes in Children and Adolescents. In: Johnson JA, editor, *Alberta Diabetes Atlas* 2009. Edmonton (AB): Institute of Health Economics; 2009:33-42.

5. Government of Alberta, Health and Wellness. About Alternate Relationship Plans [webpage on the Internet]. © 1995-2010 Government of Alberta. [cited 5 May 2010] Available from: http://www.health.alberta.ca/professionals/ARP-about.html

6. Canadian Institute for Health Information (CIHI). Physicians in Canada: The Status of Alternative Payment Programs, 2005-2006. Ottawa (ON): CIHI; 2008

7. World Health Organization. ICD Version 2007: Chapter IV - Endocrine, nutritional and metabolic diseases (E00-E90), Diabetes Mellitus (E10-E14) [webpage on the Internet]. © WHO/DIMDI 1994/2006 [updated 2006 Nov 12; cited 30 Apr 2009]. Available from: http://www.who.int/classifications/apps/icd/icd10online/ge10.htm

8. Guttmann A, Nakhla M, Henderson M, To T, Daneman D, Cauch-Dudek K, et al. Validation of a health administrative data algorithm for assessing the epidemiology of diabetes in Canadian children. *Pediatr Diabetes*, 2010;11(2):122-8

9. Johnson JA, Balko SU, Hugel G. Chapter 1: Background and Methods. In: Johnson JA, editor, *Alberta Diabetes Atlas* 2009. Edmonton (AB): Institute of Health Economics; 2009:1-10.

10. Blancquaert IR, Zvagulis I, Gray-Donald K, Pless IB. Referral Patterns for Children with Chronic Diseases. *Pediatrics*, 1992;90(1)Part 1:71-4

11. du Plessis V, Beshiri R, Bollman RD, Clemenson H. Definitions of Rural. *Rural and Small Town Canada Analysis Bulletin*. Ottawa (ON): Statistics Canada; 2001. Cat. N° 21-006-XIE

12. Canada Post. Postal Code^{OM}. In: Addressing Guidelines [webpage on the Internet]. © Canada Post Corporation [cited 2010 Mar 4] Available from: http://www.canadapost.ca/tools/pg/manual/PGaddress-e.asp#1383055

13. Lowes L, Gregory JW. Management of newly diagnosed diabetes: home or hospital? *Arch Dis Child*, 2004;89(10):934-37.

14. Stoddard JJ, Cull WL, Jewett EA, Brotherton SE, Mulvey HJ, Alden ER, (and for the AAP Committee on Pediatric Workforce Subcommittee on Subspecialty Workforce). Providing Pediatric Subspecialty Care: A Workforce Analysis. *Pediatrics*, 2000;106(6):1325-33.

15. van Dulmen AM. Physician Reimbursement and the Medical Encounter: An Observational Study in Dutch Pediatrics. *Clin Pediatr (Phila)*, 2000;39(10):591-601.

CHAPTER 4.0. GENERAL CONCLUSIONS AND DISCUSSION

4.1. Summary

Two research studies were conducted on the theme of diabetes surveillance in children and adolescents in Alberta, Canada. The studies complemented each other by using shared surveillance approaches to examine geographic variation in diabetes, and also questioned the validity of these methods. These questions were considered important owing to potential concerns with changes to physician billing policies in Alberta (and throughout Canada) and the ongoing validity of the population-based surveillance systems in Canada, which are largely based on those administrative data sources. The questions were prompted by observations from the Alberta Diabetes Surveillance System (ADSS) Alberta Diabetes Atlas 2009[1], where we observed an apparent decline in the incidence of diabetes in children and adolescents during the years 2002 to 2006, where an increase was expected.

In the first project, the objective was to compare diabetes incidence and prevalence between children and adolescents living in urban and rural areas of Alberta. We found that there was no significant difference between these locations; however, a much higher number of cases were diagnosed in urban centres. The results of no difference are in agreement with results from a type 1 diabetes registry in Colorado[2] and observations across geographic areas of Sardinia[3]. In other findings, such as those reported from Finland[4], Northern Ireland[5], Western Australia[6], and Southern Italy[7], there were significant differences in the incidence of diabetes observed between urban and rural settings;

however, the results varied with respect to the location where a higher incidence was observed.

In the second project, we looked at the source of incident cases of diabetes for all pediatric age groups across the province over a 13-year period. Using the case definition of the National Diabetes Surveillance System (NDSS), cases can be identified by one of two sources: a single hospitalization for diabetes, or two physician visits within a two-year period. We investigated the change in the proportion of cases identified through physician claims before and after the implementation of Alternate Relationship Plans (ARPs) for pediatric specialists in 2002. We found no significant change in the proportion of cases identified in this way following the policy change that coincided with the observed decline in incidence.

4.2. Strengths & Limitations

The results of the two studies broaden our knowledge concerning the extent and gravity of the diabetes burden in Alberta. The analyses performed herein relied on the use of data that was collected by the provincial ministry of health – Alberta Health and Wellness (AHW) – for health administration purposes in a publicly-funded system. These data, which were in the form of hospital discharge codes and physician billing claims, were not collected for research purposes. Though some reports indicate that the agreement between administrative data and true diabetes diagnoses is actually relatively high[8,9], several weaknesses have been identified in the use of similar data sources for research, such as diagnostic error, missing data, and data entry errors.[10] Notwithstanding such weaknesses, the strength of this resource lies is its ability to capture the denominator of nearly all residents of the province who are registered for provincially-insured medical care and the fact that we have individual-level data. In addition, evidence supporting the validity of the NDSS diabetes case definition used to capture cases has been evaluated for the pediatric age groups and showed good sensitivity and specificity.[11]

One major limitation of these projects was that the NDSS case definition could not distinguish between type 1 and type 2 diabetes from the data that we collected. This is unfortunate, as the face of diabetes among the pediatric population is changing. Although type 1 diabetes was traditionally considered a disease of children and adolescents and type 2 a condition associated with ageing, this perception is being revised. For example, a high proportion of cases identified among indigenous and Aboriginal youth populations is diagnosed as type 2.[12,13] This affects the way we interpret diabetes estimates in regions such as Alberta which has a large number of citizens who identify as Status Aboriginals.[14] The awareness of type 2 diabetes among children and adolescents may also have positive implications for public health, as targetable lifestyle habits can prevent or slow the development of type 2 diabetes.[15] Future work, focussing on linkable population-health datasets, will conceivably help us to classify diabetes type from the administrative data and to derive estimates of type 1 and type 2 diabetes incidence and prevalence for the population under 20 years of age.

Another limitation of this research is our inability to ascribe a causal link to our analyses. Some have suggested a possible relationship between population density and risk of developing type 1 diabetes[16]; however, we found that there was no association between location of residence and the incidence and prevalence of diabetes, which precludes us from supporting these theories. For our second objective, we were not able to draw a direct link between changes in case source and changes in incidence observed.

Finally, our assessment of data validity was limited to a comparison of trends based on our *a priori* hypotheses regarding the trends. In this research, we did not validate the identification of incident cases against an external data source, such as clinical charts. Such a validation could potentially demonstrate that the NDSS definition is not the most appropriate for child and adolescent diabetes surveillance in Alberta. Future collaboration with clinical centres, such as those for pediatric subspecialty care in Alberta, could help to answer our questions in this regard.

4.3. Implications

In Canada, a large number of physicians are now receiving remuneration from alternate payment plans, replacing the traditional fee-for-service. In Alberta, approximately 10% of physicians are receiving at least a portion of their salaries in this form.[17] In some provinces, this number is as high as 77%.[17] If data collection is being affected by alternate payment arrangements across other jurisdictions in Canada, by way of a similar association to that identified in

Alberta, it could have major implications for how we perform disease surveillance. Our research highlights the need for constant review and revision of our surveillance methods to provide the most accurate estimates of diabetes in Canada.

In Alberta, our results also have implications for how we manage and prevent diabetes. Understanding that living in a rural area is not associated with a lower incidence or prevalence of diabetes indicates that we need to provide equivalent health support to both regions of the population. This should be of interest to policy- and decision-makers when determining resource allocation and health promotion strategies. It is therefore important to have tools such as the ADSS Alberta Diabetes Atlas[1] which assists in the dissemination of these findings to the relevant stakeholders.

The rise in diabetes incidence among children and adolescents is well documented on a global scale.[18-20] It is important to contribute to the literature in support or opposition to these claims and to provide a Canadian perspective. It is equally critical to provide high-quality evidence that is based on valid data collection and surveillance methods. The salient strength of this research is its national comparability by way of the National Diabetes Surveillance System (NDSS). By informing the NDSS along with other provincial partners, these results support a federal agenda of diabetes prevention and population health management.[21]

4.4. Conclusions

We found that diabetes distribution among children and adolescents did not differ significantly by location of residence, but that our diabetes surveillance methods may have been jeopardized by policy changes related to physician remuneration. It is important to continue these investigations, as identification of diabetes type, distribution and accurate reporting of trends for the population under 20 years of age will improve how we manage this disease.

4.5. References

1. Johnson JA, Vanderloo SE, Marks SD, Couch RM, Pacaud D. Chapter 3: Diabetes in Children and Adolescents. In: Johnson JA, editor, *Alberta Diabetes Atlas* 2009. Edmonton (AB): Institute of Health Economics; 2009:33-42

2. Hamman RF, Gay EC, Cruickshanks KJ, Cook M, Lezotte DC, Klingensmith GJ, et al. Colorado IDDM Registry. Incidence and validation of IDDM in children aged 0-17 yr. *Diabetes Care*, 1990;13(5):499-506

3. Casu A, Pascutto C, Bernardinelli L, Songini M, The Sardinian IDDM Epidemiology Study Group. Type 1 Diabetes Among Sardinian Children is Increasing: The Sardinian diabetes register for children aged 0-14. *Diabetes Care*, 2004;27(7):1623-29

4. Rytkönen M, Moltchanova E, Ranta J, Taskinen O, Tuomilehto J, Karvonen M. The incidence of type 1 diabetes among children in Finland—rural–urban difference. *Health Place*, 2003;9(4):315-25

5. Cardwell CR, Carson DJ, Patterson CC. Higher incidence of childhood-onset type 1 diabetes mellitus in remote areas: a UK regional small-area analysis. *Diabetologia,* 2006;49(9):2074-77

6. Haynes A, Bulsara MK, Bower C, Codde JP, Jones TW, Davis EA. Independent effects of socioeconomic status and place of residence on the incidence of childhood type 1 diabetes in Western Australia. *Pediatr Diabetes*, 2006;7(2):94-100

7. Cherubini V, Carle F, Gesuita R, Iannilli A, Tuomilehto J, Prisco F, et al. Large incidence variation of Type I diabetes in central-southern Italy 1990-1995: lower risk in rural areas. *Diabetologia*, 1999; 42(7):789-92

8. Kashner TM. Agreement between Administrative Files and Written Medical Records: A Case of the Department of Veterans Affairs. *Med Care*, 1998;36(9):1324-36

9. Fowles JB, Lawthers AG, Weiner JP, Garnick DW, Petrie DS, Palmer RH. Agreement between physicians' office records and Medicare Part B claims data. *Health Care Financ Rev*, 1995;16(4):189-99

10. Peabody JW, Luck J, Jain S, Bertenthal D, Glassman P. Assessing the Accuracy of Administrative Data In Health Information Systems. *Med Care*, 2004;42(11):1066-72

11. Guttmann A, Nakhla M, Henderson M, To T, Daneman D, Cauch-Dudek K, et al. Validation of a health administrative data algorithm for assessing the epidemiology of diabetes in Canadian children. *Pediatr Diabetes*, 2010;11(2):122-8

12. Dabelea D, Bell RA, D'Agostino RB Jr, Imperatore G, Johansen JM, Linder B, et al., The Writing Group for the SEARCH for Diabetes in Youth Study Group. Incidence of diabetes in youth in the United States. *JAMA*, 2007;297(24):2716-24

13. Nadeau K, Dabelea D. Epidemiology of Type 2 Diabetes in Children and Adolescents. *Endocr Res*, 2008;33(1-2):35-58

14. Government of Alberta, Aboriginal Relations. Métis Settlements and First Nations in Alberta: Community Profiles [document on the Internet]. © Government of Alberta 2010 [cited 2010 May 27]. Available from: http://www.aboriginal.alberta.ca/documents/MetisSettlement_FirstNation_Profile.pdf

15. Knowler WC, Barrett-Connor E, Fowler SE, Hamman RF, Lachin JM, Walker EA, et al., (Diabetes Prevention Program Research Group). Reduction in the Incidence of Type 2 Diabetes with Lifestyle Intervention or Metformin. *N Engl J Med*, 2002;346(6):393-403

16. Patterson CC, Carson DJ, Hadden DR, on behalf of the Northern Ireland Diabetes Study Group. Epidemiology of childhood IDDM in Northern Ireland 1989-1994: Low incidence in areas with highest population density and most household crowding. *Diabetologia*, 1996;39(9):1063-69

17. Canadian Institute for Health Information (CIHI). Physicians in Canada: The Status of Alternative Payment Programs, 2005-2006. Ottawa (ON): CIHI; 2008

18. Bessaoud K, Boudraa G, Molinero de Ropolo M, de Sereday M, Marti ML, Moser M, et al. (The DIAMOND Project Group). Incidence and trends of childhood Type 1 diabetes worldwide 1990-1999. *Diabet Med*, 2006;23(8):857-66

19. Harjutsalo V, Sjöberg L, Tuomilehto J. Time trends in the incidence of type 1 diabetes in Finnish children: a cohort study. *Lancet*, 2008;371(9626):1777-82

20. Ehehalt S, Blumenstock G, Willasch AM, Hub R, Ranke MB and Neu A, DIARY-study Group Baden-Württemberg. Continuous rise in incidence of childhood Type 1 diabetes in Germany. *Diabet Med*, 2008;25(6):755-57

21. Public Health Agency of Canada. Canadian Diabetes Strategy [webpage on the Internet]. Public Health Agency of Canada [updated 2008 Nov 14; cited 2010 May 19]. Available from: http://www.phac-aspc.gc.ca/cd-mc/diabetes-diabete/diabetes_strategy-diabete_strategie-eng.php