Managing Type 1 Diabetes: Trends and Outcomes Over 20 Years in the Wisconsin Diabetes Registry Cohort

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ABSTRACT
Context: The Wisconsin Diabetes Registry Study is a Wisconsin cohort of patients with type 1 diabetes, who were diagnosed in 1987-1992 and actively followed. The study provides patients and health care professionals with better prognostic information and helps identify aspects of diabetes management that need improvement.

Objective: To describe diabetes management and acute and chronic complications from the time of diagnosis.

Design and Setting: All incident cases diagnosed at age <30 in 28 counties were eligible and 590 enrolled. A baseline interview, blood sample kits, biannual/annual questionnaires and study examinations at 4, 7, 9, 14, and 20 years duration were administered.

Main Outcome Measures: Diabetes management indicators, general health, and acute and chronic complications.

Results: Glycemic control was poor in adolescence, but improved with age. A high percentage of individuals do not meet treatment standards for blood pressure and lipid profile. Self-reported health deteriorated with age, and body mass index was similar to that of the general US population. Chronic complications were present at 15-20 years, but tended to be relatively mild.

Conclusion: There is room for improvement in diabetes management, especially in meeting goals for blood pressure and lipid profile. Nonetheless, individuals with type 1 diabetes can be offered a more optimistic prognosis than in the past.

INTRODUCTION
For the past 2 decades, the Department of Population Health Sciences has provided a rich environment for conducting longitudinal cohort studies. Importantly, these studies have established a framework to find all individuals in a geographic area who are diagnosed with a condition, characterized them at the time of diagnosis, and then followed them for an extended period of time in order to document future health and known complications of the condition. Two such studies are especially unique in the United States because they have followed geographically defined cohorts of children: the Newborn Lung Project (NBL) and the Wisconsin Diabetes Registry Study (WDRS).1-2 The NBL, which is following a cohort of children with very low birthweight and a representative group of children with normal birthweight born in Wisconsin in 2003-2004 was described in a previous article in the Wisconsin Medical Journal.1 Here, we describe the WDRS, which was initiated in 1987 and follows a cohort with type 1 diabetes diagnosed in southern and central Wisconsin from 1987 to 1992.

Type 1 diabetes most commonly strikes during adolescence, but many children are diagnosed with the condition as well. Type 1 diabetes onset past age 30 is uncommon. It is important to realize that type 1 diabetes is a condition very different from type 2 diabetes.3-4 In the past, the latter was a disease of older individuals, but has recently become common in children due to the obesity epidemic. While type 2 diabetes is associated with obesity and has higher incidence with lower socioeconomic level, risk factors for type 1 diabetes are largely unknown, except that genetics play a strong role. In contrast to type 2 diabetes, which is caused by an inability to use insulin, type 1 diabetes leads to complete cessation of insulin production by pancreatic beta cells within a few years of diagnosis. Hence, the condition requires intense monitoring of blood sugar and continuous insulin therapy. It is well known that
keeping blood sugar levels low helps prevent or delay chronic complications, which include diabetic retinopathy (damage to the retina of the eye), neuropathy (disorders of the nerves of the peripheral nervous system), nephropathy (a progressive kidney disease caused by angiopathy of capillaries in the kidney glomeruli), and cardiovascular disease. Keeping blood sugar low, especially in a very young person, requires much vigilance by the person and family, and can lead to dangerous episodes of hypoglycemia.

The WDRS is in a unique position to describe diabetes management, diabetes care, glycemic control, and acute and chronic complications from the time of diagnosis, allowing patients to immediately benefit from improvements made in diabetes management tools. This article presents trends in the cohorts diabetes care and general health, and compares health characteristics of the WDRS cohort with those of Wisconsin individuals available from the Wisconsin Behavioral Risk Factor Survey (BRFS); and children, adolescents, and adults in the United States. The cohort is also compared with a large European cohort of children, adolescents, and young adults to show glycemic control.

**METHODS**

Eligible individuals were all those with newly diagnosed type 1 diabetes—defined as having classic diabetes symptoms (polyuria and polydipsia) accompanied by initiation of exogenous insulin usage and <30 years of age—who were living within 28 counties in southern and central Wisconsin. The geographic area covered included two-thirds of the Wisconsin population in 1990.
Individuals were referred by physicians, nurses, diabetes educators, families, or were self-referred. A total of 726 persons were identified (estimated ascertainment rate 81%-82%), 590 of whom enrolled. The younger the individuals were at diagnosis, the higher the ascertainment rate was. Individuals have now been followed for up to 22 years of diabetes duration.

Follow-up is ongoing and has included several aspects. A baseline telephone interview was conducted to obtain data on socioeconomic variables, type of clinic, and physician names. Monitoring glycemic control via glycosylated hemoglobin (GHb and HbA1c) was targeted at 4 monthly intervals up to the year 2000 and at yearly intervals in 2001-2002. Biannual/annual questionnaires were mailed to participants. These contained standing questions on diabetes management by the patient including use of routine and emergency medical care, and also rotating questions updating information from the baseline questionnaire. The data from these questionnaires underlie much of the analyses. Study examinations were scheduled at 4 months (for southern Wisconsin only), and at 4, 7, 9, 14, and 20 years duration, with the last visit ongoing. A subset was also enrolled in cardiovascular follow-up and/or a study of bone density at 15 years. The examinations provide data on chronic complications.

Statistical analyses reported include tables and graphs of descriptive statistics (means, medians, and percent-ages) capturing diabetes care and health characteristics.

RESULTS
Cohort members still participating after 20 years (442 of the 590) appear representative, as they were similar to all enrolled at the time of diagnosis with respect to both socio-demographics and diabetes care characteristics. However, continuing members tend to more often be white (96% versus 92% originally) and are slightly younger. About half are male. Mean age at diagnosis was 11.4 years; 46% of the cohort was age <10 years, 42% age 10-19 years, and 12% >20 years old at diagnosis. Present mean age of participants is 30 years.

Diabetes management changed considerably in the past 20 years. While only 14% of the cohort injected insulin 3 or more times a day in the first year of diabetes, 96% currently use either 3 or more injections or an insulin pump. On the other hand, 78% reported checking blood glucose at least 3 times a day already in the first year after diagnosis, which remained almost unchanged at 76% at 15-20 years duration. Figures 1 and 2 show that both glucose checking and glycemic control deteriorated considerably during adolescence, regardless of age at diagnosis and duration. In addition, median HbA1c at young ages was considerably higher than in a large European study. Table 1 shows that while diabetes self-management is quite intense, relatively low percentages are meeting other ADA treatment standards specified in Table 2. The percentage of obese participants is very similar to overall Wisconsin statistics for 2007 (24.7%).

This is despite 61% of the cohort being cared for by endocrinologists, 60% reportedly receiving care from a health care team, and 91% having medical care covered by pre-paid or private insurance.

Table 3 shows acute and chronic outcomes in the cohort. Not unexpectedly, we see a steady increase in chronic complications with increasing duration, but little change in acute complications. We have previously compared our retinopathy prevalence to that in a Wisconsin cohort diagnosed 20 years earlier, and showed that retinopathy onset has been much delayed and severity decreased over the last 2 decades.
The percentage of the WDRS cohort who reported being in fair or poor health depended more on age than on diabetes duration, and was much higher than for the general US population, which falls at 7.5%-9.8% in the age range 18-44 years, but was better than the 49.3% reported by adults with either type 1 or 2 diabetes in the United States. In Wisconsin, the percentage in self-reported fair or poor health is 8.4% in the 18-24 age range, and rises to 10.5% in the 45-54 range.

**Discussion/Conclusion**

Our results imply there is room for improvement in diabetes management, especially in meeting goals for blood pressure and lipid profile. It is also clear that individuals with type 1 diabetes are subject to similar risk of excessive weight gain as the general US population. This may have serious consequences in increasing insulin resistance and adding type 2 diabetes comorbidity to this already difficult to manage disease. Our results also show a different pattern of glycemic control among young children in Europe than in Wisconsin. The trade-offs in terms of acute and chronic complications of these patterns are not yet clear.

On the other hand, the data indicate that long-term outcomes are much better now than in the past. Many individuals have no or only mild chronic complications even after 20 years duration. It is important that a newly diagnosed child or adolescent and their parents are informed of this favorable prognosis and are not led to believe the much more dismal prognosis (of only 20 years ago) still applies.

Data from longitudinal cohorts are critical in helping us gain insights into how chronic diseases such as type 1 diabetes impact individuals’ lives and health. The WDRS, NBL, and similar cohort studies in the Department of Population Health Sciences are making important contributions by generating information that
allows current and accurate prognostic information to be provided to patients and by identifying modifiable factors that can help further improve prognosis.

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REFERENCES
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