Incidence of IDDM in German Children Aged 0–14 Years

A 6-year population-based study (1987–1993)

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OBJECTIVE — Generally accepted data on the incidence of childhood diabetes in Germany have not been available up to now. To register the total number of newly diagnosed cases in Baden-Wuerttemberg (a federal state in southwest Germany), data on 1,160 children were retrospectively collected for the years 1987–1993.

RESEARCH DESIGN AND METHODS — Hospital records were the primary data source. There were 32 hospital units in Baden-Wuerttemberg included in this study. A secondary independent data source was a questionnaire circulated among the patients' association, Deutscher Diabetiker Bund. Case definition was done according to criteria EURODIAB ACE, a collaborative European study set up to assess the incidence of childhood diabetes. The degree of ascertainment was 96.2%, using the capture-mark-recapture method. The study includes a population at risk, entailing 1.5 million children, corresponding to 12.3% of all German children.

RESULTS — The incidence was found to be 11.6/100,000 (95% CI 10.9–12.2) for children aged 0–14 years. There was no significant difference between the incidence rates of boys and girls. Seasonal variation was observed, with cases increasing between November and February and incidence increasing with age. Peaks were found in early childhood (3–4 years of age) and prepuberty (10–12 years of age). There was marked geographical variation that did not correlate significantly with population density.

CONCLUSIONS — For the first time, internationally comparable data on the incidence of diabetes in children up to 15 years of age are available for Germany. The yearly incidence of 11.6/100,000 proved to be much higher than assumed so far.

For most European countries, data for the incidence of childhood diabetes are well known. Generally accepted data for Germany have not been available up to now. The absence of registries and confidentiality pose obstacles to an epidemiological approach.

A registry in the former German Democratic Republic reported an incidence of 7.4/100,000 per year for children aged 0–14 years (1). This national registry was closed after the reunification of Germany in 1989.

To register the total number of newly diagnosed cases in Baden-Wuerttemberg (a federal state in southwest Germany), we retrospectively collected data on 1,160 children treated in 32 hospital units between 1987 and 1993.

RESEARCH DESIGN AND METHODS

Geographic and population data

Baden-Wuerttemberg is located in southwest Germany and shares its national borders with France, Switzerland, and Austria. The state covers an area of 35,751 km^2, representing 10.0% of Germany as a whole. Of the total number of 9,751,496 inhabitants, 16.0% (i.e., 1,562,833) were under 15 years of age (mean values, January 1987 to June 1993). This is equal to 12.2% of all German children. Population density was 273 inhabitants per squared kilometer on an average and varied considerably, depending on whether the region is highly industrialized or predominantly rural.

All population data were drawn from the national census done in 1987 and from official yearly updates between 1988 and 1993.

Collection of data

Hospital records were the primary data source. All pediatric departments in Baden-Wuerttemberg (n = 31) and one diabetes center were included in this study. There were 1,160 records scrutinized by the same person.

Patients were registered as newly diagnosed cases of IDDM, adhering to the EURODIAB ACE criteria (2). Cases were included only if insulin treatment began before the 15th birthday and if the manifestation occurred between 1 January 1987 and 30 June 1993. Following international recommendations, the date of diagnosis was equated with the date of the first insulin injection (2).

Completeness of data

To verify whether all newly diagnosed cases were actually treated in the above-mentioned institutions, the following measures were taken as a precaution: *1*) Inquiries in 14 departments of internal medicine (covering three representative districts) on whether children with IDDM at onset were ever treated there were met with negative replies. 2) Similar inquiries in all institutions (n = 11) in Baden-Wuerttemberg that provide special care for children (e.g., sanatoria) were done. Ten answered negatively, the single remaining institution being the diabetes center included in the primary data source. 3) In districts lacking specific pediatric care (n = 19), the inquiries were conducted in departments for adult medicine. Eighteen responded negatively, while one declined to reply.

Validation of ascertainment

A questionnaire was circulated among subscribers of a patients' association journal (Deutscher Diabetiker Bund) with the aim

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Table 1—*Incidence rates, 1987-1993*

	Model I (Baden-Wuerttemberg residents)	Model II (All patients)
Patients (*n*)	1,066	1,160
Crude incidence	10.5 (9.9–11.1)	11.4 (10.8–12.1)
Sex- and age-standardized incidence rate	10.6 (10.0-11.3)	11.6 (10.9-12.2)

Data are *n*/100,000 per year (95% CI).

Table 2—*Age-specific incidence rates*

	Age (years)	Model I (Baden-Wuerttemberg residents)	Model II (All patients)
Patients			
	0–4	232	248
	5–9	400	428
	10–14	434	484
Incidence			
	0–4	6.4 (5.6–7.3)	6.9 (6.0–7.7)
	5–9	12.0 (10.8–13.1)	12.8 (11.6–14.0)
	10–14	13.5 (12.2–14.8)	15.1 (13.7–16.4)

Data are *n* or *n*/100,000 per year (95% CI).

of gaining data pertaining to the onset of diabetes. Data thus elicited was used as a secondary independent source. A total of 648 answers were evaluative. Additionally included in the secondary data source were data on 128 cases deriving from a survey done during a meeting of children and adolescents with diabetes in Baden-Wuerttemberg.

Statistical analysis

Two separate statistical calculations were done:

Model I: Children exclusively resident in Baden-Wuerttemberg at the time of diagnosis were evaluated.

Model II: Because medical care in Baden-Wuerttemberg may be also sought by patients from neighboring regions, and vice versa, we included all registered cases of this type in our analysis.

Sex and age standardization was done according to EURODIAB ACE criteria (equal distribution between both sexes and among the three age-groups). The 95% CI limits were calculated for all incidence rates assuming a normal distribution. Variations in significance were tested by means of an ordinary χ^2 test (level of significance α = 0.05).

RESULTS

Degree of ascertainment

A total of 1,160 cases were registered in the primary data source. Out of 776 patients in the secondary data source, 96 aged 0–14 years were identified as having developed diabetes during the study period. Of these, 92 were already registered in the primary data source, while 4 were not. The degree of ascertainment was calculated according to the capture-mark-recapture method (3,4), with 95.9% for the primary data source alone and 96.2% (95% CI 92.6–100.0) for the combination of both data sources.

Incidence rate

There were 1,160 newly diagnosed diabetic patients aged 0–14 years registered between 1 January 1987 and 30 June 1993. Of them, 1,066 were Baden-Wuerttemberg residents at the time of diagnosis. The incidence rates calculated are shown in Table 1. The capture-mark-recapture method can be used to compute the ascertainment-corrected incidence rates (3); in our study, this "true" incidence was 11.0/100,000 (95% CI 10.3–11.6).

Sex and age distribution

Boys comprised 51.4% (*n* = 596) of the registered cases and girls 48.6% (*n* = 564). Of the patients, 21.4% were 4 years of age or under at diagnosis, 36.9% were between 5 and 9 years of age, and 41.7% were between 10 and 14 years of age.

The age-specific incidence rates increased with age; the first peak occurred between ages 3 and 4, while the second was observed between ages 10 and 12. The second peak is more marked and appears earlier in girls than in boys (Fig. 1).

There is no significant difference between the sex-specific incidence rates. A highly significant difference, however, was found in a comparison of incidence rates relating to the various age-groups (Table 2; χ^2 = 108.09; df = 2; $P < 0.0001$).

Seasonal variation

Seasonal differences resulted in high incidence rates between November and February, followed by a decline in the months between May and August. The monthly

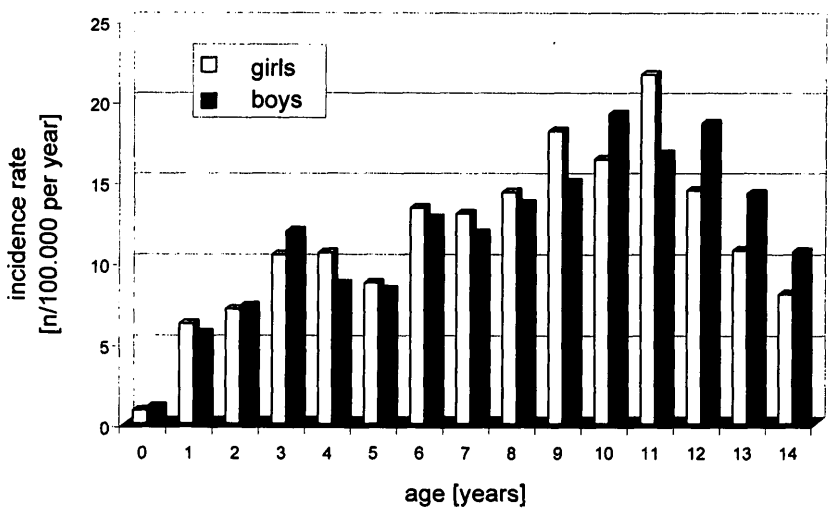

Figure 1—*Sex- and age-specific incidence rates.*

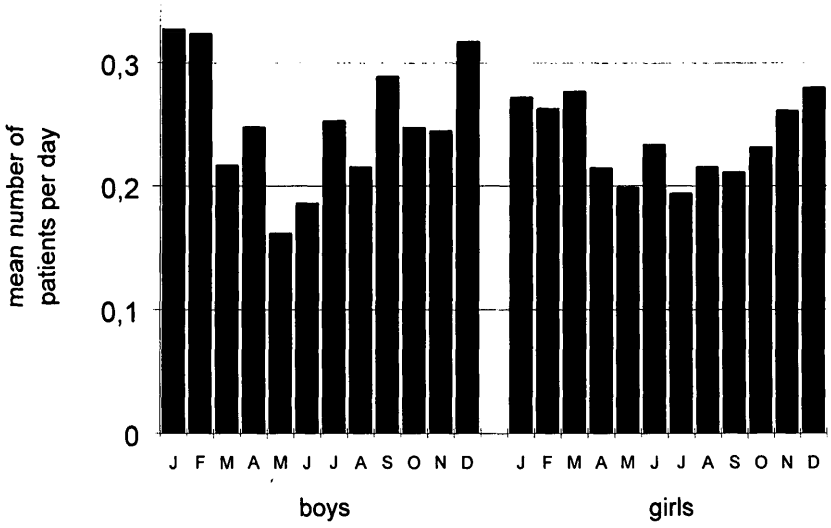

Figure 2—*Seasonal variation in boys and girls.*

differences proved to be significant (χ^2 = 25.68, df = 11, $P < 0.01$) and were particularly marked in boys (Fig. 2) and in the 10- to 14-year-old age-group (Fig. 3).

Geographic pattern

Of all registered children, 91.9% (n = 1,066) were residents of Baden-Wuerttemberg at the time of diagnosis, 6.9% (n = 80) were living in an area directly adjacent to Baden-Wuerttemberg, and 1.2% (n = 14) came from other parts of Germany, while two children resided in foreign countries. Significant differences emerged from an analysis of the incidence rates pertaining to each district (χ^2 = 61.99, df = 43, $P < 0.05$) within Baden-Wuerttemberg, ranging from a minimum of 5.5/100,000 to a maximum of 16.4/100,000 per year. There is no significant correlation between incidence rate and population density.

CONCLUSIONS — For the first time, internationally comparable data are available on the incidence of childhood diabetes in Germany. At 10.6 and 11.6/100,000 per year for Models I and II, respectively, the incidence proved to be much higher than estimated so far. By taking into account the factors of mobility as well as the patient's right to visit a physician of his or her choice, it can be reasonably assumed that the incidence rate of 11.6/100,000 (95% CI 10.9–12.2) is more realistic because it includes patients living close to the border but who are not, by definition, residents of Baden-Wuerttemberg. These circumstances are specific for Germany and different from countries in which all patients in one area seek medical care in the same (given) hospital. The secondary data source is relatively limited (n = 96) in comparison to the primary data source (n = 1,160); nevertheless, at 96.2%, the degree of ascertainment is high.

The majority of European studies have not revealed significant differences in sex-specific incidence rates. Our findings also show no significant differences between the sex-specific incidence rates for each age-group. The fact that incidence increases with age is well-documented for different regions across Europe (5–9). Our results compare well with these studies because we observed the lowest incidence rates in the 0–4 age-group and the highest in the 10–14 age-group. The peaks evident during early childhood and prepuberty have also been reported by others (10–12). We could also corroborate the fact that the second peak appears 1–2 years earlier in girls and that a drop in incidence occurs after the age of 12 (9,13).

Seasonality of diabetes onset seems to be similar all over the northern hemisphere (14–16). The degree of variation emerging from our study compares well with that described by others, in that it is most distinct in boys and older children (13,15,17). Recently published data provided by the EURODIAB ACE study group confirmed a rising amplitude with age, with a similar pattern for boys and girls (16).

The geographical pattern of different regions evidently varies considerably. While Dutch (8) and French (18) studies reported no significant differences within the analyzed region, significant differences were found in some other countries (14,19). To attribute these differences to specific environmental circumstances is difficult. Such an attempt is frequently reduced to the question of urban versus rural differences expressed by population density. The regional differences we observed were marked. It can be claimed, however, that a correlation (positive or negative) between incidence rates and population density in Baden-Wuerttemberg does not exist.

For the present study, we collected data covering 12.2% of all German children aged 0–14 years. The publication of the unexpectedly high incidence rates that have emerged could serve as the basis for improvements in structural planning in the national public health system. Obviously,

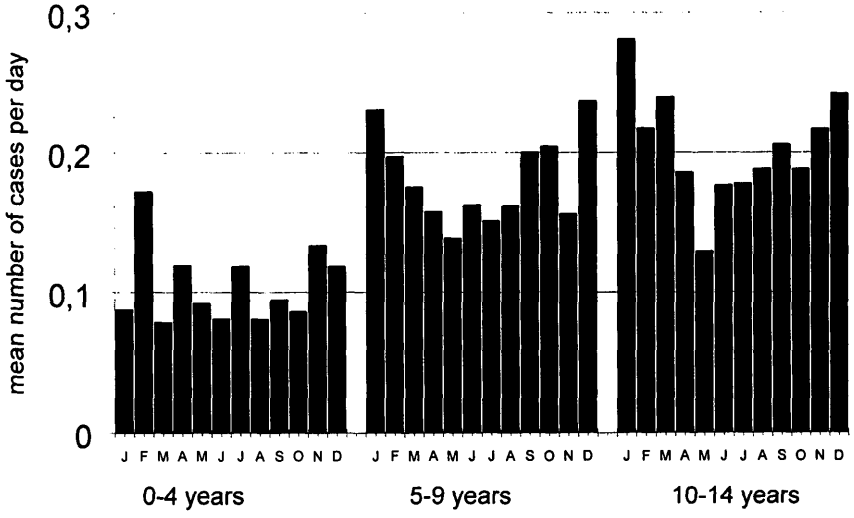

Figure 3—*Seasonal variation according to age-groups.*

an analysis of the secular trend in childhood diabetes can only follow after an extended period of observation.

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