Contents available at ScienceDirect

Diabetes Research and Clinical Practice

journal homepage: www.elsevier.com/locate/diabres

International Diabetes Federation

IDF Diabetes Atlas

Diabetes in the young – a global view and worldwide estimates of numbers of children with type 1 diabetes

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ARTICLE INFO

Article history:
Available online 1 December 2013

Keywords:
Diabetes
Incidence
Prevalence
Children
Type 1 diabetes
Type 2 diabetes

ABSTRACT

This paper describes the methodology, results and limitations of the 2013 International Diabetes Federation (IDF) Atlas (6th edition) estimates of the worldwide numbers of prevalent cases of type 1 diabetes in children (<15 years). The majority of relevant information in the published literature is in the form of incidence rates derived from registers of newly diagnosed cases. Studies were graded on quality criteria and, if no information was available in the published literature, extrapolation was used to assign a country the rate from an adjacent country with similar characteristics. Prevalence rates were then derived from these incidence rates and applied to United Nations 2012 Revision population estimates for 2013 for each country to obtain estimates of the number of prevalent cases.

Data availability was highest for the countries in Europe (76%) and lowest for the countries in sub-Saharan Africa (8%). The prevalence estimates indicate that there are almost 500,000 children aged under 15 years with type 1 diabetes worldwide, the largest numbers being in Europe (129,000) and North America (108,700). Countries with the highest estimated numbers of new cases annually were the United States (13,000), India (10,900) and Brazil (5000). Compared with the prevalence estimates made in previous editions of the IDF Diabetes Atlas, the numbers have increased in most of the IDF Regions, often reflecting the incidence rate increases that have been well-documented in many countries.

Monogenic diabetes is increasingly being recognised among those with clinical features of type 1 or type 2 diabetes as genetic studies become available, but population-based data on incidence and prevalence show wide variation due to lack of standardisation in the studies. Similarly, studies on type 2 diabetes in childhood suggest increased incidence and prevalence in many countries, especially in Indigenous peoples and ethnic minorities, but detailed population-based studies remain limited.

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0168-8227/$ – see front matter
http://dx.doi.org/10.1016/j.diabres.2013.11.005

1. Introduction

The incidence of childhood onset diabetes is increasing in many countries. There are clear indications of geographic differences in trends but the overall annual increase is estimated at around 3% [1]. Some 79,000 children worldwide are estimated to develop type 1 diabetes annually. There is some indication that incidence is increasing more steeply in some of the low prevalence countries in Europe and that, in relative terms, increases in Europe are greatest in young children [2]. There is also evidence emerging from high-incidence European countries that the increasing incidence trend seems to be levelling off which may give hope for the future [3–6].

The cause of type 1 diabetes remains unknown. There is clear evidence of a genetic predisposition and strong, but circumstantial, evidence for environmental factors triggering an autoimmune destruction of the beta cells leading to absolute dependence on insulin treatment.

Living with type 1 diabetes remains a challenge for the child and the whole family even in countries with access to multiple daily injections or an insulin pump, glucose monitoring, diabetes education and expert medical care. Poor metabolic control may result in the acute complications of hypoglycaemia and ketoacidosis, poor growth and chronic microvascular and macrovascular complications. Children are more sensitive to a lack of insulin than adults and are at higher risk of a rapid and dramatic development of diabetic ketoacidosis. Episodes of severe hypoglycaemia or ketoacidosis, especially in young children, are risk factors for structural brain abnormalities and impaired cognitive function which may cause schooling difficulties and limit future career choices [7,8]. Even in developed countries there is still significant excess mortality among children and young adults with type 1 diabetes diagnosed in childhood. A recent study from 10 European countries showed that there were twice as many deaths as expected from national age/sex specific mortality rates [9]. Over a third of the deaths could be directly attributed to diabetes, and these were mainly from metabolic disturbances, diabetic ketoacidosis and hypoglycaemia. Little is known about the mortality of type 1 diabetes in childhood in many developing countries where the prevalence of childhood diabetes is very low. It is suspected that many remain undiagnosed with the deaths attributed to malaria, gastroenteritis or other infections [10], while many that are diagnosed die within a year [11,12].

A small proportion of children diagnosed with type 1 diabetes have been shown to have monogenic diabetes and not auto-immune mediated diabetes [13]. A correct diagnosis is important as some forms of monogenic diabetes can be successfully transitioned from insulin to oral sulphonylurea medication.

Type 2 diabetes is also increasing in the childhood age group in many parts of world, especially among indigenous populations and in ethnic minorities [14], but few population-based studies are available and therefore will not be considered in detail in this review.

2. Methodology

Systematic searches of bibliographic databases were performed to identify studies that provided incidence or prevalence rates of type 1 diabetes in children as follows:

- Medline was accessed using OvidSP restricted to human studies published since 1980 and using [exp registries OR exp incidence OR exp prevalence) AND exp diabetes mellitus, insulin-dependent AND exp with the/ep [Epidemiology] sub-heading. If a country was not indexed in Medline then it was included in the search as a text word.
- PubMed using the Boolean search terms (incidence OR prevalence) AND diabetes AND.
- Published abstracts from recent international meetings including those in the Web of Science database were also searched.
- The titles and abstracts of all articles were reviewed and those likely to provide incidence or prevalence rates were obtained. The reference lists of articles were also scanned to check for further relevant publications. No restrictions were placed on the language of published articles.

The following criteria were then applied, although not necessarily in the order shown, to select the most suitable study in a given country:

- More recent studies, preferably covering periods into the 1990s.
- Studies with widest coverage within the country.
- Studies providing rates for the target age range of 0–14 years.
- Studies providing sex-specific rates for the 0–4, 5–9 and 10–14 year age groups.

Where appropriate, the numerators and denominators of rates from two or more registers within a country were combined to obtain pooled rates.

The majority of studies found by the literature search provided incidence rates rather than prevalence rates. An estimate of the number of cases in each country was obtained by multiplying the United Nations 2012 Revision population estimates for 2013 [15] in each of six age/sex subgroups (males or females aged 0–4, 5–9 or 10–14 years) by the corresponding estimated prevalence rate. Prevalence rates in each age group were obtained by averaging cumulative incidence rates for the five individual years in the age group. For example, the prevalence in the 5–9 age group was obtained as an average of:

Prevalence (age 5) = 5* (0–4 year incidence rate) + 0.5*(5–9 year incidence rate).
Prevalence (age 6) = 5* (0–4 year incidence rate) + 1.5*(5–9 year incidence rate).
Prevalence (age 7) = 5* (0–4 year incidence rate) + 2.5*(5–9 year incidence rate).
Prevalence (age 8) = 5* (0–4 year incidence rate) + 3.5*(5–9 year incidence rate).