

Executive Summary

Less than one-fifth of the people in the world who are diagnosed with diabetes receive the level of care required to maintain optimal health and quality of life. With the incidence of both type 1 and type 2 diabetes increasing at an alarming rate, this is a distressing statistic.

Despite the existence of effective national and international guidelines, too few children achieve the appropriate levels of care. Effective diagnosis and care for children with diabetes is no less than mandatory. Diabetes care for youth must be compliant with the United Nation's "Convention on the Rights of the Child", wherein it is recognized that the child is entitled to "enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health".

This document addresses key aspects of diabetes, its care and the costs of care in youth under the headings of Epidemiology; Organization of Care; Psychosocial Aspects; and Socioeconomic Aspects. The author's goals are to create a 'standard of care' which, although dependent on local and national potential and possibilities, serves as a benchmark for improved care to children and adolescents.

A recurring theme throughout these chapters is that knowledge of the goals of treatment of diabetes and the components of optimal diabetes care are now well established and well expressed in clinical practice guidelines from numerous sources worldwide. The gap that exists between knowledge and practical implementation of this knowledge is confounding progress in delivering optimal care to all individuals with diabetes including children.

The epidemiology of diabetes in children is shifting dramatically. An earlier onset of type 1 diabetes is now being observed, but it is the appearance and increasing incidence of type 2 diabetes in young people, once the sole domain of the adult, that is particularly disturbing. The increase of diabetes is closely related to socioeconomic and environmental factors together with a genetic influence. Overweight and obesity due to a shifting balance and quality of food

intake and energy output is a primary modifiable risk factor.

There is an enormous gap between knowledge and practice of optimal diabetes care, and a major factor in this gap is organization of care. The components of diabetes care being well established, it is clear that delivery of optimal care is the weak point in the process. Whatever the cause or etiology, without proper treatment diabetes is deadly and dangerous to health. Its potential severity warrants timely and effective treatment. Delivery of care has a number of confounding variables including insufficient financial resources to fund specialised healthcare personnel and in some regions, treatments including insulin; inadequate education of people with diabetes and healthcare providers to embrace the principles of optimal care; and lack of understanding of decision makers of the priority represented by diabetes care due to the impact on not only the individual but also society as a whole.

The psychosocial impact of diabetes is largely a hidden cost, but a cost that can undo even the best intentions for care. Young people with diabetes are particularly impacted by psychosocial issues because they are facing a future of living with diabetes at high risk if diabetes is not well controlled from the outset. Parents and other family members can also experience psychosocial impact from the ongoing stress associated with meeting the child's daily standards for care, and the price in human terms of poor care.

The impact of diabetes on children has particularly serious consequences for the socioeconomic health of not only the individual but also of all nations due to the compromises now and in the future for the child's education, future productivity and contributions to society. Barriers to investment in diabetes care must be replaced with informed investment based on an expanded base of evidence of the far-reaching effects and associated costs of diabetes in children.

In the face of the significant proportion of children with diabetes who are not receiving effective care – much less those who are never even diagnosed – it is an unfortunate fact that affordable and effective care

is actually achievable. Ways need to be found to expand access to specialized multidisciplinary teams at clinic level in as many communities as possible and to facilitate delivery of care in under serviced regions, thereby supporting broad-based implementation of optimal diabetes care strategies as developed by diabetes centers of excellence.

Healthcare decision makers worldwide can utilize the findings from studies to identify gaps in delivery of care and devise country-specific strategies to address shortcomings of every type (funding, education, resources, etc.) and bridge these gaps to meet the needs of their citizens with achievable diabetes management programmes. Strategies to improve diabetes care need to also transcend issues of education, early diagnosis and initiation of intensive treatment to take on primary prevention as an important priority.

As there is not yet a cure for diabetes, it is of paramount importance that the barriers to optimal

care of diabetes in children are addressed. For the child newly diagnosed with diabetes, it should simply be a part of that child's life and not its defining characteristic. For all children and their families, the right to long-term health and quality of life can best be supported with education and resources to live life well with diabetes – and to prevent diabetes where possible.

Finally, it is the author's hope that this Charter will provide the basis for much needed local, regional or country-wide improvements for children affected by diabetes and their families. Using this Charter as a tool with which to effectively introduce basic, standard or comprehensive care models – something that will require political will – is among its goals.

Conflicts of interest

The authors have declared no conflicts of interests.

Chapter one

Diabetes in children: epidemiology

Challenges

A diagnosis of diabetes in a child has typically been assumed to be type 1 diabetes, formerly classified as juvenile diabetes. However, in the last two decades, type 2 diabetes, once known as adult-onset diabetes, is being diagnosed with increasing frequency in children in countries around the world. The rapidly rising incidence of both type 1 and type 2 diabetes in young people is clear evidence that the 'rules' of diabetes epidemiology as we have known them are being broken. Type 1 is still the major form of diabetes in those under 10 yr old. It is preceded by a dangerous period, including diabetic ketoacidosis (DKA), from which children continue to die, as a result of ignorance and lack of education.

The increasing incidence of type 1 diabetes cannot solely be explained by genetics; environmental factors are influencing those with a genetic predisposition. In addition, type 2 diabetes, while strongly linked to genetics, is certainly attributable to the causative factors of diet, lifestyle and environment. Both forms are clearly linked to genes and environment. Habits of low physical activity coupled with high calorie, nutrient-deficient diets are becoming entrenched early in life.

In both developed and developing countries, common causative factors for both type 1 and type 2 diabetes appear to be converging under lifestyle and environment. The fact that these are modifiable risk factors provides optimism and incentive – to develop and implement comprehensive education and intensive management strategies to provide optimal diabetes treatment while at the same time focusing on arresting the current trend through prevention.

Introduction

Epidemiology describes patterns of disease by causation and geographical region, among other factors. Among developed nations, type 1 diabetes mellitus is one of the leading chronic diseases of childhood (1).

Both type 1 and type 2 diabetes can occur in children and adolescents, although type 1 is in most countries still more common and in fact is still often referred to as childhood or juvenile-onset diabetes.

Type 1 and type 2 diabetes present somewhat different disease patterns and require different management; people with type 1 diabetes require daily insulin, which is literally a life-saving treatment. Depending on clinical parameters and treatment success, individuals with type 2 diabetes may require insulin. Whether type 1 or type 2, all forms of diabetes pose potentially grave dangers to health.

In the 19th century, diabetes was uncommon and the incidence of childhood diabetes was relatively low and stable until the middle of the twentieth century. There has been an upturn in the incidence of type 1 diabetes in North America and northern Europe since the mid-1950s, a trend that is now observed in countries around the world. The rise has been too rapid for the explanation to be purely genetic. The causes are not yet completely understood, although various factors have been proposed such as rapid growth in early childhood, early exposure to certain food constituents (e.g. cow's milk hypothesis), enterovirus infection, chemicals and reduced exposure in early childhood to infective agents that contribute to development of a healthy immune system (the 'hygiene hypothesis') (2).

Antenatal risk factors associated with the development of childhood obesity, type 2 diabetes and cardiovascular disease include perinatal factors such as placental insufficiency and food deprivation in early pregnancy, as well as parental history of overweight and maternal overweight during pregnancy (3). Both babies that are small for gestational age and those who are large for gestational age have an increased risk of developing obesity, diabetes and associated cardiovascular disease (3, 4). Initial breastfeeding of the infant appears to protect against obesity in later life (5). Other postnatal factors that influence risk of obesity include infant overnutrition and rapid weight gain during the first few months of life (3). Recent data indicate that among preschool children, current overweight and obesity are stronger determinants of insulin resistance than birth weight (6). Significant differences in the seasonality of birth between children with diabetes and the general population have been observed in Britain, with a peak in early summer

and a trough in winter (7). Early exposure to cow's milk proteins, cereals, and heavy weight during infancy has been implicated as risk factors for type 1 diabetes.

Incidence of diabetes is rising rapidly in children

The incidence of both type 1 and type 2 diabetes is rising rapidly in children. The incidence of type 1 diabetes is increasing in children and youth by about 3% (range about 2–5%) per annum, with the greatest rate of rise in the under 4-yr-old age group (8). Type 2 diabetes was rare in this age group until recently, but the trend towards overweight and obesity is acting as a driver to the development of type 2 diabetes in youth, particularly after onset of adolescence. A rising incidence of type 2 diabetes in adolescents in Japan was first reported in 1990 (9). Further data show that type 2 diabetes is now seven times more common than type 1 in Japanese children, an increase in incidence of more than 30-fold over the past 20 yr, believed to be a function of changing diet and increasing obesity rates (10). Although certain ethnic groups such as South East Asians, Pacific Islanders, Hispanics, African-Americans and the Native North Americas (also called Aborigines or First Nations in Canada and North American Indians in the USA) are known to be at high risk, the changing patterns are not confined to these groups. The incidence is rising at a greater rate among immigrant populations.

Type 1 diabetes, still the most prominent form of diabetes seen in childhood, is an autoimmune disease characterized by destruction of the insulin-producing beta cells in the pancreas, leading to total or near total insulin deficiency (11). Type 1 diabetes often presents clinically with clear symptoms such as weight loss, excessive thirst, urination and lethargy: ketoacidosis may be observed in the child who has been experiencing these symptoms for some time before medical help is sought. The child with type 1 diabetes will require lifelong insulin replacement.

In type 2 diabetes, the major factor is insulin resistance; diabetes occurs when beta cells are no longer able to produce enough insulin to overcome this resistance. Contributors to insulin resistance include genetic factors, obesity (itself at least partly genetically driven), reduced physical activity, high or low birth weight and infections. The implications of high birth weight, maternal obesity and gestational diabetes for development of metabolic syndrome in childhood are a current subject of research (12). Dietary changes such as greater consumption of high-fat, high-energy foods, lower-fiber and processed foods and foods prepared outside the home are also believed to play a large part in the rapid increase in incidence of type 2 diabetes that we have seen in recent years.

It can be difficult to distinguish type 1 from type 2 diabetes in children and adolescents. Identification of type 1 or type 2 can be supported by the presence of beta cell-related autoantibodies in type 1, but the absence of autoantibodies does not rule out type 1 diabetes as they are lacking in 5–10% of people at diagnosis. Moreover, youth with type 2 diabetes frequently display islet autoantibodies and type 2 diabetes in the young may result from an interplay of insulin resistance and autoimmunity (13–15). Although children with type 1 diabetes are typically not overweight, the population of many countries is becoming more overweight. It is estimated that as many as a quarter of children with type 1 diabetes in these countries may be overweight at the time of diagnosis (16).

This may influence the presentation of diabetes in young people. In addition, there is evidence that type 1 and type 2 diabetes may even be one and the same disorder of insulin resistance; in the case of type 1, beta cell destruction precedes problems in production and resistance, whereas in type 2, insulin production remains intact for a longer period of time and resistance develops on the basis of other (perinatal and weight dependent) cofactors (15).

Table 1 shows the characteristic features of type 1 compared with type 2 diabetes in young people, as derived from the International Society for Pediatric and Adolescent Diabetes (ISPAD) Consensus Guidelines for the Management of Type 1 Diabetes Mellitus in Children and Adolescents (2000) (17).

In addition, there are several other less common forms of diabetes in developing countries, including fibrocalculus diabetes and malnutrition-related diabetes, shown in Table 2. In a paper from Bangladesh that studied children with diabetes under the age of 18 yr, 30.4% had type 1 diabetes, 29.6% had fibrocalculus pancreatitis, 38.5% had malnutrition-modulated diabetes and 1.6% of the children had type 2 diabetes (18).

There are also an increasing number of monogenic conditions associated with diabetes in youth (previously referred to as Maturity Onset Diabetes in the Young) or in the neonatal period that have been recognized. When there is a strong family history of early onset diabetes suggestive of an autosomal dominant inheritance, monogenic forms should be seriously considered, e.g. HNF-1 and 4 mutations, glucokinase mutation (19).

Type 1 diabetes: current global data

In 2006, the number of children globally aged 0–14 yr with type 1 diabetes was estimated by the International Diabetes Federation to be 440 000, with an annual increase of 3% per annum and 70 000 newly diagnosed cases a year. More than one quarter of these, newly diagnosed cases come from South East Asia and more than one fifth from Europe. The

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Table 1. Characteristic features of type 1 compared with type 2 diabetes in young people

Characteristics	Type 1	Type 2
Age	Throughout childhood	Pubertal (or later)
Onset	Most often acute, rapid	Variable: from slow, mild (often insidious) to severe
Insulin dependence	Permanent, total, severe	Uncommon, but insulin required when oral hypoglycaemic agents fail
Insulin secretion	Absent or very low	Variable
Insulin sensitivity	Normal	Decreased
Genetics	Polygenic	Polygenic
Race/ethnic distribution	All groups, but wide variability of incidence	Certain ethnic groups are at particular risk
Frequency (% of all diabetes in young people)	Usually 90%+	Most countries <10% (Japan ~80%)
Associations		
Autoimmunity	Yes	No
Ketosis	Common	Rare
Obesity	No	Strong
Acanthosis nigricans	No	Yes

Source: International Society for Pediatric and Adolescent Diabetes (ISPAD) Consensus Guidelines for the Management of Type 1 Diabetes Mellitus in Children and Adolescents (17).

increase in incidence of type 1 diabetes has been observed in countries with both high and low prevalence, with an indication of a steeper increase in some of the low-prevalence countries. No region is exempt from type 1 diabetes (Fig. 1) (8). The increase is not readily explained by shifts in genetic susceptibility because it has happened so quickly, but the search continues for explanations.

A 350-fold variation was observed between 1990 and 1994 among 100 populations worldwide in the incidence of type 1 diabetes in children up to the age of 14 yr. The incidence ranged from 0.1 per 100 000 per annum in China and Venezuela to 36.8 per 100 000 in Sardinia and over 40 in Finland. The lowest incidence was generally seen in China and South America. Eighteen of 39 European populations surveyed had an intermediate incidence of diabetes ranging from 5.0 to 9.99 per 100 000 population. A very high incidence, defined as greater than 20 per 100 000, was seen in Sardinia, Sweden, Norway, Portugal, the UK, Canada and New Zealand (20).

European data

The EURODIAB 2000 survey contains data from 44 centres representing most European countries. The data cover new cases in children and adolescents up to the age of 15 yr between 1989 and 1994. In general, the incidence rates are higher in northern and NW Europe and lower in southern, central and eastern Europe; this range is perhaps due to different exposure to infections or other environmental factors. The rates range from 3.2 per 100 000 in Macedonia, 5.0 in Romania and 5.4 in Poland to 40.2 per 100 000 in Finland, 36.6 in Sardinia and 25.8 in Sweden. Pooled incidence rates during this period show a 6.3%

increase for children aged 0–4 yr; 3.1% for children aged 5–9 yr and 2.4% for those aged 10–14 yr (21).

In southwest England, an overall crude incidence rate of type 1 diabetes was observed of 14.9 per 100 000 population in youth up to and including the age of 14 yr between 1975 and 1996. During this time there was a marked increase in diabetes in those aged under 5 yr, which is of concern because it can be difficult to maintain good glycaemic control in this age group, a crucial factor in minimizing the risk of development of complications (22). Among children aged 0–14 yr diagnosed with type 1 diabetes and living in the city of Bradford, UK, there was an annual increase in incidence of 6.5% in south Asians compared with an average annual increase in incidence of 4.3% in all children (23).

Data from the Middle East and Australasia

Prospective data collection in Kuwait between 1992 and 1997 showed an incidence in children under the age of 15 yr of 15.4 per 100 000 in 1992, rising dramatically to 20.9 per 100 000 5 yr later. The rise was particularly steep in those aged 5–9 yr (24).

Figures from New South Wales show that the age-standardized incidence of type 1 diabetes among children up to the age of 14 yr rose by 28% between 1992 and 1996. By comparison, the total number of children in this age group rose by 0.5% (25).

In China, data collected for children under 15 yr of age from 22 centers showed an overall corrected incidence of 0.51 per 100 000; this was the lowest incidence recorded in the World Health Organization Multinational Project for Childhood Diabetes (DiaMond) project. There was a 10-fold difference between the different centers, with higher rates in the

Table 2. Other specific types of disorders of glycemia International Society for Pediatric and Adolescent Diabetes (ISPAD)

- A. Genetic defects of β -cell function
- B. Genetic defects in insulin action
Type A insulin resistance, leprechaunism, Rabson-Mendenhall syndrome, lipotrophic diabetes, others
- C. Diseases of the exocrine pancreas
Pancreatitis, trauma/pancreatectomy, neoplasia, cystic fibrosis, hemochromatosis, fibrocalculous pancreatopathy, others
- D. Endocrinopathies
Acromegaly, Cushing syndrome, glucagonoma, pheochromocytoma, hyperthyroidism, somatostatinoma, aldosteronoma, others
- E. Drug or chemical induced
Vacor, pentamidine, nicotinic acid, glucocorticoids, thyroid hormone, diazoxide, beta-adrenergic agonists, thiazides, dilantin, alpha-interferon
- F. Infections
Congenital rubella, cytomegalovirus, coxsackie B4
- G. Uncommon forms of immune-mediated diabetes
Anti-insulin receptor antibodies, autoimmune polyendocrine syndrome deficiencies I and II, 'stiff-man' syndrome
- H. Other genetic syndromes sometimes associated with diabetes
Down's syndrome, Klinefelter's syndrome, Turner's syndrome, Wolfram's syndrome, Friedreich's ataxia, Huntington's chorea, Laurence-Moon-Biedl syndrome, Myotonic dystrophy, Porphyria, Prader-Willi syndrome

Source: International Society for Pediatric and Adolescent Diabetes (ISPAD) Consensus Guidelines for the Management of Type 1 Diabetes Mellitus in Children and Adolescents (17).

north. By ethnic group, there was a sixfold difference between the highest (Mongol) and lowest (Zhuang) incidences. Variations in eating habits and lifestyles could explain some of this diversity but there may also be a genetic element. China is much more genetically diverse than Europe (26).

DKA: a life-threatening but preventable complication

DKA is the leading cause of mortality (usually stemming from cerebral oedema) and morbidity in children with type 1 diabetes. DKA in children develops quickly and is, much more than in adults, related to severe morbidity and sequelae of associated medical complications. There is wide geographic variation in the frequency of DKA at diabetes onset: reported frequencies range between 15 and 67% in Europe and North America and may be more common in developing countries. DKA at onset of type 1 diabetes is more common in children under the age of 4 yr, children without a first-degree relative with type 1

diabetes, and those from low incidence countries, as well as those from families of a lower socioeconomic status (27). The described changing patterns of presentation of diabetes have also changed the incidence and severity of DKA in children (21).

Type 2 diabetes in children and adolescents

Recent data indicate an escalating incidence of type 2 diabetes in children and adolescents worldwide. Although type 2 diabetes used to be a condition in those over 40 yr of age, the increase and decrease of onset-age now hits children even before their teens. Among the primary risk factors for type 2 diabetes are increased weight and lack of physical activity. Over the past decade, there have been profound changes in the quality, quantity and source of food consumed in many developing countries. Processed food, for instance, typically offers greater caloric content but lower nutritional value, at a lower cost. An increasingly sedentary lifestyle and limited physical and sporting activities in school also play a part in the development of overweight and obesity. In addition, less well known factors play an important role such as sleep deprivation, factors that disturb endocrinological pathways, improved conditions of living (such as ambient temperatures in houses) and medicines (28).

Worldwide, overweight and obesity affect an estimated 10–20% of children. Due to the fact that obesity once developed is a chronic condition, there is thus an increasing tendency to develop type 2 diabetes and cardiovascular disease (29).

The complex pathophysiology of type 2 diabetes is not limited to factors of weight and physical activity. Trends in type 2 diabetes are strongly related to environmental factors, some of which are already in effect in the perinatal period. Children with overweight or diabetic mothers are more likely to have diabetes themselves. The nature of foetal and infantile nutrition is associated with later development of type 2 diabetes: poor nutrition at these stages of life is detrimental to the proper development and function of the pancreatic β cells and insulin-sensitive tissues, potentially leading to insulin resistance under the stress of obesity. The thrifty genotype hypothesis proposes that defective insulin action *in utero* results in decreased foetal growth as a conservation mechanism but at the cost of obesity-induced diabetes in later childhood or adulthood (30). The prevalence of obesity is 50% higher among never-breastfed children compared with breastfed children, and the duration of breastfeeding is inversely correlated with the risk of development of obesity (3).

Most children with type 2 diabetes are overweight or obese at the time of diagnosis; ethnic background is understood to tie in to the propensity to develop type 2 diabetes in children, thus a child from a high-risk

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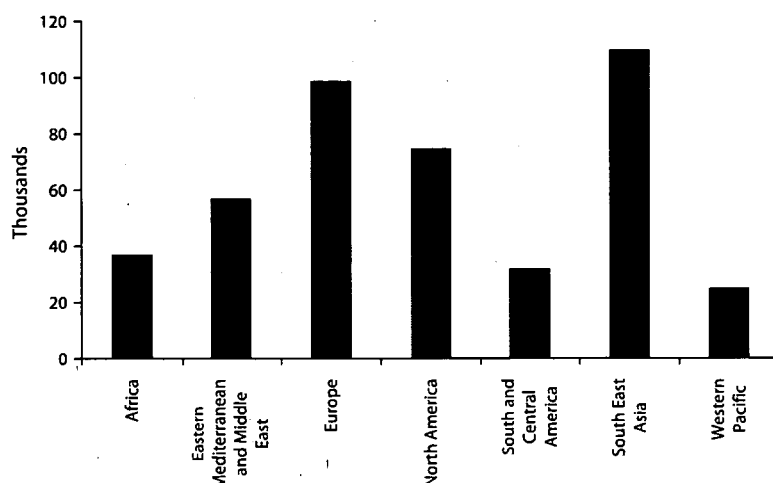


Fig. 1. Estimated number of cases of type 1 diabetes by region. Source: International Diabetes Federation World Atlas of Diabetes (2006) (8).

ethnic group such as South Asian or Pacific Islander may develop type 2 diabetes at a lower Body Mass Index than would a child of Caucasian background. Unlike those with type 1 diabetes, polyuria, polydipsia and weight loss are usually absent or mild. Major risk factors in addition to overweight or obesity include a family history of type 2 diabetes, hypertension, lipid disorders or diagnosis of acanthosis nigricans or polycystic ovary syndrome. The peak age of presentation is mid-puberty, coinciding with a peak increase in growth hormone secretion. This growth hormone tips the balance in individuals with a genetic predisposition to insulin resistance and environmental risk exposure (16).

Recent data on type 2 diabetes show increases in several parts of the world:

North American data

About 94% of children in the USA with type 2 diabetes were found in one survey to belong to minority communities, and the mean age at diagnosis was 12–14 yr. A substantial proportion of type 2 diabetes is estimated to be misclassified, undiagnosed or underreported. The most dramatic figures come from the Pima Indians in Arizona. In the years 1992–1996, the prevalence of type 2 diabetes was 22.3 per 1000 for 10–14 yr olds and 50.9 per 1000 for 15–19 yr olds. Between the years 1967–1976 and 1987–1996, the prevalence increased four- to fivefold for both age groups. Among American Indians and Alaskan Natives aged 15–19 yr, the prevalence increased by 54% between 1988 and 1996. Among white and Hispanic populations of San Antonio, Texas, type 2 diabetes represented 18% of all new cases of diabetes from 1990 to 1997 (31, 32).

Recently new data from the USA became available from the SEARCH for Diabetes Youth Study Group

(33). The overall incidence was 24.3 (per 100 000 patient years; previous study 16.5 in early 1990s) confirming the overall increase seen in other countries. Among children younger than 10 yr, most had type 1 diabetes irrespective of their race or ethnicity, with the highest rates in non-Hispanic white youth (18.6, 28.1 and 32.9 for the age groups 0–4, 5–9 and 10–14 yr old respectively). Even in adolescents from non-Hispanic, Hispanic and African-American descent, type 2 diabetes was relatively infrequent, but high rates were found in 15- to 19-yr-old minority groups (17.0–49.4 per 100 000). These data showed the continuous increase of diabetes among US youth and the imminent shift of type 2 diabetes towards younger age. In total, 15 000 youth are diagnosed with type 1 diabetes annually in the USA and 3700 with type 2 diabetes (33).

The First Nations people of Canada represent 3% of the country's population. By 1998, it was estimated that 10–20% of new cases of diabetes were presenting among these people (34).

European data

Data from 2002 estimate that there were a total of 20 000 children with diabetes in the UK at that time, and forecast that the incidence of type 2 diabetes was likely to rise substantially if the UK followed the example of the USA. According to these findings, type 2 diabetes was not limited to high-risk ethnic groups such as South East Asians (35).

Australasian data

Data from Western Australia show an increase of 27% in the incidence of type 2 diabetes in youth between 1990 and 2002. Fifty three per cent of these young people were of indigenous origin. Population-based recommendations include improving dietary intake

and increasing physical activity, including activity during school hours; these strategies should involve the whole family (36).

The incidence of type 2 diabetes is thought to be higher than that of type 1 diabetes among Japanese children. A programme has been in place since 1974 to collect early morning urine samples from schoolchildren. Testing has detected a number of children who have type 2 diabetes but are asymptomatic: 84% of children with type 2 diabetes were 20% or more overweight, and 57% had a family history of type 2 diabetes. Among primary schoolchildren, the incidence is 0.78 per 100 000 children, and among junior high schoolchildren, the incidence rises to 6.43 per 100 000 children (37).

Similarly, a mass screening program for diabetes and proteinuria has been underway for students in Taiwan, using urine testing and blood testing as appropriate. The overall rate of newly identified diabetes, as reported in 2003, was 12.0 per 100 000 students, with considerably higher rates in those aged 13–15 yr compared with those aged 6–9 yr. Compared with controls, those with type 2 diabetes had a higher body mass index, higher blood pressure, were older and were more likely to have a family history of diabetes (38).

A recent review of published data testifies to the global spread of type 2 diabetes in children and adolescents. The issue of type 2 diabetes is not limited to certain ethnic groups or to particular regions but has become almost universal. There appears to be a close relationship between rates of type 2 diabetes in adults and the eventual appearance of type 2 diabetes in adolescents. Therefore, attention to the epidemiology of type 2 diabetes in adults may help to predict the emergence of type 2 diabetes in adolescent populations, with implications for screening programs and obesity prevention programs (39).

Screening for type 2 diabetes

Type 2 diabetes develops in a gradual but persistent manner. A diagnosis of diabetes is preceded by a period of glucose intolerance in which glucose levels increase but remain lower than guideline threshold levels. These threshold levels have been developed in relation to adults, but are also used for children, as specific data for this group are lacking.

From studies in adults it is known that there may be a significant time lag to the onset of type 2 diabetes. The average adult with diabetes has experienced aberrant glucose values for 7–11 yr. During this period, vascular disease with accompanying complications may have already developed. Thus, it is of extreme importance to identify both those at risk for diabetes (primary prevention) and those with diabetes as early as possible, preferably before complications arise and pathophysiological processes become irre-

versible (secondary prevention). Screening can be applied for primary prevention, but also has a role in secondary prevention.

It is therefore important to screen for diabetes in children and youth at risk. A number of professional organizations around the world, including the American Diabetes Association, recommend testing for type 2 diabetes in children over the age of 10 yr who are overweight (body mass index >the 85th percentile) and who have any two of the following risk factors: a family history of type 2 diabetes in a first or second-degree relative; racial or ethnic high risk (such as American Indian, African-American or South Asian); or signs of insulin resistance or associated conditions.

Several (inter)national guidelines contain similar screening recommendations aimed at primary or secondary prevention; it is important to apply such recommendations as they may reduce the burden of diabetes (40).

Complications of diabetes in children

As described in the previous paragraphs, good diabetes care prevents the development of complications (secondary prevention). Despite screening for diabetes and the availability of adequate treatment guidelines, some people with diabetes (both type 1 and type 2) will unfortunately develop both medical and psychosocial complications due to lack of access to comprehensive care, inadequate practice of care routines, or lack of opportunity or ability to implement available care strategies into daily routines. The early onset of the disease in children places them at a higher risk to develop such complications at an ever younger age.

Complications are being seen at a younger age now that the onset of diabetes is occurring earlier. Thus, in the USA, 40% of children and adolescents with type 2 diabetes were observed to have microalbuminuria (MAU) after a diabetes duration of only 18 months; among Pima Indians diagnosed with diabetes during childhood, 22% had MAU at diagnosis. Studies in these special populations showed that (except for retinopathy) children have no protective or delaying factors that protect them from complications. On average, complications occurred after a similar duration than those in adults (41).

The complications of diabetes can be very severe, leading to early onset of cardiovascular disease and premature death. Other complications that are seriously detrimental to the health and quality of life of people with diabetes include blindness, kidney failure and neurological damage.

Complications are not limited to medical concerns; psychosocial complications can prevent optimal diabetes care and the achievement of treatment goals. Diabetes care poses considerable demands on children

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and their families. In addition to the normal developmental challenges of childhood and adolescence, the additional burden of diabetes, and especially intensive management, may be difficult for many children to deal with. More intensive treatment coincides with increased psychological pressure on children with diabetes and family members. This may add to the development of psychosocial complications such as adjustment problems, issues with self-esteem, depression, and particularly in adolescent girls, eating disorders. In one study in adolescents and young adults who had diabetes since childhood, about one-third needed either psychological or psychiatric counselling after (on average) 15 yr following onset of their diabetes (42).

Studies from Sweden showed that, despite the comprehensive care delivered, more than 50% of patients with childhood onset type 1 diabetes developed detectable diabetes complications after an average 12 yr of diabetes. Inadequate glycemic control, including in the first 5 yr of treatment, accelerated this (43).

A study reported in 2006 showed that, of 1433 people with type 1 diabetes and 68 with type 2 diabetes, all under the age of 18, those with type 1 diabetes had a longer duration of disease (6.8 vs. 1.3 yr) and a higher median glycosylated hemoglobin (8.5 vs. 7.3%). Significantly more people with type 2 diabetes were obese (56 vs. 7%). Retinopathy was observed in 20% of those with type 1 diabetes; MAU and hypertension were observed in 28 and 36%, respectively, of those with type 2 diabetes. These high rates of serious complications suggest that children as well as adults with type 2 diabetes should be screened for complications at the time of diagnosis. The data also argue for screening of at-risk adolescents for type 2 diabetes because early treatment may avoid or reverse complications (44, 45).

Clearly, prevention of complications is preferable to treatment of complications. More intensive treatment may contribute to the reduction of complications in children with diabetes. 'Intensive' treatment aims to maintain blood glucose as close to normal as possible on a continuous basis, and is distinguished from 'conventional' treatment by increased vigilance in blood glucose testing, responsive adjustments to insulin dosage based on current blood glucose level as well as food intake and exercise, and regular visits to the diabetes healthcare team. Among those with type 1 diabetes treated intensively, there was a decrease in nephropathy and retinopathy between 1990 and 2002 (46).

Conclusion

- (i) The incidence of type 1 diabetes is rising in children and adolescents, and there is a shift in that children are being diagnosed at younger ages.

- (ii) Type 2 diabetes is increasing rapidly, largely driven by lifestyle factors such as overweight and obesity, and is being seen in developing countries as lifestyle habits become inappropriately urbanized and modernized.
- (iii) Diabetes represents a huge burden to the individual, the family and to society. Early and aggressive treatment must be strived for, and lifestyle changes need to be made possible in order to prevent diabetes from escalating out of control worldwide. Only by achieving good control can the complications be prevented or minimized.
- (iv) There are still many gaps in the data on type 1 and type 2 diabetes in children and adolescents. These gaps need to be addressed to understand the epidemiological patterns of disease and the consequences of these patterns to facilitate appropriate management and optimal allocation of health care funding.

Recommendations

- (i) Fill in the gaps regarding the incidence and prevalence of type 1 and type 2 diabetes, in order to more fully understand the magnitude and impact of the problem.
- (ii) Initiate local, regional or nation-wide studies on the epidemiology of diabetes.
- (iii) Fill in the gaps on the incidence and cost of the complications of diabetes.
- (iv) Use this more complete knowledge for effective planning for resource allocation, comprehensive education, early detection/intervention and prevention strategies.
- (v) Build on this knowledge to formulate prevention messages for children and youth at risk of developing type 2 diabetes and their families, emphasizing nutrition and exercise strategies to maintain a healthy weight and overall health from infancy onward.
- (vi) Stimulate education and knowledge on the most important cause of death in (type 1) diabetes: DKA, by implementing education and awareness programmes.
- (vii) Develop national plans for diabetes care as suggested by the United Nations Resolution on Diabetes, with specific focus on childhood diabetes.

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Chapter two

Diabetes in children: organization of care

Challenges

Children and adolescents face significant burdens on health and quality of life associated with the early appearance of diabetes. The increased risk of complications that accompanies a longer disease duration further impacts the potential for optimal care and long-term good health.

Early detection, vigilant management, improved delivery of and access to ongoing care and consistent self-management skills are key strategies for preventing or lessening much of the burden of diabetes. Optimal diabetes care for children and adolescents is complicated by the fact that the daily demands of diabetes management must be superimposed on the already demanding challenges of physical and emotional growth. Diabetes care for children should thus be a customized team effort of specialists who are equipped to deal effectively with not only medical needs, but also the unique educational, nutritional, physical activity and behavioural needs of the child or adolescent.

However, the organization of care for diabetes, particularly in general practice where a significant proportion of care takes place, varies extensively, affected by the availability of both financial and personnel resources. Practice, patient and organizational factors all influence the level of care of people with diabetes.

Resource allocation to support optimal organization of diabetes care is a function not only of availability of funds, but also of the understanding of policy makers that diabetes care constitutes a significant health care priority. Education in support of diabetes care thus extends beyond the individual with diabetes and the physician to high-level decision makers.

Introduction

All people with diabetes deserve optimal care, but in general the quality of care remains suboptimal worldwide (1). Although adequate guidelines exist that define standards of care for every aspect of type 1 and type 2 diabetes in children and adolescents, both national and international in scope [such as those from the American Diabetes Association (ADA) 2005 (2), International Diabetes Federation (IDF) 2004 (3)

and 2005 (4), and International Society for Pediatric and Adolescent Diabetes (ISPAD) 2000 (5)], they are not always followed. Barriers to implementation of guideline recommendations include (Table 1) not just a lack of resources, including adequate numbers of health care professionals and adequate amounts of medications, but also a general lack of understanding about diabetes and of the burden that it represents to the child, his or her family, health care providers and the community.

Many children and adolescents are facing a greater burden associated with early appearance of diabetes and an increased risk of complications with longer duration of disease. Early detection, improved access to and delivery of care and better self-management are key strategies for preventing much of the burden of diabetes.

Several lines of evidence show the importance of good diabetes care to improve the quality of life, reduce the chances for acute and chronic complications and create the basic conditions to reach an independent life with diabetes. Excellent outlines for education are included in a number of clinical practice guidelines and in separate articles.

Diabetes care as recommended in clinical practice guidelines requires access to appropriate medical care and medication, but the pathophysiology and nature of the disease (with constant changes in glucose levels) requires constant adjustments to be made by the child in coordination with the parents, in turn requiring constant decisions on medication, food choices, activities, etc. Diabetes self-management education for every child and their family is thus necessary to achieve appropriate regulation of the disease.

Additional challenges of treating children with diabetes

Diabetes in children and adolescents presents particular challenges beyond those involved in the management of diabetes in adults. These include management of the disease while maintaining normal physical and psychological growth and development, dealing with family dynamics (the entire family may be viewed as

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Table 1. Barriers to implementation of diabetes clinical practice guidelines

Lack of resources: primary care and specialist health care professionals from various disciplines, diabetes educators.
Lack of medication: supplies of diabetes medications including insulin are variable and unreliable in some regions.
Lack of understanding and knowledge of full impact of diabetes on the child and need to pursue comprehensive care.

the patient when the child has diabetes) and organizing care for the child with diabetes when he or she is outside the home environment. The goal of treatment is to meet these challenges in the management of every child with diabetes, worldwide. Good organization of care helps to make best use of the resources available, and to deploy these resources for the maximum benefit of children with diabetes.

Among the first things required for proper diabetes care is collection of data, which can not only serve as the basis for daily diabetes care, but are also important to create a database on outcome parameters on either a local or a national scale. Only through proper collection and analysis of such data will political awareness and change become possible.

Data collection

To assist with planning and optimal use of resources, there is a need for more complete data not only on the incidence and prevalence of diabetes but also on patterns of disease and treatment outcomes. The value of having data on patterns of disease is exemplified by several collaborative multicenter studies such as those conducted in Japan which showed two distinct types of diabetes among Japanese children (6); multicenter studies in Denmark (7) and Germany (8) and international studies (9); all of which showed that only a minority of children and adolescents reach treatment goals, even within sophisticated health care systems.

There are major gaps in knowledge worldwide concerning the impact of diabetes. A national register by country would be useful in estimating the care required. It would also be useful to provide governments and key stakeholders (clinicians, professional associations and researchers) with appropriate data to support efforts to work towards improved diagnosis and care.

Good diabetes management requires people with diabetes to take an active role in their self-care. It is important at the time of diagnosis to provide education about what to expect in diabetes care so that the child and family feel positive and empowered. The ADA recommends as the first step to build a health care team (ideally comprising a pediatric

endocrinologist, diabetes educator, dietician, mental health professional, ophthalmologist, exercise specialist, podiatrist, pharmacist) and develop a good working relationship with the team.

Current guidelines such as those from the ADA, ISPAD and Asian Pacific Endocrine Group recommend that the child who is newly diagnosed with type 1 diabetes be evaluated by a diabetes team who can provide pediatric-specific education and treatment. At the time of diagnosis, a full baseline history should be taken, both of general health parameters and details relating to onset of diabetes. A number of measurements need to be monitored from diagnosis onwards; these are detailed in the Appendix 'Components of the initial diabetes visit and continuing visits'(2).

In addition, the following data deliver a minimal dataset for a registry:

- (i) The number of patients, and their age distribution;
- (ii) Type of diabetes, and treatment required (insulin, diet/lifestyle, antidiabetic medication);
- (iii) Mortality from diabetes and its causes [diabetic ketoacidosis (DKA), hypoglycemia, complications, coinciding diseases and conditions];
- (iv) Morbidity (such as complications, and need for hospitalization);
- (v) Access to care (ideally, 24-h access);
- (vi) Expertise of care provided (multidisciplinary, specialist, primary care, age-specific); and
- (vii) Quality of care achieved (frequency of follow-up, glycated hemoglobin levels, incidence of complications).

Structured collection of these clinically useful criteria could be organized around a simple-to-use computer database; many clinics are equipped to support this level of data collection on a patient-by-patient basis. These databases could be initiated at a community level rather than at a national level. The data obtained would help to pinpoint areas for improvement in diagnosis and care on both a national and local level while providing important baseline information for research. For example, changing a parameter in diabetes care and then evaluating the outcome could be used to inform further and more appropriate modifications to care.

Levels of care

The IDF, in its global guideline for treatment of type 2 diabetes (4), defined three levels of care. These three levels have been described in recognition of varying levels of available resources in many parts of the world, and are also applicable to the management of people with type 1 diabetes (Table 2).

Table 2. Levels of diabetes care

<p>Minimal care. The lowest acceptable level of care provided in health care settings with very limited resources (drugs, personnel, technologies and procedures). It should nevertheless provide access to adequate insulin, diabetes education, monitoring and medical care.</p> <p>Standard care. This level of care is provided in most nations with a well developed service base and with health care funding systems in place. It should provide evidence-based, cost-effective care to reduce complications and achieve full self-management.</p> <p>Comprehensive care. This level of care provides the most up-to-date and complete range of health technologies available to achieve best possible outcomes and quality of life.</p>
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Source: International Diabetes Federation Global Guideline for Type 2 Diabetes (4).

Data collection and outcomes evaluation have confirmed that even in comprehensive care systems, many children with diabetes do not reach the treatment targets.

In 21 diabetes centres in 18 countries participating in The Hvidøre Study Group studies (www.hvidoeregroupp.org), only one-third of the patients reached such recommended goals in glycaemic control, emphasizing the need for structured diabetes teams, data collection and analysis (9).

The morbidity and mortality (expressed as lost years or as quality adjusted years) of diabetes are still significant and urges for improvement of care, with a central role of the individual with diabetes and the family, aimed at prevention of complications and based on the needs and wishes of the family.

In several countries, poor outcomes in diabetes management in the young have led to centralization of diabetes care. Knowledge on treatment and outcomes is concentrated in regional centres and centres of excellence, and then used to reach out to comprehensively improve care in all regions. The need for a multidisciplinary team, the central role of education and the overlying need for better metabolic control depend on such centres. In developing care systems, such centres may develop spontaneously based on perceived need for centralized policies and action. In more comprehensive care systems such as in Europe, marginal outcome data force health care providers to redesign diabetes care which in some countries is resulting in an orchestrated center development.

Early diagnosis and intervention saves lives

Funding inadequacies affect care at all levels and lead to preventable morbidity and death. Children and adolescents with diabetes are still dying from DKA and hypoglycemia, and children with type 1 diabetes

are at especially high risk for DKA (10). Those who have poorly controlled diabetes as a result of poor access to care and diabetes education, those who lack family support or stability and families who cannot afford adequate medical care are the most vulnerable. Medical attention for these children may be delayed because of lack of knowledge or resources so that the child is more severely ill when they do present (11). A recent study showed that children with DKA had significantly more medical encounters in the week before diagnosis compared with those without DKA (12). DKA at diagnosis may represent failure to detect the signs and symptoms, it may represent more fulminant disease or it may be that the symptomatology is difficult to recognize.

Greater efforts must be made to support early recognition and intervention by ensuring more widespread professional and public education about diabetes, emphasizing recognition of early symptoms, in addition to improving access to proper care. A study in Italy showed that it is possible to prevent most episodes of DKA at diabetes onset using a relatively simple educational approach that targeted both families, school personnel and physicians (13).

In a new report, these authors showed that, 9 yr after this project, there is still a strong and lasting positive effect: virtually no DKA exists in the study region. The authors suggest repeating the initiative every 5 yr to ensure optimal knowledge in the community. ISPAD is now considering implementing this strategy in other countries (14).

Awareness of preventable complications in diabetes improves overall health and quality of life

Prevention of both acute and chronic complications because of diabetes is only possible when basic needs for care are met and glycaemic targets are maintained. If basic care is not being met, diabetes will progressively destroy the lives of those affected with accompanying impact on their families. Although primary prevention remains difficult, optimal care helps to prevent or delay the complications because of diabetes.

The Diabetes Control and Complications Trial (DCCT) confirmed that good glycaemic control and intensive treatment for diabetes (type 1) are necessary to prevent and slow the development and progress of diabetic complications (15, 16). The long-term follow-up of the DCCT cohort in the Epidemiology of Diabetes Interventions and Complications study similarly showed persistent beneficial effects on albumin excretion and a reduction in the incidence of hypertension 7–8 yr after the end of the DCCT (17). These findings suggest that a period of intensive treatment has extended benefit in comparison to

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conventional treatment, and that intensive treatment should be initiated for type 1 diabetes as soon as possible. Lower glycosylated hemoglobin is also significantly associated with better adolescent-rated quality of life and a lower perceived family burden as assessed by parents and health care professionals (18). Similar data were found for type 2 diabetes in several landmark studies in adults including the United Kingdom Prospective Diabetes Study (UKPDS). Thus, efforts to achieve optimal metabolic control are justified both on clinical grounds and quality of life grounds.

Access to care

Access to care is crucial not only to early diagnosis of diabetes and initiation of treatment, but also to effective long-term management focusing on maintaining glycemic control and avoiding complications. For children with type 1 diabetes in particular, their life depends on regular access to care and treatment. Education about diabetes, including recognition of early symptoms and urgency of initiating medical care, plays a central and crucial role in early access to care.

It is essential to ensure access to care at the community level to facilitate

- (i) Diagnosis of diabetes and identification of type 1 vs. type 2 diabetes;
- (ii) Initiation of insulin and other medications for acute and long-term management of diabetes;
- (iii) Equipment and advice for monitoring of glucose levels;
- (iv) Immediate care of diabetic emergencies;
- (v) Initiation of education and counselling about the importance of glycemic control; and strategies to support this, including medication, diet and lifestyle strategies;
- (vi) Education about the complications of diabetes, and about strategies to prevent their development;
- (vii) Counselling to provide medical and psychosocial help to the person with diabetes and family; and
- (viii) Provision of facilities to screen for diabetes, for instance in those considered to be at high risk because of their ethnicity or family history.

Deficiencies in diabetes management and their consequences

Insufficient education, management and psychosocial support for the child with diabetes and his/her family are major influences in suboptimal management of this chronic disease. Many studies worldwide have investigated these deficiencies. In developing countries, the degree of glycemic control can vary greatly by country, and even within different geographical

regions of one country. For example, in a study conducted in Malaysia, it was shown that ethnic Chinese individuals achieved better metabolic control than resident Malays and Indians (with glycosylated haemoglobin levels of 9.1 vs. 10.3 and 11.0%, respectively) (19). A survey of type 2 diabetes care in countries of the Western Pacific, with monitoring ranging between 33 and 96% among participants in the various countries, found considerable variations. Frequent home blood glucose monitoring was associated with lower glycosylated hemoglobin levels. One quarter of people with diabetes were managed with diet alone or were reported to be on no treatment, which may be inadequate for achieving glycemic control. Of concern in this study, microalbuminuria (MAU) was already present in 8% of those studied and hypertension in 25% after only 2.8 yr of follow-up. A further 20% had not been screened for MAU in the previous 12 months (20). In a recent survey conducted in Egypt, only 39.6% of children with diabetes were regularly performing self-monitoring of blood glucose (21).

A study in India found that 'fairly good metabolic control was achievable in a middle socioeconomic population in India with the assistance of a diabetes education programme'. The impediments to utilization of available resources and tools for diabetes care were identified as the high cost of insulin, test strips and lack of medical insurance; poor recognition of the value of and facilities for diabetes education; discrimination socially and with respect to employment and poor facilities for medical care (22).

Deficiencies in diabetes management are not restricted to developing countries. For instance, of children with type 1 diabetes studied in France, only one in seven were at the ADA target glycosylated haemoglobin of less than 7%. Also, 14% of these children had blood pressure levels above 130/85 mmHg. Because the risk of complications is linked to glycemic control, stricter control was recommended, with particular emphasis on the adolescent period and on those with the lowest socioeconomic status (23). Similarly, the fourth national survey of diabetes services in the UK found that, of 169 centres looking after children that were surveyed, only two clinics met all 10 of the previously published recommendations on standards of care (24).

In addition, the Hvidøre studies found that, in almost 3000 children and teenagers with diabetes, only one-third of the patients reached glycemic control as defined by guideline targets⁹, despite the presence of teams and available comprehensive care.

Insulin provision

The funding provided for diabetes care is understandably income dependent for each country. It is the responsibility of governments to provide and

make affordable insulin and other agents and equipment necessary for the diagnosis and treatment for diabetes and the monitoring of care. However, there is great variation in the availability of insulin around the world. In some countries, only \$5 per annum is allocated to support a child's health. In other countries, insulin is provided free because of its special status as a life-saving necessity coupled with the population's inability to pay (25). Fiji and Azerbaijan are examples of countries that have succeeded in providing insulin to every child requiring it.

Optimal organization of care entails efficient allocation and use of available resources. The cost of improving organization of care for children and adolescents with diabetes is much less daunting for governments than the cost of care for adults with diabetes. Partnerships between developed and less developed countries may be helpful in achieving improvements in care. In the 58 least developed countries in the world there are approximately 63 000 children with diabetes. Provision of insulin to these children would cost the relatively insignificant sum (in world terms) of \$9.5 million US\$ per annum (26).

Improving the lives of children in developing countries affected by diabetes is strongly linked to local opportunities for health care and education, as well as adequate family economics. Support of these children requires more than insulin and care. The *life for a child* programme of IDF supports children and families by offering diabetes-related educational and economic support which aims at creating independent, well-educated and informed children (www.lifeforachild.org).

The diabetes health care team

Because of the central role of self-management, the individual and family have important responsibilities in daily care. Ideally, the child with diabetes should have access to a specialized multidisciplinary team of diabetes health care professionals including a physician, a diabetes nurse educator and dietician as well as additional access to a psychologist, social worker, ophthalmologist, podiatrist and others. The diabetes health care team will require special skills based on the age of the child, level of comprehension and education of the child and his family, and be capable of dealing with language and cultural needs that vary by community.

Ways need to be found to expand access to specialized multidisciplinary teams at clinic level in as many communities as possible, including strategies to link rural and remote clinics to the nearest multidisciplinary resource, thereby supporting broad-based implementation of optimal diabetes care strategies as developed by diabetes centres of excellence.

The diabetes education toolbox

An educational 'toolbox' containing comprehensive yet easy to understand information on diabetes and diabetes care delivered in the form of booklets, CD-ROMs, DVDs and online resources is an ideal way to support children with diabetes and their families. A diabetes toolbox customized for use with schools and with health care providers can likewise serve as an important resource of standardized 'best practices' information to support education and optimal care. Parallel messaging aimed at educating the general public, paying particular attention to identifying early symptoms and including DKA, would include an urgent call to action that could help drive the family to seek early care.

For children with diabetes and families, the language of the toolbox would necessarily vary by community to take into account literacy levels, languages and cultural backgrounds of the local population. Illustrations can be used to communicate effectively with younger children and those with lower literacy levels.

In general, the diabetes educational toolbox should include

- (i) Information on the symptoms of diabetes;
- (ii) Explanation of hyperglycemia and subsequent DKA;
- (iii) Reasons for regular glucose monitoring and guidelines for target levels;
- (iv) The role of treatment and explanation of treatments;
- (v) Injection technique for insulin;
- (vi) Instructions for using strips to monitor blood and urine for glucose and ketones;
- (vii) Information on adjustment of insulin dose to coincide with activity, food, concurrent illness and travel;
- (viii) Information on proper nutrition and exercise with a sample day's menu that can be customized to the ethnic groups in the community;
- (ix) Advice for parents on communicating with schools and other organizations such as sports teams; and
- (x) Details of local diabetes representative organizations and telephone helplines that can offer further support and information.

Conclusion

- (i) The increasing burden of chronic disease including diabetes is already straining the financial and personnel resources of health services (27);
- (ii) Policy and health decision makers need to be given current evidence about the impact of

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- diabetes, including shortened life expectancy, higher disability and decreased productivity;
- (iii) Health care professionals themselves need more education including age-specific education. In many developed countries health professionals from developing countries are receiving training in public health; and
 - (iv) Health systems need to be aligned to accommodate diagnosis and long-term care as well as primary and secondary prevention of diabetes (28). Issues that need to be addressed include timely diagnosis of diabetes, availability of diabetes care, access to long-term, regular diabetes care and following the recommended patterns of care as described in diabetes management guidelines (29).

Recommendations

- (i) Data are needed on the treatment of diabetes globally (with particular focus on high-risk populations) to assess what is in place and what is needed to achieve provision of optimal care. Once baseline data are established, outcome studies can follow.
- (ii) Each country needs to press for achieving at least the minimum standard of care for young people with diabetes, working towards achieving standard and comprehensive levels of care. Better glycemic control is needed for children with diabetes to lessen the impact on health and quality of life of the disease itself along with reducing or preventing the onset of serious complications which further impact the potential for optimal long-term outcomes.
- (iii) Insulin is a life-saving treatment in children and adolescents with diabetes. Where countries have fewer resources to pay for health care, including insulin, ways need to be found to provide it in adequate quantities.
- (iv) Access to comprehensive diabetes care including treatment, monitoring support and psychosocial support, should be readily available to children with diabetes and their families.
- (v) To support access to care, the number of health care professionals with specialization in diabetes needs to be increased in order to meet care needs. The training and implementation of specialized multidisciplinary teams equipped to deal with medical as well as psychosocial factors is a priority.
- (vi) Comprehensive and ongoing education is essential on multiple levels to facilitate optimal organization and delivery of care. Age-appropriate diabetes education and support must be provided to children and their families; education for health care professionals should be formulated to

support understanding and implementation of the latest information in support of intensive management; education for schools will provide support for the child when they are away from their family's care; education for policy makers must be targeted towards giving diabetes care priority in funding.

- (vii) Educational toolboxes focused on the different needs of all stakeholders can bring together standardized messages:

- For children with diabetes and their families, the toolbox will help them to understand and manage the disease. The toolbox will need to reflect local language, culture, literacy level and education.
- Age-specific information for younger and older children should be provided to schools to increase awareness and ensure that the school is prepared to support optimal diabetes care at all ages.
- Educational strategies for health care professionals, again in the form of a standardized toolbox with customization as demanded by local demographics, can be used to support delivery of care as recommended in clinical practice guidelines.
- Policy/decision makers at varying levels of government need information on the impact of diabetes on the individual, as well as in terms of the socioeconomic aspects in the community.

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Chapter three

Diabetes in children: psychosocial aspects

Challenges

Children with diabetes are at risk not only in terms of their physical health, but also in psychosocial terms. Attention to psychosocial issues connected to diabetes is now recognized as an important part of diabetes care. Especially in young children not only the child is affected. Indeed, it is possible to think of the family as the patient.

Diabetes care imposes considerable demands on children and their families. Psychosocial effects stem from the stresses associated with a chronic disease, especially one that is so demanding of daily vigilance for monitoring and treatment to preserve health. The heightened demands of intensive management can pose a particular challenge to the child and family on a psychosocial level.

Attention to the psychosocial needs of the child and their family coupled with diabetes care education can replace misunderstanding and fear with knowledge and confidence, contributing to improved compliance with treatment, tighter glycaemic control and enhanced psychosocial functioning, contributing in a positive way to overall health and quality of life.

More research in this area is required to develop psychosocial intervention programs with age-specific focus that also include the family, and to show the cost-effectiveness of these approaches.

Introduction

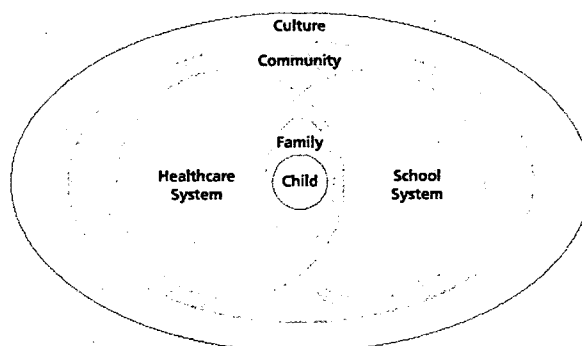
Because they are already coping with normal developmental challenges, many children and adolescents and their families may find that the additional burden of diabetes is difficult to deal with effectively. Particularly in the child's preadolescent years, families play a significant role in diabetes management and are instrumental in the implementation of interventions. The demands of daily treatment carve out new roles for the child and their family; balancing good control of blood glucose levels to avoid complications with coordination of medication, food and exercise to avoid episodes of hypoglycaemia becomes a daily and often complex focus. In addition to the physical impact, diabetes can adversely affect both psychosocial and neurocognitive functioning, thus potentially affecting the quality of life of the child and the entire family.

Psychosocial factors can also influence regimen adherence and glycaemic control. Psychosocial factors thus are an intrinsic component in the management of children and adolescents with diabetes.

As defined in the United Nations Convention on the Rights of the Child, all children have the right to participate fully in all the experiences of childhood and adolescence, whether they have a chronic disease such as diabetes or not, and whether they live in the developed or developing world. Those with diabetes also have the right to further education and to play a full role in the workforce.

Diabetes in childhood and adolescence presents very different challenges from diabetes in adults. Diabetes impacts every aspect of a child's life and experience. It imposes a burden that has to be shouldered by the child, his or her parents, siblings and the rest of the family, the school (where relevant) and local community (1). Psychosocial support is important at each of these levels as there is poor recognition of the unique human and social burden of diabetes in childhood and adolescence. Contrary to other potentially deadly diseases such as leukaemia, in which stress is concentrated within a certain time period, pediatric diabetes is characterized by the persistence and intensification of distress over a long period of time (2).

Circles of Influence



Source: Adapted from Bronfenbrenner, U. *The Ecology of Human Development: Experiments by Nature and Design*. 1979, Cambridge, MA: Harvard University Press.

The needs of the child with diabetes change as he or she grows physically, undergoes puberty and gains in maturity and independence. The child will gradually take on greater responsibility for self-management of their disease and general lifestyle. Knowledge and understanding of aspects of diabetes management therefore require ongoing and evolving education for the child and his or her family; the psychosocial needs related to diabetes will evolve and change along with the physical needs.

It is essential for the child's health that family, school systems and community be informed about the basics of diabetes, and that stigma and myths that surround this chronic disease are replaced with accurate information. Moreover, the child, the family, school and community systems need to be continually educated about provision of age-appropriate diabetes care and support as the child grows and develops into adolescence and young adulthood.

Paediatric diabetes health care

Because of the pervasive impact of diabetes on the child's growth and development, the optimal paediatric diabetes health care team is multidisciplinary, with members from medicine, education, nutrition, social services and mental health. As part of the comprehensive approach to managing diabetes, education and support for psychosocial issues are crucial components of good care. Children and their parents need to be provided with knowledge and skills for managing diabetes and support for building the self-confidence required to manage psychosocial aspects of diabetes.

Adequate and appropriate psychosocial support is associated with better control of diabetes, better coping skills for child and family, better quality of life and a decrease in diabetes-related complications (3). Ironically, when the need for achieving ongoing optimal control is well understood (4), the ongoing stress of the need for tight control imposes an additional burden on child and family. Many children with diabetes are in poor glycemic control despite the availability of effective therapies (5, 6). If patients and their parents feel unable to follow their treatment regimens, the result is additional stress that interferes with management (7). Diabetes health care workers need additional tools to explore, identify and discuss these barriers to optimal care.

Psychosocial support must be ongoing, age appropriate and evolve with the needs of the growing child. The balance of focus for psychosocial support changes as the child grows, from primary focus on the family of the young child, gradually enlisting more support from the growing child. Ultimately, the primary focus must shift to the adolescent himself/herself.

The child with diabetes and his/her caregivers must be given the help with diabetes that they need in a

culturally sensitive way so that they can be appropriately involved in diabetes management. Special educational activities such as camps and family support groups can be beneficial in this regard.

The crisis of diagnosis

The diagnosis of diabetes is a time of crisis for the child and the family. The diagnosis has an initial psychological impact on the individual, their siblings and parents. Indeed, the diagnosis may exacerbate preexisting problems. Poor initial adaptation, with depression, anxiety and low self-esteem, predicts later psychological difficulties (8). The ability of the family to provide support for the child varies depending on the educational, economic and emotional resources of the family. Although some families may take the diagnosis in their stride and manage the new responsibility well, other families at diagnosis have known risk factors for poor diabetes control, including single-parent families, families living in poverty and parents coping with other major stressful life events. These families may require extra time, education, attention and financial assistance at diagnosis. Some parents may require help to address faulty ideas such as personal shame or guilt over having a child with diabetes (Table 1).

Neuropsychological dysfunction

Type 1 diabetes appears to be associated with increased risk of mild neuropsychological dysfunction, although there is controversy over the precise cause and extent of this neuropsychological dysfunction. One study showed that shortly after diagnosis there were no significant differences in verbal or performance tests between children with diabetes and controls – but 2 yr later there were negative changes in speeds of processing and learning in children with diabetes (9). A second study found that early childhood onset of diabetes (before the age of 7 years) was associated with mild central brain atrophy and differences in intellectual performance in adulthood (10).

A recent nation-wide case-control study from Sweden also showed that diabetes influences performance negatively. Comparing all school results from 5159 children who developed diabetes between 1 July 1977 and 1 July 2000, and 1 330 968 non-diabetic controls, the authors found that despite a well-developed diabetes care system, diabetes negatively affected school achievement. Among children with a young age at onset and, therefore, longer duration, the negative effects tend to be greater (11).

Electroencephalography (EEG) abnormalities are seen frequently in children and adolescents with diabetes, and are more frequent in those who have had episodes of severe hypoglycemia. However, the significance of these findings is uncertain because