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The Global Burden of Youth Diabetes: Perspectives and Potential A Charter Paper

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Preface



unite for diabetes

It is a singular tragedy that, despite the emergence in recent years of increasingly effective strategies for the metabolic/glycaemic control of type 1 and type 2 diabetes mellitus, this disease continues to exact a terrible toll. Perhaps no group better exemplifies the diabetes crisis gripping both developed and developing nations today than the child. Children and adolescents with diabetes represent society's most vulnerable population – and it is indeed a tragedy that young lives continue to be lost to a disease for which adequate management tools and knowledge exist.

This Charter Paper has been developed as part of the International Diabetes Federation (IDF) 'Unite for Diabetes' campaign, which seeks to raise awareness of diabetes and stimulate action to help minimize its impact. This Charter Paper has been developed by a group of experts working in close association with the Unite for Diabetes Working Group on Special Populations. Among the goals of Unite for Diabetes was to create and pass a Resolution by the United Nations (UN) calling for global awareness and action on diabetes. This Resolution passed unanimously in the General Assembly of the UN on December 20, 2006, representing an important step towards better care for everyone with diabetes.

From the preparation to the celebration of this UN Resolution on Diabetes, it is now time to act. It is our sincere wish that *The Global Burden of Youth Diabetes: Perspectives and Potential* will become an agent of change. By bringing together, for the first time, a comprehensive portrait of the world of child and adolescent diabetes, we seek to motivate health systems around the world to do more for their young citizens touched by type 1 and type 2 diabetes.

Each chapter concludes with a series of tangible recommendations that we sincerely hope will inspire stakeholders in the diabetes community to advocate for positive change. Progress is possible – not in the future but today, using available resources and infrastructure. Our children deserve nothing less.

In closing, it is important to mention that the goals of IDF for improving the lives of children and adolescents with diabetes join with those of a number of committed organisations. Fourteen years ago, experts from The International Society for Pediatric and Adolescent Diabetes (ISPAD) gathered to develop the Declaration of Kos – a seminal work containing pledges to work to the following objectives by the year 2000:

- To make insulin available for all children and adolescents with diabetes
- To reduce the morbidity and mortality rate of acute metabolic complications or missed diagnosis related to diabetes
- To make age-appropriate care and education accessible to all children and adolescents with diabetes, as well as to their families
- To increase the availability of appropriate urine and blood self-monitoring equipment for all children and adolescents with diabetes
- To develop and encourage research on diabetes in children and adolescents around the world
- To prepare and disseminate written guidelines and standards for practical and realistic care and education of young people with diabetes and their families, emphasising the crucial role of healthcare professionals, and not just physicians, in these tasks around the world

While these goals have not yet all been attained, they continue to represent guiding principles for the care of young people with diabetes.

Sincerely,

Professor Martin Silink
President
International Diabetes Federation

Introduction from the Chair

July 2007

As a pediatric diabetologist I spend my professional life attending to young persons with diabetes. I am constantly heartened by the determination, positive attitude and wisdom beyond their years demonstrated by the children and their families in my center. Despite the issues, inconveniences and concern caused by their condition, these young people bring a refreshingly positive attitude through my doors each day.

When Martin Silink asked me to Chair the Youth Charter project I was immediately excited by this unique opportunity to create a publication that can motivate positive change for young people with diabetes, in countries on every continent.

This document – this chance to evolve *from charter to change* – is the result of a great deal of hard work from a number of individuals and organizations. In addition

to the International Diabetes Federation, I would like to acknowledge the International Society of Pediatric and Adolescent Diabetes (ISPAD) for their contributions to the Youth Charter. We were especially grateful to collaborate with past and present ISPAD board members for the perspective they brought on behalf of an organisation that works effectively on the advancement of care, advocacy and science of diabetes in youth. From the ISPAD Declaration of Kos 14 years ago, to the cutting edge clinical and scientific initiatives, ISPAD is truly making a difference. It is for these reasons that we are particularly proud that ISPAD has elected to enhance the voice of the Youth Charter by endorsing its aims and recommendations.

Henk-Jan Aanstoot
Rotterdam, Netherlands

Editor's Note

- Throughout this document, the words 'child' and 'children' have been used for the sake of clarity and economy. These terms will cover the age range from infancy through childhood and into young adulthood, using a cut-off point of 18 years. The age range of the children discussed in the various studies used to illustrate the Charter will be specified where relevant.
- Throughout this document, the term 'diabetes' has been used. It refers to diabetes mellitus in all cases. Type 1 and type 2 diabetes mellitus are included, and discussed individually or together as relevant.

International Society for Pediatric and Adolescent Diabetes (ISPAD)

Declaration of Kos

On September 4, 1993, on the Island of Kos, the members of the International Study Group of Diabetes in Children and Adolescents (ISGD), assembled at their 19th annual international scientific meeting and in the process of transforming ISGD into the International Society for Pediatric and Adolescent Diabetes (ISPAD), renewed their Hippocratic oath by proclaiming their commitment to implement the St Vincent Declaration to promote optimal health, social welfare and quality of life for all children and adolescents with diabetes around the world by the year 2000. They took this unique opportunity to reaffirm the commitments by diabetes specialists in the past and, in particular, unanimously pledged to work towards the following:

- To make insulin available for ALL children and adolescents with diabetes
- To reduce the morbidity and mortality rate of acute metabolic complications or missed diagnosis related to diabetes mellitus
- To make age-appropriate care and education accessible to ALL children and adolescents with diabetes, as well as to their families
- To increase the availability of appropriate urine and blood self-monitoring equipment for ALL children and adolescents with diabetes
- To develop and encourage research on diabetes in children and adolescents around the world
- To prepare and disseminate written guidelines and standards for practical and realistic care and education of young people with diabetes – and their families – emphasizing the crucial role of healthcare professionals – and not just physicians – in these tasks around the world

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 b-cell function
 - B. Genetic defects in insulin action
Type A insulin resistance, leprechaunism, Rabson-Mendenhall syndrome, lipoatrophic 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 beta 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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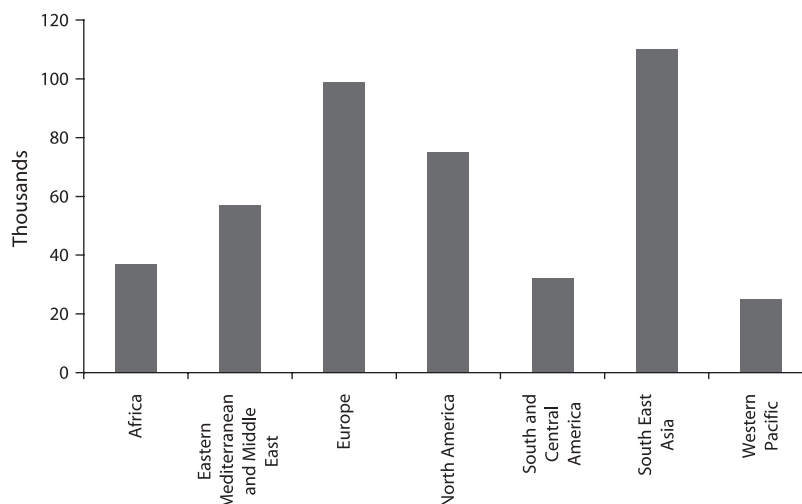


Fig. 1. Estimated number of cases of type 1 diabetes by region. Source: International Diabetes Federation World Atlas of Diabetes (2006) (8).

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, polydypsia 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 glycated 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

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.

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.

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.

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.hvidoerestudy.org), only one-third of the patients reached such recommended goals in glycemic 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 glycemic 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 glycemic 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 glycemic 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

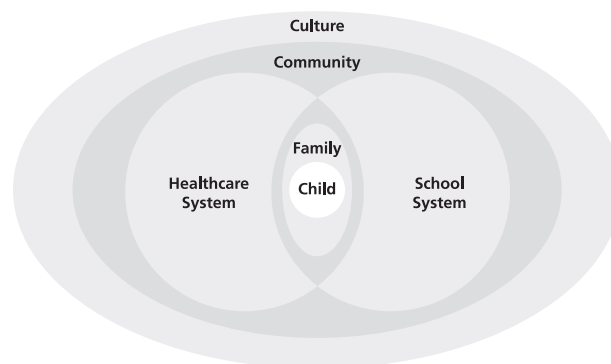
Because they are already coping with normal developmental challenges, many children and adolescents and their families may find that the additional burden of diabetes is difficult to deal with effectively. Particularly in the child's preadolescent years, families play a significant role in diabetes management 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 glycaemic 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

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Table 1. Age-related psychosocial risk factors affecting the diabetes care plan

Child
(i) Presence of other health problems (e.g., asthma, eating disorders)
(ii) Poor school attendance
(iii) Learning disabilities
(iv) Emotional and behavioral disorders including risk-taking behaviors
(v) Depression, anxiety
Family:
(i) Single-parent home
(ii) Chronic physical or mental health problems including substance abuse in parent or other close family member
(iii) Recent major life change for parent (loss of job, death in family)
(iv) Lack of adequate health insurance
(v) Complex child care arrangements
(vi) Health/cultural/religious beliefs that make it difficult to follow treatment plan
(vii) Parent with diabetes: outdated or inappropriate concept of care for the child with diabetes; anxiety/depression related to personal diabetes care affecting ability to learn and utilize recommended care for the child

Source: American Diabetes Association (ADA) statement: Care of Children and Adolescents with Type 1 Diabetes (24).

cognitive function has not been measured in any study examining EEG abnormalities in this age group (12).

The mechanism by which hypoglycemia affects cognitive function is not clear. In addition, it is confounded by the fact that individuals who experience severe hypoglycemia are also more likely to experience prolonged hyperglycaemia, which is also known to be associated with cognitive dysfunction (13).

Although the benefits of intensive therapy in preventing or delaying microvascular complications outweigh the neurocognitive risks (14) for older children, fear of hypoglycemia is an impediment to adequate control. Children (and more often their parents) who are extremely concerned about hypoglycemic episodes may keep blood glucose levels above recommended targets in an attempt to avoid hypoglycemia (12).

Recent research also indicated that hyperglycemia hampers cognition in children with diabetes. As most parents report behavioral disturbances when glucose levels have been elevated for a long time (overactivity, lack of concentration, negative mood swings) there are now studies showing that this effect is present in children as well as adults (15, 16).

Preschool children: the family is the 'patient'

For young children, the 'patient' is the entire family, as the child is too young to be able to understand or manage his condition. The early preschool years are

very demanding for the entire family when a child has diabetes; all family members need to understand how to manage this complicated disease, especially when the child is too young to have many spoken or written language skills. The burden of care must be shared among adults in the family to avoid exhaustion and burnout.

Families need help in coming to terms with the diagnosis and learning how to cope with the sobering concept of their child's lifelong chronic illness while simultaneously learning about the disease and the complexities of treatment. Siblings will benefit from psychological support as well to help them deal with issues such as guilt, fear and jealousy. This can be a very trying and stressful time, as the whole family's lifestyle has to change to accommodate a child with diabetes. For instance, in addition to a strict schedule of insulin treatment, the child with diabetes needs regular mealtimes and a meal plan carefully balanced with blood glucose readings and level of physical activity.

The prevention of social isolation of families with very young children with diabetes must be made a priority. Psychological support must be sensitive to the needs and wishes of individual family members, the community and the culture. One study found that the mother's principal worry in managing diabetes is fear of hypoglycemia, especially when the child is young. Many parents are also concerned about their child's future health and well-being (17).

At present it is believed that, especially in children under the age of 5, hypoglycemia and, in particular, recurrent hypoglycemia may hamper neurocognitive development. At this age such hypoglycemic events may alter blood flow and damage neuronal networks (18).

School-age children: the child becomes involved in diabetes self-management

When the child with diabetes enters school, the universe of those people involved in the management of his/her diabetes expands. It is critically important to educate and involve the school in diabetes management. Children with diabetes have the right to attend school without discrimination, to participate in school activities, and to have the benefit of competent and safe care while away from their family at school.

Teachers and classmates alike need to be educated about diabetes, both to dispel myths and prejudices and to effect good care. The school needs to recognize and be responsive to the particular demands that diabetes places on the child concerning medication and the balance of diet with physical activity, and to take these demands into account with respect to taking examination, playing sports, etc. The school-age child needs special considerations to help in his or her self-management, such as time and space to

perform self-monitoring of blood glucose and to follow the treatment schedule. Food and timing of meals and snacks need to be addressed with teachers and administrative personnel: if food is provided by the school rather than brought from home, the menu must offer choices that are appropriate to the needs of the child with diabetes. Children with diabetes need to be encouraged to complete their schooling, for it is documented that people with diabetes with a low attained level of education have higher total mortality (19, 20).

As they grow and develop, children with diabetes face different diabetes-related challenges in school and with peers. School personnel need to understand that the child with diabetes may go through periods of better and worse metabolic control, and similarly, that medical and psychosocial problems may wax and wane (21).

To ensure that young children with diabetes have a nurturing and positive experience while attending school, school personnel must be properly educated about the treatment and complications of diabetes, including the physical and cognitive effects of hypoglycaemia, recognizing the symptoms of hypoglycemia and knowing the appropriate treatment. An educated and supportive school environment can significantly improve the behaviour and learning of the child with diabetes, as well as enhance the child's social interactions within the classroom.

School personnel need to understand that as a child grows his/her disease changes; his/her attitudes and skills regarding diabetes and its management may also change. Children with diabetes may have more school absences because of medical appointments as well as fluctuating blood glucose levels (22). The school should also be aware and supportive of the child's potential medical and psychosocial needs. Anxiety and depression may occur more frequently in children with diabetes, and school personnel should be observant of signs of distress. Friendships are important in helping the social confidence of children with chronic diseases such as diabetes, and should be encouraged by teachers (23). Everyone involved with the child with diabetes at school also needs to learn how to talk about diabetes using neutral and constructive language.

Adolescence: the child is now at the center of care with family support

Once the child with diabetes enters adolescence, she or he is in the process of becoming more capable of managing a significant part of their daily care yet will continue to need the support and involvement of the family.

The onset of puberty may be marked by feelings of ambivalence, impulsiveness and mood swings (24).

Adolescents struggle to separate from their parents and be accepted by their peers; experimentation and risk-taking behaviours may be observed in relation to tobacco, drugs, alcohol and sex, for example. However, adolescents with diabetes have been found to be less involved in health-compromising behavior than adolescents and young adults in general.

Teenagers with diabetes may express lower life satisfaction and health perception compared with their peers without diabetes (25). However, adolescents in good glycemic control and with lower levels of glycated hemoglobin have been shown to have fewer worries, better quality of life and a decreased perception of burden of disease on the family. This emphasizes the importance of glycemic control on both physical and psychological health (26). In a study of 2101 adolescents with type 1 diabetes, it was found that lower glycated hemoglobin was significantly associated with better adolescent-rated quality of life on all four subscales used (27).

Diabetes management can be a problem during adolescence (28). Non-adherence may be associated with poor metabolic control and rehospitalizations for diabetes (7). DKA often appears to be the result of insulin omission (29). Non-adherence is particularly likely when underlying psychological disorders (depression, anxiety, eating disorders) are present, when there is a low level of education in parent or child, and when there is a low level of supervision of care by the family. Frequent experiences with hypoglycemia may lead to fear of hypoglycemia in adolescents with type 1 diabetes. In parents, on the other hand, beliefs about their adolescent's ability to cope with hypoglycemic episodes may lead to fear of hypoglycemia (30).

As adolescents become increasingly mature and independent, they can take more responsibility for diabetes self-management. However, the adolescent continues to require age-appropriate parental involvement in diabetes management and parents may have unrealistic expectations of the abilities of their teenagers. As part of this process of negotiating a new appropriate role for the parents in diabetes management, conflict between adolescents and parents may take place. At this point in development, parents and youth with diabetes may benefit from training in communication skills as well as conflict resolution skills (31, 32).

Mental health problems, including anxiety, depression, suicidal ideation and eating disorders are not uncommon among adolescents with diabetes and contribute to poor diabetes outcomes. One study found that the rate of psychological disorders was three times higher among adolescents with diabetes than those without (33). During the first 10 yr of diabetes and by the age of 20 yr, nearly half are at risk of psychological morbidity (34). Major depression is

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the most prevalent disorder. Depression may affect metabolic control, psychological adaptation to diabetes and self-esteem (35). Among 113 individuals with type 1 diabetes who were diagnosed in childhood and were followed up after (on average) 11 yr, psychiatric disorders increased from 16 to 28%, and 8% had psychiatric disorders at both assessments (36).

Knowledge alone is not enough: adolescents with diabetes need support, supervision and reinforcement for proper self-care, and these efforts need to be made particularly in the first few years after diagnosis (37). Optimal care of adolescents with diabetes is required in order to allow these young people the best opportunities to lead a full and healthy life. Psychosocial interventions to improve family communication about diabetes can also help families to negotiate these difficulties. Conflict resolution skills are strong predictors of outcome in adolescents with type 1 diabetes, for example. Telephone support and structured counselling can help young people to overcome the difficulties that they are encountering that are distracting them from diabetes self-care (38).

Recommendations

- (i) Diabetes care for children with diabetes and their families should include routine evaluation of the psychological and social situation of each child and family, and strategies to focus care and education accordingly.
- (ii) There is an urgent need for age-appropriate, ongoing psychosocial support for children with diabetes and their families to support medical strategies to improve metabolic control, reduce the risk of complications and enhance the child's overall health.
- (iii) The needs, attitudes and wants of children, youth and their families must be actively sought and incorporated into the planning and formulation of diabetes initiatives and programs.
- (iv) Different 'circles' require different approaches for education and support for the child and family with diabetes to ensure a comprehensive envelope of care for the child.
 - Programmes are needed to address all aspects of education and psychosocial needs of parents, including specific attention to points of stress including fear of hypoglycemia.
 - School personnel must be educated about diabetes in order to understand the differing medical/psychosocial needs of the child by age, and be prepared to support the child to participate fully in academic and physical activities and complete their education.
 - Children with diabetes and their families need to have access to special educational initiatives such as camps and family support groups.
- (v) Further study of psychosocial needs as well as attitudes towards diabetes, chronic disease and wishes need to be established. Such studies were performed in adults as the Diabetes Attitudes Wishes and Needs study (39–43).
- (vi) A similar approach could identify specific needs in countries and help to identify aspects that can be adapted and incorporated to make psychosocial health a regular component of optimal diabetes care.

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Chapter four

Diabetes in children: socioeconomic aspects

Challenges

Diabetes is already a major cost in health care budgets in both developed and developing countries, and the costs are rising exponentially in tandem with the rising incidence worldwide.

Diabetes care involves both direct and indirect costs. The socioeconomic impact of these costs is shouldered by the child and their family, the health care system and the economy as a whole.

Early diagnosis and intensive treatment of diabetes is especially important in the child, in whom the longer course of the disease carries a higher potential risk of poor health. But optimal diabetes treatment presumes uninterrupted access to care over the child's lifetime. Optimal diabetes care is undeniably costly, but even increased expenditure by health care systems will not automatically result in better diabetes care: resources must be optimized and applied to comprehensive education and prevention messages along with practical care strategies and guaranteed access to care.

The current and future impact of diabetes on children and young people around the world has particularly far-reaching consequences for the socioeconomic health of all nations. Good care is not expensive compared with the price of inaction: morbidity, poor quality of life and mortality.

The barriers to investment in diabetes care must be replaced with informed investment based on solid cost data. Funding decision makers must understand that investing in diabetes care and access in the short-term is profitable in both the short and long-term for the individual, society and the economy. This is one further justification for detailed research into the health economics of diabetes worldwide.

Introduction

If health is to become a human right worldwide, it must be recognized that an initial investment in health care is needed to address the deficiencies that currently exist. Health needs to be given priority because of its far-reaching effects not only on the individual and their health, productivity and quality of life, but also

on the socioeconomic well-being of the country in which they live.

Chronic diseases are now the largest cause of death in the world and it is estimated that by 2020 these chronic (non-communicable) diseases (among them cardiovascular disease and diabetes) will cause the death of approximately 50 million people, compared with 10 million deaths because of communicable diseases such as tuberculosis (TB), HIV/AIDS and malaria (Fig. 1) (1).

It is estimated that by 2025, 380 million people will have developed diabetes, amongst them an increasing number of children who will face lifelong treatment and risk for acute and chronic complications (2).

Given the enormous impact that diabetes has on a nation's health and health care costs, basic requirements for diabetes treatment and care, such as the distribution of life-saving insulin to all corners of the globe, must become a reality. An investment in health now will pay dividends in the future as premature mortality is reduced, useful working years are extended and preventable disability is avoided through ongoing optimal care.

In the face of growing evidence of the epidemiological and economic impact of diabetes, a more robust response by all stakeholders is required. Among the reasons for a delayed and inadequate response are ideas that chronic diseases affect mainly the elderly; that they are caused by factors that individuals can easily change and should be responsible for (i.e. unhealthy lifestyle); that diabetes treatment is too expensive and that chronic diseases such as diabetes should only be addressed once communicable diseases are contained. Unfortunately, these views are gravely misguided; with the rapidly increasing incidence of diabetes and onset at younger ages, the impact on national health care systems and on general health and productivity grows, positioning diabetes as a tremendous burden for the global community.

Particularly in the most vulnerable group, children and youth, optimal care can reduce the impact of diabetes and complications over the long term and can drastically reduce the costs for both individuals and society.

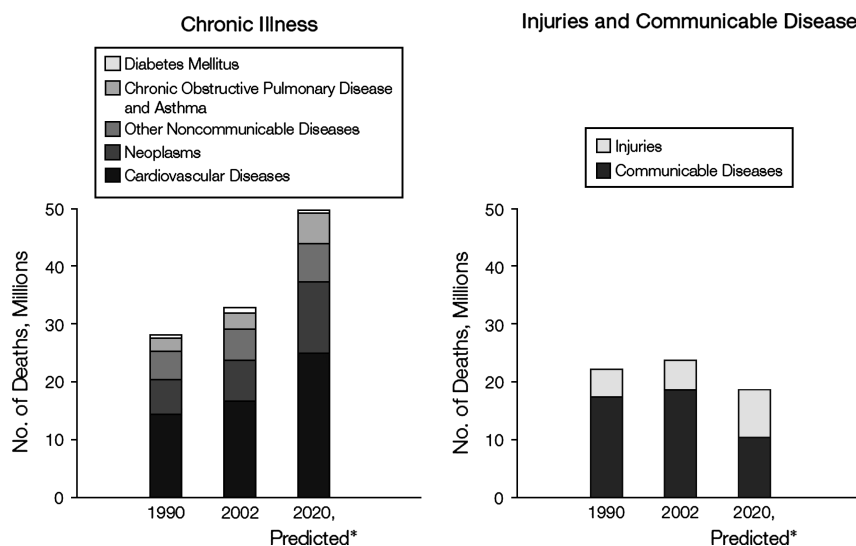


Fig. 1. Global mortality from chronic diseases (1).

Health economics and diabetes

Health economics describes the tools used to measure how we utilize resources, and it is a measure of opportunities lost and gained. The measures used include quality of life, productivity and lives saved, and are essentially different ways of looking at the same outcome – the ability to lead a healthy, full and productive life with opportunities and some degree of free choice. It is important to obtain data on the costs of disease, the costs of treatment (and conversely, the costs of no treatment) in order to allocate resources wisely.

Diabetes: a threat to every nation's health care system and budget

As the prevalence of diabetes increases exponentially around the world, it imposes an increasingly severe strain on health care resources. Yet, competition for allocation of health care resources, common in both developed and developing countries, can inevitably result in insufficient resources for diabetes care. In some African countries, for example, the percentage of gross national product spent on health care is as low as 1.5% (3).

Non-communicable and chronic diseases such as diabetes have not always been given the attention and the funding that they deserve in comparison with communicable diseases such as HIV/AIDS. Health care workers on the lookout for HIV need also to be vigilant for TB and diabetes. In the developing world, 80% of children who have type 1 diabetes presented initially with diabetic ketoacidosis (DKA).

Proper treatment of any chronic disease including diabetes should be viewed not as a cost, but as an investment in health capital. Although insulin and other diabetes treatments do have a significant impact

on families' budgets in many parts of the world, the real societal and individual cost drivers are the costs of NOT receiving treatment. Most of the costs of diabetes are indirect, and may not be seen as linked to diabetes. Understanding how these costs are generated is essential if the pattern of disease is to change. Often, discussions about cost focus on the direct costs of treatment, though for example, only an estimated 11% of the world's diabetes population use insulin.

Costs of diabetes: the price of inadequate care and underestimation of the problem

The 'rule of halves' is commonly used to describe statistics for the diagnosis, treatment and successful management of hypertension but is equally applicable to diabetes. When applied to diabetes, this rule exemplifies how only a minority of those with diabetes receive effective treatment. Thus, of people with diabetes, only half are diagnosed. Of those diagnosed, half do not receive care. Of those who receive care, half do not achieve desired treatment targets. Of those who reach treatment targets, half do not achieve desired outcomes. Using these figures, only 6% of the global population with diabetes have a successful treatment outcome (Fig. 2). Even in the presence of clinical practice guidelines and a functioning health care system, only one-third of children with diabetes are able to reach their treatment goals, showing not only a need to establish appropriate diabetes care, but also the need for effective implementation at the patient/family level.

The largest proportion of costs of current health care can therefore be viewed as generated by the lack of treatment for, or the inadequate treatment of, the other 94% of people with diabetes. For example, macrovascular complications double the average cost

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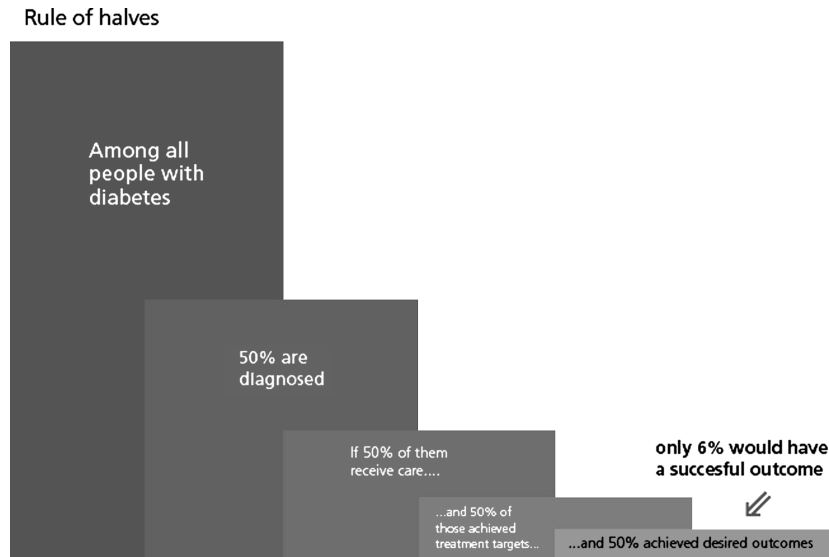


Fig. 2. The rule of halves (30).

per person, and microvascular complications more than treble the average cost. Hospitalization costs double with microvascular complications, treble with macrovascular complications and increase more than fivefold if both types of complications are present.

Thus, it is not the number of people with diabetes that generates the majority of costs but rather the progression of the disease. The individual with well-controlled diabetes who has not developed any complications (e.g. retinopathy, nephropathy, neuropathy) represents a lower cost to society than the individual with poorly controlled diabetes who has developed one or more of these comorbid conditions. For example, in Sweden in 1994 3.3 times more resources were spent on treating complications than on control of the disease itself (4).

Intensive therapy, which costs more than conventional treatment, has been shown to delay the onset and slow the progression of complications (5). In the UK Prospective Diabetes Study 41 (6), a study of type 2 diabetes, the treatment cost for intensified treatment over 10 yr was higher than for conventional treatment but the cost of complications over the same period was reduced: the total cost over 10 yr was thus lower for intensified than for conventional treatment. DCCT data support this finding (5).

Some understanding of the epidemiology of diabetes helps to put these principles into practice. Total costs of diabetes care are increasing as the incidence of both type 1 and type 2 diabetes increases (7). However, the costs of diabetes care may be underestimated if mortality and morbidity because of diabetes complications (e.g. stroke, kidney failure and blindness) are not identified as being linked to diabetes in disease registries and hospital databases. For example, in Denmark in 2001 an estimated 5608 people died from causes related to diabetes but only 1373

deaths were actually registered as being because of diabetes (8).

The impact of diabetes on family finances

It is important to focus on the 'economics of the young' to determine the short- and long-term impact of diabetes in youth. Children and young people do not have political power or the means to exert political pressure; their most important and sometimes their only advocates may be their parents. To have an ill child places an emotional burden on families, exacerbated by a double financial burden: the direct costs of dealing with the disease, and the indirect costs measured in terms of time and opportunities taken from the family. The financial constraints for the family may make it difficult for them to invest in important future needs such as education for all children in the family.

Inadequate access to insulin has economic consequences. In some countries in the developing world, insulin-dependent diabetes becomes a fatal disease if the individual is required to pay for treatment; families may be forced to make terrible choices between paying for insulin for one child and caring for and educating the rest of the family (9). In the 18 countries worldwide in greatest need of adequate insulin provision, it is estimated that there are about 63 000 children with diabetes under the age of 15 yr. Provision of insulin to all of them would cost only US\$ 9.5 million per annum (10). The costs of diabetes relate to both direct health care costs and indirect costs such as potential resources lost (11).

The rise in the incidence of diabetes, particularly type 2 diabetes, is significantly associated with the rise in obesity that is being observed in both the developed and developing worlds (12). Obesity is a socioeconomic

issue (Table 1) that relates to factors outside the individual's control such as the relative costs of healthy and unhealthy foods and the decreased physical activity entailed in many types of employment compared with that of previous generations.

Costs at different levels: primary and secondary prevention

Primary prevention of type 2 diabetes is essential and is aimed at reducing obesity and the number of people at risk for type 2 diabetes. It is important to recognize that the cost of primary prevention is lower than the cost of secondary prevention. Type 2 diabetes was once only seen in adults but now affects some obese children even before puberty. Primary prevention is essential particularly in the case of children, and is especially urgent now that type 2 diabetes is being observed in younger and younger children.

Current public health measures relating to the management of overweight and obesity include promoting good nutrition and healthy active lifestyles, and providing support for physical exercise in schools, where provision is often inadequate. In the developed world, obesity tends to be observed more frequently in low-income groups, putting a double burden on these individuals. It is expensive to be ill, but it is also expensive to stay healthy because purchasing healthy food comes with higher costs. Whether obesity is created by lack of knowledge about healthy living in low-income groups or whether it is because of the pricing of healthy foods is unclear, and needs more research. Tobacco smoking is particularly dangerous in people with diabetes because they are already more

prone to vascular disease, the basis of many of the complications of diabetes.

Investments in health, and particularly investments in children's health, require a long-term perspective. Supranational pathways may be needed to overcome national barriers to intervention (13). These do exist already; for instance, poverty reduction strategies supported by the International Monetary Fund could be amended to take into account chronic diseases such as diabetes. By making the necessary health investment now, the potentially crippling socioeconomic effects of the rise in diabetes worldwide can be forestalled.

The direct costs of diabetes

The direct costs of diabetes to health care systems are those generated by the resources used in treating or coping with a disease (Table 2).

The most common cause of death in a child with diabetes in parts of the developing world is lack of access to insulin; the cost of obtaining treatment for a child with diabetes is simply prohibitive. For example, in Sudan the median annual family income is \$1222, and the annual expenditure in looking after a child with type 1 diabetes for a year is \$283, or nearly one quarter of the total family income for the year (14).

In several sub-Saharan African countries where individuals are required to pay for medical services, diabetes (especially type 1 diabetes) is regarded as a fatal disease. If people with chronic diseases such as diabetes are not exempted from payment, it will be impossible for most people with diabetes to meet the cost of insulin and oral hypoglycaemic drugs (9).

A 1992 study in Tanzania showed that the average per capita income ranged from \$160 to \$200 per annum. An insulin-dependent person with diabetes requires \$156 for the purchase of insulin alone for 1 yr (9). At the time of diagnosis, 30% of the population in this study already had one of the chronic complications of diabetes and

Table 1. Macroeconomic burden of obesity and diabetes for selected developed and developing countries (12)

Country	Year of estimate	Total costs (% of GDP)*	% of total indirect
Diabetes			
United States	2002	1.3	30.7
Canada	1998	0.78	30.4
Mexico	2000	2.6	n/a
Brazil	2000	3.8	82.5
Tanzania	1992	0.5	n/a
Obesity			
United States	2000	1.2	47.8
Canada	2001	0.7	69.8
Switzerland	2002	0.6	n/a
Germany	1998	0.2	48.2
India	1995	1.1	67.3
China	1995	2.1	23.8

*Gross Domestic Product (GDP) calculations based on 2000 constant US\$ GDP estimates, World Development Indicators, World Bank, Washington, DC, 2005. It should be noted that these costs are not directly comparable across studies as a result of methodological differences. But they can be viewed as illustrative of the sizeable and robust.

Table 2. Direct costs of diabetes

Insulin and other antidiabetic drug treatments
Testing equipment, including that for measuring blood glucose, urine glucose and ketones
Hospitalization
Ambulatory care
Treatment of complications (e.g., blindness, kidney failure and amputations)
Education of specialized diabetes health care personnel
Education of people with diabetes and their families; continuing education is very important and necessarily intensive for children with diabetes, whose needs and understanding change over time
Research into diabetes prevention and treatment
Costs to the individual and their family directly related to treatment
Non-medical costs of treatment to the individual and their family, such as travel costs and childcare costs

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had made an average 3.8 visits to health units. In many, infection precipitated the symptoms of diabetes. This illustrates the continuing need for education about the early symptoms of diabetes. Home monitoring of blood glucose concentrations is economically impracticable for most people, but easier access to urinary dipsticks might improve control without adding greatly to total direct costs.

Another study found that total direct costs for people treated with insulin made up 25% of the official minimum wage. For 45.7%, diabetes care caused permanent financial problems. Because patients were constrained financially, they tended to attend clinics infrequently. The costs for insulin dependency were estimated to exceed the annual per capita expenditure for health by a factor of 20 (15).

The direct cost of diabetes health care is very high for many people in developing countries. Many developing countries lack effective health networks, and distribution of insulin is often irregular, and costs prohibitive. A survey in India found that about 2% of the budget in India is allocated to health care, with the thrust on eradication of communicable diseases. There is no specific provision for diabetes. In this survey, those who visited private hospitals from middle- and low-income groups spent 15 and 24% of their income, respectively, on diabetes care. The longer the duration of disease, the higher the costs of drugs and medical consultations (16).

In Bangladesh, it is estimated that only 10% of the population have an income that enables them to afford health care and medication, and that only 13% of the population, mostly in urban populations, are able to visit the free clinics. Children with diabetes may be at particular risk of inadequate care for diabetes (17, 18).

Care for people with diabetes has been investigated in a number of countries from Latin America and the Caribbean. People with diabetes had more medical visits, more hospitalizations and lengthier hospitalizations compared with the rest of the population. In the year 2000, among these countries, the total number of people with diabetes and permanent disability was believed to be 726 575. This adds up to 12 699 087 yr of productive life lost, equivalent to a loss of US\$ 50.6 billion. The estimated cost of drugs for diabetes was US\$ 4.7 billion and for treatment of complications was US\$ 2.4 billion. The hospital costs related to diabetes were much lower, at US\$ 332 million. The indirect costs accounted for 82% of the total, and the direct costs 18%, perhaps because of a lack of coverage of continuous care for a significant proportion of people with diabetes in this part of the world. In general, the costs of caring for diabetes were more than 300% higher than the average health expenditures in Latin America and the Caribbean (19).

In Germany, costs associated with treatment of type 1 diabetes in children and young people up to the age

of 20 yr (the mean age was 12.5 yr) were calculated. The mean total costs per patient-year were 2611 Euros; of this, blood glucose self-measurement made up 37%, hospital costs 26%, insulin 21%, ambulatory care 9% and injection equipment 7%. The total costs were significantly increased for higher age, longer duration of diabetes and higher glycosylated hemoglobin. The costs for hospitalization were significantly associated with the pubertal stage and poor metabolic control. Of these, 24.6% had a diabetes-related hospitalization during 2000, with a mean length of hospital stay of 7.4 d (20). It should be noted that these stays included in-patient education programs. In a further study, it was noted that the greatest economic burden, shortly after the onset of diabetes, was hospitalization (21). After that, self-measurement became proportionately more expensive. The costs of diabetes were higher among children from less educated parents.

The indirect costs of diabetes

The indirect costs of diabetes are the potential resources that are lost as a result of a disease, including the costs of morbidity, disability and premature mortality (Table 3). In an ideal world, the care of diabetes would be so good that these indirect costs would be zero. In practice, however, studies show that the indirect costs of diabetes are larger than the direct costs; limited access to health care is a primary reason for this state of affairs.

A study conducted in the USA compared the national economic burden of five chronic diseases including diabetes, ischemic heart disease, hypertension, asthma and mood disorders. The study found that 51% of people with diabetes had comorbidity with one or more of the other chronic diseases studied. Ten per cent of adults with diabetes had missed work

Table 3. Indirect costs of diabetes

For children and adolescents, diabetes and its complications do not immediately impact on earnings but they do impact on educational potential and thus future earnings
Adult caregivers for a child or adolescent with diabetes may themselves be unable to work outside the home or only be able to work part-time
Premature death from diabetes, thus loss of earnings
Disability because of diabetes and monitoring of disease, leading to loss of earnings, absence from work and early retirement
Disability from the complications of diabetes such as blindness, again leading to loss of earnings
Costs of professional home care and nursing homes, and costs to school systems for nursing care
Children of parents with diabetes may miss school, may not complete their education and may be deprived of opportunities, leading to perpetuation of poverty and lack of skills from one generation to the next

because of their diabetes. Comorbid conditions such as infections, peripheral vascular disease and microvascular damage accounted for much of the clinical and economic burden of diabetes; these are important targets for secondary prevention, including screening and early monitoring (6).

In Canada, diabetes was found to affect access to the job market, especially in jobs designated as safety-sensitive, because of concerns about the risk of hypoglycemia. Individuals with diabetes in this prospective cohort study had a lower labour market participation rate compared with those without diabetes (64.5 vs. 79.7%). Those who experienced complications were twice as likely not to be in the labor force, and they had only 72% of the total income received by those without diabetes (22).

Conclusion

Diabetes imposes a severe socioeconomic burden on the child with diabetes as well as on their family, the community and society. Costs of diabetes comprise both direct and indirect costs. In the child, costs of diabetes are calculated in current as well as future terms.

Early diagnosis, early initiation of adequate treatment and careful monitoring to avoid complications will help to maintain their health not only in childhood, but also as they grow to adulthood and become productive members of society and the economy. This is an optimal situation that is grounded in diabetes care that is accessible and meets their changing needs throughout life.

Well-organized and accessible diabetes services can result in fewer costs to the health care system. For example, in Australia, well-organized diabetes services in a particular region were found to result in fewer diabetes-related hospitalizations. The average length of stay in hospital for a newly diagnosed person with diabetes was 10.9 d, which fell to 7.3 d on subsequent admissions. These admissions were mostly for stabilization of high blood glucose, ketoacidosis or hypoglycaemia. Access to and utilization of services was an issue, especially for families with lower socioeconomic status (23).

The barriers to access to insulin and proper diabetes care are being studied in the Rapid Assessment Protocol for Insulin Access, developed by the International Insulin Foundation. Research has been carried out in Mozambique, Zambia and Mali to study the path of insulin from its arrival in the country to the point where it reaches, or fails to reach, the person who needs it effectively (24).

The DCCT (1993) found that intensive treatment of people with type 1 diabetes ($n = 1,441$) reduced the risk of development of retinopathy by 76%, and slowed its progress by 54% over a 6.5-yr follow-up period. It also reduced the risk of microalbuminuria by 60% (5).

A further analysis performed by the DCCT research group in 1996 found that, on average, people on intensive therapy, as compared with those on conventional therapy, would experience an additional 7.7 yr of sight, 5.8 yr free from end-stage renal disease and 5.6 yr free from lower extremity amputation (25). In support of the cost-effectiveness of intensive therapy, it has been estimated that the additional costs of moving to insulin pump therapy are minimal, given the potential benefits (26). Insulin pump therapy can provide an effective way to help ensure consistent glycaemic control in children and adolescents.

However, a comment on the original DCCT trial points that achieving the benefits of intensive therapy entails substantial costs and risks, with hypoglycemia the principal risk (27). Other commentators too have cautioned against a blanket approach to intensive therapy, and recommend a tailored, individualized approach to the treatment of people with diabetes.

The need for comprehensive and accessible diabetes care throughout the world has reached an urgent level because of the rapidly increasing numbers of cases. The current and future impact of diabetes on the children and young people around the world has particularly far-reaching consequences for the socioeconomic health of all nations. Investment in diabetes care – for diagnosis, early intervention and ongoing management – is required to address the deficiencies that currently exist. An investment in the health of the world's youth will pay dividends in their future productivity and quality of life.

Recommendations

- (i) Improvements in the quality of diabetes care and access to care have positive socioeconomic outcomes and benefits for the child and their family.
- (ii) The ultimate reduction in diabetes costs is found in prevention, both primary prevention (especially relating to type 2 diabetes) and secondary prevention of complications of diabetes.
- (iii) An investment in health now will reduce future morbidity and premature mortality, extend the individual's contribution to the economy through their productive working years, and prevent the costs of disability resulting from inadequate diabetes management.
- (iv) There is a need for further data, using standardized measures and methodology, to gain an accurate evaluation of current levels of direct and indirect costs of diabetes as well as the benefits of care in countries around the world.
- (v) An intensive evaluation of the structure of and access to diabetes care in each country is critical to understanding the deficiencies in care so that

planning to improve structure and delivery of diabetes care can be customized.

- (vi) Insulin is a life-saving and life-dependent drug and in compliance with the UN and UNICEF should be available for every child in uninterrupted supply. Pioneers in insulin delivery include the International Diabetes Federation Child Sponsorship Programme and Insulin for Life.
- (vii) From an economic point of view, developed countries have to show leadership to the developing world to make comprehensive diabetes care, including education and medication, readily available.
- (viii) Understanding of the goals and outcomes of intensive management needs to be understood to support funding at government level.
- (ix) Doctors, nurses and health care workers need to be made aware of the costs of diabetes during their training.
- (x) Education is a key component of prevention, early intervention and adherence to treatment and is an important target for funding. Prevention programmes incorporating even simple measures such as posters in schools have been shown to be effective in the prevention of DKA (28).
- (xi) Intensive treatment is recommended from a socioeconomic view because treatment success means that the individual is more likely to be economically productive. Increased expenditure will not automatically result in better diabetes care: the use of the increased resources must be optimized (29).
- (xii) Access to patient centered self-management education and support has been shown to improve outcomes. Costs associated with this type of support need to be elaborated, potentially within the levels of care, and funding put in place to the maximum level of care possible.

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Appendix I: Components of the initial visit and continuing visits

Medical history

- Symptoms, and results of laboratory tests related to the diagnosis of diabetes;
- Recent or current infections or illnesses;
- Previous growth records, including growth chart, and pubertal development;
- Family history of diabetes, diabetes complications, and other endocrine disorders;
- Current or recent use of medications that may affect blood glucose levels (e.g. glucocorticoids, chemotherapeutic agents, atypical antipsychotics, etc.);
- History and treatment of other conditions, including endocrine and eating disorders, and diseases known to cause secondary diabetes (e.g. cystic fibrosis);
- Lifestyle, cultural, psychosocial, educational, and economic factors that might influence the management of diabetes
- Use of tobacco, alcohol, and/or recreational drugs;
- Physical activity and exercise;
- Contraception and sexual activity (if applicable);
- Risk factors for atherosclerosis: smoking, hypertension, obesity, dyslipidemia, and family history;
- Review of Systems (ROS) should include gastrointestinal function (including symptoms of celiac disease) and symptoms of other endocrine disorders (especially hypothyroidism and Addison's disease);
- Prior A1C records*;
- Details of previous treatment programs, including nutrition and diabetes self-management education, attitudes, and health beliefs*;
- Results of past testing for chronic diabetes complications, including ophthalmologic examination and microalbumin screening*;
- Frequency, severity, and cause of acute complications such as ketoacidosis and hypoglycemia*;
- Current treatment of diabetes, including medications, meal plan, and results of glucose monitoring and use of data*.

Physical examination

- Height, weight, and BMI calculation (and comparison to age and sex-specific norms);
- Blood pressure determination and comparison to age-, sex-, and height-related norms;
- Funduscopic examination;
- Oral examination;
- Thyroid palpation;
- Cardiac examination;
- Abdominal examination (e.g. for hepatomegaly);
- Staging of sexual maturation;
- Evaluation of pulses;
- Hand/finger examination;
- Foot examination;
- Skin examination (for acanthosis nigricans SMBG testing sites and insulin-injection sites*);
- Neurological examination.

Appendices

Laboratory evaluation

- *If clinical evidence for DKA:*
- Serum glucose, electrolytes, arterial or venous pH, serum or urine ketones;
- *If signs and symptoms are suggestive of type 2 diabetes:*
- Evidence of islet autoimmunity (e.g. islet cell [ICA] 512 or IA-2, GAD, and insulin autoantibodies);
- Evidence of β -cell secretory capacity (e.g. C-peptide levels) after 1 year, if diagnosis is in doubt;
- A1C;
- Lipid profile;
- Annual screening for microalbuminuria;
- Thyroid-stimulating hormone (TSH) levels;
- Celiac antibodies at diagnosis or initial visit if not done previously.

Referrals and screening

- Yearly ophthalmologic evaluation;
- Medical nutrition therapy (by a registered dietician);
- As part of initial team education and on referral, as needed; generally requires a series of sessions over the initial 3 months after diagnosis, then at least annually, with young children requiring more frequent re-evaluations;
- Diabetes nurse educator;
- As part of initial team education, or referral as needed at diagnosis; generally requires a series of sessions during the initial 3 months of diagnosis, then at least annual re-education;
- Behavioral specialist;
- As part of initial team education, or referral as needed optimally for evaluation and counselling of the child with diabetes and family at diagnosis, then as indicated to enhance support and empowerment to maintain family involvement in diabetes care tasks and to identify and discuss ways to overcome barriers in successful diabetes management;
- Depression screening annually for children ≥ 10 years of age, with referral as indicated.

*Pertain only to those previously diagnosed, at time of initial referral, assuming prior medical management.

Appendix II: Glossary

Acronyms: Associations, Trials and Programmes

AACE – American Association of Clinical Endocrinologists;
ADA – American Diabetes Association;
CDA – Canadian Diabetes Association;
DAWN – Diabetes Attitudes, Wishes and Needs Programme;
DCCT – Diabetes Control and Complications Trial;
EDIC – Epidemiology of Diabetes Interventions and Complications;
EURODIAB – European Diabetes;
IDF – International Diabetes Federation;
IIF – International Insulin Foundation;
ISGD – International Study Group of Diabetes in Children and Adolescents;
ISPAD – International Society for Pediatric and Adolescent Diabetes;
RAPIA – Rapid Assessment Protocol for Insulin Access;
UKPDS – United Kingdom Prospective Diabetes Study;
UN – United Nations;
WHO – World Health Organization;
DiaMond – Multinational Project for Childhood Diabetes.

Terms

- A1C – HbA1c; the measurement of the amount of glycated hemoglobin in the blood. A1C provides an estimate of how well diabetes is being managed over time and is measured every 3–4 months;
- Acanthosis nigricans – skin condition characterized by dark thickened velvety patches, especially in the folds of skin in the armpit, groin and back of the neck; common in individuals with insulin resistance;
- Antenatal – prenatal; before birth;
- Autoantibodies – antibodies directed against the individual who produced them;
- Autoimmunity – misdirected immune response that occurs when the immune system attacks the body itself; type 1 diabetes is classified as an autoimmune disease;
- Autosomal – pertaining to a chromosome other than a sex chromosome;
- Beta cell – a type of cell in the pancreas that makes and releases insulin;
- BMI – body mass index;
- Body mass index (BMI) – index for relating a person’s body weight to their height. The body mass index. (BMI) is a person’s weight in kilograms (kg) divided by their height in meters (m) squared;
- Diabetes mellitus – diabetes mellitus is a group of metabolic diseases characterised by high blood glucose levels, which result from defects in insulin secretion, or action, or both;
- Diabetic ketoacidosis (DKA) – a feature of uncontrolled diabetes characterized by a combination of ketosis (accumulation of ketone bodies in the blood) and acidosis (increased acidity of the blood). Caused by producing or taking too little insulin or during illness;
- DKA – diabetic ketoacidosis;
- EEG – electroencephalogram;
- Electroencephalogram – study of electrical current within the brain;
- Endocrinopathy – disease of an endocrine gland, e.g. hyperthyroidism, hypothyroidism;
- Epidemiology – the study of populations to determine frequency and distribution of disease and measure risks;
- Fasting Plasma Glucose (FPG) – a measurement of an individual’s blood glucose level after 8 hours without food or drink;
- Fibrocalculous – as in fibrocalculous pancreatic diabetes; an uncommon form of diabetes;
- FPG -Fasting Plasma Glucose;
- Gestational diabetes – diabetes occurring during pregnancy that usually resolves upon delivery;
- Glucose – the simple sugar (monosaccharide) that serves as the main source of energy in the body; the principal sugar made by the body;
- Glucose intolerance – the body’s inability to utilize blood glucose;
- Glycaemic control – the ability to reach and sustain blood glucose levels to recommended target level;
- Glycated haemoglobin (HbA1c) – hemoglobin to which glucose is bound. Glycated hemoglobin is tested to monitor the long-term control of diabetes;
- Hemoglobin – the oxygen-carrying pigment and predominant protein in red blood cells;
- HbA1c – hemoglobin A1c; the component of hemoglobin to which glucose is bound. HbA1c levels depend on the blood glucose concentration; the higher the glucose concentration in blood, the higher the level of HbA1c. HbA1c levels are not influenced by daily fluctuations in the blood glucose concentration, but reflect the average glucose levels over the prior 3–4 months;
- Hyperglycemia – the clinical syndrome of high blood glucose that occurs when the body does not produce enough insulin or cannot use the insulin produced to turn glucose into energy;
- Hypoglycemia – the clinical syndrome of low blood glucose that deprives muscles, cells and brain of the energy needed to function; caused by excess insulin (too high a dose);
- Incidence – the frequency with which a disease appears in a particular population; the number of newly diagnosed cases during a specific time period;
- Insulin – a naturally occurring hormone secreted by the pancreas. Insulin is required by the cells of the body to use glucose from the blood for energy. Diabetes is defined by insufficient or absent insulin production (type 1); or insufficient production or utilization of insulin (type 2). Different types of insulin for diabetes treatment are categorized by time of onset, peak time and duration of action;
- Insulin resistance – the diminished ability of cells to respond to the action of insulin in transporting blood glucose from the bloodstream into muscle and other tissues. Insulin resistance typically develops with obesity and can signify the onset of type 2 diabetes;
- Ketoacidosis – see Diabetic ketoacidosis;
- Ketones – chemical substances that the body makes when it does not have enough insulin in the blood. When ketones build up in the body for a long time, serious illness or coma can result;

Appendices

- Ketosis – the accumulation of substances called ketone bodies in the blood;
- Macrovascular disease – diabetes-related complications affecting the large blood vessels, including the coronary arteries, aorta, and larger arteries in the brain and limbs. Macrovascular complications include cardiovascular disease and stroke;
- MAU – microalbuminuria;
- Microalbuminuria (MAU) – an increase in the urinary excretion of the protein albumin that cannot be detected by a conventional assay. Microalbuminuria is an early sign of diabetic kidney disease;
- Microvascular disease – diabetes-related complications affecting small blood vessels. Microvascular complications include retinopathy, neuropathy and nephropathy;
- Monogenic – pertaining to one gene;
- Monosomal – pertaining to the unpaired sex chromosome;
- Nephropathy – kidney disease; in diabetic nephropathy, the tiny blood vessels in the kidney are affected resulting in impaired kidney function;
- Neuropathy – disorder of the nervous system; diabetic neuropathy may occur in every part of the body including the organs;
- Pancreatitis – inflammation of the pancreas;
- Perinatal – pertaining to the period immediately before and after birth;
- Polycystic ovary syndrome – a disorder of abnormal ovarian function and elevated androgen levels in women characterised by irregular or no menstrual periods, acne, obesity, and excess hair growth;
- Polydipsia – frequent thirst; sign of hyperglycemia;
- Polygenic – pertaining to two or more genes;
- Polyuria – frequent need to urinate; sign of hyperglycemia;
- Postprandial – after eating;
- Postprandial glucose – a measurement of an individual’s blood glucose level after eating;
- PPG – postprandial glucose;
- Prevalence – the number of cases of a disease present in a particular population at a given time;
- Retinopathy – a complication of diabetes affecting the blood vessels in the retina, the light-sensitive membrane covering the back of the eye;
- Target – target level for glycemic control based on HbA1c; the optimal level of HbA1c as defined by various associations including the Canadian Diabetes Association: HbA1c $\leq 7\%$ ($< 8\%$ for children); American Diabetes Association: HbA1c $< 7\%$; American Association of Clinical Endocrinologists/International Diabetes Foundation: HbA1c $\leq 6.5\%$;
- Type 1 diabetes – an autoimmune disease in which the immune system attacks the insulin-producing beta cells in the pancreas and destroys them. The pancreas then produces little or no insulin;
- Type 2 diabetes – a disease in which the pancreas produces insufficient insulin for the body’s needs or in which the body cannot effectively use the insulin that is produced (insulin resistance).