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(vii) Parent with diabetes: outdated or inappropriate concept of care for the child with diabetes; anxiety/depression related to personal diabetes care affecting ability to learn and utilize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

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.

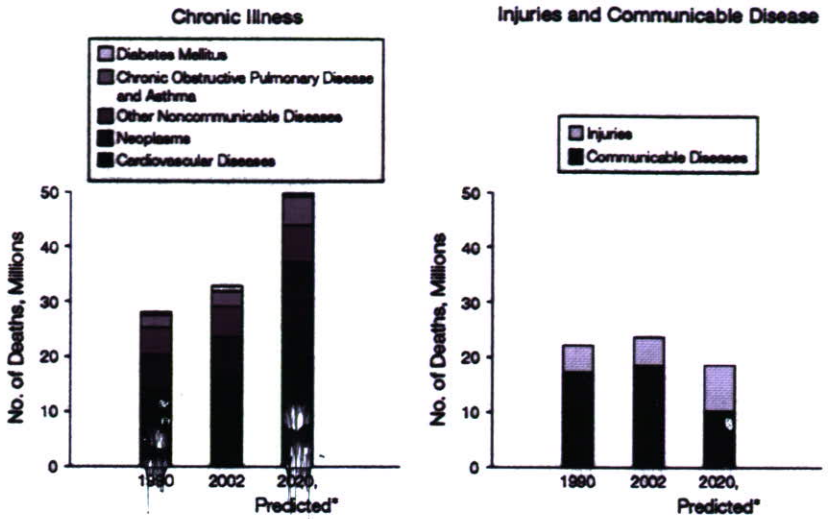

Fig. 1. Global mortality from chronic diseases (1).

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

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.

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.

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 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

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 glycated 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.

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 ß-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 $\geq$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;
Polydypsia – 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).