

Decision-making in Insulin Dependent Diabetes Mellitus

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Diabetes is the second most common chronic disease in childhood (the first being asthma). It is a disease for which there is no cure as of today. Diabetes in children is usually of the insulin dependent variety. The condition poses a major challenge to diabetic children and to their families.

Children with diabetes must take insulin injections at least twice a day, check their blood glucose regularly at home and observe several restrictions in diet and physical activity. They must make major adjustments in their lifestyle, as must other members of their families. Misconceptions about this disease are rampant — even among school and college authorities — and come in the way of the child leading a normal life. Further, the cost of managing diabetes is quite prohibitive. Unfortunately insurance companies in India do not cover this chronic ailment.

Need for awareness

Though the symptoms of diabetes are very typical, the diagnosis is often missed at an early stage because of a lack of awareness. Diabetes in children is often misdiagnosed as urinary tract infection, asthma, worms, encephalitis and appendicitis. Delay in diagnosis can prove to be fatal. Awareness must be created among the lay public and among family physicians that diabetes can occur in childhood, infancy and even the newborn period. They must also be informed of the clinical clues to this diagnosis.

Diagnosis

Many diagnostic tests are only of academic interest. In a child who has the typical symptoms, the diagnosis can be confirmed by a simple random blood glucose estimation and urine acetone test. An oral glucose tolerance test is unnecessary except in very early cases that are asymptomatic or have

vague symptoms. Baseline serum lipids, TSH, anti-thyroid antibodies, urine routine and culture and fundus examination are essential in all cases.

Other special and expensive tests (HLA typing, Islet cell antibodies, anti-GAD antibodies, insulin auto-antibodies, viral studies) are often asked for but do not change the management or prognosis in a given case. They should be performed only for academic interest in a research setting or in the occasional case where it is suspected the diabetes may not be of the type 1 variety.

After diagnosis

Acceptance of the diagnosis by the patient is the first essential step in successful management. In the initial stages following diagnosis, all patients are tempted to reject the diagnosis or the treatment (insulin therapy), or both. Misleading newspaper reports and unscrupulous quacks add to the problem by suggesting or offering alternatives to insulin therapy. We have seen many patients omitting insulin and switching over to homoeopathy or ayurveda only to return in a state of diabetic ketocidosis. One patient from a highly educated family repeated this near fatal mistake thrice before finally falling in line. In our experience the best way to tackle this problem is to get senior patients to counsel newly diagnosed cases, based on their own early experiences and misadventures.

Good diabetes control rests on four pillars — insulin therapy, meal planning, regular planned exercise and therapeutic monitoring. These pillars have to be supported by a foundation made up of patient education and emotional stability. If this foundation is weak, the entire edifice will collapse.

The doctor's role in management of this disease does not end with providing a prescription. S/he must educate the patient in self management and ensure emotional stability. This process requires a dedicated team comprising paediatric diabetologist, a psychiatrist, a clinical psychologist, a

dietician, a patient educator and a social worker.

Diabetic children and their parents / guardians must be educated in all aspects of diabetes self care (see table 2) so as to make them independent, give them a sense of control over their disability, help them achieve better diabetes control and cut down the cost of treatment. Patient education can be achieved by means of formal lectures and demonstrations or with the help of educational games, diabetes quiz contests and so on. At the Juvenile Diabetes Foundation clinic we have a fully trained patient educator in attendance. We also hold monthly meetings during which patient education is imparted. Once a year during the Christmas vacation we conduct a four-day residential camp at Khandala where the stress is on patient

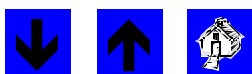
When to suspect diabetes in a child:

- 1) classical symptoms: polyuria, polydipsia, polyphagia with weakness and weight loss,
- 2) loss of weight despite excessive appetite,
- 3) secondary enuresis,
- 4) observation of ants collecting around the urine,
- 5) respiratory distress without any positive findings in the respiratory or cardiovascular systems,
- 6) in the differential diagnosis of acute abdomen, and
- 7) in the differential diagnosis of coma.

education and informal psychotherapy.

Informal psychotherapy must be given to help the patient overcome the initial shock at diagnosis, the "why me?" feeling, the sense of guilt and feeling of hopelessness. This is also the best response to false hopes, anxieties about the future, any inferiority complex, and financial worries.

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Conventional or intensive therapy?

In conventional therapy patients take two shots of insulin daily, check their blood glucose once or twice a day and adjust insulin doses every 3-5 days based on the patterns of blood glucose.

In intensive therapy patients either use an insulin pump or take three or more shots of insulin daily and check their blood glucose 4-5 times a day. Besides pattern adjustment algorithms they also take insulin supplements whenever dictated by the prevailing blood glucose or anticipated change in meal size / physical activity.

Intensive therapy, though proven to reduce the risk of micro-vascular complications of diabetes, should be recommended very selectively, only to highly motivated and intelligent teenagers. Further, intensified treatment can only be recommended by those centres which have the facility for 24-hour patient back-up service on phone.

Bringing down costs

All diabetes-related paraphernalia are available in India, but at a price. While they do cost much less than the same products in developed countries, they pose a financial burden even for well-off patients. For a 30-kg child, the monthly cost of insulin works out to Rs 450. Blood glucose monitoring once or twice a day will cost another Rs 600, and even if each syringe is used for seven days, it would cost Rs 25. The necessary laboratory tests would cost an average of Rs 200 a month. Insurance companies in our country do not cover this chronic childhood disease. The JDF helps out all poor patients by supplying these requirements free of cost or at highly subsidised rates, and expensive monitoring equipment can be lent by the JDF centre for needy patients.

Problems at school

Schools are reluctant to accept diabetic children. When a diabetic child joins school, the school authorities must be informed of the fact, and educated about the condition. They must be told that diabetes is not contagious, that it will not interfere with the child's academic progress and that the child

can and should participate in all sports activities. At the same time, the child's teachers must be educated in early recognition and first-aid management of hypoglycaemia. They must be asked to give the child time off to take his/her shots, test blood glucose levels, or

What patients should know

- 1) The implications of being a diabetic,
- 2) four procedures (insulin administration, home blood glucose testing, urine acetone testing, and glucagon administration),
- 3) the prevention, early identification and first aid management of the diabetes-related emergencies hypoglycemia and ketoacidosis,
- 4) meal planning, and
- 5) record keeping and insulin dose adjustments.

take a snack whenever necessary. They should have the contact number of the child's doctor / clinic in case of emergency.

The dangers of secrecy

Secrecy must be discouraged as it can prove to be dangerous for various reasons. When the condition is kept hidden, the child will not have the freedom to eat, to test blood or to inject insulin when required. Further, if the child suddenly develops hypoglycaemia, the teachers and friends will not be in a position to help. Diabetic children must carry a diabetic identification card on their person so that they receive appropriate treatment if they develop a seizure or aberrant behaviour due to hypoglycaemia in public places. Secrecy in marriage can also be dangerous and detrimental to marital harmony. Many of our patients have found very good life partners despite disclosing in advance that they suffer from insulin-dependent diabetes.

Marriage and reproduction

Juvenile diabetics can marry and lead successful married lives. The risk of the offspring developing diabetes is small:

two per cent if the mother is a diabetic, six per cent if the father is the patient, and 30 per cent if both parents are juvenile diabetics. A diabetic woman will need to control her blood sugars very well even before conception to reduce the possibility of congenital malformations in her offspring. Tight control throughout pregnancy is a must so that the neonate is spared the possibility of birth trauma, respiratory distress syndrome or metabolic problems particularly hypoglycaemia, hypocalcemia, polycythemia and hyperbilirubinemia.

Prevention

For family members of diabetic children, certain tests (including HLA typing, islet cell antibodies, insulin auto antibodies, anti-GAD antibodies, and first phase insulin release on intravenous glucose tolerance test) can serve as a guide to the subsequent development of diabetes. However, these tests are not fool-proof. Further, since there is no proven measure to prevent the development of diabetes, these tests are best avoided except in a research setting, as they would only add to the level of stress without any positive gain.

