Short reports

The diabetic with a diabetic parent

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SUMMARY Six of eight children with diabetes who have a parent with type I diabetes mellitus presented serious management problems. The doctor and diabetic health visitor should be aware that these families may require extra support.

Many factors affect the management and the control of diabetes. In children, the family’s attitude towards the disease and their knowledge and ability to cope with it are particularly important. Approximately four per cent of diabetic children have a parent with diabetes and they might be expected to benefit from their parents’ knowledge of the disease. We have not found this to be the case and this report reviews our experience.

Patients

In Bristol there are approximately 200 children with diabetes mellitus. Eight of these children (five boys, three girls) live with a parent who has type I diabetes mellitus. The children’s ages at diagnosis ranged from 4-5 to 14-7 years, with mean duration of disease of 4-2 years (range 3-0 to 10-9 years). In five families the mother has diabetes and in three the father. The onset of the parent’s diabetes preceded that of their child’s by at least four years (mean 19 years).

The ability of the child and his parents to manage the disease was assessed by their knowledge of diabetes and their attitude towards dietary advice, insulin injection, and to blood or urine testing. The parents degree of anxiety or depression and the presence of family conflicts was assessed during the clinic visits by the physician or during home visits by the diabetic health visitor. In those families referred for psychiatric help a more formal assessment was made.

Results

At the time of diagnosis all the diabetic parents had a poor understanding of the disease and none had the knowledge or confidence to vary their diet or insulin dose. There was serious parental conflict in three families (cases 4, 5, and 8), and in a fourth (case 1) the parents were divorced. Two of these families (cases 5 and 8) were on the at risk register for child abuse.

Three of the diabetic parents were extremely over anxious (cases 1, 4, and 8) and in each case the child responded by rebellious and manipulative behaviour.

Four of the parents (cases 4, 5, 6, and 8) had previously made little or no attempt to control their own diabetes and their children, within six months of diagnosis, had all refused injections and repeatedly provoked ketoacidosis requiring hospital admission. Three of these (cases 4, 5, and 8) continued to have such serious management problems that the families were referred to a child psychiatrist and two of these children (cases 5 and 8) are now at special boarding schools. The patient in case 6 has followed her father’s example and eats a normal diet and does not monitor control.

Only two families (cases 2 and 7) have had no major problems and both of these have stable family backgrounds (Table).

Discussion

The family plays a central role in the management and hence control of a child with diabetes. A sound knowledge of diabetes is important, but in addition well controlled children usually have a stable family background with capable, caring parents and few family conflicts or financial difficulties. In children with management problems, these factors are often absent and parents may also be over anxious or have episodes of depression.
In this study the diabetic parents had a surprisingly poor knowledge of their disease. This may have been due to lack of interest but may also have arisen because they were initially supervised in an era when patients received little education. Most of these parents had misconceptions about the disease—the most serious being that since little could be done to prevent complications there was no point in either adhering to a diet or monitoring control carefully. Where the diabetic parent behaved in this way then, not surprisingly, their children followed their example.

Many parents with a child with diabetes became over anxious and over protective. One of the commonest reasons for this is the fear of hypoglycaemia, and in these parents their excessive anxiety may reflect their own experience. Other factors may be their worry about the disease's complications or feelings of guilt at having 'passed on' diabetes to their child. Whatever the cause, their anxiety probably impaired their ability to learn about the disease and support their child, and their over protection led eventually to rebellious behaviour in their children. Prejudices, anxiety, feelings of guilt, and over protection occur in parents without diabetes but seem to be more prominent in this special group.

The risk of conflict in a marriage is increased where the husband or wife has a chronic illness; this seems to have been the case in these families and was probably an important factor underlying these children's problems.

The management of these families may be difficult. At the time of diagnosis it is important to evaluate the diabetic parent's knowledge of the disease and to listen to their prejudices and anxieties. Time must be available while the child is in hospital and at subsequent clinic visits to gain the family's confidence, to re-educate the parents, and allay their fears. Diabetic health visitors can give invaluable support to the families by visiting them at home where they can reinforce the teaching of the clinic and give support with day to day difficulties. The child should be encouraged to take some responsibility for his disease and motivation is often improved if from the age of 9 or 10 years he is seen alone in the clinic. Occasionally advice from a child psychiatrist may be necessary and in some cases a period away from home, boarding at a special school, may be needed.

This report is based on a small group of children whose problems do not seem to have been studied previously. The doctor and diabetic health visitor should be aware that these families may require more rather than less support and that management problems occur frequently.

References


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