A PROJECT IN DIABETIC EDUCATION FOR CHILDREN

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FORMAL DECLARATION

I declare that I have written this dissertation presented to the University of Edinburgh for the degree of Doctor of Medicine; that it is based upon my own observation and that, except as indicated in the thesis, the data were collected, analysed and interpreted by me.

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ABSTRACT OF THESIS (Regulation 3.5.10)

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The work in this thesis describes the effects of an informal education programme for children attending the paediatric diabetic clinic at the Royal Hospital for Sick Children, Edinburgh. This paediatric clinic was introduced in the early 1950s to provide an appropriate service for children and by the early 1980s the children within the clinic, which was staffed by a motivated team including a diabetes nurse specialist, paediatric dietitian, paediatrician and adult physician for adolescents, had reasonably good diabetic control compared with other specialist clinics.

A recent survey of the clinic, however, identified problems, including difficulties teaching about diabetes, limited dietitian time and little time to discuss stress-related problems. To address these issues, a 2 year randomised cross-over trial was devised to determine whether an informal education programme (Diabetic Club) could improve knowledge about diabetes, reduce stress in diabetic families and thereby improve diabetic control. Forty-eight of 92 families with children less than 13 years on 1st October 1985 volunteered for the study and were randomised to Groups A and B. Those families who elected not to participate were significantly older, and had had diabetes for longer, but their diabetic control was similar to the participants. Group A attended the Diabetic Club for 10 afternoons of education in the first year while Group B continued at the routine clinic (5 visits per year). For the second year Group A returned to the clinic, Group B attended the Club. The education programme covered all aspects of diabetes care based on small group teaching and semi-structured discussion groups for parents and children.

In both groups glycosylated haemoglobin (HbA_1) remained stable while attending the Club but rose significantly while attending the clinic. Other indices of diabetic control were unchanged. Diabetic problem-solving scores of mothers improved significantly during the Club year, but their knowledge of diabetes did not correlate with their child's HbA_1. Dietary intake showed a significant reduction in percentage energy taken as fat during Club attendance. The percentage of parents reporting helpful social contact between families increased significantly during their Club year. Psychological measurements remained unchanged during the study. Attendance was good at the Club (86%) despite the extra time demanded of the families (38 hours per year compared with 11 hours per year attending the clinic) and correlated with social class but not distance to travel.

Diabetic control of children from our specialist clinic was compared with that of children attending paediatric clinics in three district general hospitals in adjacent areas in Scotland. The children attending the specialist clinic were admitted to hospital for significantly fewer days and HbA_1 was significantly better compared with children attending the general paediatric clinics.

The incidence of insulin dependent diabetes is rising particularly in children and better resources will need to be available. This study showed that an education programme for diabetic children may stabilize diabetic control in the short term, but the main benefit is the support provided by increased social contact with other diabetic families. Small group teaching and discussion, and grouping families to visit together may be incorporated cost-effectively into routine clinics to help to motivate families and thereby improve diabetic control.

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CONTENTS

PUBLICATIONS

ABBREVIATIONS USED:

RHSC - Royal Hospital for Sick Children, Edinburgh

IDDM - Insulin dependent diabetes mellitus

HbA_1 - Glycosylated haemoglobin

RDA - Recommended daily amounts

BDA - British Diabetic Association

CHAPTER 1

INTRODUCTION AND AIMS OF THE THESIS

The quality of life of children with insulin dependent diabetes mellitus (IDDM) has improved considerably over the last 30 years due to a variety of factors, but in some centres care still remains far from ideal. There is evidence that the incidence of diabetes in children is increasing (1) but the reasons for this remain unclear. Research into the aetiology and possible prevention of diabetes has not provided answers. Good diabetic control may prevent complications and may even in some circumstances reverse those already established (2). It is therefore essential that the care of young diabetics is optimal to reduce the morbidity and mortality of this disease.

Epidemiology; evidence that IDDM is becoming a more common disorder

Epidemiological studies have consistently shown marked geographic differences in the risk of developing IDDM (Table 1). The data in this table was compiled from available national registries throughout the world (3). They vary in the ages of the patients recorded but all are less than 20 years of age. There is a striking difference between Finland which has an incidence of 28.6 per 100,000 population at risk per year of developing IDDM, and Japan which has the lowest of 0.8 per 100,000 (3). There is a strong correlation (r 0.76) between incidence of IDDM and distance from the equator with the most northerly countries having the highest incidence of the disease (4). In Scotland the incidence quoted is 13.8 per 100,000 per year while in England the

figure is 7.7 per 100,000 per year (1975)(4). A very recent study (1989) from the Oxford area (5) shows an incidence of 15.6 per 100,000 population <21. Similarly a recent Scottish study (1988)(6) shows an incidence of 21.7 in male and 20.2 per 100,000 population upto 18.

There is also evidence for both an increasing incidence and prevalence of the disease. Finland, which has the highest incidence (Table 1), in 1982 had a prevalence three times that recorded in 1953 (1). A study from the United Kingdom of 10 and 11 year olds from a national cohort study shows a prevalence in 1946 of 10 per 100,000 which by 1970 had increased to a prevalence of 130 per 100,000 (7). The numbers in this study, however, were small and by chance these numbers may be exaggerated. Data for hospital admissions in Scotland collected between 1968 and 1976 showed an incidence in 1968 of 10 per 100,000 population per year rising to 18 per 100,000 per year by 1976 (8) and rural populations had an incidence three times that of urban populations. Information from hospital paediatric admissions in Glasgow collected between 1933 and 1976 showed that between 1973 and 1976 113 new cases were admitted compared to the 21.2 cases which would be expected based on the 1933 figures (9). A recent Scottish study (6) showed a rapid rise in incidence between 1977 and 1983 in agreement with other European centres. The most recent survey of the incidence of IDDM in children under 15 years was performed for the British Isles in 1988 (10) and unlike previous surveys (4) had a very good case ascertainment of 90%. Sixteen hundred children had a confirmed diagnosis of IDDM, giving a national incidence of 13.5/100,000 per year. There was considerable regional variation in incidence ranging from the lowest (in the Republic of Ireland) 6.8/100,000 to the highest

(Scotland) 19.8/100,000 per year. A quarter of the children were under 5 years. This suggests environmental influences may be concerned, though it might mean that susceptible individuals are presenting earlier (11).

A study from the United Kingdom also showed prevalence to be greater the higher the social class (Social Class I 2.5 per 1000; Social Class II 2.1 per 1000; Social Class IIIN 0.9 per 1000; Social Class IIIM 1.6 per 1000; Social Classes IV, V and VI no cases) (7). A survey from Montreal showed an association between increasing prevalence of the disease and increasing income and postulated that the onset of IDDM in children may be linked to the dietary changes associated with a higher income (12).

These figures therefore all show that IDDM is the most common endocrine disease of childhood with a prevalence of approximately 1 in 500 in the United Kingdom for children less than 16 years, ie every large secondary school may have at least one diabetic child. Scotland in particular has a relatively high incidence which is rising.

Control of Diabetes and the Development of Complications

Diabetes requires a daily regimen of insulin injections, adjustment of dosages, a carbohydrate controlled diet and frequent self-monitoring either by blood or urine testing. This daily routine may be interrupted by unpleasant hypoglycaemic episodes or episodes of hyperglycaemia during infections sometimes requiring hospital admission. All diabetics face the risk from microvascular and macrovascular complications. It is the leading cause of new cases of blindness and end-stage renal disease in adults and diabetics are at increased risk of myocardial infarction and amputation (2).

Recently, there has been evidence that longterm microvascular complications are linked to antecedent poor metabolic control and that good metabolic control can both prevent these complications developing and arrest progression of established disease (2). One study from the Joslin Clinic (13) showed that patients maintaining good control for over 20 years had a complication rate of 10% to 15% compared to 70% to 80% in those judged to be in poor control. Conversely there were some patients in the poor control group who had no vascular complications even after 20 years of diabetes. Pirart who followed 4400 diabetic patients for 20 years reached similar conclusions (14).

Prospective studies in humans to assess whether improved control can prevent complications are difficult to achieve. The Kroc Collaborative Study Group (15) has randomly allocated patients to either conventional insulin treatment or continuous subcutaneous insulin infusions (CSII). In the latter group of patients undergoing CSII, near normoglycaemia was achieved and after 12 months the progress of retinopathy in this group was arrested or retarded compared with those receiving conventional treatment. Similar results have been obtained in a Danish study (16) although there has been some concern that sudden improvement in metabolic control may worsen retinopathy initially before improvement occurs (17).

There is also some evidence that early microvascular changes may be reversed by good metabolic control. Microalbuminuria, the earliest functional sign of diabetic nephropathy, may be reversed by improved control, but when significant proteinuria has developed strict metobolic control will not restore renal function to normal (18).

The evidence from these retrospective and prospective studies indicates that good metabolic control is desirable to prevent complications (19). Such control requires a high degree of patient education, motivation and compliance as well as a considerable commitment by health care staff. Each child with diabetes should be managed to maintain good diabetic control compatible with physical and psychological wellbeing of the patient and his family.

Milestones in Diabetic Care

The management of diabetes has developed considerably since the introduction of insulin in the 1920s. This progress is marked by certain milestones of innovations in diabetic care.

1. Clinics - Initially all diabetics, including children, were under the care of adult physicians who were either diabetologists or general physicians and it is only in the last 30 years that children with diabetes have been under the care of paediatricians; indeed in some areas they are still cared for by adult diabetologists. An adult diabetic clinic which may have visible evidence of the longterm complications of diabetes, such as blindness and amputation, does not seem to be an ideal place to care for diabetic children who are attempting to lead normal lives.

   The introduction of specialist paediatric diabetic clinics with a paediatrician specifically interested in diabetes or a paediatric endocrinologist have been shown to make a considerable difference to diabetic control in children (20). In Birmingham a new specialist clinic was introduced to care for a total of 83 diabetic children who had previously been looked after by adult physicians and general

paediatricians at different general clinics. Mean glycosylated haemoglobin fell from 15.8% to 9.9% within 2 years. Ten per cent of the children entering this clinic already had longstanding diabetic retinopathy or nephropathy. Only 2% had a glycosylated haemoglobin of less than 10% at the introduction of the clinic; two years later 59% of the children had a glycosylated haemoglobin below 10% (normal reference range for their laboratory 5-9%).

2. Blood Glucose Monitoring - The introduction of routine home blood glucose monitoring in adults has been shown to improve glycosylated haemoglobin and diabetic control but only if enthusiastically supported by clinic staff (21). A similar study in children showed no improvement in diabetic control as expressed by glycosylated haemoglobin but did show improvement in blood glucose levels (22). In both studies, however, between 60% and 90% of the patients preferred blood glucose monitoring to urine testing and it helped to reduce the anxiety of coping with their daily regime of testing and insulin injections.

3. Glycosylated Haemoglobin - The recent development of measuring glycosylated haemoglobin (HbA_1) in blood samples (23) now provides an extremely useful objective measure of diabetic control and enables appropriate adjustments to be made in the diabetic regimen.

4. Insulin and Its Administration - The introduction of disposable syringes, purified pork insulins and now human insulin may have all contributed to the improvement in diabetic care by reducing the incidence of lipoatrophy and the generation of insulin antibodies. New regimes of multiple injections using implements such as the Penject may also have a role to play in the older adolescent

patients. Continuous subcutaneous insulin infusion (CSII) has met with variable success in children. Davies et al in their study in 1984 (24) showed a significant improvement in glycosylated haemoglobin in 7 patients on continuous subcutaneous infusion (HbA_1 dropped from 11.5% to 9.1%), while in 6 patients on an intensive regime glycosylated haemoglobin dropped from 11.8 to 10.4gm%. In this group of patients the pump proved to be more acceptable than the intensive regimen. In a review of other studies (25) HbA_1 was maintained within the normal range by continuous subcutaneous infusion, however there was a number of patient related problems including local skin inflammation, haematoma of needle insertion site and forgetting extra meal doses. One adolescent death has been reported with CSII (26).

5. Diabetes Nurse Specialists - Diabetes nurse specialists have contributed considerably to the improvement in diabetic care. In the United States of America the diabetes nurse specialist is the prime educator, teaching both the theoretical and practical skills required by the diabetic patient. Nurses may often develop a better rapport with the patient than the medical staff who may appear authoritarian and far removed from the practical day-to-day considerations of diabetic care. The nurse specialist is an essential part of the team (27). They have a key role in improving a patient's confidence and motivation.

All the innovations listed above have improved the quality of control and the quality of life for diabetic children but further improvements might still be made.

The Role of Patient Education

Diabetes is a unique disease in that the patient manages his own therapy on a day-to-day basis. This requires, at the very least, a basic knowledge of the action of insulin, how to adjust insulin dose, the composition of a healthy diet, carbohydrate spacing and the rationale for blood and urine testing. The patient then has to use this knowledge to solve the problems of maintaining metabolic balance during the rigours of everyday life. In the past it has been assumed that poor metabolic control is due primarily to the patient's poor knowledge about his diabetes. Many strategies to improve diabetic control have been aimed at patient education. Several studies have shown that diabetics may often have poor knowledge about diabetes (28) and have shown both improved metabolic control and reduced hospital admission rate with intensive education programmes(24, 30, 31). They have also shown a correlation between good knowledge about diabetes and HbA_1 (32). Other studies, however, have shown that although intervention programmes may improve metabolic control there is in fact no correlation between improved knowledge and improved glycosylated haemoglobin (33), indicating that education programmes may improve diabetic control by mechanisms unrelated to improvement in knowledge of diabetes. A variety of methods of diabetic education have been attempted and these will be discussed in detail later but briefly they include one-to-one interviews, group discussions, sessions using primarily videotaped material, ensuring continuity of care and teaching based on patient participation. Jovanovic reviewed eight programmes which used several different educational methods and results. This comparison showed that the team approach and group discussions were most successful (34).

The Role of Stress and Anxiety

The role of stress and anxiety in influencing metabolic control remains controversial. Physical and environmental stress may increase hyperglycaemia in diabetes. These effects are probably mediated via the central and sympathetic nervous system as well as through the hypothalamic pituitary axis (35). Diabetic children have shown a raised blood glucose level in response to an adrenalin infusion compared to non-diabetic children (36).

It has been said that children with unstable diabetes come from unstable families. In a recent study of 30 children admitted for persistently poor control, 75% of families showed inadequate parenting, 80% were single-parent families and 80% had poor living conditions (37). In a study by Gath et al (38) poor diabetic control correlated with poor psychosocial circumstances, psychiatric problems and reading backwardness. In an extensive review of psychosocial factors in diabetes Greydanus (39) reached similar conclusions.

More recently, however, some workers have concluded that some degree of stress and anxiety is to be expected in this disease and may in fact fulfil a useful function. Fonagy et al (40) found that those children with the best diabetic control (as measured by HbA_1) while not overtly disturbed had the highest anxiety levels. Dunn (41) has suggested that "feeling better" about having diabetes does not necessarily lead to good control.

Current Diabetic Control in Children

At the moment, glycosylated haemoglobin A_1 (HbA_1) (which is proportional to the overall blood glucose during the preceeding 2-3 months) is the most widely used index of diabetic control. The aim of diabetic control is for patients to have HbA_1 within the normal range of 5-8%. Mann and Johnson in 1982 studied 148 children attending a specialist diabetic clinic with a mean age of 11.2 years. The mean HbA_1 for children less than 12 years was 12.4 % and for children greater than 12 was 13.4% in the boys and 14.3% in the girls (42). Daneman et al (43) report only 1.4% of 477 children from a large paediatric clinic had glycosylated haemoglobin within the normal range.

In our clinic at the Royal Hospital for Sick Children in Edinburgh (RHSC) in 1985, children <13 years of age had a mean HbA_1 of 10.3%, a figure better than that quoted above but one still well above the normal range (4.9-7.9% for our laboratory).

Aims of Thesis

In a recent survey (44) of adult diabetics who had previously attended the clinic at the Royal Hospital for Sick Children in Edinburgh over two-thirds professed themselves unhappy with some aspects of their diabetic management. From this we identified several problems with our own clinic structure. These were:-

1. Too much information is given too soon at diagnosis, but thereafter information is given piece-meal in response to patient demand rather than as a review of basic diabetic knowledge and technique repeated at regular intervals.
2. Dietitian time is limited (she may see stable diabetics only once per year, more often if problems arise or on request).

3. Diabetic families do not meet each other in the current clinic setting increasing their sense of isolation and being 'different'. Most diabetic children know no other diabetics.
4. It is difficult to tackle stress-related problems in the short clinic time available.

To address these problems we therefore developed an informal education programme covering all aspects of diabetic care in a supportive, non-threatening environment. Our aims were to determine if such a programme could improve knowledge and understanding of diabetes by children and their families, reduce stress and thereby improve diabetic control.

Contents of Thesis

The main thrust of this thesis is the careful assessment of the effects of an informal education programme on children and their families. I have studied their knowledge about diabetes, measured stress and anxiety and monitored their level of diabetic control. The effects of the programme were assessed in a group of 48 children less than 13 years of age by means of a 2 year prospective cross-over study.

To place this work in perspective I have compared children enrolled in the project with a similar group of children with diabetes mellitus attending the routine RHSC diabetic clinic during the same two year time period.

Furthermore I have also compared the results obtained from the children in the study with those attending clinics in 3 district general hospitals.
Information was also obtained concerning ease of access, travel time and cost, and time spent visiting the hospital for both the routine clinic and the education programme.

Finally, with the information obtained, improvements will be suggested in the organisation of paediatric diabetic care.

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TABLE 1:1 THE ANNUAL INCIDENCE OF IDDM IN VARIOUS COUNTRIES FOR CHILDREN LESS THAN 20 YEARS 1977-1980 (REF 1, 3)

Country	Risk per Year/ 100,000 Population
Finland	28.6
Sweden	22.6
Norway	17.6
USA	14.7
Scotland	13.8*
Denmark	13.7
Netherlands	10.9
New Zealand	10.4
Canada	9.0
England	7.7
Kuwait	5.6
Israel	4.3
France	3.7
Japan	0.8

CHAPTER 2

THE DIABETIC CLINIC AT THE ROYAL HOSPITAL FOR SICK CHILDREN, EDINBURGH

INTRODUCTION AND HISTORICAL PERSPECTIVE

A specialist paediatric diabetic clinic was set up in Edinburgh in 1953 by Dr J.W. Farquhar to serve the paediatric population in the South East of Scotland including Fife and the Borders. Since the clinic was initiated there have been changes in both the size of the clinic and clinic policies. A major innovation was the introduction of a home care team in 1968. I undertook a retrospective casenote review primarily to ascertain the impact of the home care team on diabetic care. In reviewing the clinical records of this large number of patients I also documented the clinical and social characteristics of the children attending the RHSC over this time.

The Home Care Team

The home care team was set up in 1968 and consisted initially of one and then two, and now three, nursing sisters who are responsible for various aspects of care of children with chronic diseases discharged from hospital to the community. Each nurse has a primary responsibility in different clinical areas including diabetes, cystic fibrosis, cerebral palsy and sudden infant death syndrome, each nurse taking a primary role in one specialty but with some overlap if necessary.

For the diabetic child, the nursing sister makes contact with the family while the patient is still in hospital at the first admission. She then visits the family at home frequently during the first few months after diagnosis to ensure that the practical details of diabetic management are understood by the family. Thereafter she is easily accessible by telephone for advice about any intercurrent problems and she visits families at home if any particular crises concerned with diabetic management arise. She also visits the school of the diabetic child to ensure that teachers and staff understand the needs of the child within the school setting, particularly in relation to school meals. The aims of the home care team are to reduce both the initial and recurrent hospitalisation of the child and to shift the care of the diabetic child from being hospital based to being community based.

Assessment of the Home Care Team and Paediatric Clinic

I was interested to assess the impact of the home care team and the introduction of the paediatric diabetic clinic on the care of diabetic children during the previous 30-40 years. Therefore a retrospective review of casenotes of children attending the clinic between 1953 and 1985 was undertaken.

METHODS

The exact numbers of children newly diagnosed or attending the clinic in each year were obtained from either ward admission registers or from the total admissions for each year for the whole hospital. Disease coding was introduced in the 1960s and facilitated the identification of diabetic children who had been treated at the hospital. The majority of diabetic children in South East Scotland attend the RHSC but some attend the Western General Hospital, Edinburgh and the Border's Hospital.

Data recorded included age at diagnosis, sex, duration of symptoms prior to first admission, duration of first admission in days, state and initial management at that admission, number of years attending the diabetic clinic, number of diabetic admissions per year, number of days admitted for diabetic reasons per year, number of clinic visits, whether or not telephone was present at home, area of domicile, social class by occupation according to the Registrar General's Classification, and month of diagnosis. Data collected was grouped together for those diagnosed before 1960 and thereafter in 4 year blocks to ascertain changing patterns over the time period studied. This data was incorporated into a computerised data base (Appendix 1).

RESULTS

Some casenotes from the early years were unobtainable and for the years 1965 to 1968 we were only able to obtain notes for 62% of children attending the clinic whereas for the periods before 1960 and from 1981 to 1985 the case records obtained were greater than 90% and therefore give a very representative sample of diabetic children attending the clinic.

Age at Diagnosis

Mean age at diagnosis was 6 years and 2 months to 6 years and 4 months for the first five time periods studied (Table 2:1). For the last two time periods studied, ie 1977-81 and 1980-85, mean age of diagnosis was higher at 7 years 11 months and 8 years and 3 months respectively. (It should be noted that there was a change in policy in the clinic from 1973 when the age limit for the clinic was raised from 12 years to 16 years).

Duration of Symptoms

Duration of symptoms of diabetes prior to first admission was on occasions difficult to estimate retrospectively. There was evidence of a decreased duration of symptoms prior to admission during the last period examined, 1981-85, but figures for other periods were similar (Table 2:1).

Duration of First Admission

Prior to 1960 the mean length of stay at first admission was greater than four weeks (Table 2:1) and although this showed a gradual trend to become shorter there was a dramatic change after the initiation of the home care team in 1968 with duration of admission falling from a mean of 22.3 days to 10.8 days. Thereafter there was a slow but gradual trend to shorter stay with a mean in 1981-85 of 7.5 days.

Number of Admissions per Year

The actual number of admissions per patient per year appears to have varied considerably from time period to time period. It does not show a trend to be reduced. This probably indicates that in the earlier days, admissions were more frequently for episodes of hyperglycaemia which may have required longer admissions, but now children may be briefly admitted more frequently for hypoglycaemic episodes.

Number of Days Admitted per Year

The mean number of days admitted per patient per year has reduced from a mean of 8.8 days prior to 1960 to less than one day (0.96) by 1981-85, a tenfold reduction. The major fall in the number of days

admitted per year took place before the introduction of the home care team in 1968. (In the time period 1965-68 we were unable to obtain 40% of the casenotes and therefore the low number of days admitted in this time period may be inaccurate. If this time period is elimiated one can see that there is a definite trend to reduction in the number of days admitted per year but that the home care team did not appear to make any significant impact in this area).

Number of Clinic Visits

This has not changed over the time period studied and again was unchanged by the home care team.

Telephone at Home

Prior to 1960 only 18% of households possessed a telephone; since 1969 80-90% of all households have been in possession of a telephone. The number of families possessing a phone doubled (44% to 88%) after the initiation of the home care team who often sought provision of the telephone for those families who could not afford one (Table 2:2).

Sex

The male/female ratio is 1 to 1.1 and although this varies from year to year (see Table 2:2) overall we could not demonstrate a difference in incidence between the sexes.

Clinical Condition on Admission

The clinical state of the patients at first admission has shown a decline in the number of patients first admitted in a drowsy or comatose condition. Since the latter half of the 1960s more than 80% of those first admitted were fully alert at the time of first admission.

Initial Management

Before 1960 intravenous fluids were used in the initial management of 35% of cases, patients who were seriously ill. There was an increase in the use of IV fluids in the period 1961-65 when many patients admitted were seriously ill and subsequently there has been a tendency to use more IV fluids even though children are now admitted in better clinical condition. Over the period of observation there has been a greater use of intravenous therapy in all aspects of paediatric care as well as changing regimens of insulin administration in the acute phase of the disease. Low dose continuous infusions of insulin introduced in the late 1970s are now much safer than the previous large doses given intravenously and may result in more rapid stabilisation of the patient.

Area of Domicile

This is illustrated in Table 2:3 which shows that initially proportionately more patients came from Fife, and very few from the Borders. Over time proportionately fewer patients have come from Fife; over this period local facilities have been improved with the appointment of paediatricians with an interest in diabetes. Only 39% of our patients come from within the Edinburgh area and therefore travel for some patients entails a considerable degree of commitment in both time and distance to attend the clinic regularly.

Social Class

Social Class distribution consistently showed that 30-40% of patients with IDDM are in Social Class I and II (Table 2:4). If this is expanded to include IIIN then over 40% of children come from families within this category. It is extremely difficult to ascertain the exact social class composition of the catchment area from which the patients come but within Edinburgh some 20% of the population are within Social Class I and II and therefore there appears to be an excess of diabetic children from the higher social classes (1981 Census Data)(1).

Month of Diagnosis

There was an excess of newly diagnosed diabetic children presenting in the early winter months, a drop in late Spring and Summer and then a rise again in Autumn (Table 2.5). The exception to this, however, is December which has the lowest incidence over the time periods studied. These findings appear to be consistent from time period to time period. These findings are consistent with those in most studies (2).

DISCUSSION

Has diabetic care improved in our clinic population during the time period studied? Glycosylated haemoglobin which is currently the most objective assessment of diabetic control has only been available routinely in our clinic since 1983 and we could therefore not use this for an accurate assessment. The number of days admitted per patient, however, has dropped tenfold in the time period studied and as an index of overall control probably shows that the quality of care and quality

of life for diabetic children has improved. The length of the initial admission to hospital and the psychosocial problems associated with hospital admissions have probably also been reduced. The major change in care of diabetic children over this period has been the introduction of the home care team and the team approach to the care of diabetic children. We believe that this has had a major part to play in the dramatically reduced length of initial admission and probably has had a similar though more subtle effect in other areas of care after initial diagnosis. The introduction of a specialised paediatric diabetic clinic has been shown to be effective in Birmingham (3) and the team approach has been shown to be most effective (4). The individual role of home care team nurse was not assessed.

The average age of clinic attenders rose during the mid to late 70s. Initially children up to 12 years of age were cared for at the Royal Hospital for Sick Children and thereafter teenagers were all referred to the adult physicians for their care. The adult ward and clinic, however, seemed to be an inappropriate place for the care of 13 or 14 year old children and therefore in 1973 agreement was reached with the adult physicians that children up to 16 years of age were cared for at the Royal Hospital for Sick Children both in the ward and in the clinic. An adult physician from the Royal Infirmary of Edinburgh was integrated into the Royal Hospital for Sick Children's Diabetic Clinic to facilitate transfer of adolescents to the adult clinic at around the age of 16 years or when thought appropriate by all parties. The fall over time in the number of days admitted is probably multifactorial in origin - a combination of increased GP skills, availability of purer insulin, disposable syringes and some contribution from the home care team.

Some children in our catchment area attend the Western General Hospital and some the Borders Hospital. Therefore it is difficult to ascertain exact numbers of newly diagnosed diabetics, but we have identified a rise in the number of newly diagnosed diabetic children attending our clinic (Table 2:1). The population of South East Scotland has risen only very slightly during this period (1981 Census Data). It appears therefore that we may be experiencing a true increase in incidence as described in other areas (5, 6).

Cruachan

Cruachan was a Dr Barnardo's Home set up in 1958 to care for diabetic children from all over Scotland who were not being adequately managed within the home by families and their physicians. The home was funded partly from Dr Barnardo's and partly by the local authority from which the children lived and referrals were from the local physicians. Care of children while in Edinburgh was undertaken by the diabetic clinic at the Royal Hospital for Sick Children and therefore some information about these children is available for the time period 1958-84. A review of their casenotes was undertaken and data collected as for the study at the beginning of this chapter. Information was available for 67 children and the characteristics are shown in Table 2:6 and Table 2:7. 39 children came from the South East of Scotland and 28 children from elsewhere. There are some striking differences between the children attending Cruachan and the general population from the clinic as shown in Table 2:8. Social class distribution shows a completely different pattern for the children attending Cruachan with a preponderance of children from the

lower social classes and in particular 23% of children coming from unemployed families. Most families who find it more difficult to cope with their children are those who may not have the motivation or ability to understand the complexities of the diabetic regimen or whose children have considerable behaviour problems. Interestingly, while in residential care these children still had a considerable number of problems as shown by the fact that they had twice the number of admissions per year than the Sick Children's population, they were admitted for three times as many days per year and the length of their first admission was at least 50 per cent longer than the average of a child attending the Royal Hospital for Sick Children. They required slightly more visits to the diabetic clinic per year despite the fact that they were getting a lot of supervision at the Dr Barnardo's Home.

Despite the fact that Cruachan was obviously fulfilling a need in the care of diabetic children particularly those from the most disadvantaged families, this facility was closed in 1986 and therefore there is now no residential home for diabetic children in Scotland.

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TABLE 2:1 CHARACTERISTICS OF CHILDREN ATTENDING RHSC DIABETIC CLINIC 1953-1985 Mean (SD)

	Age at Diagnosis	Duration of Symptoms (days)	Duration of 1st Admission (days)	Time Attending Clinic	No. Admissions per patient per year	No. Days Admitted per patient per year	No. Clinic Visits
Pre 1960 (n=24)	6yrs 4mths (3yrs 4mths)	39.5 (36.0)	30.8 (11.8)	6yrs 0mths (3yrs 7mths)	0.72 (2.0)	8.8 (21.5)	7.4 (3.7)
1961-64 (n=22)	6yrs 2mths (3yrs 4mths)	22.0 (22.5)	25.1 (18.2)	6yrs 7mths (3yrs 10mths)	0.51 (0.47)	4.7 (5.8)	5.9 (2.2)
1965-68 (n=24)	6yrs 4mths (3yrs 7mths)	37.5 (28.8)	22.3 (19.4)	6yrs 1mth (4yrs 4mths)	0.24 (0.26)	1.5 (2.0)	6.0 (3.2)
1969-72 (n=39)	6yrs 4mths (3yrs 5mths)	27.2 (28.3)	10.8 (3.2)	7yrs 1mth (4yrs 4mths)	0.36 (0.37)	2.3 (2.6)	6.1 (2.6)
1973-76 (n=56)	6yrs 3mths (3yrs 1mth)	32.3 (48.9)	8.8 (5.2)	7yrs 2mths (3yrs 6mths)	0.6 (1.0)	2.6 (5.0)	5.4 (1.8)
1977-80 (n=80)	7yrs 11mths (3yrs 4mths)	31.1 (34.6)	9.8 (12.6)	5yrs 4mths (2yrs 5mths)	1.4 (8.9)	2.1 (4.1)	5.6 (3.6)
1981-85 (n=111)	8yrs 3mths (3yrs 7mths)	24.7 (25.9)	7.5 (1.9)	3yrs 3mths (1yrs 5mths)	0.31 (0.52)	0.86 (1.6)	6.7 (2.3)

TABLE 2:2 CHARACTERISTICS OF CHILDREN ATTENDING RHSC DIABETIC CLINIC 1953-85
(Continued) No.(%)

	Telephone	Sex		State on Admission			Initial Management	
	At Home	Male	Female	Alert	Drowsy	Comatose	Oral Fluid	I.V. Fluid
Pre 1960	4/22 (18%)	17	7	14(64%)	5(23%)	3(13%)	16(67%)	8(33%)
1961-64	5/18 (28%)	10	12	10(50%)	7(35%)	3(15%)	7(35%)	13(65%)
1965-68	7/16 (44%)	8	16	15(83%)	3(17%)	0(0%)	13(72%)	5(28%)
1969-72	22/25 (88%)	20	19	29(81%)	5(14%)	2(5%)	26(70%)	11(30%)
1973-76	41/49 (84%)	26	32	33(80%)	7(17%)	1(3%)	29(71%)	12(29%)
1977-80	62/71 (90%)	45	36	59(83%)	9(13%)	3(4%)	49(69%)	22(31%)
1981-85	82/95 (88%)	48	63	90(88%)	11(12%)	0(0%)	67(66%)	35(43%)

TABLE 2:3 AREA OF DOMICILE OF CHILDREN ATTENDING RHSC DIABETIC CLINIC 1953-1985

	DOMICILE						
	Edinburgh	MidLoth	East Loth	West Loth	Borders	Fife	Other
Pre-1960 (n=24)	11	1	1	3	0	7	1
1961-64 (n=22)	8	4	2	3	2	3	0
1965-68 (n=24)	8	5	0	4	1	3	2
1969-72 (n=39)	17	7	3	4	5	2	1
1973-76 (n=55)	17	11	8	11	3	4	1
1977-80 (n=80)	34	10	6	15	4	3	8
1981-85 (n=111)	45	23	11	23	5	2	2
Total Number	140	61	31	63	20	24	15
%	39	17	9	16	6	7	4

TABLE 2:4 SOCIAL CLASS DISTRIBUTION

	SOCIAL CLASS I	II	IIIN	IIIM	IV	V	VI	Student	Retired	Armed Forces	Other
Pre 1960 (n=24)	2	4	2	7	7	0	1	0	0	0	0
1961-64 (n=22)	1	2	4	9	5	0	0	0	0	0	1
1965-68 (n=24)	2	3	4	8	3	0	0	0	1	1	1
1969-72 (n=39)	0	9	5	17	4	0	1	0	0	1	2
1973-76 (n=54)	7	16	5	17	6	0	0	1	0	1	1
1977-80 (n=80)	9	16	9	25	7	5	0	1	1	2	5
1981-85 (n=110)	13	27	10	25	8	6	8	1	1	0	11
Total Number	34	77	39	108	40	11	10	3	3	5	21
%	9.7	21.9	11.1	30.8	11.4	3.1	2.8	0.8	0.8	1.4	6.0

TABLE 2:5 MONTH OF DIAGNOSIS OF CHILDREN ATTENDING RHSC DIABETIC CLINIC 1953-1985

	MONTH OF DIAGNOSIS											
	Jan	Feb	March	April	May	June	July	Aug	Sep	Oct	Nov	Dec
Pre-1960 (n=24)	2	0	1	3	0	3	3	1	3	2	6	0
1961-64 (n=20)	1	0	5	1	0	2	2	2	3	1	3	0
1965-68 (n=22)	4	2	5	0	1	1	1	3	2	2	0	1
1969-72 (n=37)	4	1	7	2	5	2	4	4	2	3	2	1
1973-76 (n=49)	5	3	4	2	8	3	3	2	4	9	4	2
1977-80 (n=74)	9	6	5	6	5	5	6	5	9	9	5	4
1981-85 (n=109)	13	10	14	5	4	6	9	9	10	9	13	7
Total	38	22	41	19	23	22	28	26	33	35	33	18

TABLE 2:6 CHARACTERISTICS OF CHILDREN RESIDENT AT CRUACHAN 1958-1984

1. Mean age at diagnosis 7 year 8 months (3 years 7 months)
(n=67)

2. Years attending diabetic clinic 3 years 3 months (3 years 2 months)

3. Area of Domicile (Numbers)	1. Edinburgh	12
	2. Midlothian	10
	3. East Lothian	4
	4. West Lothian	5
	5. Borders	2
	6. Fife	6
	7. Other	28

4. M/F 36/31

TABLE 2:7 CHARACTERISTICS OF CHILDREN ATTENDING CRUACHAN vs CHILDREN ATTENDING RHSC CLINIC (Values are mean (S.D.))

Social Class	RHSC Clinic (n=356) 1958-1984	Cruachan (n=67) 1958-84
I	10%	2%
II	22%	4%
IIIN	11%	9%
IIIM	31%	36%
IV	11%	21%
V	3%	6%
VI	3%	23%
Number of Admissions per Year 1958-85	0.64 (1.9)	1.2 (1.4)
Number of days admitted per year 1958-85 (days)	2.4 (3.5)	7.1 (8.3)
Duration of symptoms (days)	29.3 (31.5)	33.2 (63.1)
Length of first admission 1958-85	12.2 (14.1)	18.3 (11.3)
Number of clinic visits per year 1958-85	6.1 (2.6)	7.4 (3.2)

CHAPTER 3

STRUCTURE OF PAEDIATRIC DIABETIC CLINIC ROYAL HOSPITAL FOR SICK CHILDREN, EDINBURGH, 1985

The current diabetic clinic at the Royal Hospital for Sick Children takes place during the afternoon from 1.30 p.m. to 4.30 p.m. in the general paediatric outpatient department. There is another clinic running concurrently for children with cystic fibrosis, and all patients wait in a central patient waiting area which includes a general reception and appointments desk, a small cafeteria and a children's playroom. It is not designed specifically to cater for the needs of a diabetic clinic although one corner currently has a small video screen installed for viewing BDA videos, there is diabetic equipment available at cost from a volunteer desk set up one afternoon a week and a room for blood tests.

The clinic staff usually includes 4 doctors, one of whom is a consultant paediatrician with an interest in endocrinology, an adult physician, the two remaining members of staff may be either a senior registrar from the adult diabetic clinic, a paediatric senior registrar or registrar or a community paediatrician depending on the staff available. No very junior staff take part in the clinic and most staff members are involved in the clinic for a considerable length of time and get to know the patients to some degree.

There is a dietitian available in a separate room who will see patients on a one to one basis as problems arise and she tries to review each patient at least once per year. A dental hygienist is also available and at the time of the small survey to be discussed shortly a chiropodist was also available for advice. The home care team nurse is also available for informal discussion.

As well as this, patients have their height, weight and urine checked and blood taken for blood glucose and glycosylated haemoglobin. A maximum of 24 patients are booked in each afternoon and each patient is allotted a 20 minute appointment with a doctor. At the end of the afternoon if time permits there is a discussion by all members of the team of problems which have arisen. Patients are seen on average every 3 months, more frequently if problems arise. Urine is checked for protein, and blood pressure measured and fundoscopy performed in those >12 years.

"TIME AND MOTION" STUDY

To ascertain whether clinic time was well utilised (as it is commonly assumed that patients have long waiting times) a short "time and motion" study was performed from April to June 1985.

METHODS

The time the patient entered and left the clinic was recorded at the Reception Desk. Each doctor, the dietitian and the chiropodist also recorded the time each patient spent with them. No estimation was made of the time spent with dental hygienist, home care team or technician for blood taking or of the time actually spent in the waiting area.

RESULTS

The mean total time a patient spent at the clinic was 76 minutes but with a very wide range from 17 to 140 minutes (Table 3:1). Time spent with the doctor was a mean of 25 minutes but again there was an

extremely wide range from 10 to 70 minutes. The dietitian saw approximately one-third of the patients seen by the doctor for the time period recorded and when she did see a patient it was for a mean of 19 minutes with a range from 5 to 40 minutes. The time spent with the chiropodist was a mean of 7 minutes (she saw most patients) with a range of 2 to 22 minutes. This shows therefore that on average about 30 minutes of clinic time is left for talking to the dental hygienist, the home care nursing sister on an informal basis and for assessment of height, weight and collection of blood and urine specimens. Therefore it appears that patients do not wait considerable lengths of time at the clinic and that the clinic time is currently relatively well utilised.

DISCUSSION

In this study we found the average visit to be just over an hour but that clinic time was fairly well utilised in agreement with a review of clinics in the USA (1). However the problems of diabetic clinics have been highlighted in another article.(2).

As stated in the introduction, a survey of patients who had previously attended our clinic highlighted a number of problems (3). These included the lack of continuity of education, because after an initial week of instruction as an inpatient, education tended to be piecemeal and only in response to patient demand rather than as an ongoing update and review of knowledge and techniques. Dietitian time is extremely limited. She is only able to see a few patients each afternoon and only those who have specific problems are seen frequently.

The clinic structure with a general waiting room area, and appointment times which are staggered through the afternoon mean that families do not talk to each other or meet each other on a regular basis. Most diabetic families do not know any other families with diabetic children and this increases the sense of guilt and isolation which many diabetic families encounter. Although appointment times are generous compared with many other clinics, there is still not the time and often not the facility of staff to tackle stress related problems in great depth or detail. There is excellent liaison with a psychiatrist within the hospital but he is not a regular contributer to the clinic and is not seen as an integral part of the diabetes management team. Other clinics have a psychiatrist/psychologist as an integral part of the team (4). Staff members within the clinic are relatively stable but families often complain that they see a different doctor at each visit and do not establish a rapport with any one member of staff.

Therefore it appears that although diabetic control within the clinic is reasonable (the mean glycosylated haemoglobin (HbA_1) for children less than 13 years of age is 10.3%) there are areas where changes may be made to improve the control and quality of life for our diabetic children and their families. These issues will be addressed in the final chapter.

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TABLE 3:1 RESULTS OF TIME AND MOTION STUDY APRIL-JUNE 1985

TOTAL CLINIC TIME PER PATIENT PER VISIT (Number of visits recorded = 111)	Mean	76 mins
	SD ±	25 mins
	Range	17-140 mins
TIME WITH DOCTOR (Number of visits recorded = 93)	Mean	25 mins
	SD ±	9 mins
	Range	10-70 mins
TIME WITH DIETITIAN (Number of visits recorded = 33)	Mean	19 mins
	SD ±	8 mins
	Range	5-40 mins
TIME WITH CHIROPODIST (Number of visits recorded = 88)	Mean	7 mins
	SD ±	4 mins
	Range	2-22 mins

CHAPTER 4

CHARACTERISTICS OF DIABETIC CHILDREN AND THEIR FAMILIES ATTENDING THE ROYAL HOSPITAL FOR SICK CHILDREN, EDINBURGH

INTRODUCTION

The main objective of the research described in this thesis is the assessment of the effect of a diabetic education project by means of a randomised crossover trial. In any such trial it is essential to clearly define the population from which the randomised study is drawn. If the study population is not representative of the total population then the results of the trial may not be applicable to it. Furthermore the total population from which the study group is drawn may differ in important ways from populations in other geographical areas, and results from the study population may not be applicable there. Therefore I decided to obtain comprehensive data about all eligible children attending the RHSC diabetic clinic. To assess whether the population attending the RHSC clinic differed from the general population in Lothian I also compared some simple demographic variables.

PATIENTS AND METHODS

Medical and social data about all children less than 13 years of age on the 1st of October 1985 attending the RHSC diabetic clinic were obtained. The data base used to obtain this information is contained in Appendix 3. Information was obtained by interviewing usually the mother of each child on attendance at their routine clinic visits (by

myself in the majority of cases but for some children, who continued to attend the routine clinic, by a research health visitor, Miss Elsie Wilkinson). In only one case was a personal interview not obtained because of particular problems, and data was therefore obtained from the medical casenotes. The first part of this chapter describes the medical and social background of these diabetic families. In the second half of the chapter some comparisons are made with the non-diabetic population in Lothian. This information was obtained from the 1981 Census Tables for Scotland (10% sample) (1).

RESULTS

Ninety-two children attending the diabetic clinic were less than 13 years on 1st October 1985.

1. Social Background of Families. Area of domicile (Table 4:1) shows that only 39% of families live within the Edinburgh area, with a large proportion travelling from West Lothian, six patients from the Borders, this entailing up to a 60 mile journey round trip for some patients attending the clinic. The question concerning a telephone at home shows that 88% of families have a telephone within their own home, although some may have easy access to a nearby neighbour or relative. Male/female ratio shows a predominance of females at this time although this did not occur in previous years (see Chapter 2). Assessment of the parental situation showed that 86% of them are married and that 10% are functioning as one parent families. Mean age for parents is in the late 30s although there is a wide range from 21 to 65 years.

2. Parental Social Class and Occupation. Social class distribution (Table 4:2) shows a preponderance of families within social class I, II and III(N). This forms over 40% of the total diabetic population. An assessment of occupation shows that only 4% of fathers to be unemployed, whilst 35% of mothers are not economically active. However, of the mothers who do work the majority undertake part-time employment (52%) whether sociable or unsociable in terms of hours worked, very few mothers working fulltime.

3. Medical Problems of Parents. Medical problems experienced by fathers and mothers are shown in Table 4:3, 76% of fathers and 70% of mothers have no current medical problems. Of the fathers, four have autoimmune diseases with three insulin dependent diabetics. As one would expect, for mothers this number is increased with 3 insulin dependent diabetics, 2 with thyrotoxicosis, 2 with hypothyroidism and 1 with rheumatoid arthritis, giving a 10% incidence of autoimmune disease in this group.

4. "Nerve" Problems in Parents. The results to the question whether either parent has experienced nervous problems which have required them seeking medical advice, whether or not treatment was initiated are illustrated in Table 4:4. No parent had been hospitalised for any of these problems and none had had psychiatric referral for themselves. 9% of fathers had exhibited some sort of problem, with 6.6% showing anxiety. For mothers, however, this was considerably increased with 23% of mothers having experienced some sort of nervous problem for which they sought advice from their own general practitioner, equally divided between anxiety and depression. Once again, however, it must be stressed that the majority of these did not receive any medication and none were hospitalised.

5. Social Habits of Parents. The social habits of the parents are illustrated in Table 4:5 and 52% of fathers and 72% of mothers are non-smokers. In Scotland comparable figures from 1984 data (2) shows 51% men and 60% women in age group 35-49 years are non-smokers. Alcohol intake did not appear to be excessive with fathers' intake being less than one unit per day and mothers' around a third of a unit per day. There was, however, quite a wide range and this may well be under-reported. 26% of fathers and 49% of mothers left school at 15 and experienced no further education of any sort, including technical college or apprenticeships. 14.6% of fathers and 8.7% of mothers were university graduates. Two fathers and three mothers had experienced some schooling or reading difficulties and this potentially could cause difficulties with management of their child's diabetic regimen.

6. Siblings. There were a total of 138 siblings for these 92 families and 7.6% were only children. The medical problems in the siblings of the diabetic children were few but interestingly 6 out of the 138 children were insulin dependent diabetics. If fathers and mothers with IDDM are included this gives an incidence of insulin dependent diabetes in first degree relatives of 3.7%. One sibling had rheumatoid arthritis but there was no evidence of any other autoimmune diseases in this population. Seven exhibited behaviour problems and four were undergoing special education. Very few households had a third adult resident and in these 92 families no grandparents were resident.

7. Housing. Details about housing are contained in Table 4:6. Interestingly 57.6% were private householders owning their own house, none came from highrise accommodation and 80% expressed satisfaction with their current housing arrangements. 70% of diabetic children had their own room. This may be more important for the diabetic child, particularly the adolescent, than the non-diabetic child in that they can have privacy and safely manage their own diabetic care without other family members interfering.

8. Diabetic Relatives. Information concerning diabetic relatives is contained in Table 4:7. 38 families had no experience of any diabetic relative but interestingly a similar number of families had an insulin dependent diabetic relative and similarly the same number had a non-insulin dependent diabetic relative, and of these 34 were dead, three were blind and 4 experienced nephropathy but none were currently undergoing dialysis or had had renal transplantation. Problems with peripheral circulation existed in seven family members. Therefore from this Table it can be seen that many families with a diabetic child have had some experience of diabetes in other family members, albeit at some distance with second degree relatives. Some of the experiences were clearly unpleasant and for the children themselves may represent a source of concern for their future.

9. The Diabetic Children. Some information concerning the diabetic children themselves is presented here although the majority of this will be presented in the ensuing chapters. 37 of the 92 children were diagnosed before the age of 5 years but in our population there appeared to be an even distribution of age at diagnosis with no

obvious peak incidence. 20% of diabetic children have other medical problems and these are illustrated in Table 4:8 and show the problems experienced in each of the three years studied. Three children became hypothyroid but the rest of the diseases show the normal distribution for any childhood population with asthma, eczema and enuresis being the commonest problems experienced by these children in the three years studied. Hypoglycaemic fits appeared to increase in incidence by the second year of the project. This will be discussed further in Chapter 6. Other than hypothyroidism, at this age there is no evidence of other autoimmune diseases. The numbers of children referred for psychiatric help vary from year to year.

SOME COMPARISONS OF DIABETIC FAMILIES ATTENDING THE ROYAL HOSPITAL FOR SICK CHILDREN WITH THE NON-DIABETIC POPULATION IN LOTHIAN

Information in this section was obtained from the Report for Lothian Region from the 1981 census (10% sample). This data was supplied by the Information and Statistics Division of the Common Services Agency of the Scottish Health Service (1).

1. Social Class and Employment. Comparisons of social class are shown in Table 4:9 and shows the social class of the economically active persons classified by men age 16 to 64 which covers the age range of our diabetic families. It can be seen from this Table that diabetic families are over-represented in social class I and II and under-represented in social classes V and VI. In Lothian, women in fulltime employment are 40% of the sample compared with 12% of mothers in the study and 21.8% of mothers in Lothian are in part-time employment compared with 52% of mothers of diabetic children. Those economically inactive are 38% in Lothian and 35% in our diabetic families.

2. Housing. In Lothian 42.4% of households are owner-occupied, in the Borders Region 36.4% are owner-occupied, whereas in our sample 57.6% owned their own house. Overcrowding, ie more than one person per room per household, is present in 11.8% in families within Lothian whereas in our diabetic population only 3.3% of families fall within this category.
3. Car Ownership Families within Lothian who do not possess a car are 49.5%. In the Borders, however, this is less at 38.4%. Within our own diabetic population 37% of families do not possess a car but some of these may in fact have access to a car for hospital appointments if necessary. This will be explored in more detail in the later chapter concerning travel.

DISCUSSION

From the above results it can be seen that the diabetic population does differ from the general population within South East Scotland in that there is greater preponderance of social class I and II, there are more home and car owners. The general health of diabetic children in terms of other illnesses, other than hypothyroidism, does not differ significantly from that of the general population of less than 16 years of age. The presence of problems of anxiety or depression in approximately one-quarter of mothers within our sample indicates the stresses which diabetes places on families. This will be discussed in detail in the chapter concerning psychological assessments.
If the total clinic of 180 patients less than 16 years of age is taken as representing all children referred from the Borders and Lothian (which have a combined population less than 16 years of age of 179,540)

(1) this gives a prevalence of Type 1 diabetes in this population of 1 in 1000 under 16 years. This is an underestimate as some children of this age are cared for at the Western General Hospital in Edinburgh and some at general paediatric clinics in the Borders and West Lothian.

As over one third of our children are diagnosed before age 5 a good proportion of the clinic population are young and of preschool age and they will attend the clinic for some time therefore giving considerable scope for the clinic to alter their diabetic control and to prevent complications in the future.

The fact that one-third of our families come from social class I and II is similar to figures available from studies in Oxford (3) but in their study no comparison was made with the social class composition of their non-diabetic population. Also the under-representation of diabetics in social class V and VI is in agreement with another study which showed no children represented in social classes V and VI for children age 10 and 11 (4). The reason for this social class distribution may indicate that some environmental influence for children from advantaged families predisposes them to the development of IDDM or the earlier appearance of this disease in susceptible individuals.

It is unacceptable that families who have a child with a chronic illness that may on occasions have life-threatening crises do not have immediate access to a telephone.

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TABLE 4:1 SOCIAL BACKGROUND OF PARENTS

DATA (FREQUENCY DISTRIBUTION) ON TOTAL STUDY POPULATION (n = 92)

(All values percentages unless otherwise stated)

Area of Domicile	Edinburgh	39.1
	Midlothian	14.1
	E. Lothian	13.0
	W. Lothian	22.8
	Borders	6.5
	Fife	2.2
	Other	2.2
Phone at Home	Yes	88
	No	4.3
	Neighbour	4.3
	Relative	2.2
	Not Known	1.1
Sex (Number)	M/F	39/53
Parental Situation	Married	85.9
	Single	1.1
	Divorced	4.3
	Separated	4.3
	Widowed	1.1
	Remarried	1.1
	Stable relationship	2.2

Age	Mean (SD) (Range)
Father	39.7 (6.7) (21-65)
Mother	37.1 (6.0) (21-54)

TABLE 4:2 PARENTAL OCCUPATION AND SOCIAL CLASS

Social Class%				
	I	7.6	IV	14.1
	II	26.1	V	4.3
	IIIN	9.8	VI	6.5
	IIIM	30.4	Student	1.1

Occupation %	Father	Mother
Unemployed	4.3	34.8
P/T Sociable	2.2	28.3
P/T Unsociable	1.1	23.9
F/T Sociable	51.1	6.5
F/T Unsociable	38.3	5.4
Missing	3.3	1.1

Sociable = 9 am to 5 pm Unsociable = 5 pm to 9 am

TABLE 4:3 MEDICAL PROBLEMS - PARENTS

Medical Problems (Father) No medical problems 76.1%

Types of medical problems (Number)

Asthma	3	Psoriasis	1
IDDM	3	Thyrotoxicosis	1
Hypertension	3	Migraine	1
Back problems	2	MI	1
Duodenal Ulcer	2	RTA	1
Lymphoma	2		
Osteoarthritis	1		

23.9% one medical problem, 5.4% two medical problems, none had 3 medical problems

Medical Problems (Mother) No medical problems 69.6%

Types of medical problems (Number)

IDDM	3	Hypothyroid	2
Osteoarthritis	3	MODDM	1
Obesity	3	Psoriasis	1
Asthma	2	CA thyroid	1
Thyrotoxicosis	2	Back problem	1
Migraine	2	Hypertension	1
Gynaec Probs	2	Anaemia	1
Hay Fever	1	Duodenal Ulcer	1
Rheumatoid Arthritis	1		

30.1% one medical problem, 4.3% two medical problems, none had 3 medical problems

IDDM - Insulin dependent diabetes mellitus
MODDM - Maturity onset diabetes mellitus

TABLE 4:4 "NERVE" PROBLEMS - PARENTS

"Nerve" Problem				
	Father	Yes	9.1	
		No	90.9	
	Type	Anxiety	6.6	None hospitalized
		Depression	3.3	
	Mother	Yes	22.8	
		No	77.2	
	Type	Anxiety	11.9	None hospitalized
		Depression	12.0	

All values %

TABLE 4:5 SMOKING AND ALCO HOL INTAKE - PARENTS

Smoking

	Father	Mother
Non-smoker	51.7	71.7
<10/day	10.3	7.6
10-20/day	11.5	15.2
20-40/day	17.2	5.4
>40/day	1.1	0
Cigars	4.6	0
Pipe	3.4	0

Alcohol

	Father	Mother
Intake Units per day	0.98 ± 1.1 (0-5)	0.32 ± 0.36 (0-2)

TABLE 4:6 HOUSING

Housing	Own house	57.6
	Private Rental	5.4
	Public Rental	37.0
	House	82.6
	Low-rise	17.4
	High-rise	0
Rooms per House	2 1.1	6 5.5
	3 18.7	7 2.2
	4 51.6	8 2.2
	5 15.4	>8 3.3
Persons per House	2 3.3	5 19.6
	3 18.5	6 2.2
	4 52.2	7 4.3
Index Child Own Room	Yes 70.3	
	No 29.7	
Satisfaction with Housing	Yes 80.4	
	No 18.5	
Supplementary Benefit	12	

All values %

TABLE 4:7 DIABETIC RELATIVES - 2^{o} Relatives
(Numbers)

Diabetic Relatives			
	None	38	
	IDDM	38	
	NIDDM	38	
	Dead	34	
Retinopathy	9		
Blind	3		
Nephropathy	4	(None dialysed or transplanted)	
Neuropathy	0		
MI	9		
PCP-compromised	4		
PCP-Amputated	3		

PCP - Peripheral Circulatory Problems

TABLE 4:8 MEDICAL PROBLEMS - DIABETIC CHILIDREN N = 92

Year 0		Year 1		Year 2	
Asthma	4	Asthma	4	Asthma	5
Eczema	3	Eczema	3	Eczema	3
Enuresis	3	Enuresis	3	Enuresis	1
Hypothyroid	1	Hypothyroid	3	Hypothyroid	3
Deaf	1	Deaf	1	Deaf	2
Short Stature	1	Short Stature	1	Short Stature	1
Abdominal pain	1	Abdominal pain	2	Abdominal pain	3
UTI	1	UTI	2	UTI	1
Allergic Rhinitis	1	Allergic Rhinitis	1	Hay fever	1
VSD	1	VSD	1	Nose Bleeds	1
Hypoglycaemic Fit	1	Hypoglycaemic Fits	3	Hypoglycaemic Fits	5
T & A	1	T & A	1		
PDA-ligated	1	PDA-ligated	1		
Recurrent Ear Infection	1	Fractured Arm	1	Fractured Arm	1
Appendicectomy	1	Spinal A-V malformation	1		
Behaviour problem	1				

Psychiatric Referral	
Year 0	7
Year 1	4
Year 2	8

All values are numbers

TABLE 4:9 COMPARISON OF DIABETIC FAMILIES Vs NON-DIABETIC FAMILIES - SOCIAL CLASS

Social Class	Lothian	Diabetic Families RHSC
I	6.6	7.6
II	18.0	26.1
IIIN	11.3	9.8
IIIM	31.0	30.4
IV	14.1	14.1
V	5.8	4.3
U/E	10.1	6.5

All values %

CHAPTER 5

STRUCTURE OF THE DIABETIC EDUCATION PROJECT (DIABETIC CLUB)

INTRODUCTION

Despite all the advances in diabetic care and improvement in diabetic control in our clinic population in recent years, the care of children in our diabetic clinic was far from ideal and further improvements could be made as have been discussed in the introduction. A survey of the clinic by Mok, Laing and Farquhar (1) highlighted the areas where problems existed. These included inadequate knowledge about management of diet, injections and urine testing and failure to address stressful situations such as family conflict and school difficulties. The aims of the project, therefore, were to examine if two approaches could improve diabetic control. Firstly an intensive education programme, in an informal atmosphere, was designed to improve knowledge about and ability to manage all aspects of diabetic regimen, including diet, insulin and blood testing. Secondly the programme aimed to reduce the stress and anxiety associated with diabetes in childhood; stresses related to the need to adhere to a fairly rigid regimen every day of the child's life and anxieties associated with episodes or loss of diabetic control. The project, therefore, was designed as an intensive education programme in an informal, supportive environment in which staff and diabetic families had an active participation.

This chapter describes the design and organisation of the diabetic education project.

PATIENTS AND METHODS

1. Subjects. 92 patients attending the Royal Hospital for Sick Children's diabetic clinic were less than 13 years of age and had had diabetes of more than three months duration and were considered eligible for the two year project. Patients and families were approached by letter to ask them to participate in the two year project which required that for one year they would attend the hospital for 10 afternoons of informal education, each afternoon lasting about 2½ hours. For the other year of the project they would continue at the routine paediatric diabetic clinic where on average they would visit on five occasions in the year.

Forty-eight patients volunteered to participate in the study.* Forty-four families declined to participate in the project, 25% because mothers worked fulltime, 25% because of distance to travel to the clinic, and a further 10-20% because they felt that current services were satisfactory already (see Chapter 12). These 44 non-participants differed from the 48 participants in several respects and these will be discussed later. They were, briefly, significantly older, had had diabetes for longer but did not differ for area of domicile, social class, car ownership or diabetic control measured by glycosylated haemoglobin.

*Two patients dropped out prior to the study commencing, one family because they moved from the area, the second family because mother refused to comply with all aspects of the study design. These two places were filled by two families who became eligible, one had recently moved into the clinic from another area and the second family because of change in circumstances at home with mother discontinuing work meant they were able to participate in the project.

2. Experimental Design. The project was designed as a two year two period crossover controlled trial as described by Armitage and Hills (2). This time scale was chosen so that the effects of seasonal variation on diabetic control could be avoided. In any diabetic patient, particularly children, diabetic control as a function of the seasons varies between winter and summer with worse control in the winter months when children are more sedentary and are prone to more frequent intercurrent infection. Control improves in the summer months when there are fewer intercurrent infections and children are more active out of doors.
The 48 participants were divided into two groups of 24, Group A and Group B, matched for age, sex, social class, duration of disease and area of domicile. Group A attended the education programme (diabetic club) for one year while Group B continued at the routine paediatric diabetic clinic. Then for the second year of the project Group A returned to the routine clinic while Group B took part in the diabetic club (Table 5:1). Each group of 24 families in Groups A and B were further divided into smaller groups of 6, each matched as far as possible for age, sex, social class, and duration of disease. Each of these small groups attended the diabetic club for ten visits per year. All groups covered each topic. Replacement sessions took place for missed visits.

3. Setting. The essence of the diabetic club was informality, therefore a setting outwith the hospital clinic was chosen to enhance this aspect of the project. The visits took place in a house adjacent to the hospital which is currently used as the School of Community Paediatrics. This enabled us to have the use

of a large lounge for lunch, a kitchen for preparation of the lunch, a large room for the parents' discussion and a fourth smaller room for individual interviews as necessary, thus giving a totally different atmosphere to the project visits from those encountered in any routine clinic visit. Measurements of height, weight and skinfold thickness and the taking of blood samples occurred in a building adjacent to the School of Community Paediatrics in which the laboratory facilities were sited. Therefore the families did not enter the hospital as such at any of the club visits. Staff involved in the project included firstly two paediatricians (SB & JWF) one of whom was present on each occasion, a part-time dietitian who organised the lunches and had a teaching commitment to the project, a part-time psychologist with a purely assessment role, a part-time secretary as well as medical and nursing staff from the routine diabetic clinic who took part in the teaching and discussion sessions on an intermittent basis. Also a research health visitor helped with data collection.

4. Structure of the Intervention Programme. The programme was designed to cover all aspects of diabetic management in eight sessions, some with, some without children present, plus two sessions at the end during the summer for patient initiated topics to be discussed. One of the prime aims of the project was that parents and children should spend their afternoons in separate groups to encourage free discussion in both. Each afternoon had essentially the same format (Table 5:2), the families arriving at 12 noon and between 12 noon and 13.15 each child had height, weight and skinfold thicknesses measured and a blood sample taken for

blood glucose and glycosylated haemoglobin. Thereafter, lunch took place in the lounge with parents, children and staff all eating together. The lunches were planned and prepared by the dietitian for the project who used this opportunity to teach families about healthy eating and each visit covered a particular topic, such as high fibre, low fat or low salt diet. The menus and recipes for each lunch were discussed and proved very popular (all recipes used were available for families to take home). During this time families were also seen individually by a paediatrician for discussion of events marked in their diabetic diaries since the previous visit.

(i) Parents' Programme. At 13.15 parents and children separated with parents attending a short talk followed by discussion given by one of the members of staff, either a paediatrician, adult diabetologist, diabetic nurse specialist or dietitian, with a break for tea at 14.00 hours followed by a further three-quarters of an hour discussion. Time was available at the end of the afternoon to discuss in depth any individual problems if necessary. Topics covered in the parents programme dealt with all aspects of diabetes and included some basic physiology, digestion and absorption of food, mechanism of action of insulin as well as practical techniques for insulin injection (including innovations such as the Penject and Novopen), blood testing, dealing with hypo and hyperglycaemia, exercise, weather and sport, problems with diabetes in school, travel and eating out, diabetic complications and pregnancy (these last two sessions were attended by parents only), careers and future problems.

(ii) Children's Programme. Topics covered in the children's programme were essentially the same as those for the adult programme except that complications were not discussed in detail but only in passing. A variety of strategies were used for teaching the children which was difficult on occasions because the age range within each group ranged from toddlers to 13 year olds. A volunteer playleader from Ward 2 at the Royal Hospital for Sick Children helped with the children's programme. Computer based teaching programmes including "Junior's Choice" were used, story telling, drawing, and games (such as pin the tail on the donkey or "put the injection in the man") which we used to emphasise the meaning of the topics discussed. Cooking helped the children understand their diet and in particular carbohydrate exchanges. Many of the children formed firm friendships with other members of their group. Some of the pictures drawn by the children about their diabetes emphasised the dramatic impact which having diabetes has on the lives of these children (Appendix 2).

5. Assessments Designed to Measure the Effectiveness of the Intervention Programme (the Education Project). The assessments used will be discussed in detail in the following chapters but briefly the following assessments were carried out at baseline and at the end of the first and second years of the project:

(i) Medical/social background. A data base (Appendix 3) was designed to gather information about the family background and structure, illness in the family, diabetic relatives, housing, social class and education. Methods of diabetic care and diabetic events were also recorded. A diabetic diary was designed to

enable us to gather information consistently from each patient during the project. To measure stressful life events unrelated to diabetes the assessment questionnaire as designed by Coddington (3) was used (Appendix 4). School performance, and relationships at school were also recorded.

(ii) Metabolic control. This was assessed by glycosylated haemoglobin (HbA_1)(4) as the only objective measure of diabetic control currently available in our clinic. Fructosamine was not at that time routinely assayed, and C-peptide was not measured. Records of days in hospital, days absent from school (obtained from education authority), number of infections, and change in insulin dose were also made.

The following assessments were also made and each will be described in detail in the relevant chapter.

(i) Diabetic knowledge was assessed by two questionnaires designed from the questionnaires of Dunn et al (5) (Appendix 5 & 6) for parents and Eiser (6) for children (Appendix 7).

(ii) Three dietary surveys were performed to assess eating patterns using the 7 day weighed record (7, 8, 9).

(iii) Psychological measures of stress and anxiety were utilised (10. 11, 12).

(iv) Parental views of the programme were elicited using three different questionnaires which will be described in detail later (Appendix 8).

Stastical Analysis

The methods described by Armitage and Hills (2) for two-period crossover trials were used when measurements had been made at the end of both the first and second years of the study using Wilcoxon rank sum tests for quantitative observations. Where baseline measurement was also available, these tests were carried out on the changes from baseline to the end of the later periods. For binary observations or those on short ordinal scales, chi-squared tests with Yates' correction or Wilcoxon rank sum tests were used. For comparison of the two groups for measurements made only once, and for comparison of the study groups and the non-participants at entry and at the end of the study, chi-squared or Wilcoxon tests were used as appropriate. Mean values of results are given with the standard deviation in brackets.

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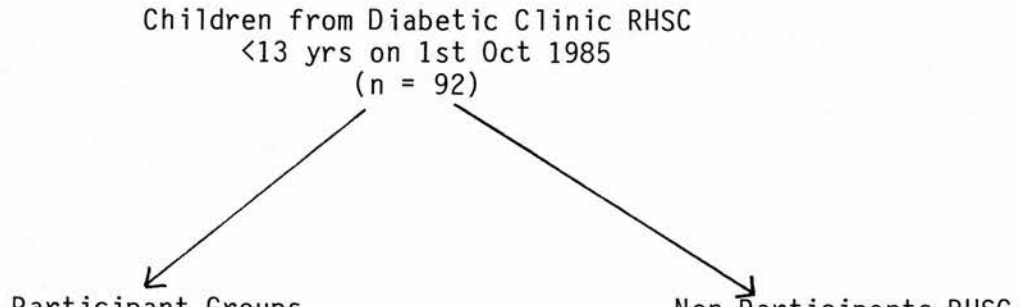
TABLE 5:1 STUDY DESIGN OF EDUCATION PROJECT



	A n = 24	B n = 24	
Year 1	CLUB	CLINIC	CLINIC
Year 2	CLINIC	CLUB	CLINIC

TABLE 5:2: Outline of the programme for the Diabetic Club

DIABETIC CLUB

12 NOON

Group Lunch with Dietitian

Measurements and Diabetic Diary

13.15

Children	Parents
Educational Play	Discussion 1
Stories	14.00
Painting	Tea + snack
Cooking	14.15
Computer	Discussion 2

15.15

Individual Advice if Desired

CHAPTER 6

RESULTS OF MEDICAL AND SOCIAL ASSESSMENTS

The medical and social characteristics of all eligible patients and their families are presented in this chapter; over 70 variables were assessed for each subject. I considered it important to clearly determine any differences between the population included in the study and those who did not participate, as any such differences might have an impact on the application of the results of the study to other populations of diabetic children.

Comparison of Groups on Entry to the Study

The main baseline characteristics of participants and non-participants are in Table 6:1, and shows comparisons between Groups A and B and then A plus B versus non-participants. Firstly, there were very few significant differences between the matched groups prior to entering the study. There was no difference in age on entry, duration of disease, sex, social class, number of days admitted to hospital, number of hypoglycaemic episodes at home, number of clinic visits, glycosylated haemoglobin, TSH, insulin dose, height, weight, or percentage of children remaining prepubertal. The only difference was in the number of infections experienced in the preceding year with Group A having more infections than Group B (<0.05). In addition to these characteristics there was no difference for area of domicile, phone at home, parental situation, educational level of both parents, type of housing, other medical problems or methods of diabetic care

other than the fact that Group B performed routine ketone testing more frequently than Group A (56% vs 21%, $p<0.05$). Family size, and number of diabetic relatives were all similar. Anthropometric measurements showed no difference in height, weight, height velocity or weight velocity. Weight percentile, however, was significantly greater in Group B (78th percentile vs 57th percentile, $p<0.01$) showing that Group B were in fact a heavier group for age. Some aspects of school experience did differ with Group B having a better school performance ($p<0.05$), better relationship with teachers ($p<0.01$), and a better relationship with peers ($p<0.05$) indicating that in some areas Group B appeared to be a better adjusted group than Group A.

Baseline characteristics differed compared with the non-participant group in several areas. The main ones of importance being that the non-participants were older ($p<0.05$), had had diabetes for longer ($p<0.01$), had fewer clinic visits and were significantly taller and took part in more daily exercise than the participants. Other factors, such as area of domicile, distance from hospital, and parental situation, did not differ significantly.

Results of Crossover Trial

Participants

Medical and Social Background

Many characteristics of the participants measured at baseline were unchanged by the intervention of the club and included psychiatric referral rate, number of infections experenced and TSH levels (Table

6:2). However, there did appear to be a lower incidence of other medical problems in Groups A and B during their year attending the club ($p<0.05$) compared with their years attending the routine clinic. TSH showed a period effect decreasing over the two years; this was probably due to increased accuracy of reporting of TSH.

Life Events

Life events unrelated to diabetes which may be stressful and therefore influence diabetic control were assessed by the method of Coddington (1) who has produced two scoring systems designed for children who are at primary school and one for children at secondary school (Appendix 4). These scores were completed for the year prior to entry and each year of the project for both participants and non-participants. There were no significant differences between Groups A and B. (For actual scores see later in Chapter).

Indices of Metabolic Control

1. Glycosylated Haemoglobin

Glycosylated haemoglobin (HbA_1) was measured as the only objective measurement of diabetic control currently available in our clinic, and gives an integrated value of diabetic control over the preceeding 10 to 12 weeks.

Blood glucose was also measured but this data was difficult to use because while attending the diabetic club blood was taken prior to lunch, but at the diabetic clinic the blood would be taken at any time during the afternoon either following lunch or preceding afternoon snack. Glucose levels therefore were only useful in giving immediate advice to the families and were not utilised as an index of overall control.

HbA_1 was measured by the Corning electrophoretic method (2) (normal reference range for our laboratory 4.9-7.7% and between assay SD 0.45%) and mean values over the year for each patient were summed and the results are presented in Table 6:3 and Figure 6:1. Mean HbA_1% for Group A was 9.6 at entry to the study, remained at 9.6 after attending the diabetic club for one year, then rose to 10.7 when returning to the routine clinic. For Group B mean HbA_1% was 8.9 at entry to the study rose to 10.4 after their year attending the routine clinic and remained stable at 10.5 while attending the diabetic club. This gave a significant treatment effect of $p<0.001$ for attending the club.

2. Other Indices of Metabolic Control

Attendance at the diabetic club did not have an effect on the number of days admitted to hospital, the overall number of patients admitted to hospital or insulin dose (Table 6:4). School performance (Table 6:5) showed no change in relation to attendance at the diabetic club. Similarly relationships with teachers and peers (which were almost all satisfactory) were unchanged. The frequency of exercise taken and the percentage of children taking daily exercise did appear to be affected by attendance at the diabetic club. For Group A, the frequency of daily exercise increased during their club year and diminished slightly on returning to their routine clinic. For Group B, attendance in the first year at the clinic did not significantly increase daily exercise but in the second year at the diabetic club with suitable encouragement the amount of exercise they took did increase. Interference by diabetes in school life appeared to diminish over time in both Groups and was unaffected by club attendance.

3. School Absences

Information concerning school absences was obtained with parental permission for each child from their individual schools for three years including the year prior to entry into the project (Table 6:6). This information was also obtained for those who did not participate in the club. At baseline there was no significant difference between the number of absences from school between Group A and Group B although Group B remained consistently lower over the three years assessed. Attendance at the diabetic club did not significantly reduce school absences although this almost reached significance by the end of the second year ($p<0.06$). There was, however, a very wide range in the number of days absent from school and one individual in Group A consistently had a very large number of absence from school for each year assessed.

4. Hypoglycaemia

One of the adverse factors which may occur if diabetic control is improved is the increased incidence of episodes of hypoglycaemia. Events recorded are illustrated in Table 6:7. The number of hypoglycaemic attacks encountered at home in Group B significantly increased ($p<0.05$) during their year attending the diabetic club compared with previous years and compared with Group A attending the routine clinic. This might have been a result of attempting to improve diabetic control. Episodes of hypoglycaemia at school and elsewhere did not increase significantly nor did the number of hypoglycaemic fits increase either during club attendance. The episodes of severe hypoglycaemia requiring glucagon increased significantly ($p<0.01$) in both Groups in parallel over the two year

period and was unaffected by club attendance. This may have been due to increased awareness of the need for using glucagon, a true rise in severe hypoglycaemia, or the fact that during the second year of the study the glucagon pack was changed in format and became much easier and less complicated to use.

5. Methods of Diabetic Care

Some methods of diabetic care did change during attendance at the diabetic club (Table 6:8). The number of children performing urine monitoring only decreased in both Group A and Group B during their year attending the diabetic club so that almost all children performed blood tests. Frequency of monitoring did diminish but this may have been partly our policy that children when they are older perform fewer blood tests. Ketone testing was unchanged. There was, however, a significant difference in both Group A and Group B with Group B consistently performing more ketone testing than Group A. The frequency of insulin injections increased significantly over the time period studied due to children becoming older and requiring two injections per day and was unrelated to club attendance. The number of types of insulin used did not change. The number of injections sites did increase during the year attending the diabetic club for each Group, with significantly more children using 3 or 4 injection sites, ie also including abdomen and buttocks as well as arms and legs. Injection sites were examined by the physician at each visit at both the club and the clinic and were assessed as either having no evidence of hypertrophy, some hypertrophy, or marked hypertrophy with or without atrophy. The percentage of patients with injection sites assessed as good without

hypertrophy was better during the year attending the diabetic club for both Group A and Group B. This is a very subjective assessment and while attending the diabetic clinic sites were assessed by at least four or five different physicians.

Anthropometric Measurements

At the diabetic club children were measured by one person on most occasions (SB). Height, weight, triceps and infrascapular skinfold thicknesses were measured at each visit to the diabetic club. At the diabetic clinic height and weight were measured at each clinic visit. Height and weight velocities were calculated for each year. Descriptive statistics are available firstly for all patient and secondly for those who remained prepubertal throughout the two years of the project. Tests of significance of treatment were undertaken only for those who remained prepubertal since the effect of puberty may possibly overwhelm any effect of treatment and results are presented in Tables 6:9 to 6:12. The measurements for all participants at baseline, end of Year 1 and end of Year 2 showed no significant differences in the time period studied (Table 6:9). When percentile values (Table 6:10) are assessed, at baseline Group B patients showed a preponderance of children with a weight above the 50th percentile and this persisted through the next two years.

Measurements for patients who remained prepubertal throughout the two year period (Table 6:11) showed the expected increases in height and weight but slowing of the height velocity which is appropriate. When percentile values are assessed (Table 6:12) the weight percentile

at baseline shows Groups B to be significantly heavier ($p<0.01$) and this is again true at the end of Year 2 although the value is not significant at the end of Year 1. Overall, therefore, it appears that attendance at the diabetic club had little or not effect on growth in height or weight. Group B patients tended to be taller and heavier than Group A patients but overall as a group both height and weight are normally distributed.

Characteristics of Non-Participant Group Over the Two Year Period

Data was collected for the 44 non-participating patients during their routine attendance at the diabetic clinic. The only data not available on these patients was skinfold thickness. There were some significant differences between the study groups and non-participants, including age, and duration of disease indicating that the non-participating group were older and had had diabetes for longer. There was no difference in area of domicile, social class, or any other problems encountered other than diabetes.

At the end of the two year study period there were once again very few significant differences between the two groups and in particular indices of metabolic control were essentially the same. Glycosylated haemoglobin showed that at baseline the two groups were comparable with the mean HbA_1 for the participants of 9.2% (1.5) and for the non-participants 9.4% (1.5). At the end of the two year period the participants had a mean glycosylated haemoglobin of 10.6% (1.7) while the non-participating group had a mean HbA_1 of 10.9% (1.8). Hospital admission rate, hypoglycaemic fits or severe hypoglycaemia requiring glucagon, school performance, school absences (Table 6:5) and

relationships with peers and teachers at the school were not significantly different from the participants. When assessing life events by the method of Coddington (1), the participants scores for baseline, Years 1 and 2 were 75, 76 and 87, and for the non-participants baseline, Years 1 and 2 59, 69 and 45 respectively. By the end of the second year the scores for participants and non-participants were significantly different ($p<0.001$). There was no correlation, however, at baseline between these stressful life events and glycosylated haemoglobin. Also all scores were relatively low as a life event score is not regarded as unduly stressful until it has reached a level of >90 (for the study groups the mean score did approach this at the end of the second year).

Some aspects of diabetic care were different, with the participants performing significantly more ketone testing (those regularly performing ketone testing 46% vs 17% in the non-participants $p<0.05$). The number of injection sites also differed considerably, with 31% of the participants using 3 or 4 sites compared with 12% in the non-participants ($p<0.01$). The number of infections apparently experienced by the participants was considerably more than the non-participants with a mean value of 2.17 (1) compared with 0.7 (1.1) in the non-participants ($p<0.01$). This, however, could be due to reporting, in that with more detailed interviews undertaken for the participants the incidence of infection may be more easily elicited and remembered. Insulin dose was the same in both groups. Anthropometric measurements showed that the non-participants were taller and heavier because they were an older group but the percentile distribution for each measurement was not different from the participants.

DISCUSSION

In this study, HbA_1 remained stable while children attended the club, but rose significantly while they attended the routine clinic. In a group of children, some of whom are relatively recently diagnosed and some of whom are entering adolescence, one would anticipate a rise in overall glycosylated haemoglobin due to waning pancreatic function in the newly diagnosed children and the difficulties encountered by most adolescents when they enter puberty. Thirty-one per cent of the participants entered puberty during the study. Therefore attendance at the diabetic club may have prevented an anticipated rise in glycosylated haemoglobin.

The need to take more frequent exercise was understood by children when they attended the club and may have influenced HbA_1.

Attendance at the diabetic club may have had some influence on school absence rate despite the fact that we demanded a large time commitment of them and greater absences from school merely by attending the diabetic club. For normal school children in Lothian no overall statistics of school absence are available. However, in the year 1986-1987 5.8% of the school population (5,565) school children were referred to the Lothian Education Welfare Department for absenteeism (personal communication from the Department of Education). This is defined as being absent for more than 2 out of 15 school days without a good reason, ie without a good medical or other reason. Therefore a child absent for more than 24 days for non-medical reasons in one year would be referred to the Welfare Service. In fact, only one diabetic child, the one mentioned above, was actually referred to the Welfare Service during the three years. The figures which we have for school

absence rate include for some children clinic visits and also time taken out at holidays. We were unable, however, to elucidate from the figures that we have whether or not diabetic children have a higher absence rate from school than non-diabetic children, it would seem that diabetic children are not absent from school any more than non-diabetic children.

Hypoglycaemia did increase during club attendance, but it did not appear that the incidence of hypoglycaemia during improved diabetic control was distressing or unacceptable to the patients.

Some methods of diabetic care practices did change during club attendance and may have influenced diabetic control. These include more frequent blood testing, and rotating injection sites thus reducing the incidence of hypertrophy. Therefore the education programme had a small but significant effect on diabetic control. Small group teaching and semi-structured discussion groups have been shown to be the most effective way of improving motivation and diabetic control (3, 4). The children selected for this study who attended the routine clinic already had an acceptable HbA_1 at baseline (5, 6, 7) and it may be difficult to further improve control in this group. The wide age range (3 years to 13 years) of children within each small teaching group made instructing the children together difficult. Grouping children of similar ages together might have resulted in a greater success.

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TABLE 6:1: CHARACTERISTICS OF CHILDREN <13 YEARS ATTENDING THE DIABETIC CLINIC AT THE ROYAL HOSPITAL FOR SICK CHILDREN IN YEAR PRIOR TO ENTRY TO THE STUDY

	Participants			Non-participants	
	Group A n = 24	Group B n = 24	(a) p value	n = 44	(b) p value
Age on entry(yr)	9.1 (3.1)	8.9 (2.9)	NS	10.4 (2.4)	<0.05
Duration of disease (yr)	2.8 (2.4)	2.7 (1.9)	NS	4.5 (3.2)	<0.01
Sex M/F	12/12	9/15	NS	18/26	NS
Social Class I+II(%)	33	29	NS	36	NS
U/E(%)	8.3	8.3		4.5	
Number of days admitted to hospital	1.5 (2.9)	1.6 (1.7)	NS	1.4 (5.6)	NS
Number of hypos at home	3.8 (3.3)	3.4 (2.1)	NS	3.3 (3.4)	NS
Number of infections	1.5 (1.3)	0.7 (1.7)	<0.05	1.0 (1.4)	NS
Number of clinic visits	5.6 (1.8)	5.5 (1.7)	NS	4.6 (0.8)	<0.01
HbA_1(%)	9.6 (1.7)	8.9 (1.3)	NS	9.4 (1.5)	NS
TSH mU/L	2.7 (1.4)	2.8 (1.0)	NS	3.0 (2.7)	NS
Insulin dose $UKg^{-1}24\ hr^{-1}$	0.80 (0.25)	0.81 (0.25)	NS	0.86 (0.2)	NS
Height (cm)	131.8 (19.2)	132.0 (16.0)	NS	139.0 (15.4)	<0.05
Weight (kg)	31.8 (12.2)	33.6 (10.2)	NS	36.4 (10.1)	NS
Prepubertal(%)	83	83	NS	86	NS
Taking daily(%) exercise	14	14	NS	40	<0.01

Figures shown are Mean (SD): Group A = Club first Group B = Club second:
Hypos = hypoglycaemic episodes: U/E = unemployed:
(a) = Group A vs Group B: (b) = Study groups vs non-participants

TABLE 6:2 SOME CHARACTERISTICS OF STUDY GROUPS

	Year	A	Vs	B	Significance of intervention*
Any medical problems? % Yes	0	28.6		25.0	
	1	24.0		46.7	$p<0.05$
	2	57.1		33.3	
Psychiatric Referral (Number per year)	0	4		0	
	1	2		1	NS
	2	3		2	
TSH	0	2.7 ± 1.4(1.1-7.7)		2.8 ± 1.0(1.3-4.5)	
	1	3.1 ± 1.6(0.1-7.3)		2.7 ± 2.9(1.0-16.0)	NS
	2	2.2 ± 1.4(0.9-6.0)		1.8 ± 2.9(0.5-3.2)	

* ie attendance at the diabetic club

TABLE 6:3 GLYCOSYLATED HAEMOGLOBIN HbA_1

Year	A	Vs	B	Significance of Intervention
0	9.6 ± 1.7 (7.0-13.1)		8.9 ± 1.3 (6.8-12.6)	
1	9.6 ± 1.4 (7.4-12.3)		10.4 ± 1.4 (8.0-12.5)	p<0.001
2	10.7 ± 2.1 (8.3-17.1)		10.5 ± 1.4 (7.7-13.0	

All values mean% (SD) (Range) unless otherwise stated

TABLE 6:4 OTHER INDICES OF METABOLIC CONTROL

	Year	A	Vs	B
Number of Days Admitted	0	1.5± 2.0(0-12)		0.16 ± 1.7(0-8)
	1	0.33 ± 0.9(0-4)		3.0 ± 10.9(0-53)
	2	1.2 ± 23 (0.8)		1.3 ± 44 (0-21)
Any Hospital Admissions (number of patients per year)	0	8		4
	1	5		5
	2	8		4
Insulin Dose Ukg^{-1} $24h^{-1}$	0	0.8 ± 0.25(0.4-1.43)		0.81 ± 0.25(0.33-1.2)
	1	0.9 ± 0.22(0.53-1.32)		0.86 ± 0.21(0.47-1.28)
	2	1.0 ± 0.31(0.62-2)		0.98 ± 1.17(0.67-1.34)

Values are mean ± SD (Range)

No significant difference between variables

TABLE 6:5 SCHOOL PERFORMANCE OF STUDY GROUPS

	Year	A	Vs	B	Significance of Intervention
School performance Good/excellent	0	57%		90%	
	1	86%		91%	NS
	2	83%		96%	
Relationship Teachers Good	0	76%		95%	
	1	86%		92%	NS
	2	87%		96%	
Relationship Peers Good	0	76%		100%	
	1	82%		96%	NS
	2	91%		100%	
Frequency Exercise Daily	0	14%		14%	p <0.05
	1	31%		17%	Treatment effect
	2	24%		33%	
Interference Schooling Yes	0	24%		14%	
	1	14%		21%	NS
	2	4%		12.5%	

TABLE 6:6 SCHOOL ABSENCES IN DAYS PER YEAR

Year	A	Vs	B	Significance of Intervention	Non-Particants	Significance vs Participants
0	22.1 ± 19.0 (0-73)		13.8 ± 5.5 (4-21)		16.8 ± 13.6 (0-59)	
1	20.3 ± 17.6 (0-72)		15.7 ± 15.9 (1-67)	p<0.06	16.8 ± 11.2 (1-48)	NS
2	25.8 ± 24.0) (4-102)		13.2 ± 9.0 (3-35)		17.1 ± 16.2 (1-74)	

Mean ± SD (Range)

TABLE 6:7 HYPOGLYCAEMIA

	Year	A	Vs	B (Mean ± SD (Range))	Significance of Intervention
Number of hypos at home	0	3.8 ± 33 (0-10)		1.3 ± 2.1 (0-7)	
	1	3.7 ± 4.1 (0-15)		3.8 ± 4.1 (0-12)	
	2	2.4 ± 3.5 (0-10)		4.7 ± 3.6 (0-13)	p<0.05
Number of hypos at school	0	0.87 ± 1.5 (0-4)		0.95 ± 2.1 (0-8)	
	1	0.83 ± 1.4 (0-6)		1.6± 2.7 (0-12)	NS
	2	1.2 ± 1.9 (0-8)		2.1 ± 2.3 (0-8)	
Number of hypos outside	0	1.0 ± 1.8 (0-6)		0.36 ± 0.66 (0-2)	
	1	0.96 ± 1.7 (0-7)		1.0 ± 1.4 (0-6)	NS
	2	1.1 ± 1.9 (0-6)		0.37 ± 0.65 (0-2)	
Number of hypo-glycaemic fits	0	0		0	
	1	0		1	NS
	2	2		1	
Severe hypo-glycaemia needing glucagon	0	4		4	
	1	5		6	NS
	2	9		13	(p<0.01 for increase with time)

All values are mean(SD) per patient per year
Hypos = hypoglycaemic episodes

TABLE 6:8 DIABETIC CARE PRACTICES

	Year	A	Vs	B	Significance of Intervention
Type of monitoring (urine only)	0	29%		30%	
	1	4%		12.5%	p <0.01
	2	12.5%		4%	
Frequency of monitoring > x2/day	0	87%		87%	
	1	87%		87%	NS
	2	42%		79%	
Ketone Testing Yes	0	21%		56%	
	1	37%		58%	NS
	2	33%		58%	
Insulin Frequency x 1/day	0	33%		22%	
	1	17%		8%	NS
	2	0%		4%	
Number of types of insulin x 1 day	0	29%		17%	
	1	12.5%		0%	NS
	2	4%		0%	
Number of injections sites used (3 or 4 sites)	0	8%		0%	
	1	28%		4%	p <0.05
	2	33%		29%	
Injection sites Good	0	67%		54%	p <0.01
	1	71%		29%	
	2	46%		42%	

TABLE 6:9 ANTHROPOMETRIC MEASUREMENTS FOR GROUPS A AND B

Year		0	1	2
Height (cm)	A	131.817(19.199)	137.675(19.306)	143.671(18.758)
	B	132.135(16.005)	138.762(14.512)	144.029(14.194)
Height (cm per yr) Velocity	A	6.712(1.757)	6.500(1.429)	5.529(2.134)
	B	6.182(1.788)	6.625(2.043)	5.712(1.507)
Weight (kg)	A	31.796(12.318)	35.212(13.358)	35.212(14.931)
	B	33.622(10.255)	36.996(11.139)	41.775(13.293)
Weight (kg per yr) Velocity	A	3.621(2.865)	3.762(1.930)	4.737(2.500)
	B	3.768(1.895)	3.583(2.559)	5.079(2.782)
Triceps Skinfold Thickness (mm)	A	10.604(2.396)	11.104(3.511)	12.317(4.239)
	B	-	13.757(3.493)	13.243(3.920)
Infrascapular Skinfold Thickness (mm)	A	6.400(2.335)	7.183(2.747)	7.425(3.054)
	B	-	6.991(1.754)	6.774(2.175)

Mean (SD) for all values

TABLE 6:10 MEAN PERCENTILE VALUES FOR GROUPS A AND B

Year		0	1	2
Height	A	51	53	49
	B	60	61	59
Height Velocity	A	57	52	35
	B	47	51	38
Weight	A	57	57	57
	B	78	71	71
Weight Velocity	A	46	39	49
	B	58	47	53
Triceps Skinfold Thickness	A	56	56	62
	B	-	70	65
Infrascapular Skinfold Thickness	A	45	48	48
	B	-	48	45

TABLE 6:11 ANTHROPOMETRIC MEASUREMENTS FOR PREPUBERTAL CHILDREN IN STUDY GROUPS A AND B (A n = 11 and B n = 14)

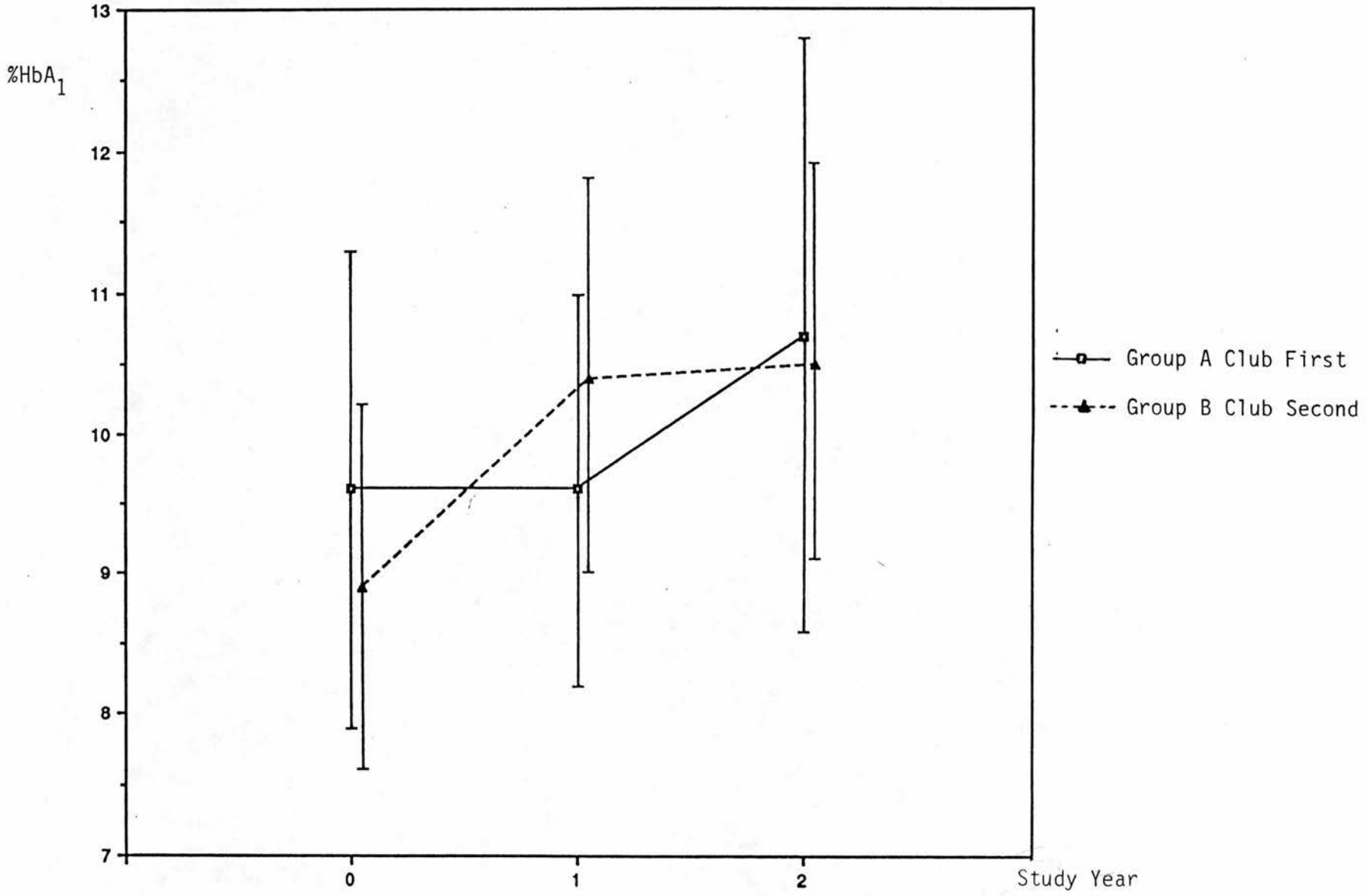
Year		0	1	2
Height cm	A	115.445(13.558)	120.955(12.997)	127.055(12.463)
	B	125.507(16.598)	132.150(14.808)	137.579(14.394)
Height Velocity cm per yr	A	6.791(1.318)	6.355(1.184)	5.700(0.760)
	B	6.246(2.161)	6.757(2.116)	5.907(1.413)
Weight kg	A	21.427(4.875)	23.818(5.248)	26.809(5.167)
	B	29.179(9.214)	31.857(9.485)	35.464(9.485)
Weight Velocity kg per yr	A	2.036(1.096)	2.582(1.122)	2.782(0.914)
	B	3.246(1.475)	2.686(1.517)	3.879(1.439)
Triceps Skinfold Thickness mm	A	9.790(1.790)	10.060(2.282)	10.727(2.816)
	B	-	12.554(2.787)	12.062(2.993)
Infrascapular Skinfold Thickness mm	A	5.320(1.248)	5.720(1.304)	5.455(1.227)
	B	-	6.138(1.150)	6.077(1.115)

Mean (SD) for all values

TABLE 6:12 MEAN PERCENTILE VALUES FOR PREPUBERTAL CHILDREN IN GROUPS A and B (A n = 11 B n = 14)

Year		0	1	2
Height	A	48	50	49
	B	54	57	47
Height Velocity	A	57	63	47
	B	46	50	41
Weight	A	47	50	38
	B	75	67	68
Weight Velocity	A	41	51	48
	B	56	53	59
Triceps Skinfold Thickness	A	56	53	59
	B	-	69	67
Infrascapular Skinfold Thickness	A	42	44	38
	B	-	48	40

FIGURE 6:1 CHANGES IN $\%HbA_1$ (MEAN S.D.) FOR GROUPS A AND B DURING THE 2 YEAR STUDY



CHAPTER 7

MICROALBUMINURIA

INTRODUCTION

In the routine clinical situation the urine is tested for albumin by the dipstick method (Albustix, Ames) and a definite positive 1+ respresents an albumin concentration of 300 mg/l. The urine of a normal person has an albumin concentration of 10 mg/l, undetectable by Albustix. Microalbuminuria is the term used to describe levels of urinary albumin raised above normal but not detectable by Albustix.

The concentration of substances in the urine is affected by urinary flow rate which varies throughout the day. Microalbuminuria also describes the urinary albumin excretion rate (AER) above the normal range (<12 micrograms/minute) but less than that in clinically detectable proteinuria (>350 micrograms per minute).

Microalbuminuria can be measured on a variety of samples but all have their problems - 24 hour urine collections are cumbersome and prone to patient error; day time timed samples are affected by exercise and posture, timed overnight samples give lower AER. Several workers (1, 2) have compared overnight, daytime and 24 hour samples with a single morning urine sample and have shown that the concentration of albumin in a single morning specimen correlates very well with a 24 hour AER, is very sensitive and fairly specific. They recommended an albumin concentration of greater than 20 mg/l as being predictive of a 24 hour AER of 20mg/day indicative of microalbuminuria in children who have a lower AER than adults (2). Other workers prefer a

level of 30 mg/l on a single morning sample to indicate microalbuminuria (3). Others (4) have suggested that measuring albumin: creatinine ratio on the same specimen improves sensitivity of the test. They suggest using a ratio of >3.5 (correlating with an AER >30 micrograms/minute) to be indicative of microalbuminuria.

It has been shown in adults that the presence of microalbumin is a good predictor of the later development of diabetic nephropathy (5, 6). Viberti et al (6) followed 55 patients for 14 years and showed that the risk of developing clinical nephropathy was 24 times greater in those with AER greater than 30 micrograms/ minute than in those below this level.

In children microalbuminuria has been detected in patients over 12 years of age or post puberty (7) and incidence in adolescence is quoted at between 7.6 and 20.0% (7-10).

The link between microalbuminuria and diabetic control remains controversial and poor diabetic control is not necessarily followed by the development of microalbuminuria and nephropathy. Some workers have found a correlation between renal function and glycosylated haemoglobin (8). Others have found no significant association (7, 9). In adults there is some evidence that improved diabetic control and therapeutic intervention may reduce microalbuminuria and even reverse early nephropathy (11).

As part of our project we assessed microalbuminuria in both participant and non-participant groups. At the commencement of the project, microalbuminuria was not routinely assessed in our clinic, so the first samples were obtained at the end of the first year.

Material and Methods

It was decided to use the first morning urine specimen as an ideal sample to collect in the clinic for assessing microalbuminuria (1, 2). Patients were provided by post with a sterile urine container one week prior to their club or clinic visit and were requested to bring the first morning sample passed on the day of that visit. Aliquots of urine were stored at -20^{o}C with 20 microlitres of inactivated rabbit serum added to help prevent absorption of albumin to the storage tubes. Samples were then batched and analysed by ELISA (enzyme linked immunoabsorbent assay) (12). Creatinine was measured by the picric acid method. Samples on participants were obtained at the end of the first year and end of the second year of the project. Samples from non-participant diabetic children were obtained on one occasion during the second year of the project.

RESULTS

Results of albumin concentration in the urine on early morning urine specimens is shown in Table 7:1. There was no effect of the diabetic club on microalbuminuria between Groups A and B, therefore results were pooled for participants. A wide range of microalbuminuria was seen. If a level above 30 mg per litre is taken as indicative of microalbuminuria then a total of 13 children had values in this range. If greater than 20 microlitres is taken as evidence of microalbuminuria, then 19 children were above the normal range. Only one individual had a raised value on specimens taken one year apart. He also had a raised albumin creatinine ratio on two occasion. The results of albumin creatinine ratio performed on the same sample are shown in Table 7:2. There were 6 values above 3.5 micro gms per micromol. The remaining 73 samples were well within the normal range.

If urinary albumin concentration is plotted against age in years (Fig 7:1) it can be seen that there is an increase with age (formal statistical correlations were not performed) and most children with raised values are certainly above 10 years of age. There is not a similar association with duration of disease (Fig 7:2) where the raised values are scattered and unrelated to duration of disease. Only one child in our study had microalbuminuria on two samples taken one year apart. He was over 12 years and had HbA_1 of 12.0 %.

DISCUSSION

There are few studies of normal values of albumin excretion for children using the method of assay used by ourselves but it appears that a value above 20 milligrams per litre of urinary albumin concentration is indicative of further study in any child (2). We have found values above this level in some younger children, although most raised values are in children above 12 years of age. This finding is in agreement with Dalquist (10) who found a strong association between albumin excretion rate and increasing age. Twenty per cent of their diabetics had AER values exceeding the upper level for healthy controls, most were older than 12 years and 5 per cent had values exceeding those reported to be predictive of later development of overt nephropathy in adults. In this same study when diabetic children of less than 12 years were compared with those older than 12 years at the same duration of disease, the older children had significantly higher AER values. Other studies have confirmed this (7). No sex difference was found in either study. They recommend, and our study supports this, that routine screening for

microalbuminuria should be carried out as part of paediatric diabetic care after the age of 12 years. Duration of disease appears to be a much less significant factor than age and the onset of puberty for the development of microalbuminuria.

If an abnormal value is found, then that patient should be carefully followed with assessments of renal function and greater attention given to better metabolic control as this may improve microalbuminuria (13). A study of adolescents (14) showed a direct relationship between HbA_1 and AER where microalbuminuria was already present. Recently, captopril (angiotensin converting enzyme inhibitor) has been used to decrease microalbuminuria in diabetic children (15). Therefore, identifying the children at risk of developing nephropathy is important as therapy may be available.

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TABLE 7:1 URINARY ALBUMIN CONCENTRATION IN A SINGLE MORNING SAMPLE (mg/l)

	Participants		Non-Participants
	Year 1	Year 2	Clinic
	n = 45	n = 33	n = 32
Range	1.5-143	1.8-112	1.8-110
Median	6.4	8.5	8.3
No. of Specimens:			
> 30 mg/l	4	5	4
20-30 mg/l	1	2	3
10-20 mg/l	8	7	6
<10 mg/l	32	19	19

TABLE 7:2 URINARY ALBUMIN/CREATININE RATIO IN SINGLE MORNING SAMPLE

Albumin/Creatinine Ratio
(values microgm per micromol)

n = 79

6 values:- 35.8, 28.0, 10.1, 7.71, 7.37, 4.34

73 values:- Range 0.14 - 1.57

FIGURE 7:1 ALBUMIN CONCENTRATION IN URINE COMPARED WITH AGE

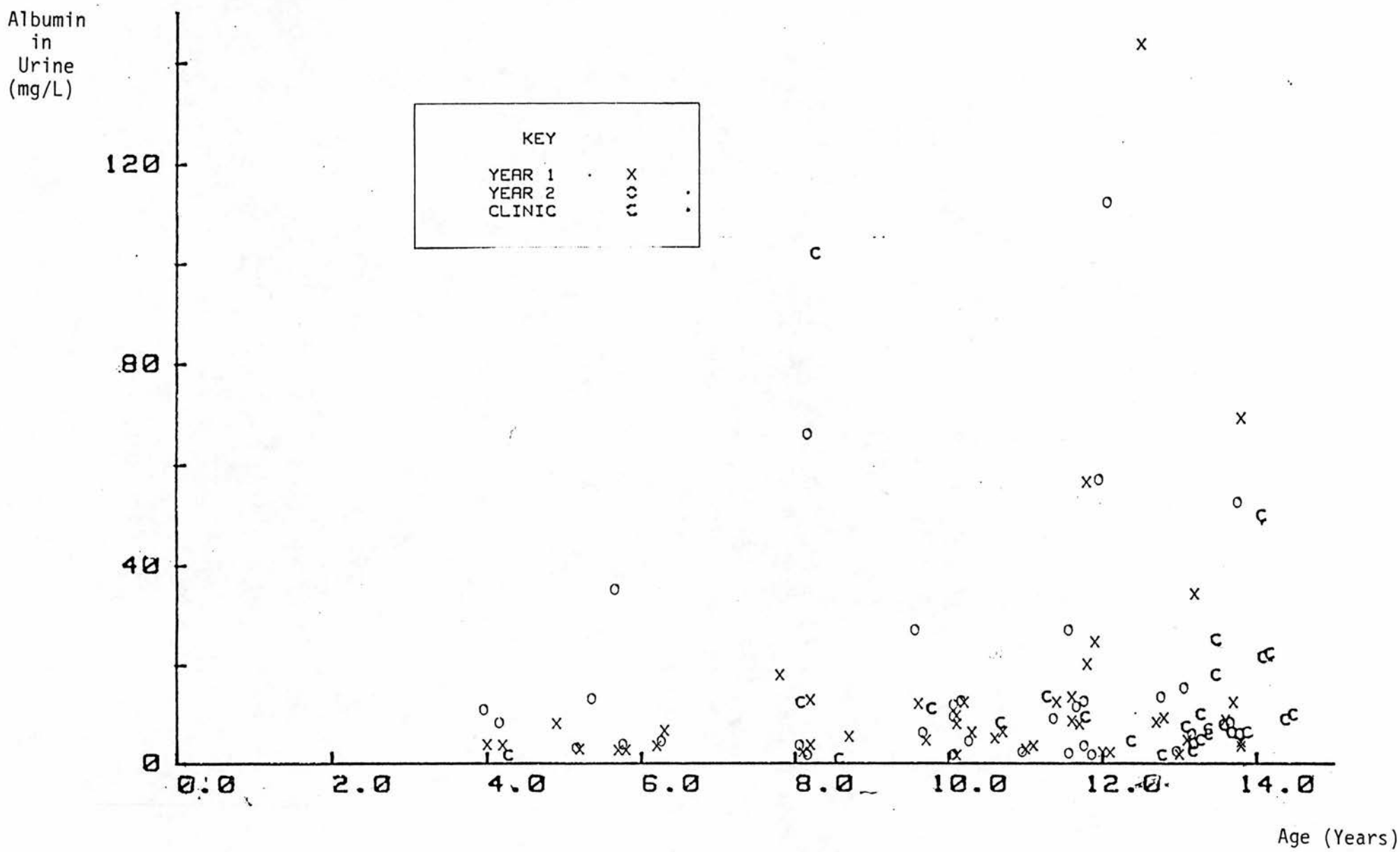
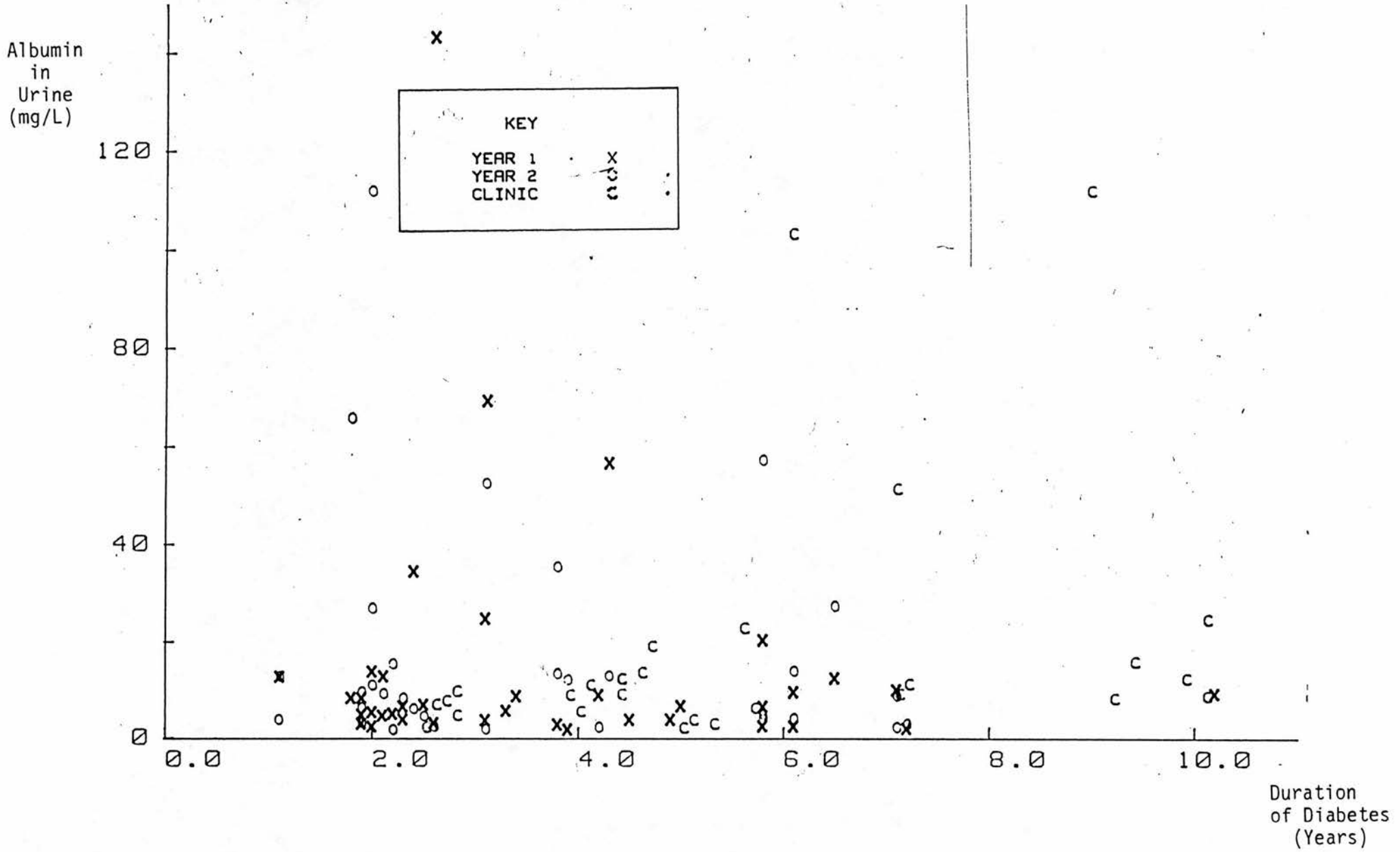


FIGURE 7:2 ALBUMIN CONCENTRATION IN URINE COMPARED WITH DURATION OF DIABETES



CHAPTER 8

ASSESSMENTS OF KNOWLEDGE ABOUT DIABETES

INTRODUCTION AND METHODS

To assess the effectiveness of the educational component of the diabetic club in improving knowledge about diabetes we devised assessments of diabetic knowledge. Dunn (1) has stressed the importance of validation of any questionnaire used and also stressed that any such test instrument used on a routine clinical basis should be brief and reproducible. Dunn et al (1) assessed the type of questionnaire format which was most suitable and reliable and also the minimum number of questions which could adequately be used to assess whether diabetic patients had adequate knowledge. They showed that the multiple choice format was preferable to "true/false" questions or those requiring open-ended answers needing interviewer interpretation. They formulated 15 questions which were useful in assessing the basic information essential for any diabetic to manage his disease adequately.

We therefore utilised this core of 15 questions plus items from dietary questionnaires used by Sheard (2) and problem-solving questionnaires used by Bennett (3) and added additional questions formulated by our study group. To maintain brevity we divided these questions into two questionnaires. The first questionnaire (DKT1) contained simple, straightforward multiple choice questions requiring only one answer; the second questionnaire (DKT2) contained questions that required often more than one answer and were problem-solving in

nature rather than an assessment of simple factual knowledge. DKT1 and DKT2 are shown in Appendix 5 and 6. Because of the constraints on time and because we were demanding a large degree of commitment from our patients an assessment of practical technique was not undertaken although this was informally assessed and appropriate instruction given at the diabetic club visits.

Questionnaires were administered to mothers of children at the beginning of the first year, end of the first year and end of the second year of the diabetic education project. The questions were answered in a group at a club visit with one of the members of staff present to explain any questions or points which were not clear. One mother had reading difficulties and therefore the questionnaire was administered verbally for her in a separate room. It was stressed to the parents that this questionnaire was not for us to assess how good or bad their knowledge was for each individual but to assess the effectiveness of our educational programme for the group. All answers were confidential. The test scores were not known by the members of staff during the year in which the educational programme took place to enable us to concentrate on group education and avoid focusing on any one individual. Scores were available to parents after the end of the project if they so wished. (No-one in fact asked for their scores at the end of the project as they all felt there had been some improvement which they themselves could assess.) As in other aspects of this study non-participants were also assessed by using the same questionnaires at baseline and at the end of the study (administered by EW at clinic visits.)

RESULTS

Scores at Entry to the Study

Tests of factual knowledge (DKT1) and problem-solving (DKT2) were performed by mothers in all cases except one (a father), therefore statistical analysis refers only to mothers. At baseline mean scores were high at >80% for DKT1 and >70% for DKT2 (Table 8:1), but there was a wide range. At baseline in Group A the minimum score on DKT1 for one individual was 19% and for DKT2 was 10%, but a few individuals scored 100%. No individual in Group B scored less than 50%. There was no significant difference in test scores between groups on entry to the study.

There was no significant change in mean scores attained in DKT1 in both Group A or Group B over the two year period. For Group A mean scores for DKT1 rose from 84% to 89% at the end of their club year and rose slightly further to 91% and the end of their clinic year. For Group B mean scores for DKT1 were 82% at baseline, rising to 86% at the end of their clinic year, and 88% at the end of their club year. There was a significant improvement in scores attained in DKT2 for Groups A and B at the end of their year attending the club ($p<0.01$). In Group A mean scores for DKT2 rose from baseline of 74% to 81% at the end of their club year, and 82% at the end of their clinic year. For Group B mean scores for DKT2 at baseline was 76%, 74% at the end of their clinic year, and 79% at the end of their club year (Table 8:1). It is interesting to note that after returning to routine care in the diabetic clinic for the second year Group A's scores were maintained.

Non-Participants

The parents of the non-participants (mothers in all but two cases) performed both tests at the beginning of the project and at the end of the second year, to ascertain whether there was any change over time in the knowledge of the clinic population. The results illustrated in Table 8:2 show that the scores attained in the non-participant group at baseline and at the end of the second year for both DKT1 and DKT2 were not significantly different and were comparable with the study groups.

Questions Found Most Difficult

Certain questions showed that there were some areas where knowledge or attitudes were not changed by club attendance and scores were consistently lower than for the other questions. The question which scored lowest of all in both groups on all three occasions was question 2 of DKT2 (Table 8:3). This question concerned the seriousness of diabetes as a disease and clearly many parents did not regard diabetes as a very serious disease and this attitude was only marginally changed by attendance at the club. This may represent parents' true feelings about the disease or may in fact be that they are trying to regard their children as normal and that the children appear completely healthy most of the time. Question 3 on DKT2 concerned exchanges of fruit, some of which may not be eaten by many of the families, and again scores were slightly improved by club attendance.

Correlation of Diabetic Knowledge Tests with HbA_1

There was no correlation at baseline between an individual's glycosylated haemoglobin and the score for DKT1 or DKT2 (see Figs 8:1 & 8:2). It can be seen that the individual with the lowest score on DKT1 and DKT2 did not have a child with the highest HbA_1, conversely some of the children with a high HbA_1 had mothers with very good scores on these tests. Similarly there was no correlation between change in glycosylated haemoglobin and change in DKT2 scores during their club year for either group (see Fig 8:3). From this Figure, however, we can observe some trends of how parents' scores improved during their club year. It can be seen that 21 parents' scores improved and their child's glycosylated haemoglobin improved; 14 parents' scores improved but their child's glycosylated haemoglobin rose; 6 parents' scores were less good over the club year but their child's glycosylated haemoglobin improved; 1 parent's score stayed the same and the child's glycosylated haemoglobin improved, and finally 4 parents' knowledge worsened and their children's glycosylated haemoglobin rose. Therefore, overall, although glycosylated haemoglobin significantly improved during their year attending the club and their parents' knowledge also significantly improved on the problem-solving test there was no close relationship between the two.

Children's Questionnaire

The childhood diabetes questionnaire concerning knowledge and attitudes to diabetes taken from Eiser (4) (Appendix 7) was answered by the children at baseline, at the end of Year 1, and at the end of Year 2. There was a problem with this questionnaire, however, in that the

data was patchy with only a total of 32 children answering the questionnaire at baseline and not all the same children answering the questionnaire for the next two years. This was due firstly to young children, those of the pre-school age, who found it difficult to answer these questions, even when administered verbally, and secondly some of the older adolescents who latterly refused to fill in the questionnaire. These data are too patchy to make a valid quantitative comparison, but some interesting qualitative information emerges.

Questions concerning knowledge were analysed by the stratified chi-squared test and those concerning ordered scales or opinions by stratified Wilcoxon test. All results showed no significant change in either knowledge or attitude (Table 8:4) over the two year period, within the limitations stated above. All questions concerning the causes and treatment of hypoglycaemia were answered successfully by most children, showing that this was the area where their knowledge was excellent. The question concerning the timing of insulin injections was adequately answered by most children. Questions where difficulties arose were those concerning the rotation of injection sites, the mechanism of action of insulin and how to adjust insulin during illness. Also some of the questions concerning diet and its components were less well answered.

Some information about the children's attitude to their diabetes was elicited from this questionnaire (Table 8:5). This shows that only approximately half the children have read a book concerning diabetes and not all the children wear any diabetic identity on their person which may cause obvious problems in the event of hypoglycaemia. Questioned further as to why they did not like wearing identity disks

most children stated that they did not want to feel different at school and that wearing any sort of identity disk singled them out from their peers. When questioned about what they thought was the worst thing about having diabetes, injections and performing regular routine tests proved to be the worst thing for most children, with diet and hospital visits being less significant for them. One or two children did not feel there was anything bad about having diabetes.

At the beginning of the project one-third of the children knew no other diabetic child and the rest only know 1 or 2. By the end, all knew at least 5 other children with diabetes.

DISCUSSION

We have shown no significant change in basic factual knowledge about diabetes with attendance at the diabetic club, but a significant improvement in problem solving ability of parents. There was no clear correlation between scores in the questionnaires and diabetic control as assessed by HbA_1. This may be because in our participants the overall knowledge of the group at baseline was excellent at greater than 70-80%. At baseline, therefore, the majority of parents had adequate knowledge to manage their child's diabetes albeit that one or two individuals had very poor knowledge. (The questionnaires such as those utilised in our programme might be useful in identifying which parents have poor knowledge.) It is possible that scores were high because our questionnaires were too easy, but the questionnaires adequately covered the basic core of knowledge necessary for parents to manage their child's diabetes. There was an improvement in diabetic knowledge on DKT2 and in glycosylated haemoglobin but no correlation between the

two. It therefore appeared that overall our clinic population had a good knowledge of diabetes at baseline with only a small margin for further improvement thus making it potentially difficult to detect a beneficial effect from the diabetic club. A more positive result might have been found if the clinic population had a lower level of knowledge at baseline.

A review of the literature concerning education programmes reveals that opinion is divided as to the relationship of knowledge and HbA_1. A large study in America (5) of over 500 obese, elderly diabetics showed that knowledge improved after an education programme at six months but was not sustained beyond 14 months, although skills in self-care behaviour remained improved. There was a modest improvement in blood glucose levels of approximately 30 mgms% and a small reduction in HbA_1 of 0.4%. No correlation was made between improved knowledge and HbA_1.

A study of a children's clinic in Hull (6) showed that education programmes improved knowledge, particularly in adolescents, but no assessment was made of diabetic control. A survey of knowledge of insulin-dependent diabetics (7) showed overall low scores on the questionnaire used and scores were unrelated to the age of the patients, duration of disease or HbA_1. A survey of 36 adults taking part in evening self-help groups (8) showed a significant improvement in HbA_1 from 12.4 to 10% and improved knowledge scores from 58 to 69%, but as in our study there was no correlation between the two. Conversely McCowen et al (9) showed some correlation between diabetic knowledge, diet, HbA_1, socio-economic group and age at diagnosis. Korhonen et al (10) with two randomised groups of 38 insulin-dependent

diabetics, showed improved metabolic control initially after an intervention period but this was significantly greater in the intensive education group after three months. However, at 9 months after the education sessions finished metabolic control had returned to previous levels. Fishbein in Rhode Island (11) reviewed 691 insulin-dependent diabetics for three years and showed that an education programme consisting of 5 two-hour evening sessions dramatically reduced readmission rate but no other parameter of metabolic control was measured. Muhlhauser et al (12) showed improvement in metabolic control for up to 22 months following a teaching programme and again reduced admissions from 10 days per patient per year to 1 day per patient per year and HbA_1 significantly improved. However, diabetes-related knowledge did not correlate with any of the variables investigated in the study. Compliance (defined as complying with various aspects of the self-care regimen), however, did improve significantly. Hackett et al (13) in a recent study in Newcastle showed that HbA_1 improved most in those whose knowledge questionnaire scores improved after their education programme. Dunn (14) makes the point that while educational aspects of any programme are important, it is probably the group support which is most beneficial in improving motivation and control.

Therefore, it appears that while adequate knowledge to manage diabetes is essential, further improvement of that knowledge in itself does not have any effect on diabetic control and that it may well be other aspects of the programme, such as the group teaching, the group effect and social interaction, and effects on coping mechanisms of parents and children which significantly improve control.

"Simple human interaction" may be as effective as structured education in improving metabolic control (13).

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TABLE 8:1 RESULTS OF DIABETIC KNOWLEDGE TESTS (DKT1 and DKT2) FOR STUDY GROUP PATIENTS

	Group	Entry	End Year 1	End Year 2	Significance of intervention
DKT1	A	84 (16)	89 (13)	91 (8)	NS
	B	82 (13)	86 (11)	88 (7)	
DKT2	A	74 (18)	81 (12)	82 (12)	$p<0.01$
	B	76 (11)	74 (8)	79 (10)	

Group A = Club first; Group B = Club second

Figures shown are Mean (SD) % correct

TABLE 8:2 RESULTS OF DIABETIC KNOWLEDGE TESTS (DKT1 and DKT2) FOR PARTICIPANTS (A & B) vs NON-PARTICIPANTS (NP)

	Group	Entry	End Year 2	Significance
DKT1	A & B	81 (14)	90 (8)	NS
	NP	89 (10)	90 (11)	
DKT2	A & B	75 (14)	80 (11)	NS
	NP	80 (9)	81 (9)	

(Mean (S.D.) % correct

TABLE 8:3 SCORES FOR QUESTIONS FOUND MOST DIFFICULT BY PARENTS

Question		Entry	End Year 1	End Year 2
DKT2 2 Attitude to Diabetes	A	37	54	38
	B	16	29	37
DKT2 3 Fruit Exchanges	A	52	70	68
	B	67	74	63
DKT2 6 Urine Testing	A	47	61	70
	B	46	51	62

% Correct (Mean)

TABLE 8:4 CHILDREN'S QUESTIONNAIRES

	Entry	End Year 1	End Year 2	Significance
Group A	62 (27)	74 (20)	72 (23)	NS
Group B	74 (16)	70 (20)	81 (17)	NS

% Correct (Mean (S.D).

TABLE 8:5 CHILDREN'S ATTITUDES TO DIABETES

	Group	Entry	End Year 1	End Year 2
Have you read a Book about diabetes? % Yes	A	58	58	71
	B	33	40	59
Do you wear a diabetic ID? % Yes	A	79	89	71
	B	89	85	89
Worst thing about diabetes?				
Injections % Yes	A	32	32	43
	B	78	21	11
Tests % Yes	A	21	10	21
	B	0	21	39
Food % Yes	A	16	10	10
	B	11	21	11
Hospital % Yes	A	16	21	14
	B	0	16	6
Anything Else? Teasing, Feeling Different % Yes	A	5	16	14
	B	11	5	22

FIGURE 8:1 CHILD'S HbA_1 COMPARED WITH PARENT'S SCORE FOR DIABETIC KNOWLEDGE TEST 1 (DKT1) AT BASELINE

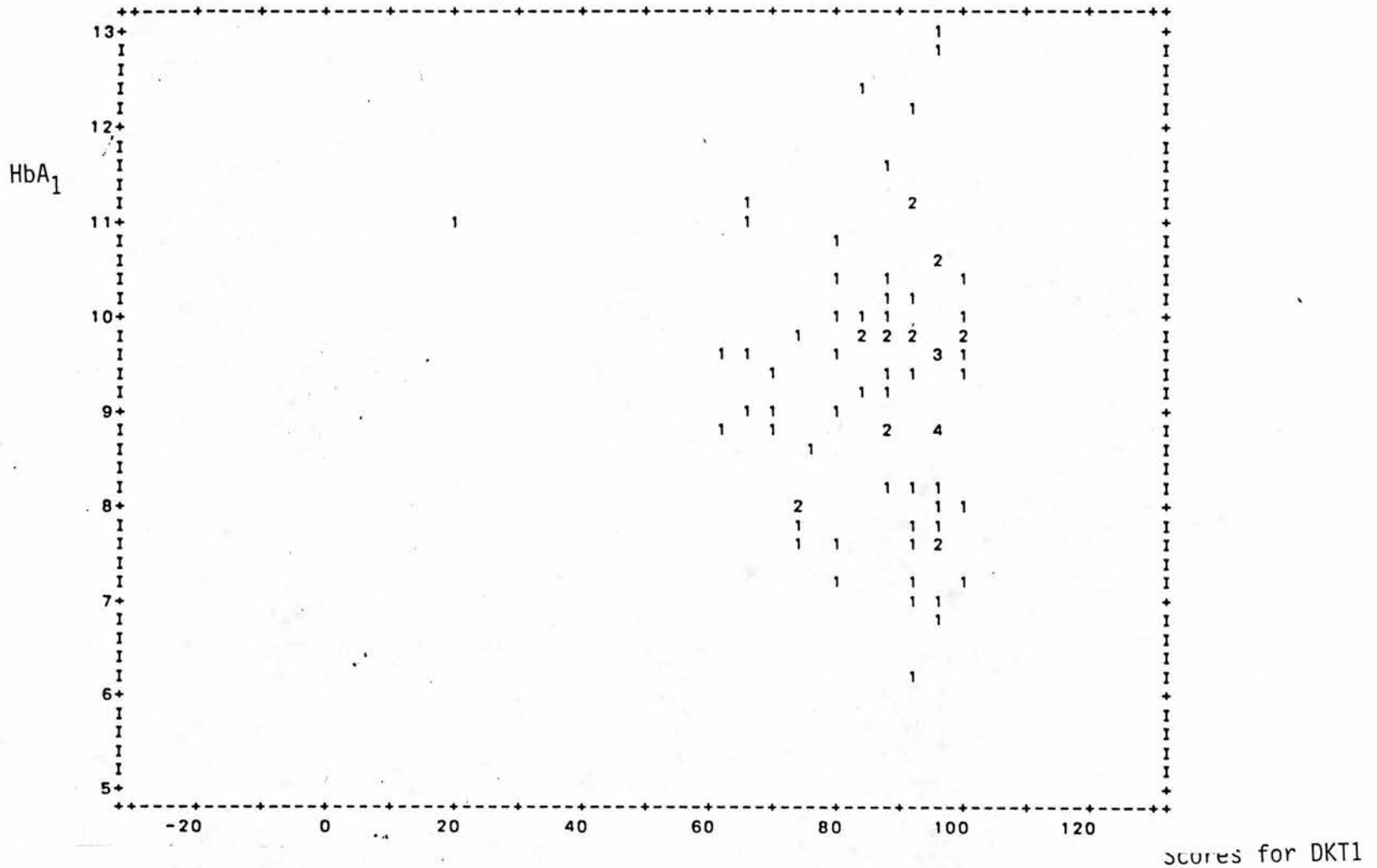


FIGURE 8:2 CHILD'S HbA_1 COMPARED WITH PARENT'S SCORE FOR DIABETIC KNOWLEDGE TEST 2 (DKT2) AT BASELINE

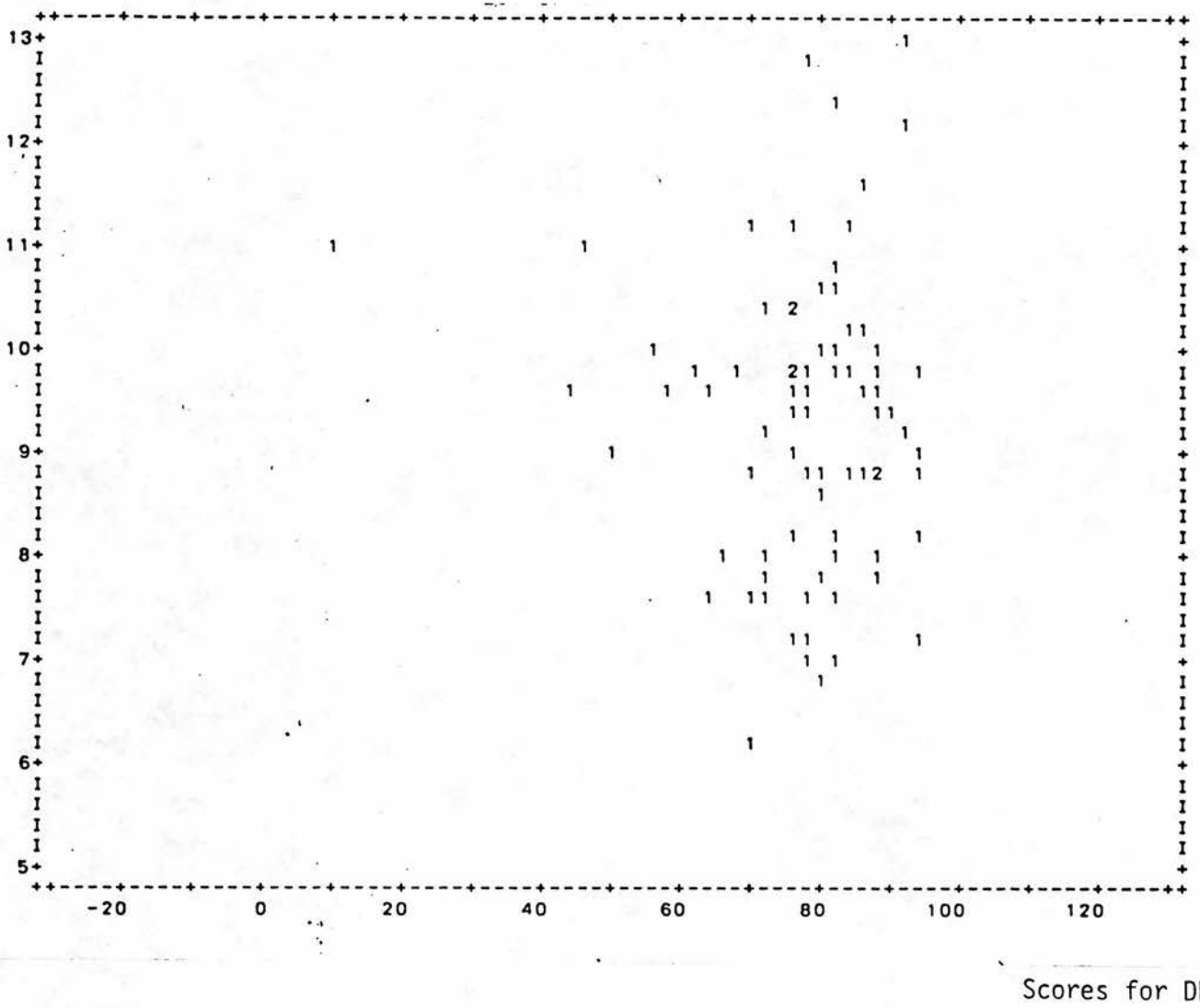
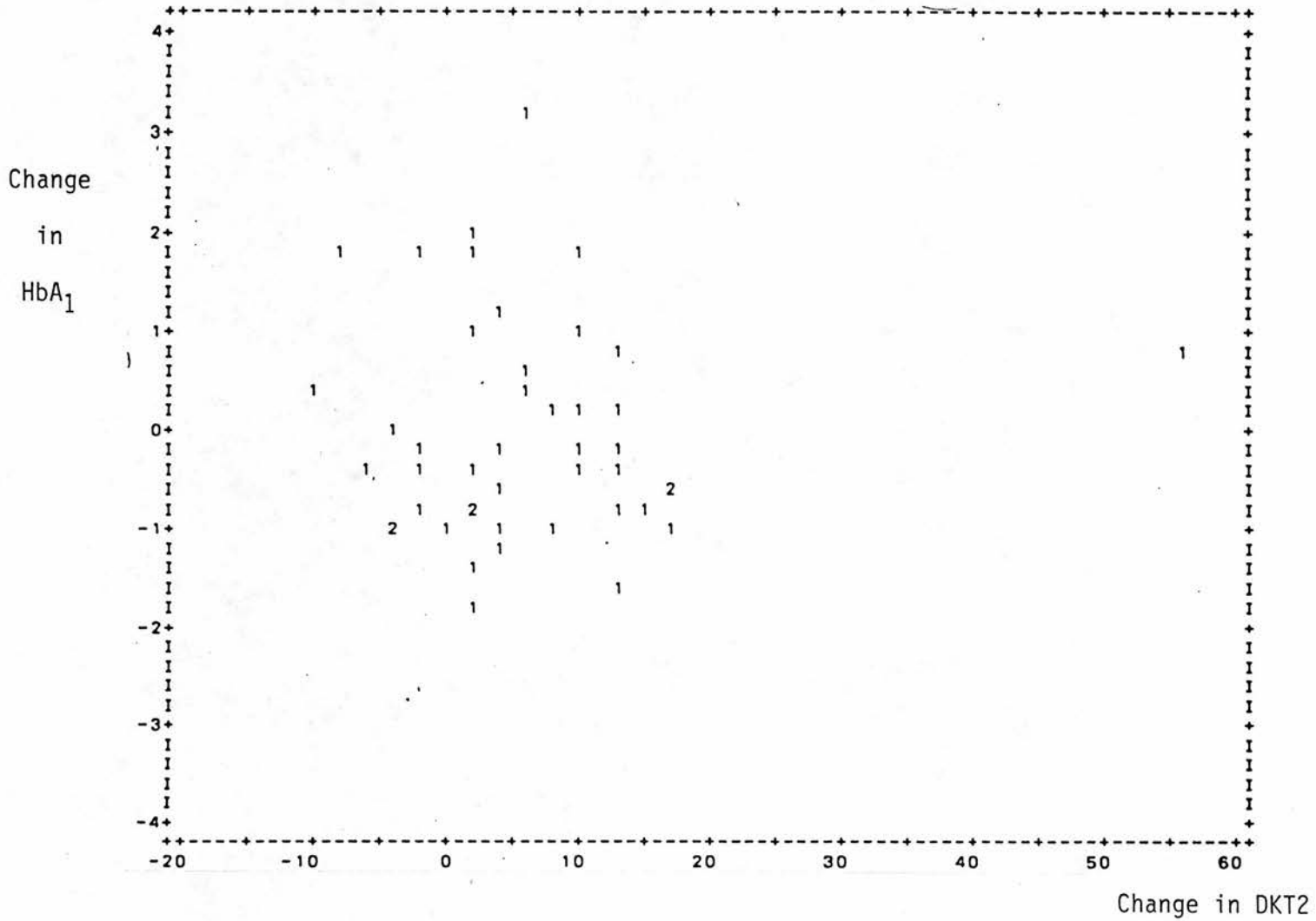


FIGURE 8:3 CHANGES IN CHILD'S HbA_1 COMPARED WITH CHANGES IN PARENT'S SCORES FOR DKT2



CHAPTER 9

AN ASSESSMENT OF THE DIET OF DIABETIC CHILDREN AND EFFECTS OF THE DIABETIC CLUB

INTRODUCTION

The modification of diet has remained an integral part of the management of diabetes mellitus for many years and in the past was based on a diet essentially restricted to one containing 40% energy as carbohydrate. Recent evidence, however, has shown that this may well lead to an unacceptable increase in fat intake (to maintain adequate energy intake) and to an increase in cardiovascular disease (1). Unlike the United States of America, diabetic diets in this country have concentrated almost entirely on carbohydrate control rather than a total diet plan. Many children find the restrictions on their diet difficult.

The dietary recommendations for children with diabetes (1) are similar to those for the general population (2) and diabetic children should be able to eat with the family with little dietary modification. Therefore for the successful promotion of a healthy diet for such children the family as a whole may require education in 'good eating habits'.

At the Paediatric Diabetic Clinic at the Royal Hospital for Sick Children a dietitian is available for consultation at every clinic. She counsels all patients attending the clinic at least once per year and at other times at the request of the patient or doctor if problems arise. Even within a specialist clinic time is limited (3), therefore the promotion of family nutritional education in parallel with dietetic advice for the diabetic child demands other approaches.

Education towards a healthy diet for the diabetic children and their families was incorporated as a substantial component of the education programme within the diabetic club. The particular aims of the planned nutritional education programme within the study were:-

1. To carefully document the diet of this population of diabetic children at entry to the study and to compare their actual diet with that which had been prescribed and that recommended by the British Diabetic Association (BDA).
2. To assess whether the education programme within the Diabetic Club influenced dietary intake, compliance with carbohydrate prescription and diabetic control.

METHODS

A part-time dietitian was employed specifically for the dietary education programme and to carry out the dietary assessments. Families attended the Club in groups of 6 families as described in Chapter 5.

The Club was held between 12 noon and 3 pm in an informal setting in a house adjacent to the hospital (School of Community Paediatrics). Its education programme was repeated for four consecutive weeks to cover each sub-group's monthly visit to the Club and covered all aspects of diabetes including diet. At each visit lunch and mid-afternoon snack, planned by the dietitian, were provided for families and staff. Lunch consisted of a selection of hot and cold dishes, sweet and savoury, served buffet style and these dishes were based on the dietary recommendations for diabetics (4). Each visit's menu and discussion emphasised one particular objective, eg fat

reduction, while also following healthy eating guidelines. Recipes were available to the families. Children were encouraged to choose their own carbohydrate portions at each meal and snack. The discussion also included topics of interest concerning food and diabetes, either initiated by the dietition or the group. After lunch the parents and their children separated for teaching based on semi-structured discussion groups. For the parents, the dietary sessions consisted of a demonstration of nutrients available in basic foods and a slide presentation of the principles of healthy eating for diabetics, including consistency of carbohydrate intake and spacing. The same topics were included in the children's education programme but using practical exercises, eg baking, identifying 10g carbohydrate portions from a selection of foods, use of the British Diabetic Association (BDA) computer game (Junior's Balance): and the BDA game Countdown. Throughout the club year, the families were counselled individually by the dietitian if any specific problems were raised. The programme of education and meals served were repeated exactly for each of the two years.

Dietary Policy in the Diabetic Clinic

At diagnosis the dietitian interviews the child and family and in conjuction with the medical staff, arranges the dietary prescription according to the child's appetite, previous eating habits, age and lifestyle. This education is carried out during the 5 or 6 days in hospital. On going home, scales, carbohydrate list and countdown books are provided. The dietitian sees them frequently initially and the home care team make visits at home.

The 10g carbohydrate portion exchange system is used. The children are requested to follow their menu plans as closely as possible allowing extra carbohydrate for exercise and hypoglycaemic episodes.

The BDA recommendation (4) that 50% of the calories are taken as carbohydrate is not strictly adhered to but aimed at. It is recommended that sugar is not used as a sprinkle sweetener but can be used in baked goods in limited amounts in preference to the use of fructose or sorbitol (1, 5, 6). Reduction of fat intake is advised and also a change to polyunsaturated margarine and oil and semi-skimmed milk for children over 5 years. Protein foods are advised in normal portions at meal times. An increased fibre intake is encouraged by promoting the eating of carbohydrate exchanges as wholegrain cereal products, pulses, fruit and vegetables.

Dietary Policy in the Diabetic Club

The Diabetic Club broadly adopted the dietary policy of the Diabetic Clinic so that the alternative method of dietary education could be assessed rather than the effect of policy changes. The family as a whole were encouraged to make longterm adjustments to their diet in line with healthy eating. In addition advice was given on the reduction of salt in the diet. If a child complained of being hungry the carbohydrate prescription was increased accordingly. Overweight children had carbohydrate and insulin adjusted. The results of completed dietary surveys were not known to the dietitian conducting the education programme.

Dietary Assessment

A detailed dietary survey was conducted at the beginning of the first year, end of the first year and end of the second year. The dietary assessment used was an adaptation of the 7-day weighed record

(7, 8, 9), with the weighing of sugar, butter, margarine, jam and other spreads as previously described (9). All meals, snacks, extra food for exercise and food for hypoglycaemia were to be included with the time at which they were consumed. The dietary survey was conducted over 7 continuous days including 5 school days. Nutrient analysis was carried out using computerised food tables (10, 11, 12, 13). Foods eaten but not appearing in these tables were incorporated, the information being obtained from food manufacturers or recipe information.

Statistical Methods

The effect of the Diabetic Club on dietary intake was tested by Wilcoxon rank sum test using the methods for two period crossover trials described by Armitage and Hills (14). For nutrient intakes at entry to the study, relationships with other quantative variables were tested by Kendall rank correlations and groups were compared using Wilcoxon rank sum tests. Comparisons on intake between weekdays and weekends were made by Wilcoxon signed rank tests.

RESULTS

Over the 2 year study period of 139 dietary surveys requested, 123 (88%) were satisfactory. Two children were not asked to complete the survey in the final year due to overwhelming family problems.

Baseline Measurements

Dietary Intake: Carbohydrate

At entry to the study the mean total energy intake was 93.5 ± 10.9% of the recommended dietary amount of energy (RDA) (15). This proportion was similar for all age groups and for each sex (Table 9:1). The mean carbohydrate (CHO) intake was 42.2 + 4.3% of the RDA energy intake, and this proportion was also similar for all age groups and for each sex (Table 9:1). Seventy-two per cent of the children were taking 45% or more of their energy as CHO and 15% were taking 50% or more.

A comparison was made of the actual CHO intake, the CHO intake prescribed at the clinic, the CHO intake recommended from BDA guidelines (50% of RDA energy), and the CHO intake expected from the measured total energy intake (50% of measured energy intake). All groups consumed more carbohydrate than prescribed but less than that recommended (Table 9:2). The mean actual CHO intake was 116% of that prescribed, but only 85% of that currently recommended by the BDA. Indeed the mean prescribed CHO intake was only 75% of the amount currently recommended (Table 9:2).

We also calculated the expected CHO intake as 50% of the actual total energy consumed. The mean actual CHO intake was 92% of expected CHO intake; the prescribed intake was then 80% of the expected CHO intake (Table 9:2).

Variability of carbohydrate intake throughout the day

The children had a consistent meal pattern with 3 meals and 3 snacks. The mean actual intake of CHO was greater than that prescribed for all six occasions. The mean actual total intake of CHO was 28.6 $\pm$ 26.1 grammes more than that prescribed. The extra intake was greatest at evening snack at 130% of prescription (Table 9:3). There was a wide range of intake at all occasions in all age groups and for both sexes.

Day to Day variability of nutrients

The consumption of fat, protein, CHO, lactose, total sugar and starch was recorded for 7 consecutive days. The variability in intake of these nutrients was expressed as a coefficient of variation. The lowest coefficient of variation was 9.8% for carbohydrate (showing this to be the most carefully controlled) and the greatest was 32.0% for lactose (probably associated with whether or not cereal is eaten on any particular day)(Table 9:4). For the group as a whole the range of day to day variability was wide for all nutrients. There was a positive correlation between the carbohydrate intake (g) and the intake of fat and protein. When weekdays were compared to weekends there was no difference in intake for energy and nutrients except lactose (significantly more was taken on weekdays than weekends (21.9% v 18.0%, $p<0.01$)).

Dietary Compliance was defined as how closely the total daily carbohydrate prescription was adhered to* (16). It did not correlate at any time in the study with improvement in HbA_1, number of days in hospital, incidence of infection, and the number of days absent from school.

Fibre Intake and Glycosylated Haemoglobin. On entry to the study fibre intake and glycosylated haemoglobin were related (Fig 9:1), the negative correlation having borderline significance ($p = 0.053$). There was no correlation between changes in glycosylated haemoglobin and fibre intake during their club year. However, as previously stated, glycosylated haemoglobin during the club year in fact remained static rather than showing the predicted rise for this age group. It may therefore be that in our group of children fibre intake did influence glycosylated haemoglobin and diabetic control.

Dietary Effects of Attendance at the Diabetic Club

The dietary survey conducted at baseline was repeated at the end of each year of the two year study period for both the group attending the Diabetic Club in the first year and the group attending the Diabetic Club in the second year. Attendance at the Diabetic Club was associated with a significant decrease in fat intake ($p<0.05$). The mean energy intake did not decrease and the reduction in energy from fat was compensated for by an increase in carbohydrate but this did not reach statistical significance ($p<0.10$) (Table 9:5). The increase in

*Mean squares of differences between actual intake and prescribed intake for all 6 meals

carbohydrate intake was due to an increase in both starch and sugar intake. There was no significant difference in fibre intake for the group as a whole. When children were grouped for age (those children under or over 5 years of age) and sex the fibre did increase significantly in older children and girls, whereas it did not in younger children and boys ($p<0.05$)(95% confidence limits for change in fibre intake, girls +0.1, +0.9 vs boys -1.1, +0.6, older +0.1, +1.1 vs younger -1.3, +0.4).

Attending the Diabetic Club had no effect on the actual amount of energy taken as a percentage of the RDA, the carbohydrate intake overall as a percentage of that prescribed, or carbohydrate taken at each meal. The carbohydrate prescriptions at the club did not change significantly, nor did compliance with dietary prescriptions improve.

DISCUSSION

This part of the study has shown that the diet of our diabetic children attending the routine paediatric diabetic clinic staffed by a motivated team of doctors, nurses and dietitians is already reasonable despite the limited time available for individual teaching. The children consumed adequate amounts of energy from protein, the majority consumed more than 45% of energy from carbohydrate (approaching the 50% of RDA energy recommended by the BDA) and fibre intake was 2.9 gm/MJ, slightly greater than the average (2.3gm/MJ) for non-diabetic children (17). Despite the children taking only around 90% of the RDA energy, all children were growing within normal limits. Children today may be more sedentary than when energy requirements were originally assessed.

In all age groups (Table 9:3) carbohydrate prescription was well below that recommended (50% of RDA energy as carbohydrate) but actual intake was above prescription (some of the carbohydrate taken above prescription will be due to the inclusion in calculations of foods containing small amounts of carbohydrate not normally counted by diabetics). The day to day variability in daily energy intake is great (as in non-diabetics (18)) but with carbohydrate the least variable nutrient so that some effort to comply with prescription has been made. The children did not consume excess amounts of high protein, high fat foods which may be detrimental to health (1) to make up for carbohydrate restrictions.

The children spaced carbohydrate into three main meals and three snacks as requested but with a wide variation against prescription with the largest excess intake in the evening indicating either unsatisfied hunger or fear of overnight hypoglycaemia (19).

This study has demonstrated that participation for one year in an education programme significantly decreased the percentage of fat in diabetic children's diets with an almost significant increase in carbohydrate. Despite the strong emphasis on high fibre foods at the club, fibre intake did not rise for the group as a whole. When the group was analysed by sex and age, fibre intake did improve significantly in girls and in the children over 5 years of age. This agrees with the difficulties in persuading toddlers to eat high fibre foods and in boys to change their diet. One study (20) concerning high fibre/high carbohydrate diets in children found that glycaemic control improved after eating a wholefood diet but most of the children found the restricted amount of meat and cheese difficult to tolerate

and after the trial, the children reverted to a diet similar to that of our study groups. Further work, therefore, needs to be conducted on this aspect of diet in children. Aiming to take a very high fibre diet may cause undue stress to children with diabetes, particularly if there are no adequate proofs of ultimate benefit. Therefore, to achieve the level of fibre recommended (1) for improvement in diabetic control, it will be necessary to specify that a certain number of carbohydrate exchanges daily are taken as high fibre foods.

There was no change in any of the other dietary variables measured. Eating habits are very difficult to influence as recognised by the NACNE discussion paper (2) which suggests 15 years as a target for dietary modification in the general public. Previous studies have shown an education programme to be effective in adults (16) but not children (21). The one year period of our education programme was probably too short to achieve complete success in changing the diet of the whole family to comply with current recommendations (1, 4).

Compliance with dietary prescriptions is known to be poor in both adults (22-24) and children (18, 25) and this was also demonstrated in our study. Total energy intake of the children is not excessive, but actual carbodydrate is above that prescribed. Therefore carbohydrate prescriptions are not matching children's appetites. The children will thus be unable to comply with demands set by doctors and dietitians leading to conflict, stress and feelings of inadequacy with the family.

The reasons why inappropriate prescriptions are made have been described (26) and suggestions made on how they can be ammended (25, 27, 28) by frequently estimating intake, by a qualitative history or by

using appropriate tables for age groups. All methods have problems. Tables for energy intake RDA (15) or those of Whitehead et al (29) tend to overestimate some individual's needs, while a dietary history may have low reliability. Once initiated in the art of the diabetic diet, the patient offers a spurious rather than an actual account of their daily intake. This may account for some shortfall in prescription.

It should be stressed to families that carbohydrate prescriptions are not static, that persistent hunger is an indication of an energy need and this should be reported to the clinic. There is considerable day to day variability in carbohydrate intake consistent with varying degrees of activity and the diets of non-diabetic children. This was not changed by our education programme. Some of the extra carbohydrate taken above prescription may be accounted for by the carbohydrate taken for exercise and hypoglycaemia. This was not analysed separately and therefore we cannot state how far this influenced results. No other study has taken this into account, so it would be useful to do so in future studies.

To make appropriate carbohydrate prescriptions requires a regular review of diet and dietary history together with an awareness of RDA tables.

Individual assessment and teaching by a dietitian in a routine clinic is very time-comsuming and seeing children and parents together may prevent concerns being voiced.

The informal groups in the Diabetic Club provided an excellent form of teaching larger groups of adults and children separately and effectively. Much discussion was generated. Parents reported a significant increase in social contact with the parents of other

diabetic children while attending the Club compared with the routine clinic (3). They found this contact very helpful in the management of their child's diabetes. Through the lunches, the dietitian was able to assess which children could manage their own diet, and thus provide practical help and encouragement to parent and child. Therefore incorporating some form of group education plan and discussion into the rountine clinic would allow groups of families to be taught effectively despite time constraints. This study has shown it to be an effective method of altering the eating habits of diabetic children even within a short timescale.

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TABLE 9:1 ENERGY AND CABROHYDRATE CHO INTAKE AS PERCENTAGE OF RECOMMENDED DAILY AMOUNTS (RDA) AT BASELINE (MEAN (SD)). n = 39

AGE	SEX	MEAN ENERGY as % OF RDA	MEAN CHO as % OF RDA ENERGY
Less than 5 years	Male	95.3 (12.0)	45.0 (5.9)
	Female	92.2 (10.7)	41.5 (2.8)
6-9 years	Male	91.5 (7.8)	41.8 (3.2)
	Female	97.1 (13.3)	43.1 (6.3)
10-11 years	Male	89.6 (14.7)	39.5 (3.8)
	Female	94.3 (8.8)	42.1 (2.6)
12+ years	Male	89.1 (14.60)	40.0 (4.1)
	Female	95.2 (14.9)	41.9 (1.5)
For entire population		93.5 (10.9	42.2 (4.3)

TABLE 9:2 COMPARISON OF ACTUAL CARBOHYDRATE (CHO) INTAKE WITH PRESCRIBED, RECOMMENDED AND EXPECTED CHO INTAKE

Age	Sex	Total Energy MJ	CHO (g) Intake				Actual Intake as % Presc	Actual Intake as % Rec	Presc as % of Rec	Actual Intake as % Expected	Presc as % Expecte
			Actual	Prescribed	Recommended+	Expected*					
3-5	M	6.3(0.7)	189(25)	156(20)	210(9)	197	121	90	74	96	79
	F	5.6(0.9)	161(19)	147(11)	193(9)	175	109	83	76	92	84
6-9	M	7.5(1.1)	218(32)	181(30)	260(2)	234	120	84	70	93	77
	F	7.7(1.2)	219(37)	178(13)	252(10)	241	123	87	71	91	74
10-11	M	8.3(1.6)	233(25)	190(14)	295(8)	259	123	79	64	90	73
	F	7.9(0.7)	226(12)	204(16)	269(3)	247	111	84	76	91	83
12-13	M	9.1(1.4)	261(25)	245(38)	326(9)	284	107	80	75	92	86
	F	8.3(1.3)	233(9)	195(7)	278(0)	259	119	84	70	90	75

+Recommended CHO = 50% RDA Energy
*Expected CHO = 50% Actual Energy

Figures shown are mean ± SD

TABLE 9:3 VARIABILITY IN INTAKE FROM THE CARBOHYDRATE (CHO) PRESCRIPTION AT BASELINE

Meal	Mean Intake above Prescription in g CHO	(SD) Range g CHO	Percentage of Prescription	(SD) Range Percentage
Breakfast	+7.0	9.3(-9.0 to +31.0)	119.9	25.8(80.7 to 177.5)
Mid-morning	+1.6	4.2(-6.1 to +12.8)	110.6	26.0(79.7 to 202.4)
Lunch	+7.7	7.9(-10.3 to +30.2)	119.1	21.0(80.4 to 200.7)
Mid-afternoon	+1.2	8.4(-21.1 to +27.3)	110.7	36.8(47.2 to 236.5)
Dinner	+6.3	7.9(-17.4 to +19.5)	114.9	18.1(71.0 to 148.7)
Evening Snack	+4.7	12.5(-57.7 to +22.8)	130.2	39.6(3.8 to 214.0)
Total Difference	+28.6	26.1(-36.4 to +94.9)	116.2	14.2(88.3 to 152.7)

TABLE 9:4 DAY TO DAY VARIATION OF DIFFERENT NUTRIENTS AT BASELINE

NUTRIENTS	C.V.	STD DEV	RANGE
KJ / Day	13.9	4.8	(5.9 to 23.8)
Protein*	14.7	6.4	(6.9 to 36.4)
Fat*	11.2	4.3	(2.9 to 18.9)
Carbohydrate*	9.8	3.3	(4.4 to 19.4)
Lactose*	32.0	11.2	(12.5 to 68.0)
Total Sugar*+	22.1	8.1	(8.9 to 44.6)
Starch*	13.3	4.5	(5.6 to 23.4)
G.Fibre/1000KJ	21.8	8.0	(9.6 to 48.2)

*expressed as a % of energy
+including lactose, sugar occurring naturally in food and added sugar
C.V. = Coefficient of Variation

TABLE 9:5 DIETARY INTAKE DURING THE STUDY PERIOD FOR STUDY GROUP PATIENTS

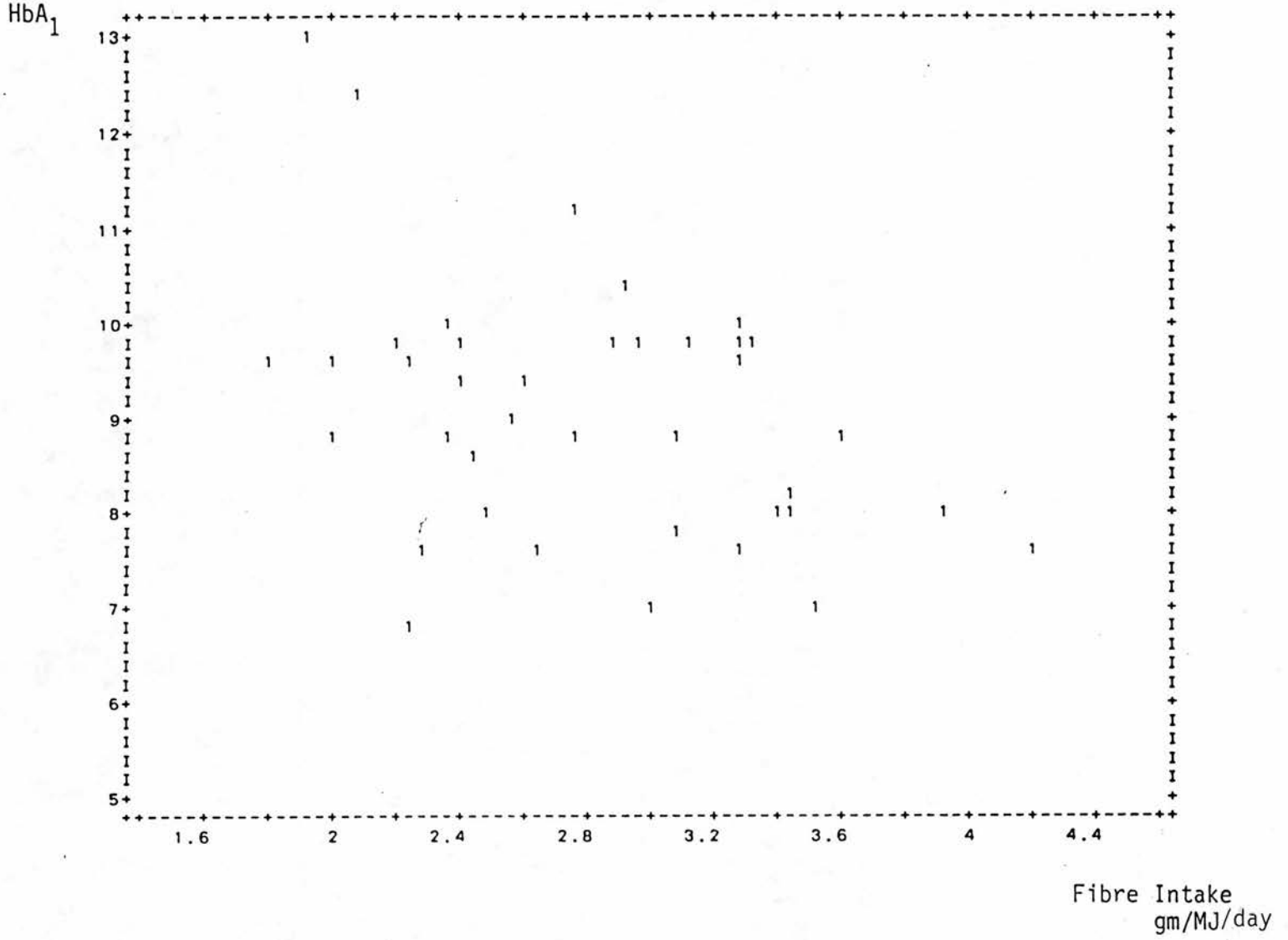
	CLUB FIRST GROUP (A)			CLUB SECOND GROUP (B)			SIGNIFICANCE
	Baseline	End Year 1	End Year 2	Baseline	End Year 1	End Year 2	OF INTERVENTION*
Mean daily energy(KJ/Kg body wt)	270 (70)	263 (61)	243 (63)	239 (60)	243 (49)	216 (57)	NS
Energy from protein (%)	14.4 (1.8)	13.5 (1.9)	13.7 (1.6)	13.9 (1.7)	14.0 (1.8)	14.1 (1.9)	NS
Energy from fat (%)	39.5 (3.8)	39.1 (3.2)	39.9 (2.8)	40.0 (4.6)	40.0 (4.2)	37.8 (5.2)	$p<0.05$
Energy from CHO (%)	46.2 (3.1)	47.6 (3.1)	46.4 (2.9)	46.3 (3.9)	46.4 (3.6)	48.1 (4.7)	$p<0.10$
Energy from lactose (%)	4.3 (1.8)	3.8 (1.5)	3.7 (1.4)	4.4 (1.5)	4.6 (2.1)	4.4 (1.9)	NS
Energy from sugar (%)+	17.3 (4.1)	17.8 (4.2)	16.4 (4.1)	15.9 (3.3)	16.4 (2.9)	17.0 (3.6)	NS
Energy from starch (%)	28.5 (4.1)	29.5 (3.3)	29.6 (4.7)	29.9 (3.2)	29.6 (3.9)	30.7 (2.8)	NS
Fibre (g/1000 J)	2.9 (0.6)	2.9 (0.7)	2.9 (0.4)	2.8 (0.6)	2.8 (0.8)	3.0 (0.6)	NS

*significance of change in diet when attending the diabetic club compared with the routine diabetic clinic for both groups in first and second year

+includes lactose, sugar occurring naturally in food and added sugar

Figures shown are Mean ±SD

FIGURE 9:1 GLYCOSYLATED HAEMOGLOBIN COMPARED WITH FIBRE INTAKE AT BASELINE



CHAPTER 10

PSYCHOLOGICAL FACTORS AND DIABETES - EFFECTS OF THE DIABETIC CLUB

INTRODUCTION

The psychological impact of developing IDDM is profound for the child and his family. The interrelationship between IDDM, its control and management and psychosocial stress is complex. In a recent editorial Jacobsen (1) gave a very useful review of the current status and results of psychosocial research in diabetes, some of it relevant to children. There is no evidence that IDDM per se causes overt psychiatric illness (2, 3) but there is evidence that diabetes may result in more subtle psychological disturbance (4, 5). This disturbance may represent coping responses by children (6, 7), and it has been suggested that some degree of anxiety may be necessary to cope adequately with diabetes (8). There is also evidence that IDDM can lead to altered cognitive functioning (9, 10, 11). It is thought by many families and children that external stress independent of patient action is responsible for poor metabolic control, and there may be a biochemical basis for this (12) although a recent study fails to support it (13).

Many studies have linked poor diabetic control with poor psychosocial circumstances (8, 14, 15), and emotional difficulties in children (16). Good psychosocial adjustment by children and their families appears to be linked to good diabetic control in many studies (6, 14, 17, 18) but some degree of emotional involvement and anxiety may be needed for the appropriate degree of vigilance necessary to manage diabetes (6, 8). Assessment of psychosocial factors may be useful in assessing compliance with the diabetic regimen (17).

In view of the above, psychosocial intervention may have a large part to play in the management of diabetic children and their families. Few studies have been done in this area but some have shown benefits (19). Many educational programmes have not had specific psychosocial intervention as part of their remit, but most have acknowledged that the extra support provided by such programmes may enhance the outcome of educational intervention (6, 20, 21).

Therefore, as part of our education programme we decided it was essential to assess the degree of stress present in our diabetic children and their families and whether this stress was reduced by the environment provided by the diabetic club.

METHODS

Psychological Assessment

A psychologist was employed on a part-time basis to perform assessments, but she had no therapeutic role in the education programme. The psychological assessments and parental questionnaires (see below) were administered by the psychologist either at their initial club/clinic visit or a separate appointment at the Department of Child Life and Health. Intelligence was measured at baseline using the Stanford-Binet Intelligence Scale (for children <7 years) or the Wechsler Intelligence Scale for children (revised). Psychological assessment was based on the Rutter Behaviour Scale (22) and the Vineland Social Maturity Scale (23).

The psychological questionnaires were administered at baseline, end of Year 1 and end of Year 2; the non-participants were not assessed.

Parental View of the Programmes

The parent's view of the education programme was assessed by questionnaires in three areas:

(a) Benefits provided by the club compared with the clinic in relation to topics covered (such as hypoglycaemia) and the support provided by the programme.

(b) The degree of child involvement in the treatment regimen ('responsibility') as previously assessed by Allen at al (24).

(c) Effects of diabetes on 'family life' and whether this was changed by attendance at the club. Questions assessed daily practical difficulties, such as blood testing, the integration of the diabetic regimen into the family routine, and its effect on other family members and relationships.

All parental questionnaires utilized a visual analogue scale (Appendix 8) and were administered at the end of years 1 and 2.

Unfortunately because of industrial action, we were unable to administer the Rutter Behaviour Scale B for teachers.

For each child, a volunteer was found in his/her class at school matched for age, sex and social class. The Rutter A_2 Scale was sent by post to their parents. Mothers were requested to respond to each item on a 10-point visual analogue scale to gauge the degree of perceived difficulty. Previous research (25) has found it to be sufficiently sensitive for this purpose.

Statistical methods (see Chapter 5)

RESULTS

Psychological Assessment

Measurements of intelligence quotients (Group A mean IQ 99.6, Group B mean IQ 100.3), behavioural disturbance, and social maturity on entry to the study were within the normal range for children of this age and there was no significant difference between Groups A and B. Scores for social maturity were not significantly changed by attendance at the diabetic club. It is of note that the mean Vineland Maturity Scale scores was higher than the mean age of the group.

Forty-seven mothers completed the Rutter A_2 Behaviour Scale for children to assess behavioural disturbance. Six reported no symptoms and 41 mothers reported the presence of various symptoms in the scale. Although the group as a whole had a score within the normal range, fourteen children (30%) had scores greater than 13 (the level indicating the presence of psychiatric disturbance) at some time during the two year study (Table 8:1), eight had scores >13 throughout. In contrast 10% of the matched control sample of non-diabetic children (5/47) had a score greater than 13 ($p<0.01$). There was no significant difference in age, social class distribution or sex of child between these non-diabetic controls and our diabetic children.

When the group of diabetic children with scores greater than 13 were compared with those below this level, there was no difference between the groups for glycosylated haemoglobin (HbA_1), age, duration of disease, age at diagnosis, sex, IQ scores, maternal scores on the diabetic knowledge tests, number of hospital admissions, or clinic visits. HbA_1 values showed no correlation with maternal responses to particular items of manageability in the behaviour scale (eg behaviour problems, confidence).

Parental Assessment of the Programme

The percentage of parents reporting frequent social contact with parents of other diabetic children was significantly greater during their year attending the diabetic club compared with the routine clinic (Group A 61% vs 33%; Group B 52% vs 17%, $p<0.001$). Furthermore, parents in both groups found this increased social contact during their year attending the diabetic club very helpful in the management of their child's diabetes (Group A 78% vs 50%, Group B 57% vs 32%, $p<0.001$).

There was no discernible effect of attending the club in responses to the 'responsibility' or 'family life' aspects of the questionnaires.

DISCUSSION

In this study we could demonstrate no reduction of stress with the measurements utilized. Thirty per cent of the children were found to have some degree of psychiatric disturbance using a well validated test instrument (22). Our high level of disturbance is in agreement with other recent studies using the same test instrument; Close et al (16) found 28% disturbance in a group of 60 diabetic children aged 9-18 years, Fonagy 25% disturbance in 6-16 year olds (8), Gath 20% disturbance in 76 children aged 5-16 years (14). The prevalence of disturbance in our control group of non-diabetic children was 10%. The presence of disturbance in the general population of under 15 years old can be ascertained from general practice figures (26). Three per cent of general practice consultations by children are described as occurring from "mental disorders" including behaviour problems, anxiety, insomnia and enuresis. Hospital outpatient attendance takes

place for 1 in 6 children under 16 and of these 20.4% are for mental, psychological and nervous disorders. There is, therefore, in our group of diabetic children a widespread and often unrecognised amount of psychiatric disturbance not found in children without diabetes. The administration of a valid test instrument to ascertain the extent of disturbance may be worthwhile in the routine clinic to bring to attention families needing extra support who would otherwise be missed. This approach has been advocated by Jacobson (17). The mean IQ of our group of diabetic children was within normal limits and the IQ levels were normally distributed showing that diabetes had had no obvious effect on cognitive functioning in our population.

We could demonstrate no link between disturbance and metabolic control as measured by HbA_1. Some studies show an association between poor control and psychiatric problems (14, 15). Gath et al (14) in a review of 76 children with IDDM aged 5-16 years using the Rutter Scale, psychiatric interview, and assessment of school performance showed that 39% of families had psychosocial problems, 25% showed some disturbance, 30% had some reading backwardness and these all correlated with poor diabetic control. White et al (15) identified 30 children with poor control and of these 80% were one parent families and had poor living conditions, 50% had reduced self-esteem and 30% were depressed. Conversely others have shown better control with high disturbance scores. Fonagy et al (8) found that children with higher neuroticism symptoms scores on the Rutter Scale had a lower HbA_1 and Close (16) found that children who were assessed as depressed had better HbA_1 levels. Therefore it appears that it is not the presence or absence of disturbance which is important, but the patients' and families' ability to cope with anxieties and use them positively to manage their diabetes.

There was no difference in social circumstances and maternal diabetic knowledge between the disturbed and non-disturbed children in our study. We did not measure maternal depression but 20% of mothers consulted their GP because of their "nerves" although none received drug or hospital treatment. A recent study in Newcastle (27) found similar anxieties.

One of the main benefits of the diabetic club appeared to be the significant increase in social contact between families, and parents found this helpful in managing their child's diabetes. Group therapy has been shown to be effective in improving control in a small study (19). The realisation that others are experiencing similar difficulties and the opportunity within the groups to discuss problems helps overcome the feelings of guilt and isolation felt by many parents of diabetic children. Therefore "simple human contact" may be as effective as structured education in improving ability to cope with diabetes and thereby improve diabetic control (29).

The diabetic children in our study knew few other diabetic children prior to the start of the project. By the end they all knew at least 5 other children who had the same problems and difficulties as themselves (see Chapter 6). The group support was appreciated by the families, but we did not have a specific psychotherapeutic intervention plan. It has been suggested (29) that a psychiatrist or psychotherapist be a part of the diabetes team and we might have demonstrated a great effect in stress reduction if this had been included in our programme.

From this study it can be seen that diabetic families may be far more stressed than is realised and that formal assessment is useful in bringing these families to the attention of the diabetes team. Secondly, seeing families in groups and allowing discussion may help families to cope better with having a diabetic child.

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TABLE 10:1 BEHAVIOURAL AND EMOTIONAL PROBLEMS

	Group	Year 0	Year 1	Year 2
Problems noted at home	A	5	7	7
(symptom score >13)*	B	4	4	3
No psychological problems	A	19	17	17
(symptom scores <13)	B	19	20	21

*Rutter Behaviour Scale A_2

CHAPTER 11

CARE OF DIABETIC CHILDREN AT OTHER CLINICS

INTRODUCTION

It has been assumed, in the past, that a specialist paediatric diabetic clinic provides better care for diabetic children resulting in better diabetic control. Few objective studies, however, are available looking at populations which are comparable. In a recent study in East Birmingham (1) the introduction of a specialist paediatric diabetic clinic where none previously existed resulted in a remarkable improvement in diabetic control in their patients, with mean HbA_1 dropping from 15.6 % to 10.3 %. Prior to the introduction of that clinic patients had been cared for either by general paediatricians, adult physicians with an interest in diabetes, or general practitioners. In 1982, however, a report of diabetic control from another specialist clinic again in Nottingham (2) showed that mean glycosylated haemoglobin for their diabetic population was around 12gm%. Tattersall (3) has stated that only 1.5% of diabetic children have a glycosylated haemoglobin consistently within the normal range even when attending clinics with considerable expertise.

Therefore, some comparisons of the specialist paediatric diabetic clinic available in Edinburgh were made with three district general hospital paediatric clinics who cared for some diabetic children within similar geographical areas to ascertain whether the specialist clinic was achieving a better standard of diabetic control.

METHODS

In adjacent geographical areas of Scotland three district general hospitals (A, B and C) provide care for diabetic children within a general paediatric clinic setting. One centre does attempt to group diabetic children together into one clinic. The consultants in charge of patients in these three clinics agreed to allow us access to their patient records and volunteered to give us information about their patient prospectively over one year during the period of the diabetic education project. At these clinics diabetic children were seen by a consultant paediatrician or paediatric registrar. A dietitian was available in all these clinics, and a diabetes nurse specialist shared part-time with the local adult clinic was sometimes available. Neither were specifically paediatric trained.

Information about children under 13 years of age on 1 October 1985, and with diabetes of more than three months duration, was obtained. Data included a medical and social profile, methods of diabetic care, diabetic events, anthropometric measurements, and measurements of glycosylated haemoglobin (HbA_1) at each visit. All blood samples for HbA_1 were sent to and analysed at RHSC by the Corning electrophoretic method; the normal reference range is 4.7-7.9%. Samples were analysed within one week and remained stable (4).

We ran into problems in that due to pressure of work within these district general hospital paediatric clinics a lot of forms were not being filled in by the relevant medical staff. Therefore two members of our team (EW & UG) visited each hospital at intervals to obtain information retrospectively from the case records of the patients in the study.

RESULTS

Comparison Between Specialist Diabetic and General Paediatric Clinics

Data about diabetic control was available for a total of 88 children. Comparisons were made with 89 children of the same age attending the specialist diabetic clinic and the diabetic club at RHSC at the mid-point of the study (1st October 1986). There was no difference in diabetic control between the club and clinic groups so data was combined for these comparisons.

Comparisons were made at the end of one year (a) between the three general paediatric clinic populations, and (b) for all these three clinics combined with RHSC paediatric diabetic clinic. Age, duration of disease and age at diagnosis, the number of boys,and social class distribution were similar (Table 11:1). The average time spent with the paediatrician at each clinic visit was 25 minutes at RHSC and approximately 15 minutes in the general clinics (personal communication).

Children attending the clinic at RHSC were admitted to hospital for significantly fewer days (Table 11:2) and those admitted for poor control and hyperglycaemia were also significantly fewer. There was a significant difference between the three general paediatric clinics in the number of children admitted with hypoglycaemia.

Mean HbA_1 concentration for the year was similar for children attending each of the general paediatric clinics but significantly lower in those attending the RHSC clinic ($p<0.001$).

Daily insulin dose was similar for all children but methods of administration differed. Two injections per day were used more by children attending clinic A, and two different insulins per day (that is, short and intermediate acting insulin) as opposed to one insulin per day (intermediate acting) were used more often by children attending clinic C. Fewer clinic attendances per year were made by children attending clinic C. Attendance rate at all clinics was greater than 80%. Anthropometric measurements including growth velocities were not significantly different between groups and were within the normal range. (Anthropometric data is difficult to analyse as measurements for the district general hospitals were performed by three different sets of individuals on different apparatus with no standardisation performed between centres.) Statistical analysis was performed, however, and gave no significant difference between the three district general hospitals.

In an attempt to explain the difference in HbA_1 between centres correlations were carried out to ascertain whether frequency or type of insulin injection used had any effect on HbA_1 as this was one area where policies differed considerably from centre to centre. Firstly in Edinburgh there was no difference between HbA_1 and the types of insulin used. In the three other clinics there was a trend for a lower HbA_1 in those using two injections per day rather than one but this did not reach significance. This aspect of diabetic care did not, therefore, appear to influence diabetic control significantly.

DISCUSSION

We have observed in diabetic children who were similar in age, duration of diabetes, and social class, that diabetic control was better in those attending a specialist paediatric diabetic clinic than in those attending general paediatric clinics. Control in children attending the general clinics was in fact not dissimilar from that reported previously from another specialist centre (2). The number of days admitted to hospital per year was significantly less in those children within Edinburgh. This is due to the fact that those children admitted for hyperglycaemia were far fewer in Edinburgh. Tighter diabetic control in the Edinburgh children may be reflected in the fact that more of them were admitted due to hypoglycaemia.

What are the possible explanations for the better control achieved by the specialist paediatric diabetic clinic? The number of clinic visits to the specialist clinic at RHSC were significantly fewer and the time spent with the doctor was similar in comparison with the general clinics. Access to a paediatrician with a special interest in diabetes may be beneficial, but the diabetes team he leads might be a more important factor. This includes specialist nurses, both in the ward and clinic, whose roles are supportive and educational. There is 24 hour access by telephone for advice, a dietitian with specific expertise in diabetes and paediatrics, and a dental hygienist. All play a part in education and motivating families towards good control and are often more accessible than medical staff.

These results must, however, be interpreted with caution in endorsing wholeheartedly the merits of a specialist centre as the results achieved may not be commensurate with the extra facilities

available. In our specialist centre there is a diabetes team which deals with diabetes frequently but there are sometimes complaints that because of the larger numbers of medical staff available patients do not see the same doctor at each visit and do not become familiar and well known to their medical carers unlike those attending the peripheral hospitals where one consultant will see most of the children.

The annual incidence of insulin dependent diabetes mellitus has almost doubled in a decade in Scotland (5), a trend found in most developed countries (6), and these young people will place an increasing burden on health care resources. The evidence that good control can reduce future complications is growing (7), and their incidence may be reduced if diabetic children can achieve optimal control.

The district general hospital clinics we studied, however, have levels of glycosylated haemoglobin comparable with those described previously in other specialist centres (2, 3) and may therefore in fact be utilising the facilities which they have available to the fullest potential.

Some aspects of the specialist clinic may, however, be introduced to district general hospital paediatric clinics at relatively little cost and may provide great savings in the number of days admitted to hospital and ultimately in the prevention of diabetic complications. Firstly, the diabetes nurse specialist has probably made as great an impact as any other innovation in the care of diabetic children and areas where there is an insufficient paediatric population she may be shared with adult diabetic patients. Secondly, some aspects of our

diabetic education programme could be introduced to general clinics at relatively little cost and may help to improve diabetic control. Semi-structured discussion groups between diabetic families could play an integral part in the care of diabetic families giving a greater degree of support and encouragement not necessarily engendered in the routine clinic setting. The specialist clinic can act as an advisory, educational, and training resource for other clinics. This will be discussed at greater length in the final chapter.

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TABLE 11:1 CHARACTERISTICS OF DIABETIC CHILDREN <13 YEARS ATTENDING PAEDIATRIC CLINICS IN DISTRICT GENERAL HOSPITALS (A, B, C) AND A SPECIALIST PAEDIATRIC DIABETIC CLINIC (RHSC)

	A	B	C	RHSC
	n = 40	n = 24	n = 24	n = 89
Age in years	10.7 (2.6)	11.1 (1.9)	10.2 (2.4)	10.6 (2.8)
Duration Diabetes in years	4.2 (2.5)	4.9 (2.8)	3.3 (1.7)	4.6 (2.8)
Age at Diagnosis in years	6.6 (3.0)	6.2 (3.1)	6.9 (2.8)	6.0 (2.8)
M/F	16/24	10/14	7/17	39/50
Social Class I & II (Numbers)	13	6	12	32

Mean values (1 standard deviation) are shown. There was no significant difference between groups in any parameter.

TABLE 11:2 COMPARISON OF INDICES OF DIABETIC CONTROL BETWEEN RHSC AND THREE GENERAL PAEDIATRIC CLINICS OVER A ONE YEAR PERIOD:

	A	B	C		RHSC	
	n=40	n=24	n=24	(a)	n=89	(b)
No. days admitted per year(Mean SD)	2.7(6.8)	3.1(6.0)	2.4(4.4)	NS	1.2(5.8)	$p<0.05$
% patients admitted for hyperglycaemia	17%	33%	35%	NS	3%	$p<0.001$
% patients admitted for hypoglycaemia	14%	0%	0%	$p<0.05$	16%	NS
HbA_1	12.0(2.6)	12.1(3.0)	11.2(1.9)	NS	10.3(1.6)	$p<0.001$
No. Clinic Visits per year	5.7(1.7)	6.09(2.5)	4.3(1.6)	$p<0.001$	4.8(1.2)	$p<0.01$
Insulin dose Units/kg/24° (mean)	0.92(0.2)	0.95(0.3)	0.9(0.2)	NS	0.91(0.2)	NS
%patients 2 injections per day	87%	46%	57%	$p<0.01$	91%	$p<0.01$
%patients 2 insulins per day	80%	33%	96%	$p<0.01$	94%	$p<0.01$

(a) comparison between 3 general paediatric clinics
(b) comparison of 3 general clinics combined vs RHSC Clinic

CHAPTER 12

TRAVEL, ATTENDANCE AND COSTS FOR DIABETIC CLUB AND DIABETIC CLINIC

INTRODUCTION

It is important that social costs incurred by families attending the RHSC for diabetic consultation and education be assessed as such costs might limit parental attendance.

A picture of the financial and social costs involved in attending a central hospital may help to illuminate the wider question of whether specialist diabetic services are better located centrally or peripherally. The current trend is towards centralisation of services as this is usually thought to be most cost effective for the provision of services within the National Health Service.

Few studies have been performed to assess the ease of access for patients to a specialist service which can entail a long journey (some of our patients travel 80 miles for one outpatient visit), and can be costly in terms of time and money.

METHODS

Participants and non-participants attending the club and the clinic were asked to complete a travel form (Appendix 9) at each visit detailing any special arrangements necessary for the visit (eg time off work) and details of journey. The latter included composition of party, origins of journey, travel time, travel cost, and mode of transport. Costs included fares for buses, trains or taxis. For car users, costs were calculated from details of journey, distance, make of car and average monthly petrol costs (information supplied by the

Automobile Association). Parking costs were ascertained. No attempt was made to assess actual loss of earnings incurred by families due to hospital visits. Time of arrival and departure were recorded for all visits to the club and clinic for participants and non-participants.

For non-attenders, an interview was performed at the next visit (by EW) to ascertain the reason for non-attendance. Attendance was correlated with place of domicile, car ownership, and social class.

The families who opted not to participate in the diabetic club were asked to give their reasons for not taking part on a written form prompted by open ended questions. No-one was obliged to fill in the form if they did not wish to do so. Three groups were assessed:

1. Participants attending the club
2. Participants attending the clinic
3. Non-participants attending the clinic.

To assess the cost of care at different centres, ie a specialist centre and a general clinic, costs of outpatient visits and inpatient days were obtained from the Lothian Health Board for the RHSC for the year 1986-1987 and from the Fife Health Board for 1986-1987 respectively.

Costs for the diabetic club visits were calculated from the salaries of the dietitian and doctor involved (the research psychologist was not included as she had a purely assessment role and was not involved in running the service) plus an amount to include use of facilities - heating, lighting, etc, and blood tests.

The cost per child per year for different types of care was then calculated by multiplying the number of visits or inpatient days per child by the cost of one visit or one inpatient day.

RESULTS

Satisfactory information was obtained on 86 subjects. The mean number of visits possible to the club (11.0) was more than twice that made to the routine clinic (5.2), and the attendance rate was 80% or more for all groups (Table 12:1). The total mean time (including waiting time) spent at the hospital for each visit to the Club was 138 mins and was nearly twice the mean time spent at each visit to the clinic (76 mins). The total time spent at the hospital in a year attending the diabetic club was a mean of 22 hours 54 mins compared with a mean of 5 hrs 24 mins attending the routine clinic (Table 12:1) for participants. The non-participant group had a slightly lower total attendance with a mean of 4 hrs 54 mins.

The total mean time spent travelling to and from the club over one year was 16 hours 40 mins and 5 hours 58 mins travelling to and from the clinic for both groups. The mean combined time spent travelling and at the hospital over one year for a patient attending the diabetic club was therefore 39 hrs 36 mins compared with 11 hrs 22 mins while attending the routine clinic. Thus an additional 28 hrs 14 mins was required over the course of one year by children and their families to attend the diabetic club.

Total cost of travelling to the diabetic club for one year was £16.92 compared with £6.65 travelling to the routine diabetic clinic. Thus the excess cost of additional attendance at the diabetic club over the course of one year was £10.27. Two families required reimbursement from research funds for this extra cost incurred.

Percentage attendance was higher for those living in Edinburgh and with access to a car, but this was not statistically significant. There was significant correlation with social class ($p<0.01$) with the higher social classes having a better attendance rate (Table 12:2).

The reasons for non-attendance are shown in Table 12:3. The main reasons for non-attendance were the illness of child or parent, parent working, and "forgot" or other unspecified reason. For 20% of participants and 13% of non-participants a reason was not obtained. Only one episode of non-attendance was due to babysitting problems.

The special arrangements which families had to make to enable them to make visits to either the diabetic club or the diabetic clinic are shown in Table 12.4. Approximately half the visits required no arrangements in all groups, but some arrangement was required for the rest. It is noticeable that babysitting arrangements were required twice as frequently while attending the club compared to the clinic - 151(32%) vs 28(15%) of visits. More mothers in the non-participant group needed to take time off work (more mothers worked fulltime in this group compared with the participants - 21% vs 4%) and a quarter of these lost pay. In the participant group mothers took time off work more often during the club year compared with the clinic year - 53(11%) vs 8(4%).

The families who elected not to participate in the project gave their reasons for not being involved in the diabetic club in 24 out of 44 cases. (The non-participants were not pursued to give an answer to avoid generating feelings of guilt or hostility.) The reasons for not participating are illustrated in Table 12:5 with some families giving more than one reason. The most common reasons for not participating were inability to get time off work or regarding the demands of the club too great in terms of time, distance and cost.

Cost of Services

The costs to the NHS of outpatient and inpatient care per child per year were calculated for a district general hospital, a specialist paediatric clinic and for the diabetic club (Table 12:6).

The cost of attending outpatients at a specialist clinic (£94.94) was 50% more than attending a district clinic (£61.43). This was offset, however, by the length of hospital admission and the greater cost of inpatient care at the district hospital (£231.04) compared with the specialist paediatric clinic (£188.77). Outpatient care at the diabetic club was expensive (£253.00) but inpatient care per child per year was similar to those attending the paediatric clinic (£187.41).

DISCUSSION

In this summary of the time and costs involved for patients attending a diabetic education programme compared with the routine diabetic clinic there was a good attendance rate in all the groups despite the much greater time demanded of the families and the increased costs incurred. The high attendance rate suggests that the extra services and education offered by the club were regarded as worthwhile by the families. In a recent study of an education programme in Newcastle (1) which required attendance at four 1½ hour evening visits attendance was 68%. Attendance rate at the routine clinic was good for both groups showing that the non-participants were not necessarily less motivated but that they have greater constraints on their time preventing them being involved in a more intensive programme. Attendance at the diabetic club meant that more than 20 hours extra were spent at the hospital each year.

In a review of eight educational programmes (2) it was concluded that those programmes with 20 hours or less of professional time had little effect on diabetic control while those with more than 20 hours time in a six month period were successful in maintaining a normal HbA_1 particularly if group teaching was the basis of the programme.

Distances to travel to the club and clinic did not affect attendance rate (some families had a round trip of 80 miles for clinic attendance) indicating that our families were willing and able to travel to a specialist centre. There was a trend for increased attendance rates in the higher social classes. In our study, however, all social groups had a good attendance rate. Many families needed to make special arrangements for visiting the club particularly babysitting and time off work, but again this did not prevent them attending. Most reasons for non-attendance were unavoidable, eg illness in the family.

The frequency of visits to the club as well as the length of time for each visit may have had some beneficial effect. In a study of elderly patients (3) monthly visiting did not improve HbA_1 but did affect lower fasting blood sugar compared with those who visited at six monthly intervals in whom fasting blood sugars and HbA_1 rose significantly indicating loss of motivation in the group seen infrequently.

The reasons given for not participating in the diabetic club largely suggest that time budgeting was a main concern for the family - work and distance to travel, and balancing the best interests of the child - school vs clinic. A clinic later in the afternoon after school might have attracted a larger number of participants. Many adolescent clinics and diabetic groups elsewhere already take place in the early evening (4, 5).

The cost to the NHS of attending a specialist clinic is 50% greater in our study than attending a paediatric clinic in a district general hospital. This is offset, however, by the higher inpatient costs at the district general hospital due to the greater number of hospital admissions.

The outpatient costs of the diabetic club were obviously the highest and could not be run on a service basis. This was, however, a research project, and relevant parts of the club could be introduced cost-effectively into routine clinics. This will be discussed further in the final chapter.

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TABLE 12:1 TRAVEL. TIME TAKEN AND COST OF JOURNEY FOR PATIENTS TO ATTEND THE DIABETIC CLUB OR DIABETIC CLINIC, AND THOSE PATIENTS ATTENDING THE DIABETIC CLINIC BUT NOT PARTICIPATING IN THE STUDY, ALL AT RHSC

	Participants n= 46		Non-participants n= 40
	Club Year Group A + Group B	Clinic Year Group A + Group B	
Number of visits possible	11.6(1.3)	5.2(1.9)	4.8(1.1)
% attendance	86(13)	82(18)	80(15)
Time for each hospital visit(mins)	138(8)	76(25)	76(25)
Time spent at hospital over 1 year	22 hrs 5 mins (3 hrs 8 mins)	5 hrs 24 mins (3 hrs 30 mins)	4 hrs 52 mins (2 hrs 24 mins)
Time of inward journey (mins)	51(31)	45(28)	48(22)
Travelling time over 1 year	16 hrs 40 mins (10 hrs 40 mins)	5 hrs 59 mins (3 hrs 52 mins)	5 hrs 58 mins (2 hrs 54 mins)
Cost of inward journey (pence)	87(79)	83(71)	84(57)
Total cost of travel over 1 year	£16.92(£15)	£6.62(£6.10)	£6.18(£4.30)

(Results are presented for a period of one year as mean values (Standard Deviation))

TABLE 12:2 PERCENTAGE ATTENDANCE FOR AREA OF DOMICILE, CAR OWNERSHIP AND SOCIAL CLASS

		% Attendance (SD)	Significance
1. Area of domicile	1. Edinburgh	84 (12)	NS
	2. Outside	81 (13)	
2. Access to car			
	1. Yes	84 (13)	NS
	2. No	79 (14)	
3. Social Class	I	93 (5)	
	II	82 (14)	
	IIIN	86 (18	
	IIIM	79 (13)	p<0.01
	IV	82 (11)	
	V	73 (0)	
	VI	82 (9)	

TABLE 12:3 REASONS FOR NON-ATTENDANCE AT BOTH CLUB AND CLINIC FOR PARTICIPANTS AND NON-PARTICIPANTS

	Participants		Non-participants	
	No.	%	No.	%
Child Ill	16	(14%)	17	(21%)
Parent Ill	15	(13%)	7	(9%)
Parent Working	16	(14%)	13	(16%)
Bad Weather	5	(4%)	5	(6%)
Transport Problem	3	(3%)	0	(0%)
Family Bereavement	6	(5%)	0	(0%)
School Related	9	(8%)	5	(6%)
Sibling Ill	2	(2%)	0	(0%)
Holiday	4	(3%)	2	(2.5%)
Babysitting Problem	1	(1%)	0	(0%)
Other	17	(15%)	16	(20%)
Don't Know	22	(19%)	15	(13%)
Total	116		80	

TABLE 12:4 SPECIAL ARRANGEMENTS MADE TO ALLOW VISITS TO DIABETIC CLUB AND DIABETIC CLINIC TO TAKE PLACE

	Participants		Non-Participants
	Club Year No. %	Clinic Year No. %	No. %
No arrangements	234 (49%)	111 (59%)	160 (47%)
"Babysitting"	151 (32%)	28 (15%)	30 (9%)
Mother time off (Total)	53 (11%)	8 (4%)	64 (19%)
Mother time off + loss of pay	13 (3%)	1 (0.5%)	16 (5%)
Father time off (Total)	19 (4%)	12 (6%)	39 (11%)
Father time off + loss of pay	0 (0%)	1 (0.5%)	5 (1%)
Borrow a car	3 (0.6%)	5 (3%)	11 (3%)
Other	3 (0.6%)	21 (11%)	16 (5%)
Total No. Visits	478 (100%)	189 (100%)	307 (100%)
Not Known	1 (0.2%)	7 (3.5%)	0 (0%)

All values - Numbers (%)

TABLE 12:5 REASONS GIVEN FOR NON-PARTICIPATION IN THE DIABETIC CLUB

	Number of responses
Inability to get time off work	9
Overall club demands too great: time, distance and cost	8
Concern about child missing school	4
Inconvenient time	4
Difficulty with childminding or collecting from school	3
Lack of transport	1
Satisfaction with current sources	1
Concern about upsetting well-adjusted diabetic child	1

TABLE 12:6 COMPARATIVE COSTS TO THE NATIONAL HEALTH SERVICE OF ATTENDING DIFFERENT TYPES OF DIABETIC CARE PER CHILD PER YEAR - OUTPATIENT AND INPATIENT COSTS 1986-87

	Outpatient	Inpatient
Cost of attending district general hospital paediatric clinic	£61.43	£231.04
Cost of attending specialist paediatric clinic	£94.94	£188.77
Cost of attending diabetic club	£253.00	£187.21

Costs for one year calculated by number of visits or days admitted multiplied by cost of a single visit or inpatient day

CHAPTER 13

SUMMARY AND CONCLUSIONS

The introduction of a specialist paediatric diabetic clinic at the RHSC in the early 1950s was a new concept in diabetic care and provided a more appropriate service for children. The home care nursing team, which started in 1968, had a further impact on diabetic care and after its introduction inpatient stay at initial diagnosis for the child fell from an average of 22.3 days to 10.8 days. It is now 7.5 days. Thereafter, the team approach in the paediatric diabetic clinic including a dietitian with paediatric experience, a diabetes nurse specialist, a dental hygienist, chiropodist and a relatively constant staff of experienced doctors (including an adult physician for adolescents) ensured that diabetic control for the children was on par with other specialist centres (1, 2). A review of adults who had previously attended the clinic (3), however, highlighted areas where they thought care had been less than optimal, mainly in relation to providing adequate knowledge and allowing enough time for discussion of problems.

To address these issues we therefore developed an informal but structured education programme covering all aspects of diabetic care in a supportive environment (Diabetic Club). Our aims were to determine if such a programme could improve knowledge and understanding of diabetes by children and their families, reduce stress and thereby improve diabetic control. We decided to assess this in a randomised prospective study.

Ninety-two children less than 13 years on 1st October 1985 who attended the clinic were eligible for the project, 48 volunteered. These patients differed from those who elected not to participate in the project in that they were younger (9.0 years vs 10.4 years) and had been diabetic for a shorter time (2.8 years vs 4.5 years) but there were no other significant differences particularly in diabetic control as assessed by HbA_1 (HbA_1, 9.3 vs 9.6%). The study was designed as a randomised, prospective two year two period crossover controlled trial (4) to reduce the effect of seasonal variation on diabetic control. The 48 participating families were allocated to eight groups of 6 by stratified randomisation based on social class and four of these groups were randomly allocated to each treatment group A and B. Group A attended the education project (Diabetic Club) first while Group B continued at the routine clinic. For the second year, Group A returned to the routine clinic while Group B attended the Club. Each small group of six families attended the Diabetic Club together for 10 visits per year, each visit from noon to 3.30 pm in an informal setting. Lunch was provided and teaching based on semi-structured discussion groups. A dietitian, doctor and sometimes a diabetes nurse specialist were available at each visit. The routine clinic visits occurred on an average of 4.6 times per year with a one to one interview with a paediatrician (or adult physician for adolescents), and a dietitian available if needed.

Assessments to ascertain the effectiveness of the club were carried out on entry, end of Year 1 and end of Year 2 for the participants and at entry and end of year 2 for the non-participants. These assessments were:

(i) medical and social background (including life-events unrelated to diabetes (5))

(ii) measurement of diabetic control (HbA_1, days spent in hospital, hypoglycaemia, insulin dose, number of infections, growth velocity and days absent from school)

(iii) knowledge about diabetes with a factual and problem-solving questionnaire

(iv) dietary surveys (a modification of the 7-day weighed record) (6)

(v) psychological assessments including IQ, Rutter Behaviour Scale (7) and Vineland Social Maturity Scale (8)

(vi) parental view of the programme including benefits provided by the club compared with the clinic, the degree of responsibility given to the child and the effects of diabetes on family life and whether this was changed by attendance at the club.

All participants completed the two year programme and attendance was excellent at 86% at the Club despite the considerable extra time demanded of the family (38 hours vs 11 hours per year) and some extra financial cost (£16.92 v £6.62 for travelling).

The positive results of the Diabetic Club included a stabilisation of diabetic control as assessed by HbA_1 in both groups while attending the Club, not sustained in Group A on return to the routine clinic ($p<0.01$). The percentage of energy taken as fat was significantly reduced in both groups while attending the club ($p<0.05$) and the problem-solving scores in the assessment of diabetic knowledge of mothers also improved significantly ($p<0.01$). There was no significant correlation between improvements in HbA_1 and improvements in either knowledge or diet. There were significantly more children performing routine blood testing ($p<0.01$) and using 3 or more injection sites ($p<0.01$) while attending the Club.

The percentage of parents reporting frequent social contact with parents of other diabetic children was significantly greater while attending the club and furthermore parents in both groups found this helpful in managing their child's diabetes ($p<0.001$). The main benefit of the programme may have been the social support provided and this may have affected diabetic control.

No other aspect of diabetic control, diet or stress was changed by the Club with the measurements we used. Although stress was unchanged and the groups overall had a mean stress score within the normal range, 13/47 (27%) of children scored above the index for showing significant stress, a finding similar to other studies (9). Fonagy et al (10) have shown in their study that children with the highest anxiety levels have the lowest HbA_1 levels.

One interesting finding from the dietary surveys was the persistent shortfall in dietary carbohydrate prescription for the children of between 15-25% compared with their recommended daily amounts (RDA) for carbohydrate. Children eat more carbohydrate than prescribed to satisfy their hunger and are therefore unable to comply with their prescriptions. This has been shown in an other study (11).

This intensive educational programme had only a small measurable effect on diabetic control, a finding similar to the results of a recent educational programme in Newcastle (12). In that study, utilising two packages of four evening meetings, there was a significant fall in HbA_1 in children over 11 years at 7 months after the programme, an improvement in mothers' knowledge about diabetes, and a non-significant trend to some improvement in diet. The modest improvements due to our education programme may be due to several

reasons. Firstly, the children were already attending a specialist clinic and had an acceptable HbA_1 at baseline. Secondly, many parents already had sufficient knowledge to manage their child's diabetes. Thirdly, the diet for children was reasonably good at baseline with carbohydrate approaching 50% of RDA and fat less than 5% above the 35% of energy intake recommended by the BDA. It might be expected that it would be difficult to achieve improvement in such a group in a short time.

We also showed that care for diabetic children is better in our paediatric specialist clinic than in three general paediatric clinics in three district general hospitals in adjacent areas in Scotland with similar populations of diabetic children. There were significantly fewer days admitted to hospital for hyperglycaemia (1.2 v 2.7) and HbA_1 was better (10.3% v 11.7%) in the children attending the specialist diabetic clinic.

Children and their families travelled considerable distance to attend both our routine clinic and Diabetic Club and gave of their time to the Diabetic Club. Attendance was excellent (86%), therefore distance to travel and any inconvenience incurred in terms of time and cost to the patient does not seem to be a barrier if the services provided are percieved as worthwhile by the patient. The increased costs of providing services in a specialist centre may be offset by the reduction in the number of days admitted to hospital with the better services provided. The costs of our research project were high both in terms of time and money and could not be implemented on a routine service basis.

From this study, what recommendations can we make for the future care of diabetic children? As has been very recently shown (13), IDDM in children is increasing in incidence particularly in Scotland, perhaps because susceptible individuals are appearing earlier. The implications for health care are that increasing and better resources will need to be available despite the current financial constraints.

Some beneficial aspects of the diabetic club could easily be implemented cost-effectively into routine clinics, particularly the small group teaching and discussion which has been also shown in other studies to be effective (12, 14, 15, 16). Grouping families to visit together increases helpful social contact and gives particularly the more recently diagnosed families the support they need. We found that a meal or snack shared by families and staff fostered easy discussion and provided a chance to learn about food. A greater flexibility in the timing of clinics may be useful with early evening clinics giving fathers the opportunity to be involved and for adolescents who may not want to miss school. The needs of families with diabetic children change, with intensive input necessary initially or when problems arise, but a review of knowledge and techniques is needed by even the most stable diabetic from time to time. In Oxford (17), clinics for under 5s, adolescents, and annual review in addition to the routine clinic already occur.

From our own study and others (12) it does appear that educational input needs to be repeated at regular intervals to be effective, as there is a deterioration of any improvements in control over time. This is time consuming on a one-to-one basis but more efficient if it occurs in groups with discussion (15, 16). The specialist centre does

appear to provide better care than that provided in the paediatric units of district general hospitals, but the difference may not be commensurate with the greater resources available. It may be that care could be shared with the role of the specialist centre being the maintenance of specialist knowledge of the subject and regular updating of paediatric staff. They could perform an annual review of children attending district clinics and the provision of surveillance tests including measurement of urinary microalbumin and ophthalmological screening.

The appropriate prescription of carbohydrate requires frequent assessment of children's needs and reference to the appropriate RDA tables for age. This is time consuming for the dietitian, but again grouping families together for dietary education and discussion would make more efficient use of time.

The routine utilization of an assessment such as the Rutter Behaviour Scale (7) may be useful in a clinic to ascertain which families are unduly stressed and in need of extra help and support.

We have shown that the introduction of diabetes specialist nurses improved the quality of care and they are both popular with patients and effective. The development of diabetes day centres (18) for older patients is effective but it is unlikely that the NHS will be able to afford the development of such specialised services on a large scale.

What do the patients want? Our study indicates that families need more time with the professionals involved to discuss problems and learn to be able to help themselves. They need to reduce their feelings of guilt and isolation. Small group teaching and discussion groups within routine clinics help to fulfil these needs and should be incorporated into the routine clinic. Diabetic families in our study appreciated and benefited from group teaching and their attendance was good.

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APPENDIX 1

DATA COLLECTION SHEET FOR HOME CARE TEAM SURVEY

HomeCare

DIABETIC HOME CARE TEAM SURVEY

NAME .....

HOSPITAL NO. .....

STUDY NO. .....

CODING CONVENTION:-

(0) No or None

(1) Yes

(9) Not known

Page No. ☐ 1

A. Study Number ☐☐☐ 2-4

B. Date of Birth ☐☐☐☐☐☐ 5-10

C. Date of Diagnosis (1st admission) ☐☐☐☐☐☐ 11-16

D. Age at Diagnosis (years, months) ☐☐.☐☐ 17-20

E. Area of Domicile ☐ 21

1. Edinburgh
2. Midlothian
3. East Lothian
4. West Lothian
5. Borders
6. Fife
7. Other

F. Telephone at Home ☐ 22

0. No
1. Yes
2. Neighbour/Relative
9. Not known

G. Male (1) Female (2) ☐ 23

H. Father's Occupation:

Working ☐ 24

0. No
1. Part-time
2. Full-time

Actual Occupation .....

I. Social Class (Registrar General's Classification (1-8)) ☐ 25

J. Number of Siblings ☐ 26

K. Rank in Family ☐ 27

L. Duration of Symptoms (days) on 1st Admission ☐☐ 28-29

M. State at Admission:

1. Alert
2. Drowsy
3. Comatose

☐ 30

N. Initial Management:

1. Oral fluids
2. I.V. fluids

☐ 31

O. Duration of First Admission (days) ☐☐ 32-33

P. Years and Months Attending Diabetic Outpatient Clinic ☐☐·☐☐ 34-37

Q. Total Number of Diabetes-related Admissions ☐☐ 38-39

R. Average Number of Diabetes-related Admissions per year (Q/P) ☐·☐ 40-41

S. Average Number of Days Readmitted per Year ☐☐·☐ 42-44

T. Average Number of Outpatient Visits per Year ☐☐·☐ 45-47

U. Resident at Cruachan
0. No
1. Yes

☐ 48

V. Average Glycosylated Haemoglobin in Last Year of Clinic (1980 ---) ☐☐·☐ 49-51

W. Average Number of Visits by Home Care Team per Year ☐☐·☐ 52-54

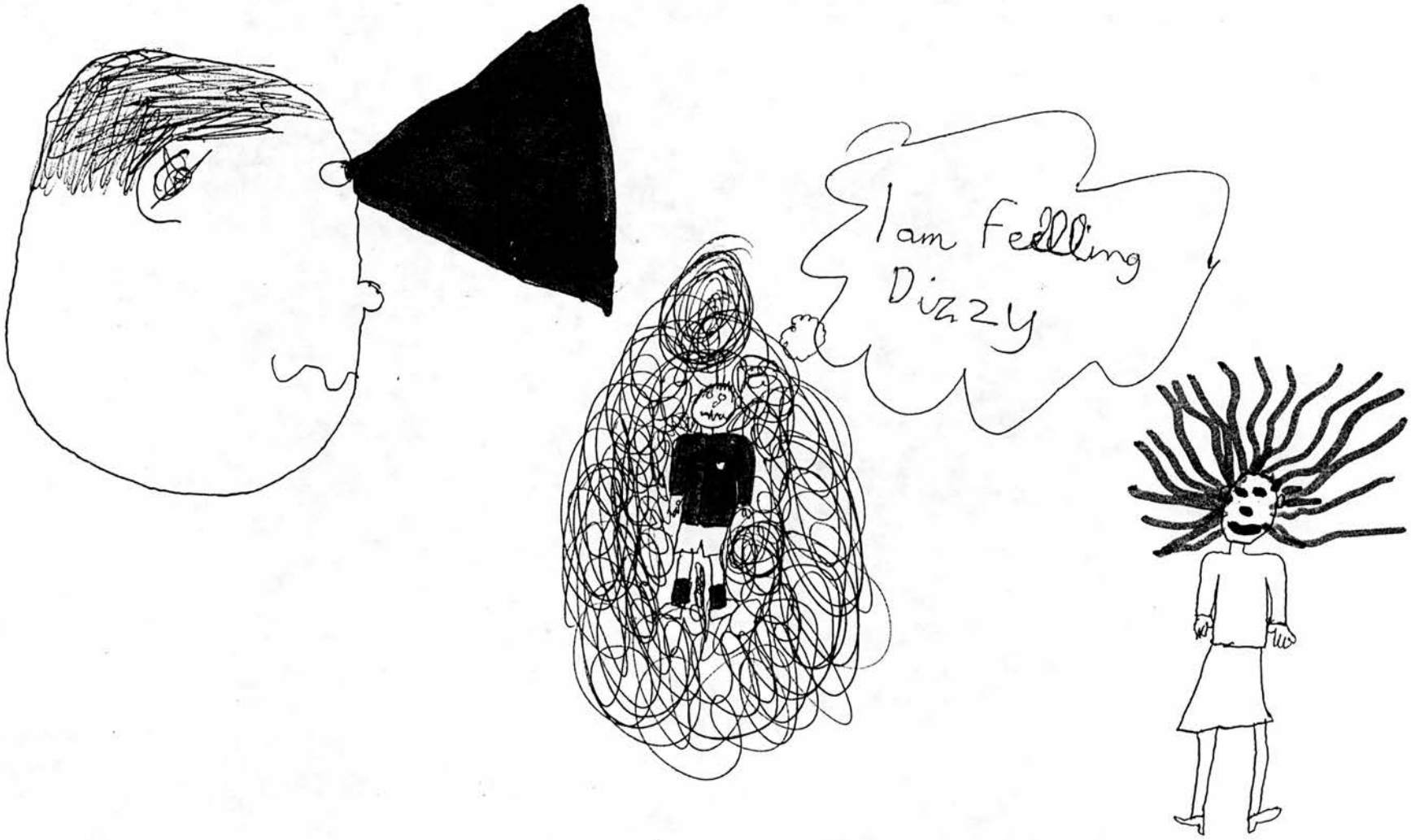
APPENDIX 2

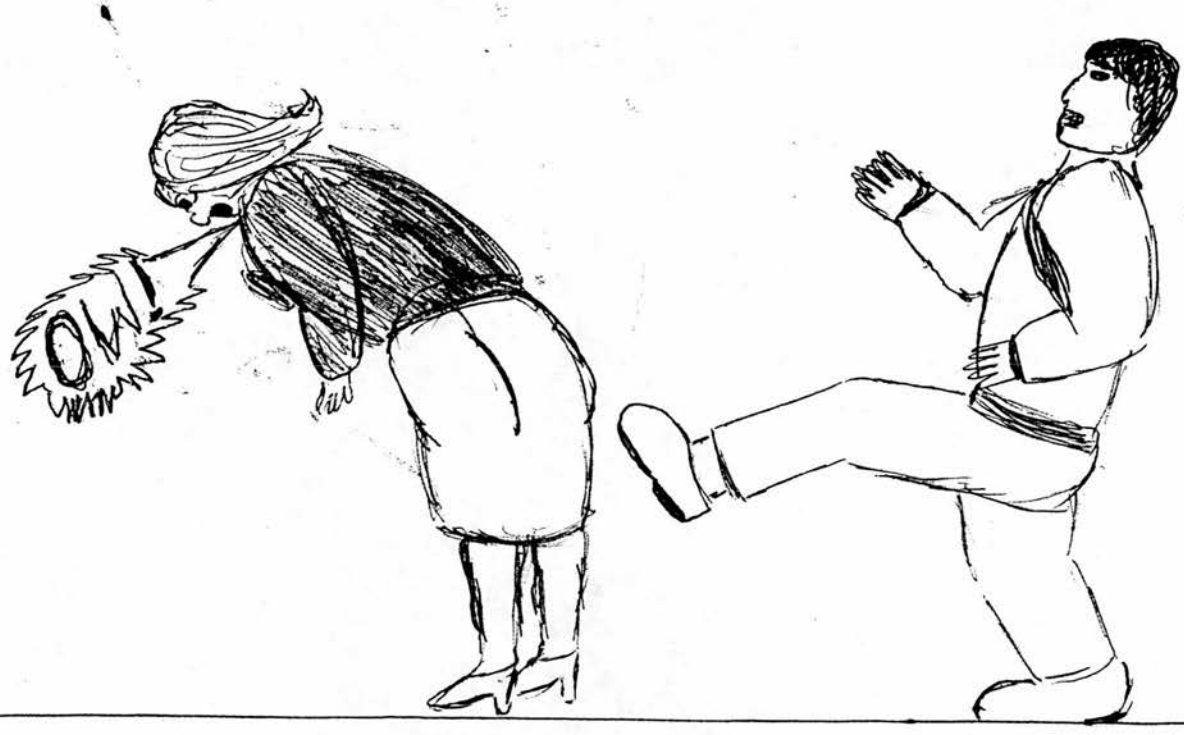
DIABETIC CHILDREN'S DRAWINGS

200.

When I am hypo my teacher goes mad. When I go hypo I go dizzy.

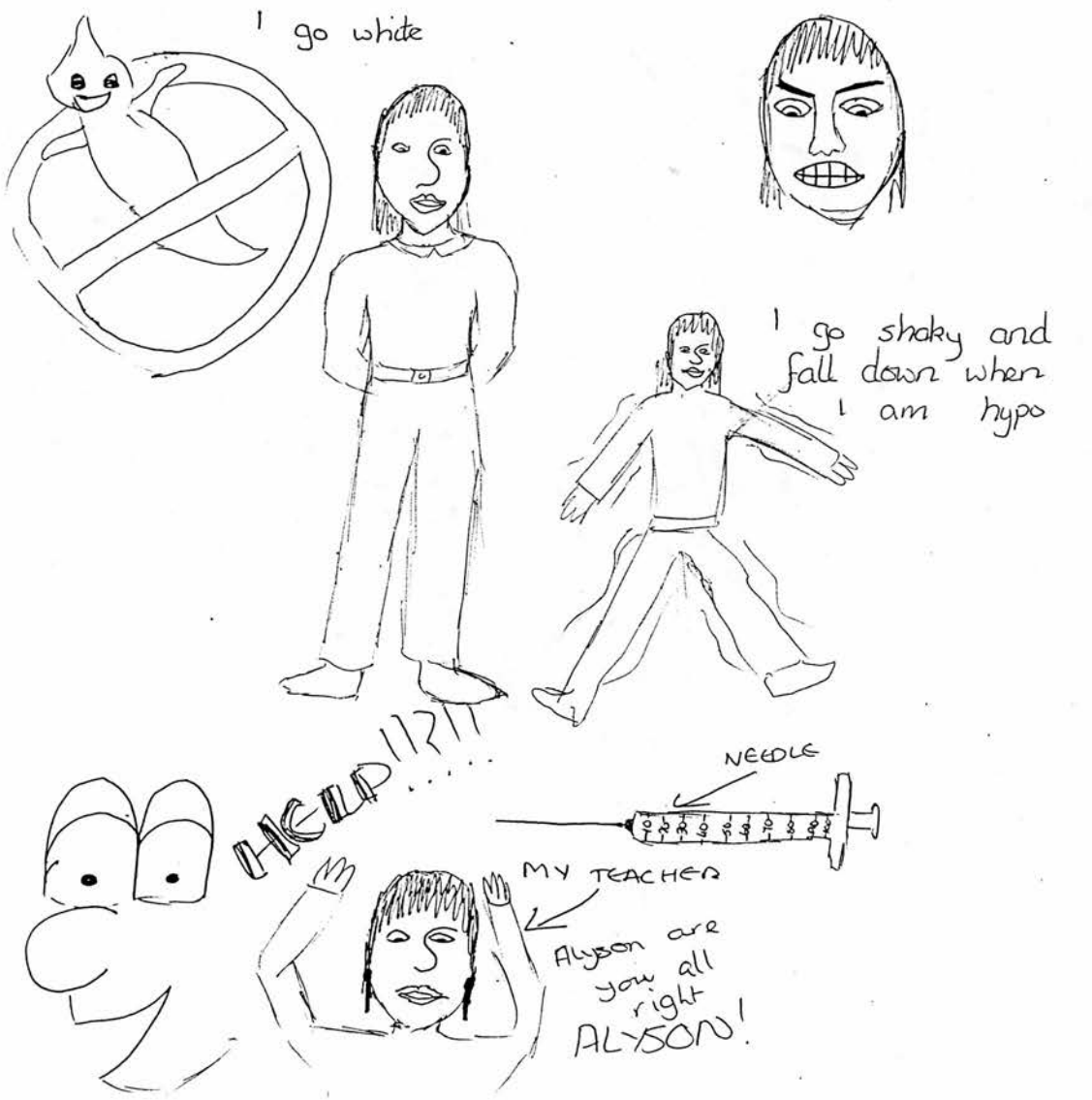
When I go hypo I take glucose!




OW!

When I go Hypo I feel dizzy and shaky. I go pure white and fall all over the place.

When I go hypo I usually take a dextrosol or if it is near a meal I take the meal earlier.



I went to hospital

-ast year when I went to hospital it was
orrible. When I went in everyone greeted me.
was getting my insulin changed when I
ent in. Every day my auntie and uncle
ame in and every night my mum and
lad came in. My auntie and uncle mum
nd dad brought carrots cucumber
lettuce diabetic juice is to me. The
ext again day my auntie arrived with
illions of cards and some more food
n. Later on in the night it was only
y dad that arrived in and my
mum didn't come in. Then the nurse
ame and said could I take Jerome
way for a little while. So my dad
aid yes ok. So I went away and
when I came back I had a
wooden board on my arm with a
andage wound round it. It in there
as a massive needle with about
our holes init so instead of keep
iving me blood injection every day
hey will just take the blood out thrayth
he holes. I think it was very
ind of my auntie and uncle
mum and dad to come and

ee me every day. When I got
ome I felt very very happy
o be home again.

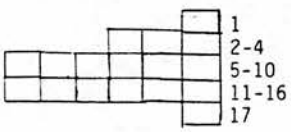
APPENDIX 3

DATA COLLECTION SHEET FOR EDUCATION PROJECT

CARD 1

GENERAL BASE

A. Group in Study
B. Study Number
C. Date of Birth
D. Date of diagnosis (1st admission)
E. Area of domicile



1. Edinburgh
2. Midlothian
3. East Lothian
4. West Lothian
5. Borders
6. Fife
7. Other
Specify.....

F. Telephone at home

1. Yes
2. No
3. Neighbour
4. Relative
5. Not known

☐ 18

G. Male (1) Female (2) ☐ 19

H. Parental situation ☐ 20

1. Married
2. Single
3. Divorced
4. Separated
5. Widowed
6. Remarried
7. Stable relationship

I. Father's Occupation ☐ 21

Working 0. No
1. Part-time (sociable)
2. Part-time (unsociable)
3. Full-time (sociable)
4. Full-time (unsociable)

Actual Occupation .....

J. Mother's Occupation

Working 0. No ☐ 22
1. Part-time (sociable)
2. Part-time (unsociable)
3. Full-time (sociable)
4. Full-time (unsociable)

Actual Occupation.....

K. Social Class (Registrar General's Classification 1-8) ☐ 23

L. Child's Situation ☐ 24

1. Child living with 2 natural parents.
2. Child living with true mother alone.
3. Child living with true mother and father substitute.
4. Child living with true father alone.
5. Child living with true father and mother substitute.
6. Child living with third person.
7. Child living in any institution.
8. Not Known.

Specify if third person .....

Is the child in the care of local authority or in a children's home or foster home or has he/she ever been so? ☐ 25

1. Yes, currently
2. No, never
3. Not now, but has been in the past
4. Not Known

If Yes, Specify .....

M. PARENTS	FATHER	MOTHER
Living 1. Yes 2. No	☐ 26	☐ 27
Age in Yrs	☐☐ 28-29	☐☐ 30-31
Any Medical Problems Specify..... (see separate Index for Code)	☐☐ 32-33 ☐☐ 36-37 ☐☐ 40-41	☐☐ 34-35 ☐☐ 38-39 ☐☐ 42-43
Smoker 1. No 2. <10/day 3. 10-20/day 4. 20-40/day 5. <40/day	☐ 44	☐ 45
Alcohol Frequency per week..... Type..... Amount..... Units alcohol per day	☐☐ 46-47	☐☐ 48-49
Any Psychiatric/"Nerves" Problems 1. Yes 2. No	☐ 50	☐ 51
If Yes Specify..... (see separate Index for Code)	☐ 52	☐ 53
Educational level attained 1. Left school at 15/16 2. Apprenticeship 3. Technical College 4. College graduate, eg teacher training 5. University graduate 6. Other further education Specify	☐ 54	☐ 55
Any difficulties in schooling 1. Yes 2. No If Yes, specify	☐ 56	☐ 57
Any difficulties in reading 1. Yes 2. No If Yes, specify	☐ 58	☐ 59

COMMENTS

Any changes in parents' situation over two year period?

e.g. Work

Medical Problems

Smoking

Marital Status

CARD 2

N. SIBLINGS	1	2	3	4	5	6
Age in Yrs	1-2	3-4	5-6	7-8	9-10	11-12
Sex 1. M 2. F	13	14	15	16	17	18
Living 1. Yes 2. No	19	20	21	22	23	24
Any Medical Problems (see separate Index for Code)	25-26 37-38 49-50	27-28 39-40 51-52	29-30 41-42 53-54	31-32 43-44 55-56	33-34 45-46 57-58	35-36 47-48 59-60
Any Behavioural Problems 1. Yes 2. No Specify.....	61	62	63	64	65	66
Needing Special Education 1. Yes 2. No Specify.....	67	68	69	70	71	72
Still Resident at home 1. Yes 2. No	73	74	74	76	77	78

CARD 3

O. OTHER MEMBERS OF HOUSEHOLD

Who? 1. Grandparent 2. Uncle/Aunt/Cousin 3. Lodger 4. Other (specify.....)	1	2	3
Age	4-5 10	6-7 11	8-9 12
Sex 1. M 2. F			
Any Medical Problems specify (see separate Code for Index) Index)	13-14 19-20 25-26	15-16 21-22 27-28	17-18 23-24 29-30
Helpful 1. Yes 2. No particularly 3. Hinderance!	31	32	33

P. HOUSING

Type

1. Own 2. Rented - Private 3. Rented - Public ☐ 34

1. House 2. Flat-Low Rise 3. Flat High-Rise ☐ 35

No. of Rooms in the home (other than kitchen & bathroom) ☐ 36

No. of persons per household ☐☐ 37-38

Does Index child have own room 1. Yes 2. No ☐ 39

Is Housing satisfactory 1. Yes 2. No ☐ 40
If No, specify problems .....

In receipt of Supplementary Benefit 1. Yes 2. No ☐ 41

Q. TRAVEL

	Yr1	Yr2	Yr3
1. In your household does anyone own a car or have one provided by an employer? 1. Yes 2. No	☐ 42	☐ 43	☐ 44
If Yes, how many vehicles in household? 1. One 2. Two 3. Three or more	☐ 45	☐ 46	☐ 47
2. Which members of the household have a current driving licence?			
Husband 1. Yes	☐ 48	☐ 49	☐ 50
2. No			
Wife 1. Yes	☐ 51	☐ 52	☐ 53
2. No			
Other 1. Yes	☐ 54	☐ 55	☐ 56
2. No			
Specify who			

CARD 4

R. DIABETIC RELATIVES	1	2	3	4
Who? 1. Grandparent 2. Aunt/Uncle 3. Other, specify.....	☐ 1	☐ 2	☐ 3	☐ 4
1. Type I IDDM 2. Type II IIDM	☐ 5	☐ 6	☐ 7	☐ 8
Living 1. Yes 2. No	☐ 9	☐ 10	☐ 11	☐ 12
Age	☐☐ 13-14	☐☐ 15-16	☐☐ 17-18	☐☐ 19-20
Sex 1. M 2. F	☐ 21	☐ 22	☐ 23	☐ 24
Retinopathy 1. Yes 2. No	☐ 25	☐ 26	☐ 27	☐ 28
Blind 1. Yes 2. No	☐ 29	☐ 30	☐ 31	☐ 32
Nephropathy 1. No 2. Yes, no Treatment 3. Dialysed 4. Transplant	☐ 33	☐ 34	☐ 35	☐ 36
Neuropathy 1. No 2. Reversible 3. Permanent	☐ 37	☐ 38	☐ 39	☐ 40
Myocardial Infarction 1. Yes 2. No	☐ 41	☐ 42	☐ 43	☐ 44
Peripheral Circulation Problem 1. No 2. Compromised 3. Amputation	☐ 45	☐ 46	☐ 47	☐ 48

S. PATIENT DATA

CARD 5

	On Entry (year previous)	End Year 1	End Year 2
Medical Problems			
Specify (see separate Index for Code)	1-2 7-8 13-14	3-4 9-10 15-16	5-6 11-12 17-18
Psychiatric Referral 1. Yes 2. No	19	20	21
Number of Days Admitted to Hospital	22-23	24-25	26-27
Specify reasons 1. Hypoglycaemia	28	29	30
2. Hyperglycaemia	31	32	33
3. Other	34	35	36
Illness at Home (See Appendix I)			
No. Hypo at home	37-38	39-40	41-42
No. of Hypo at school	43-44	45-46	47-48
No. of Hypo outside	49-50	51-52	53-54
No. episodes Ketonuria	55-56	57-58	59-60
No. Infections	61-62	63-64	65-66
Specify 1. 'Flu' or cold	67	68	69
2. Sore Throat	70	71	72
3. Diarrhoea	73	74	75
4. Vomiting			
5. Other			

T. PHONE CALLS

CARD 6

No. to GP	1-2	3-4	5-6
No. to Hospital Ward	7-8	9-10	11-12
No. to Home Care Sister	13-14	15-16	17-18
No. to Hospital Doctor	19-20	21-22	23-24
No. visits Home Care Team	25-26	27-28	29-30
No. visits to Diabetic Clinic/Club	31-32	33-34	35-36
No. visits to Other Clinics	37-38	39-40	41-42
Specify Clinic			
No. visits to GP Surgery (prescriptions)	43-44	45-46	47-48
" " (Diabetes)	49-50	51-52	53-54
Monitoring			
Type 1. Urine only 2. Blood only 3. Urine and Blood	55	56	57
Frequency 1. X1/day 2. x2/day 3. <x2/day 4. Occasional	58	59	60
Ketone Testing 1. Yes 2. No 3. Occasional	61	62	63
Microalbuminuria	64	65	66

CARD 7

	On Entry (year previous)	End Year 1	End Year 2
U. INSULIN			
Units/KG/24hr (mean)	1-3	4-6	7-9
Range (min)	10-12	13-15	16-18
Range (max)	19-21	22-24	25-27
Frequency 1. x1/24hr 2. x2/24hr 3. >x2/24 hr	28	29	30
Type 1. Velosulin 2. Insulatard 3. Initard 4. Mixtard 5. Actard 6. Monotard	31 34	32 35	33 36
Sites Used Arms 1. Yes 2. No	37	38	39
Legs 1. Yes 2. No	40	41	42
Buttocks 1. Yes 2. No	43	44	45
Abdomen 1. Yes 2. No	46	47	48
V. BIOCHEMICAL FINDINGS			
HbA_1c (Mean over previous year - not first 3 months when diagnosed)	49-51	52-54	55-57
Range (Max)	58-60	61-63	64-66
(Min)	67-69	70-72	73-75

CARD 8

TSH	1-3	4-6	7-9

W. PHYSICAL DATA (see Appendix II)			
Ht in cm	10-13	14-17	18-21
Ht Percentile (3-97)	22-23	24-25	26-27
Ht Velocity in cm/yr	28-30	31-33	34-36
Ht Velocity Percentile(3-97)	37-38	39-40	41-42
Wt in Kg	43-45	46-48	49-51
Wt Percentile (3-97)	52-53	54-55	56-57
Wt Velocity in Kg/yr	58-60	61-63	64-66
Wt Velocity Percentile (3-97)	67-68	69-70	71-72

CARD 9

Ponderal Index Wt/Ht^2m	1-3	4-6	7-9

	On Entry (year previous)	End Year 1	End Year 2
Skinfolds			
Triceps in mm	10-12	13-15	16-18
Triceps percentile (3-97)	19-20	21-22	23-24
Infrascapular in mm	25-27	28-30	31-33
Infrascapular percentile (3-97)	34-35	36-37	38-39
Pubertal Grading: 1. Prepubertal 2. Pubertal	☐ 40	☐ 41	☐ 42
Injection Sites 1. Good (no atrophy) 2. Fair (some fat atrophy) 3. Poor (obvious fat atrophy)	☐ 43	☐ 44	☐ 45

CARD 10

X. EDUCATIONAL

Type of School 1. State 2. Private 3. Boarding 4. Special Education 5. List 'D'	☐ 1	☐ 2	☐ 3
Actual School.....			
Class	☐ 4	☐ 5	☐ 6
School Performance 1. Excellent	☐ 7	☐ 8	☐ 9
(from school report 2. Good reported by parents) 3. Fair/Average 4. Poor 5. V. Bad			
Relationship with Teachers 1. Good 2. Fair/Average 3. Poor	☐ 10	☐ 11	☐ 12
Relationship with peers 1. Good 2. Fair/Average 3. Poor	☐ 13	☐ 14	☐ 15
Frequency of Physical Recreation 1. Daily 2. x2-x3/week 3. x1/week 4. None	☐ 16	☐ 17	☐ 18
Problems with Diabetes at School/ Interference with schooling 1. Yes 2. No	☐ 22	☐ 23	☐ 24
If Yes, specify 1. Hypos	☐ 25	☐ 26	☐ 27
2. Teasing 3. Made to feel different 4. Other			
Days missed at school per year	☐☐ 28-29	☐☐ 30-31	☐☐ 32-33

APPENDIX 4

LIFE EVENTS SCORING SHEET

LifeRec

LIFE EVENT RECORD

PRESCHOOL AGE GROUP

Rank	Life Event	Life Change units	Year 1	Year 2	Year 3
1	Beginning nursery school	42			
2	Increase in number of arguments with parents	39			
3	Change in parents' financial status	21			
4	Birth of a brother or sister	50			
5	Decrease in number of arguments between parents	21			
6	Change in father's occupation requiring increased absence from home	39			
7	Death of a grandparent	30			
8	Outstanding personal achievement	23			
9	Serious illness requiring hospitalization of parent	51			
10	Brother or sister leaving home	39			
11	Serious illness requiring hospitalization of brother or sister	37			
12	Mother beginning to work	47			
13	Change to a new nursery school	33			
14	Change in child's acceptance by peers	38			
15	Decrease in number of arguments between parents	22			
16	Increase in number of arguments between parents	44			
17	Serious illness requiring hospitalization of child	59			
18	Loss of job by a parent	23			
19	Death of a close friend	38			
20	Having a visible congenital deformity	39			
21	Addition of third adult to family	39			
22	Marital separation of parents	74			
23	Discovery of being an adopted child	33			
24	Jail sentence of parent for 30 days or less	34			
25	Death of a parent	89			
26	Divorce of parents	78			
27	Acquiring a visible deformity	52			
28	Death of brother or sister	59			
29	Marriage of parent to step-parent	62			
30	Jail sentence of parent for 1 year or more	67			
	N = 806				
		TOTAL			

LIFE EVENT RECORD

ELEMENTARY AGE GROUP

Rank	Life Event	Life Change Units	Year 1	Year 2	Year 3
1	Beginning another school year	27			
2	Outstanding personal achievement	39			
3	Beginning school	46			
4	Move to a new school district	46			
5	Increase in number of arguments with parents	47			
6	Change in parents' financial status	29			
7	Death of a grandparent	38			
8	Decrease in number of arguments between parents	25			
9	Mother beginning to work	44			
10	Becoming a full fledged member of a church	25			
11	Brother or sister leaving home	36			
12	Serious illness requiring hospitalization of parent	55			
13	Decrease in number of arguments with parents	27			
14	Change in father's occupation requiring increased absence from home	45			
15	Change in child's acceptance by peers	51			
16	Increase in number of arguments between parents	51			
17	Death of a close friend	53			
18	Birth of a brother or sister	50			
19	Pregnancy in unwed teenage sister	36			
20	Serious illness requiring hospitalization of brother or sister	41			
21	Loss of job by a parent	38			
22	Failure of a grade in school	57			
23	Divorce of parents	84			
24	Suspension from school	46			
25	Addition of third adult to family	41			
26	Marital separation of parents	78			
27	Serious illness requiring hospitalization of child	62			
28	Marriage of parent to step-parent	65			
29	Having a visible congenital deformity	60			
30	Acquiring a visible deformity	69			
31	Death of a brother or sister	68			
32	Discovery of being an adopted child	52			
33	Becoming involved with drugs or alcohol	61			
34	Jail sentence of parent for 30 days or less	44			
35	Jail sentence of parent for 1 year or more	67			

N = 887

NB Death of parent was inadvertently omitted from this form

N = 1014

LIFE EVENT RECORD
JUNIOR HIGH AGE GROUP

Rank	Life Event	Life Change Units	TOTAL	Year 1	Year 2	Year 3
1	Outstanding personal achievement	45				
2	Breaking up with a boyfriend or girlfriend	47				
3	Increase in number of arguments with parents	46				
4	Beginning junior high school	45				
5	Beginning to date	55				
6	Brother or sister leaving home	33				
7	Decrease in number of arguments between parents	29				
8	Suspension from school	54				
9	Not making an extracurricular activity he/she wanted to be involved in	24				
10	Becoming a full fledged member of a church	28				
11	Death of a grandparent	35				
12	Death of a close friend	65				
13	Increase in number of arguments between parents	48				
14	Becoming involved with drugs or alcohol	70				
15	Mother beginning to work	36				
16	Decrease in number of arguments with parents	29				
17	Change in parents' financial status	40				
18	Move to a new school district	52				
19	Serious illness requiring hospitilization of parent	54				
20	Serious illness requiring hospitalization of brother or sister	44				
21	Failure of a grade in school	62				
22	Change in child's acceptance by peers	68				
23	Change in father's occupation requiring increased absence from home	42				
24	Pregnancy in unwed teenage sister	60				
25	Loss of job by a parent	48				
26	Birth of a brother or sister	50				
27	Divorce of parents	84				
28	Addition of third adult to family	34				
29	Serious illness requiring hospitilization of child	59				
30	Marital separation of parents	77				
31	Marriage of parent to step-parent	63				
32	Death of a parent	94				
33	Having a visible congenital deformity	70				
34	Fathering an unwed pregnancy	76				
35	Acquiring a visible deformity	83				
36	Jail sentence of a parent for 30 days or less	50				
37	Death of a brother or sister	71				
38	Unwed pregnancy of child	95				
39	Discovery of being an adopted child	70				
40	Jail sentence of a parent for 1 yr or more	76				

APPENDIX 5

DIABETIC KNOWLEDGE TEST 1

NAME..... DATE.....

A. DIABETIC KNOWLEDGE TEST 1.

There is one correct answer to each question. Please put a tick next to the answer which you think is correct. If you do not know, please tick "don't know" rather than guessing!

*1. In uncontrolled diabetes the blood sugar is:-

a. Normal
b. Increased
c. Decreased
d. Don't know

2. Does diabetes tend to run in families?

a. Yes
b. No
c. Don't know

3. In people who have diabetes which part of the body is not working?

a. Stomach
b. Liver
c. Pancreas
d. Lungs
e. Don't know

*4. Which one of the following is true?

a. It does not matter if diabetes is not fully controlled as long as the person does not have a coma.
b. It is best to show some sugar in the urine to avoid hypos.
c. Poor control of diabetes could result in a greater chance of complications later.
d. Don't know

5. Should a diabetic avoid physical exercise?

a. Yes
b. No
c. Don't know

*6. The normal range for blood glucose is:-

a. 4-8 mmol/l
b. 7.15 mmol/l
c. 2-10 mmol/l
d. Don't know

7. What is an "exchange"?

a. A helping of "food"
b. A set amount of carbohydrate
c. A set amount of protein
d. Don't know

8. Is it important for a diabetic to eat regularly?

a. Yes
b. No
c. Don't know

9. What do you think carbohydrate produces in the diet?

a. Vitamins
b. Energy
c. Water
d. Fat
e. Don't know

*10. Rice is mainly:-

a. Protein
b. Carbohydrate
c. Fat
d. Mineral + vitamins
e. Don't know

11. A diabetic diet is:-

a. A guide for planning only the carbohydrate or sugar content of a meal
b. A well-balanced diet that the whole family can eat
c. A carefully planned system of special foods and measured insulin
d. Don't know

12. A diabetic should:-

a. Have his/her food cooked separately from the rest of the family
b. Eat the same food at the same time each day
c. Vary his/her diet by substituting different foods correctly from his/her diet exchange list
d. Don't know

13. Which food would supply you with a lot of roughage?

a. Baked beans
b. Corned beef
c. Custard
d. White bread
e. Don't know

14. During a bad attack of "flu" would the blood sugar level of a diabetic be:-

a. Lowered
b. Raised
c. Unchanged
d. Don't know

*15. The presence of ketones in the urine along with glucose is:-

a. A good sign
b. A bad sign
c. A usual finding in diabetes
d. Don't know

*16. If a diabetic feels the beginnings of a "hypo", he/she should:-

a. Immediately inject some insulin
b. Immediately lie down and rest
c. Immediately eat or drink a source of sugar
d. Don't know

17. Which food should a person cut down if they wanted to lose weight?

a. Cauliflower
b. Meat
c. Cheddar cheese
d. Tomatoes
e. Don't know

*18. Butter is mainly:-

a. Protein
b. Carbohydrate
c. Fat
d. Minerals + vitamins
e. Don't know

19. What does protein provide in the diet?

a. Energy
b. Vitamins
c. Material for growth
d. Don't know

20. Do you think diabetics should change the amount of fat in the diet by:-

a. Increasing the amount of fat
b. Decreasing the amount of fat
c. Keep the fat content the same
d. Don't know

21. What do you think fibre provides in the diet?

    a. Iron
    b. Vitamins
    c. Bulk
    d. Energy
    e. Don't know

22. Which of the following complications is not associated with diabetes:-

    a. Changes in vision
    b. Changes in the kidney
    c. Changes in the lung
    d. Don't know

23. If a Diastix test constantly shows an orange colour, does the diabetic need:-

    a. More insulin
    b. Less insulin
    c. The same insulin
    d. Don't know

*24. When a diabetic on insulin becomes ill and unable to eat the usual food:-

    a. He/she should immediately stop taking insulin
    b. He/she must continue to take insulin
    c. Don't know

*25. A diabetic can eat as much as he/she likes of which one of the following foods:-

    a. Apples
    b. Tomatoes
    c. Meat
    d. Honey
    e. Don't know

*26. A hypo is caused by:-

    a. Too little insulin
    b. Too much insulin
    c. Too little exercise
    d. Don't know

APPENDIX 6

DIABETIC KNOWLEDGE TEST 2
(PROBLEM-SOLVING QUESTIONS)

NAME..... DATE.....

B. DIABETIC KNOWLEDGE TEST 2.

In the following questions, there may be more than one correct answer to each question. Please put one tick next to each answer which you think is correct.

*1. A kilogram is:-

a. A metric unit of weight
b. Equal to 10 pounds
c. A unit of energy
d. A little more than 2 pounds
e. Don't know

2. How serious a disease is diabetes?

a. Very serious
b. Quite serious
c. Not at all serious
d. Don't know

3. Which measures of fruit may be exchanged for a medium eating apple?

a. 4 large prunes
b. A small banana
c. 1 large pear
d. 1 tangerine
e. 1 large orange
f. Don't know

4. Two of the following substitutions are wrong. Which are they?

a. One portion (1oz) bread = 4 exchanges
b. One egg = 1 small lamb chop
c. 5oz milk = 5oz orange juice
d. 5 tablespoons cornflakes = 15 tablespoons puffed wheat

5. Which of the following may cause a "hypo"?

a. Infection
b. Missing out insulin
c. A lot of exercise
d. Over eating
e. Taking too much insulin
f. Missing meals
g. Don't know

6. A 2% urine test in the pre-lunch specimen may mean:-

a. Too little short-acting insulin in the morning injection
b. A hypoglycaemic episode mid-morning
c. Too little long-acting insulin in the morning injection
d. Don't know

7. Which of the following symptoms are typical of hypoglycaemia?

   a. Passing a lot of urine
   b. Headache
   c. Poor concentration
   d. Shakiness
   e. Thirst
   f. Don't know

8. Which of the following are true about insulin:-

   a. Cloudy insulin has a longer duration of action than clear insulin
   b. Insulin is absorbed at different rates from different injection sites on the body.
   c. Skin infections are common when disposable syringes are used repeatedly.
   d. The plastic disposable syringe should be kept in spirit
   e. Don't know

*9. If a diabetic does not feel like the egg for his/her tea should he/she:-

   a. Have extra bread
   b. Have an ounce of cheese instead
   c. Have a small lamb chop
   d. Forget about it
   e. Don't know

10. If a diabetic wakes one morning with diarrhoea and vomiting should he/she:-

   a. Take no insulin in the morning injection
   b. Take a half dose of insulin in the morning injection
   c. Take the normal dose of insulin and behave as though nothing is wrong
   d. Take the normal dose of insulin and attempt to take carbohydrate as a sugar drink
   e. Wait till lunchtime before doing another blood or urine test
   f. Check the urine or blood every 2 hours and give extra short-acting insulin if necessary
   g. Don't know

11. A diabetic child is training for the school swimming team and practice is due in the mid-afternoon. His/her urine tests are usually negative before lunch and before tea. Should he/she:-

   a. Decrease his/her insulin on the days of practice
   b. Eat a larger lunch that day
   c. Increase his/her insulin to give him/her more energy that day
   d. Don't know

12. A diabetic child has a big test coming up in his/her hardest subject. He/she is very worried and thirty minutes before the test feels weak, shaky and sweaty, should he/she:-

   a. Go to the school nurse and not take the test
   b. Eat something
   c. Take extra insulin to be ready for the test
   d. Don't know

APPENDIX 7

CHILDREN'S QUESTIONNAIRE

Name: _____

CHILDHOOD DIABETES QUESTIONNAIRE CHILD

1. Have you read a book about diabetes YES / NO

   If the answer is YES, what was the book called

   _____

2. Do you wear a necklet or bracelet or carry a card about being a diabetic? YES / NO

3. How many other children with diabetes do you know? NONE / ONE / TWO / MORE THAN TWO

4. The cause of your diabetes is-
   - The kidneys not controlling sugar in urine
   - the pancreas gland not making enough insulin
   - eating too much sugar and sweet food
   - don't know

5. The pancreas gland is-
   - in the kidneys
   - in the chest near the heart
   - in the tummy near the liver
   - don't know

6. The pancreas gland makes-
   - sugar
   - glucose
   - insulin
   - don't know

7. When diabetes is not controlled properly by insulin the blood sugar goes-
   - up
   - down
   - stays the same
   - don't know

8. When diabetes is <u>not</u> controlled properly by insulin the sugar in urine goes-

- up
- down
- stays the same
- don't know

9. If the urine test is always orange how much sugar is there?

- too much
- not enough
- don't know

10. If the urine test is always orange do you need?

- less insulin
- more insulin
- don't know

11. Does the amount of insulin you need change when you have a cold or sore throat?

YES NO DON'T KNOW

12. If you think the amount of insulin you need when you have a cold changes, how much do you need?

- More
- Less

13. Do you know what a hypo is?

YES NO

14. If you have a hypo do you have-

- more insulin
- some sugar (glucose)
- some water only
- don't know

15. An "insulin reaction" or "hypo" may be caused by?

- Too much insulin
- not enough insulin
- don't know

16. An "insulin reaction" or "hypo" may be caused by?

- not enough food
- too much food
- don't know

17. An "insulin reaction" or "hypo" may be caused by?

- not enough exercise
- lots of exercise
- don't know

18. If just one of your tests is blue do you?

- eat more than usual
- eat the same as usual
- don't know

19. An injection of insulin tends to make the sugar in blood?

- go up
- go down
- don't know

20. The injection of insulin should be?

- below the skin in the fat layer
- in the surface skin
- in the muscle
- don't know

21. The insulin should be given?

- after meals
- during meals
- before a meal
- don't know

22. Another word for low sugar in the blood is?

- diabetes
- "hypo" or hypoglycaemia
- don't know

23. Lots of exercise (in running, swimming, football, gymnastics, etc) for children with diabetes is?

- good
- bad
- not allowed
- don't know

24. If you do lots of exercise you might need?

- more sugar
- less sugar
- don't know

25. Sugar is called?

- protein
- fat
- carbohydrate
- don't know

26. To diabetics, protein is?

- harmful
- useful
- not needed
- don't know

APPENDIX 8

FAMILY LIFE AND RESPONSIBILITY QUESTIONNAIRE

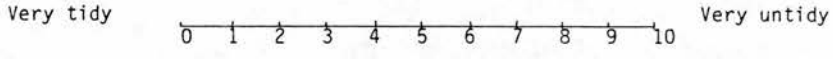
HOW TO ANSWER OUR QUESTIONS

This questionnaire looks at the types of thoughts and feelings experienced by you and your family. Please answer all questions as each one is an important source of information to us. If you cannot answer a particular question because it does not apply to you, just write NA (not applicable) opposite that question (for example, questions about school when your child has not yet started school). At the end of the questionnaire is a blank sheet of paper in case you want to make additional comments.

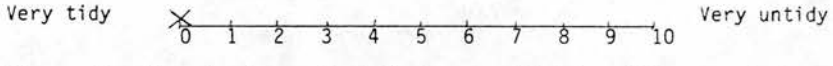
Each question may be answered on a scale that allows you to indicate just how strongly you feel about certain things or how frequently certain things happen. The numbers on the scale have nothing to do with whether or not an answer is right or wrong. There is NO right or wrong answer to any of these questions. We just want to know how you feel about your life and so the numbers are there to allow you to tell us how strong these feelings are. Here are some examples to show you how to answer our questions.

EXAMPLES

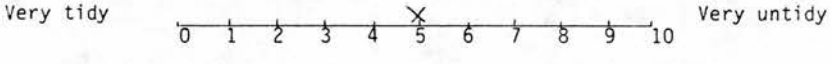
1. Is your child tidy or untidy?



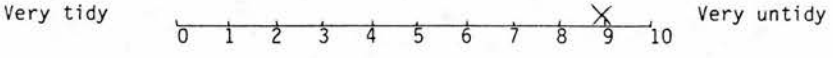
If your child is very tidy - he always puts his toys away, makes his bed etc. - then you would cross "0":



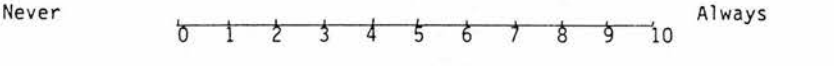
If, on the other hand, you feel that your child is neither particularly tidy nor untidy, but his lack of tidiness is not so bad that it is a big problem between you and him, then you may choose to cross "5":



Now, if you think that your child is very untidy, and you do have lots of angry arguments with him about it, then you may cross "9" or "10" (depending on how bad you feel it is):

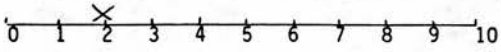


2. Do you feel that your child is lonely?

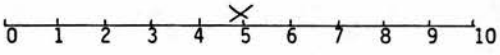


Now, if you think that your child is never lonely, then you would cross "0":

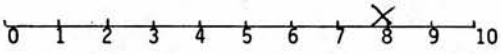
If you occasionally have the feeling that your child is lonely, but these times seem "few and far between", then a number like "1" or "2" would be appropriate

Never  Always

If, on the other hand, you feel that your child is a "bit of both" - that is to say, he is quite often lonely, but he does spend a fair amount of time with friends - then "5" would be a good number for you to cross:

Never  Always

However, if your child is indeed often lonely and you are very worried about him, you might choose to cross "8" (depending on how bad you feel the situation is):

Never  Always

NewsLetl

I. MOODS AND FEELINGS

1. Do you think the diagnosis of diabetes has affected your child's self-confidence?

It makes no difference — 0 1 2 3 4 5 6 7 8 9 10 — Less self-confident

2. Are you having problems with his behaviour?

No problems — 0 1 2 3 4 5 6 7 8 9 10 — A lot of problems

If you are having problems with your child's behaviour, please describe them:

.....

.....

.....

.....

3. Is your child quite outgoing or does he tend to go into a shell a lot?

Very outgoing — 0 1 2 3 4 5 6 7 8 9 10 — In a shell most of the time

4. Does your child lean on you all the time or does he insist on doing things on his own?

He insists on doing everything on his own — 0 1 2 3 4 5 6 7 8 9 10 — He leans on me all the time

5. Does your child prefer activities that are away from home (e.g. playing football) or does he tend to stay around the house a lot (e.g. reading)?

He goes out a lot — 0 1 2 3 4 5 6 7 8 9 10 — He stays at home a lot

6. Do you find it difficult or easy to manage and control his behaviour?

Very easy to manage — 0 1 2 3 4 5 6 7 8 9 10 — Very difficult to manage

7. Does your child ever feel that he has particular difficulties at school because of diabetes? (For example, does he feel that he "stands out" from other children because of the nature of his diet?)

No difficulties at school 0 1 2 3 4 5 6 7 8 9 10 A lot of difficulties at school

If your child is experiencing difficulties at school, please describe them:

.....

.....

.....

.....

8. Do you think your child feels different from other children because of diabetes (e.g. not being able to buy sweets)?

He does not feel different 0 1 2 3 4 5 6 7 8 9 10 He feels completely different

9. Does your child ever feel that he is sometimes a burden to you and your family?

He never feels that way 0 1 2 3 4 5 6 7 8 9 10 He always feels that way

10. Have the special needs of your diabetic child brought you closer to him than to your other children?

It has not brought us closer together at all 0 1 2 3 4 5 6 7 8 9 10 It has brought us closer together

11. On the other hand, do you ever feel that the special needs of your diabetic child have made you less close to him than to your other children?

It has not made us less close 0 1 2 3 4 5 6 7 8 9 10 It has made us less close

12. Do you ever have the feeling that your child blames himself for his condition (e.g. eating too many sweets)?

He does not blame himself 0 1 2 3 4 5 6 7 8 9 10 He blames himself completely

13. Are you "easier" on your diabetic child than on your other children when it comes to discipline?

I am not any easier 0 1 2 3 4 5 6 7 8 9 10 I am a lot easier

14. Do you feel that your child could achieve more without diabetes or do you feel that it has been no real hindrance?

It is no real hindrance 0 1 2 3 4 5 6 7 8 9 10 He could achieve more

15. Does your child eat quite easily or do you have trouble getting him to eat?

He eats very easily 0 1 2 3 4 5 6 7 8 9 10 I have great trouble getting him to eat

16. Do you worry about your ability to look after your child?

I never worry 0 1 2 3 4 5 6 7 8 9 10 I always worry

17. Have you seen a change in your child's moods since the diagnosis of diabetes?

Yes No

If you have answered YES, please tell us whether he is more or less moody now.

Less moody 0 1 2 3 4 5 6 7 8 9 10 More moody

II. YOUR CHILD'S ACTIVITIES

1. Does your child seek the company of friends or does he prefer to spend a lot of time on his own?

He spends all his time with friends — 0 1 2 3 4 5 6 7 8 9 10 — He is alone all the time

2. Do you ever feel a need to keep an eye on his activities?

I do not need to watch what he is doing — 0 1 2 3 4 5 6 7 8 9 10 — I watch what he is doing all the time

3. Is your child involved in a variety of hobbies and activities (e.g. swimming, computers)?

He is always involved in some sort of hobby or activity — 0 1 2 3 4 5 6 7 8 9 10 — He never shows any interest in hobbies and activities

4. Do you feel that your child is able to join in physical activities (e.g. tennis, football, swimming, running, etc) to the same extent as children without diabetes?

He can participate in any physical activity — 0 1 2 3 4 5 6 7 8 9 10 — He should not participate in physical activities at all

Are there any particular activities you would discourage your child from engaging in?

Yes No

If you have answered "Yes", please describe these activities.

.....

.....

.....

.....

Are there any particular activities you encourage your child to engage in?

Yes No

If you have answered "Yes", please describe these activities:

.....

.....

.....

.....

5. Do you worry about your child when he is away at school or out with friends?

I do not worry at all 0 1 2 3 4 5 6 7 8 9 10 I worry the whole time

6. Do you ever feel that your child's school has unnecessarily restricted his involvement in activities such as sports and school outings?

He is allowed to do everything 0 1 2 3 4 5 6 7 8 9 10 He is not allowed to do anything

If the school does restrict your child's involvement in activities, please describe these restrictions.

.....

.....

.....

.....

7. Has diabetes had any effect on your child's progress at school?

Absolutely no effect 0 1 2 3 4 5 6 7 8 9 10 A very bad effect

Please tell us in what way diabetes is affecting your child's progress at school (if you think it is)

.....

.....

.....

.....

III. FAMILY ACTIVITIES

1. Do you ever feel that your child's diabetes restricts the following family activities?

   (a) Shopping?

   No restrictions on family activity — 0 1 2 3 4 5 6 7 8 9 10 — Not a family activity anymore

   (b) Eating in restaurants?

   No restrictions on family activity — 0 1 2 3 4 5 6 7 8 9 10 — Not a family activity anymore

   (c) Visiting friends or relatives?

   No restrictions on family activity — 0 1 2 3 4 5 6 7 8 9 10 — Not a family activity anymore

   (d) Receiving friends or relatives in your home?

   No restrictions on family activity — 0 1 2 3 4 5 6 7 8 9 10 — Not a family activity anymore

   (e) Going to the films or theatre?

   No restrictions on family activity — 0 1 2 3 4 5 6 7 8 9 10 — Not a family activity anymore

   (f) Day trips to the country etc?

   No restrictions on family activity — 0 1 2 3 4 5 6 7 8 9 10 — Not a family activity anymore

   (g) Family holidays?

   No restrictions on family activity — 0 1 2 3 4 5 6 7 8 9 10 — Not a family activity anymore

   (h) Family celebrations?

   No restrictions on family activity — 0 1 2 3 4 5 6 7 8 9 10 — Not a family activity anymore

2. Do you ever feel that your child's diabetes ties you more to the home than you would be otherwise?

   I do not feel tied to the home at all — 0 1 2 3 4 5 6 7 8 9 10 — I feel completely tied to the home

3. Do you ever feel that you do not pay enough attention to the needs of your other children because of the special requirements of your diabetic child?

I do feel I pay enough attention — 0 1 2 3 4 5 6 7 8 9 10 — I do not feel I pay enough attention

4. Do you ever feel that life is made more difficult for your other children because of diabetes in the family or do you feel that it has had no effect on their lives?

No difficulties at all — 0 1 2 3 4 5 6 7 8 9 10 — A lot of difficulties

If your children are finding life difficult, please describe the kind of problems they have:

.....

.....

.....

.....

5. Do you ever feel that the responsibility of a diabetic child makes it impossible for you to go out to work?

The responsibility does not stop me from working — 0 1 2 3 4 5 6 7 8 9 10 — The responsibility does stop me from working

Is money "tight" for you and your family because you do not work?

Yes No

6. Do you ever feel that the problems associated with having a diabetic child in the family have made it more difficult for your husband to get on in his job?

My husband's job has not been affected — 0 1 2 3 4 5 6 7 8 9 10 — My husband's job has been affected

7. Does your family have meals together or does each person just eat when he is hungry?

The family has meals together — 0 1 2 3 4 5 6 7 8 9 10 — People just eat when they are hungry

8. Are there particular times of the day when you find attending to the needs of your child very difficult or do you find the routine quite easy now?

Morning (Breakfast)

Not difficult 0 1 2 3 4 5 6 7 8 9 10 Always difficult

Afternoon (Lunch)

Not difficult 0 1 2 3 4 5 6 7 8 9 10 Always difficult

Evening (Dinner/Tea)

Not difficult 0 1 2 3 4 5 6 7 8 9 10 Always difficult

9. Do you ever restrict the activities of your other children (e.g. not buying them sweets or a birthday cake) in order not to upset your diabetic child or do you make no special allowances for him?

I do not restrict their activities at all 0 1 2 3 4 5 6 7 8 9 10 I always restrict their activities

10. Do you allow your child to eat meals that are not made by you?

Always 0 1 2 3 4 5 6 7 8 9 10 Never

Under what circumstance do you allow your child to eat meals made by someone else?

.....

.....

.....

.....

11. Does your diabetic child eat the same meals as the rest of the family or does he have something different?

He always has the same meal 0 1 2 3 4 5 6 7 8 9 10 He always has something different

12. Do you ever feel that your other children resent the extra attention received by your diabetic child or do they not seem to be bothered by it all?

The children do not seem to be bothered 0 1 2 3 4 5 6 7 8 9 10 The children are resentful

IV. DIABETIC CARE

1. Do you worry about your child "cheating" over food when he is away from home?

I never worry 0 1 2 3 4 5 6 7 8 9 10 I always worry

2. Do you think that your child takes on enough responsibility in looking after himself (e.g. diet, injections)?

He takes on complete responsibility 0 1 2 3 4 5 6 7 8 9 10 He takes on no responsibility at all

3. On the other hand, do you think your child knows enough in order to look after himself?

He knows enough 0 1 2 3 4 5 6 7 8 9 10 He does not know enough at all

4. Do you feel that your child's school has enough understanding of his condition (e.g. how to deal with a "hypo")?

Enough understanding 0 1 2 3 4 5 6 7 8 9 10 Absolutely no understanding

5. Do you feel that your child is trustworthy when it comes to doing all the things he has to do for his diabetes (e.g. urine testing, eating at the right time, etc.)?

I can trust him completely 0 1 2 3 4 5 6 7 8 9 10 I cannot trust him at all

6. Do you ever find planning and preparing family meals particularly difficult in view of your child's dietary needs or does the whole thing seem quite routine now?

Planning and preparing meals is never difficult 0 1 2 3 4 5 6 7 8 9 10 Planning and preparing meals is always difficult

7. Does your child know which foods he can (or cannot) eat or do you have to tell him?

He always knows what he can eat 0 1 2 3 4 5 6 7 8 9 10 I always have to tell him what he can eat

8. Do you ever feel a bit alarmed when your child tells you that he is hungry?

I never feel alarmed 0 1 2 3 4 5 6 7 8 9 10 I always feel alarmed

9. Do your other children worry about becoming diabetic themselves?

They never worry — 0 1 2 3 4 5 6 7 8 9 10 — They always worry

10. Do your other children worry about having diabetic children?

They never worry — 0 1 2 3 4 5 6 7 8 9 10 — They always worry

11. Are the following a source of conflict between you and your child?

FOOD

Never conflict — 0 1 2 3 4 5 6 7 8 9 10 — Always conflict

URINE TESTING

Never conflict — 0 1 2 3 4 5 6 7 8 9 10 — Always conflict

BLOOD TESTING

Never conflict — 0 1 2 3 4 5 6 7 8 9 10 — Always conflict

INJECTIONS

Never conflict — 0 1 2 3 4 5 6 7 8 9 10 — Always conflict

12. Do you ever worry about your child's future with respect to the following?

(a) Getting a Job

I never worry — 0 1 2 3 4 5 6 7 8 9 10 — I always worry

(b) Marriage

I never worry — 0 1 2 3 4 5 6 7 8 9 10 — I always worry

(c) Leaving Home

I never worry — 0 1 2 3 4 5 6 7 8 9 10 — I always worry

(d) Sticking to the Diabetic Requirements
(e.g. diet, injections, urine testing, etc)

I never worry — 0 1 2 3 4 5 6 7 8 9 10 — I always worry

(e) Long-term Complications

I never worry — 0 1 2 3 4 5 6 7 8 9 10 — I always worry

13. Do you feel that you have been "left on a limb" to cope with things on your own or do you feel that the hospital does provide enough support?

The hospital does provide enough support — 0 1 2 3 4 5 6 7 8 9 10 — I have been left to cope with things on my own

14. Does your child get upset when he sees other children eating things (sweets, cakes, etc.) that he cannot eat?

He does not get upset at all — 0 1 2 3 4 5 6 7 8 9 10 — He gets very upset

15. What is the worst thing about diabetes?

the injections
the tests
the food
the hospital
anything else .....

.....

.....

V. PARENT'S RELATIONSHIP

1. Do you ever feel that your partner is not assuming enough responsibility in meeting the requirements of a diabetic child?

My partner does take on enough responsibility — 0 1 2 3 4 5 6 7 8 9 10 — My partner never takes on enough responsibility

2. On the other hand, does your partner ever feel that you are taking on complete responsibility and excluding him from involvement in the care of your child?

My partner does not feel excluded at all — 0 1 2 3 4 5 6 7 8 9 10 — My partner feels completely excluded

3. Do you feel that your relationship with your partner is very good or very bad?

Very good — 0 1 2 3 4 5 6 7 8 9 10 — Very bad

4. Do you ever feel that your relationship with your partner has changed since your child's diabetes was diagnosed?

It has not changed at all — 0 1 2 3 4 5 6 7 8 9 10 — It has changed completely

If you do feel your relationship has changed, in what way is it different from what it was before?

.....

.....

.....

.....

5. Do you feel that you and your partner never have an opportunity to spend time with each other (e.g. going to the films or out for a drink)?

We do spend enough time with each other — 0 1 2 3 4 5 6 7 8 9 10 — We are never alone together

6. Does having a diabetic child cause conflict between you and your husband insofar as the following areas are concerned?

(a) General worry over your child's health

Never conflict 0 1 2 3 4 5 6 7 8 9 10 Always conflict

(b) Financial difficulties due to your child's diet, travelling to hospital, etc.

Never conflict 0 1 2 3 4 5 6 7 8 9 10 Always conflict

(c) Your child's diabetic control

Never conflict 0 1 2 3 4 5 6 7 8 9 10 Always conflict

(d) Maintenance of the diabetic requirements (e.g. diet, injections, urine testing, etc)

Never conflict 0 1 2 3 4 5 6 7 8 9 10 Always conflict

7. Does your partner ever feel that you are so preoccupied with the care of your child that you do not really have any time for him?

He never feels that way 0 1 2 3 4 5 6 7 8 9 10 He always feels that way

APPENDIX 9

DATA COLLECTION SHEET FOR TRAVEL INFORMATION

TRAVEL STUDY

For today's visit to the club:-

1. My relationship to the patient is: (please tick)

   Mother ☐ Father ☑ Other relative ☐ Friend ☐

2. Who came with you? (please tick)

   The patient ☑ ~~Husband~~/wife ☑ No one else ☐

   Another child/ children ☐ Other adult ☐

3. How did you travel? (please tick)

   By:-

   Bus ☑ Private car ☐

   Train ☐ Walking all the way ☐

   Taxi ☐ Other method ☐

   (please specify .....)

4. For bus, train or taxi travellers only*

   What was the cost of SINGLE fares for all those who made the journey?

   £..... p.75..

   * (for car users we have standard methods of calculating costs)

5. How long did it take you to make the journey to the hospital? (include from the time youleft home or work, collected someone on the way if necessary, until you arrived at hospital)

   ..1....hrs ..15..mins

6. Did you have to make any special arrangements to enable you to come? (For example, did you have to take time off work, arrange for someone to look after a child or borrow a car? - anything at all like that?)

   Yes ☐ No ☑

   If Yes, please specify: .....

   .....

THANK YOU FOR YOUR HELP

PUBLICATIONS

DM ORIGINAL ARTICLES

A Project in Diabetes Education for Children

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Forty-eight families with children less than 13 years old attending a paediatric diabetic clinic volunteered for a 2-year randomized crossover trial to determine whether an informal education programme (diabetic club) could improve diabetic control. Group A attended the diabetic club for 10 afternoons of informal education in the first year, while Group B continued at the routine clinic (5 visits per year). For the second year Group A returned to the clinic, Group B attended the club. Glycosylated haemoglobin (HbA_1) remained stable while attending the club but rose significantly ($p < 0.01$) while attending the clinic in both groups (HbA_1 at baseline, 1 year, and 2 years: Group A, 9.6 (SD 1.2), 9.6(1.4), 10.7(2.1) %; Group B 8.9(1.3), 10.4(1.4), 10.5(1.4) % (normal reference range 4.7–7.9 %)). Other indices of control were unchanged. Diabetic problem-solving scores of parents improved ($p < 0.01$) but their knowledge of diabetes did not correlate with their child's HbA_1. Dietary intake showed a reduction in percentage of energy taken as fat (40 % vs 37.7 %, $p < 0.05$) during club attendance. The percentage of parents reporting helpful social contact between families increased during their club year (Group A 50 to 78 %, Group B 32 to 57 %, $p < 0.001$). Psychological measurements remained unchanged. An education programme for diabetic children may stabilize diabetic control in the short term but this effect is not sustained. The main benefit was the support provided by increased social contact with families of other diabetic children within the informal framework of the diabetic club.

KEY WORDS **Type 1 diabetes Patient education Psychology Diet Children**

Introduction

Diabetic control in some children is not ideal[1,2] possibly because of lack of knowledge about diabetes and the anxiety associated with a chronic disease which involves a constant complex daily routine of treatment involving both short- and long-term threats. Traditional clinic services may not be appropriate for all patients.

In a recent survey[3] of diabetic adults who had previously attended the paediatric diabetic clinic at the Royal Hospital for Sick Children, Edinburgh, two-thirds had unhappy recollections about some aspects of their care. As a result of this survey several problems with our current paediatric diabetic clinic were identified:

1. Too much information is given at diagnosis, but thereafter is given piecemeal in response to patient demand rather than as a regular review of knowledge and technique.
2. Dietitian time is limited (she may see stable diabetic children once per year, more often only if problems arise or on request).
3. Diabetic families seldom talk to each other in the current clinic setting. Many diabetic children know no others with the condition.
4. It is difficult to tackle stress-related problems in the short clinic time available.

An informal education programme covering all aspects of diabetic care in a supportive environment was developed and assessed by a 2-year prospective crossover trial. The aims were to determine if such a programme would improve knowledge and understanding of diabetes by children and their families, reduce stress, and thereby improve diabetic control.

Patients and Methods

Patients

Ninety-two patients attending the Royal Hospital for Sick Children clinic were less than 13 years of age, had diabetes of more than 3 months duration, and were thus eligible to enter the 2-year project. Forty-eight families agreed to participate.

Experimental Design

The project was designed as a 2-year, two-period crossover controlled trial[4] to reduce the effects of seasonal variation, including intercurrent infections, on diabetic control. The 48 participating patients were allocated to eight groups of six by a stratified randomization based on social class, and four of these groups were randomly allocated to each treatment group A and B. Group A attended the education project (diabetic club) for the first

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year while Group B continued at the routine clinic. For the second year Group A returned to the routine clinic while Group B took part in the diabetic club. Data were also collected prospectively on the 44 non-participants and their families who continued to attend the routine diabetic clinic.

Each small group of six families attended the diabetic club together ten times per year. Visits took place from 1200–1530 h in an informal setting in a house adjacent to the Hospital (School of Community Paediatrics). Lunch was planned and prepared by the dietitian who used this opportunity to teach about healthy eating for all the family.

Thereafter teaching was based on semi-structured discussion groups and covered all aspects of diabetes care including diet, control, planning for social activities and the future, and possible complications. Parents and children were seen separately. Various teaching strategies were used for the children including cooking, drawing, story-telling, and computer-based teaching programmes with the help of a play leader. Videos produced by the British Diabetic Association were also used. Glycosylated haemoglobin, height and weight, skinfold thicknesses, and diabetes-related events were recorded at each visit. Time was available for individual discussion with a paediatrician if needed.

The routine clinic visits occurred on average five times per year with a one-to-one interview with a paediatrician (or adult physician for adolescents). A dietitian, chiropodist, and specialist nurse were available if needed. Time spent at each club and clinic visit was recorded.

The following assessments were carried out on entry to the study, at the end of Year 1 and the end of Year 2.

Medical and Social Background

A profile of each child was obtained including a history of diabetes-related events, methods of diabetic care, exercise taken, problems with diabetes in school, school performance (by parental report). Family structure and any history of family illness were recorded and changes in life events unrelated to diabetes were scored by the method of Coddington.[5] A diary was used to gather information about diabetes-related events from each patient.

Measurement of Diabetic Control

Glycosylated haemoglobin (HbA_1) concentration was measured at each visit. Days spent in hospital, episodes of hypoglycaemia, insulin dose, number of infections, growth velocity, and days absent from school (from education authority) were also recorded. HbA_1 was measured by gel electrophoresis after removal of the labile fraction throughout the period of the study[6] (normal reference range for HbA_1 for our laboratory 4.7–7.9 %).

Knowledge about Diabetes

Parents were assessed by a simple factual questionnaire (DKT1), and one based on problem solving (DKT2) devised from Dunn *et al.*[7] The children were given a brief questionnaire assessing factual knowledge.[8]

Dietary Surveys

The dietary assessment used was a modification of the 7-day weighed record.[9] The families were instructed in groups in the diabetic club, or at home. Written instructions were supplied with the daily record sheets, pocket diary for items eaten away from home, and the necessary weighing and measuring equipment to conduct the survey. Families telephoned the dietitian if necessary.

Nutrient intakes were computed using standard food tables.[10,11] Foods not in these tables were incorporated using information obtained from the manufacturers.

Psychological Assessments

Intelligence was measured at baseline using the Stanford-Binet Intelligence Scale (for children <7 years) or the Wechsler Intelligence Scale for children (revised). Psychological assessment was based on the Rutter Behaviour Scale[12] and the Vineland Social Maturity Scale.[13]

Parental View of the Programmes

The parents' view of the education programme was assessed by questionnaires in three areas:

(a) Benefits provided by the club compared with the clinic in relation to topics covered (such as hypoglycaemia) and the support provided by the programme.
(b) The degree of child involvement in the treatment regimen ('responsibility') as previously assessed by Allen *et al.*[14]
(c) Effects of diabetes on 'family life' and whether this was changed by attendance at the club. Questions assessed daily practical difficulties, such as blood testing, the integration of the diabetic regimen into the family routine, and its effect on other family members and relationships.

All questionnaires utilized a visual analogue scale.

Statistical Analysis

The methods described by Armitage and Hills[4] for two-period crossover trials were used when measurements had been made at the end of both the first and second years of the study using Wilcoxon rank sum tests for quantitative observations. Where baseline measurement was also available, these tests were carried out on the changes from baseline to the end of the later periods. For binary observations or those on short ordinal scales, chi-squared tests with Yates' correction or Wilcoxon rank sum tests were used. For comparison of the two groups for measurements made only once, and for comparison of the study groups and the non-participants at entry and at the end of the study, chi-squared or Wilcoxon tests were used as appropriate. Results are presented as mean (SD).

Results

All participants completed the 2-year study, with an attendance rate of >80 %. The non-participants were significantly older and taller, had had diabetes for longer, had made fewer clinic visits in the year prior to entry, and more often took part in daily exercise than those in Groups A and B. There were no other significant differences (Table 1). The two randomized groups A and B were also comparable except for the number of infections occurring during the year preceding entry (Table 1). Other variables found to be similar included episodes of severe hypoglycaemia, number of injections and injection sites used per day, height velocity, triceps and subscapular skinfold thicknesses, methods of monitoring control, incidence of medical and psychiatric problems (as judged by referral to a psychiatrist) in parents and children, and the incidence of stressful life events unrelated to diabetes.

Medical and Social Background

At the end of the study only 12 % of non-participants used more than three injection sites compared with 28 % of those in Groups A and B ($p < 0.01$), and only 17 % regularly performed ketone testing compared with 46 % of those in Groups A and B ($p < 0.05$). No other significant differences were observed. There was no significant difference between Groups A and B during the study for incidence of medical problems, psychiatric referrals, the incidence of stressful life events, anthropometric indices including height velocity and triceps and subscapular skinfold thickness, or percentage of children entering puberty (31 %). Daily exercise increased to 55 % in both groups.

Some of the methods of diabetic care did change during the study. In Group A 70 % routinely performed blood tests at entry; 96 % after attending the club, but this fell to 87 % after returning to the routine clinic. In Group B, 70 % performed blood tests at entry, 87 % after 1 year at the routine clinic and 96 % when they attended the diabetic club. This demonstrates a significant effect of attending the club ($p < 0.01$). Three or more injection sites were used by 28 % of children in both Group A and Group B after attending the club for 1 year compared with 8 % of Group A and 4 % of Group B at the beginning ($p < 0.05$).

Measurement of Diabetic Control

HbA_1 for the non-participants was 10.8(1.9) % at the end of the study, not significantly different from those in Groups A and B, and there was no significant difference in any of the variables listed in Table 2. In both Groups A and B mean HbA_1 remained stable during their year attending the diabetic club but rose during their year attending the routine diabetic clinic (Table 2). This demonstrates a significant effect for attending the club ($p < 0.01$). There was no correlation between scores achieved on knowledge tests by mothers and changes in their child's HbA_1 for the whole study period.

Table 1. Characteristics of children <13 years attending the diabetic clinic at the Royal Hospital for Sick Children, Edinburgh, in the year prior to entry to the study

	Participants (Group A)	(Group B)	p	Non-participants	p^a
n	24	24		44	
Age at entry (yr)	9.1 (3.1)	8.9 (2.9)	NS	10.4 (2.4)	< 0.05
Duration of disease (yr)	2.8 (2.4)	2.7 (1.9)	NS	4.5 (3.2)	< 0.01
Sex M/F	12/12	9/15	NS	18/26	NS
Social class I+II (%)	33	29	NS	36	NS
Unemployed (%)	8	8	NS	5	NS
Admissions to hospital (days)	1.5 (2.9)	1.6 (1.7)	NS	1.4 (5.6)	NS
Hypoglycaemic episodes at home (events $year^{-1}$)	3.8 (3.3)	3.4 (2.1)	NS	3.3 (3.4)	NS
Number of infections	1.5 (1.3)	0.7 (1.7)	< 0.05	1.0 (1.4)	NS
Number of clinic visits	5.6 (1.8)	5.5 (1.7)	NS	4.6 (0.8)	< 0.01
HbA_1 (%)	9.6 (1.7)	8.9 (1.3)	NS	9.4 (1.5)	NS
TSH (mU l^{-1})	2.7 (1.4)	2.8 (1.0)	NS	3.0 (2.7)	NS
Insulin dose (U kg^{-1} 24-h^{-1})	0.80 (0.25)	0.81 (0.25)	NS	0.86 (0.2)	NS
Height (m)	1.32 (0.19)	1.32 (0.16)	NS	1.39 (0.15)	< 0.05
Weight (kg)	31.8 (12.2)	33.6 (10.2)	NS	36.4 (10.1)	NS
Prepubertal (%)	83	83	NS	86	NS
Taking daily exercise (%)	14	14	NS	40	< 0.01

Mean (SD), or number or percentage.
HbA_1 normal reference range 4.7–7.9 %.
[a]Significance vs participants.

Table 2. Diabetic control and diabetic knowledge in participants during 2-year education programme

	Entry		End Year 1		End Year 2		Significance of intervention p	95% Confidence limits for intervention
	A	B	A	B	A	B		
HbA_1 (%)	9.6 (1.7)	8.9 (1.3)	9.6 (1.4)	10.4 (1.4)	10.4 (1.2)	10.5 (1.4)	< 0.01	−0.09, −1.07
Admission to hospital (days)	1.5 (2.9)	1.6 (1.7)	0.3 (0.9)	3.0 (10.9)	1.2 (2.3)	1.3 (4.4)	NS	−3.8, +1.2
Hypoglycaemic events	3.8 (3.3)	2.3 (2.1)	3.7 (4.1)	3.8 (4.1)	2.4 (3.5)	4.7 (3.6)	< 0.05	−0.1, +2.1
Insulin dose (U kg^{-1} 24-h^{-1})	0.80 (0.25)	0.81 (0.25)	0.90 (0.22)	0.86 (0.21)	1.00 (0.31)	0.98 (1.17)	NS	−0.04, +0.06
Absences from school (days)	22.1 (19.0)	13.8 (5.5)	20.3 (17.6)	15.7 (15.9)	25.8 (24.0)	13.2 (9.0)	< 0.1	−9.4, −0.5
Diabetic Knowledge Test 1 (% correct)	84 (16)	82 (13)	89 (13)	86 (13)	91 (8)	88 (7)	NS	−1.9, +2.8
Diabetic Knowledge Test 2 (% correct)	74 (18)	76 (11)	81 (12)	74 (8)	82 (12)	79 (10)	< 0.01	+1.6, +5.1

Mean (SD) unless otherwise stated.
Group A = club first year; Group B = club second year.
HbA_1 normal reference range 4.7–7.9 %.

Hospital admission rates, incidence of infections, and insulin dose and days absent from school were similar during each year but the mean number of hypoglycaemic episodes was significantly higher in Group B during the year attending the club ($p < 0.05$) (Table 2).

Knowledge and Understanding of Diabetes

Tests of factual knowledge (DKT1) and problem solving (DKT2) were performed by mothers. Overall scores were high but with a wide range. The scores attained by mothers in the non-participant group at baseline (DKT1 89.3 (9.6) and DKT2 79.8 (9.1) % correct) and at the end of the second year (DKT1 90.4 (11.0) and DKT2 80.6 (9.0) %) were similar to those achieved by mothers of children in Groups A and B.

There was no significant difference in test scores between Groups A and B on entry to the study (Table 2), or in scores attained in DKT1 over the 2-year period. There was a significant improvement in scores attained in DKT2 for both Group A and Group B at the end of their year attending the club ($p < 0.01$) (Table 2). After returning to the diabetic clinic these increased scores were maintained in Group A.

Children in the study groups similarly completed a questionnaire about diabetes and there was no significant difference in scores during their year attending the club.

Dietary Assessment

Dietary surveys were successfully completed by 88 % of Groups A and B. Mean daily energy intake was unchanged but the percentage obtained from fat was significantly reduced during the club year (Table 3). There was a corresponding but not significant ($p < 0.10$) increase in carbohydrate intake (Table 3). The proportion of energy taken as starch, sugar, and protein, and total fibre intake did not change significantly (Table 3).

Psychological Assessment

Measurements of intelligence quotient, behavioural disturbance, and social maturity on entry to the study were within the normal range for children of this age and there was no significant difference between Groups A and B. Scores for behavioural disturbance and social maturity were not significantly changed by attendance at the diabetic club.

Parental Assessment of the Programme

The percentage of parents reporting frequent social contact with parents of other diabetic children was significantly greater during their year attending the diabetic club compared with the routine clinic (Group A 61 % vs 33 %; Group B 52 % vs 17 %, $p < 0.001$). Furthermore, parents in both groups found this increased social contact during their year attending the diabetic club very helpful in the management of their child's diabetes (Group A 78 % vs 50 %; Group B 57 % vs 32 %, $p < 0.001$).

There was no discernible effect of attending the club in responses to the 'responsibility' or 'family life' questionnaires.

Discussion

In this study diabetic control has been observed over a 2-year period in a group of children aged under 13 years

Table 3. Dietary intakes during the study period for study group patients

	Entry		End Year 1		End Year 2		Significance of intervention	95% Confidence limits for intervention
	A	B	A	B	A	B	*p*	
Mean daily energy (kJ kg^{-1})	270 (70)	239 (60)	263 (61)	234 (49)	243 (63)	216 (57)	NS	−6, +10
Energy from protein (%)	14.4 (1.8)	13.9 (1.7)	13.5 (1.9)	14.0 (1.8)	13.7 (1.6)	14.1 (1.9)	NS	−0.28, +0.31
Energy from fat (%)	39.5 (3.8)	40.0 (4.6)	39.1 (3.2)	40.0 (4.2)	39.9 (2.8)	37.8 (5.2)	< 0.05	−1.38, +0.04
Energy from CHO (%)	46.2 (3.1)	46.3 (3.9)	47.6 (3.1)	46.4 (3.6)	46.4 (2.9)	48.1 (4.7)	NS	−0.02, +1.30
Energy from lactose (%)	4.3 (1.8)	4.4 (1.5)	3.8 (1.5)	4.6 (2.1)	3.7 (1.4)	4.4 (1.9)	NS	−0.29, +0.26
Energy from sugar (%)	17.3 (4.1)	15.9 (3.3)	17.8 (4.2)	16.4 (2.9)	16.4 (4.1)	17.0 (3.6)	NS	−0.12, +0.91
Energy from starch (%)	28.5 (4.1)	29.9 (3.2)	29.5 (3.3)	29.6 (3.9)	29.6 (4.7)	30.7 (2.8)	NS	−0.31, +0.87
Fibre (g MJ^{-1})	2.9 (0.6)	2.8 (0.6)	2.9 (0.7)	2.8 (0.8)	2.9 (0.4)	3.0 (0.6)	NS	−0.05, +0.17

Mean (SD).
Group A = club first; Group B = club second.

at entry. In children of this age glycosylated haemoglobin tends to rise due to waning pancreatic B-cell function, and deterioration in control on entering puberty. In this 2-year randomized crossover study there was a rise in mean glycosylated haemoglobin by the end of the study period during which 31 % of the children in the randomized groups entered puberty. In both Groups A and B, however, there was no rise in mean glycosylated haemoglobin during the year the children attended the diabetic club. This suggests a significant benefit of attending the club. The effect was not sustained, however, in Group A who returned to the clinic in the second year of the study. There was a significant increase in the number of hypoglycaemic episodes reported by Group B in their year at the club but these were not severe. There was no difference in glycosylated haemoglobin between children in the two randomized study groups A and B, and the non-participants who were observed over the same period. These non-participants had had diabetes for longer and might be expected to come from families who were more confident about managing diabetes and therefore did not volunteer for the study which offered considerable extra support.

There were beneficial effects of attending the diabetic club. Parents' diabetes problem-solving improved during the club year. There was, however, no correlation between individual parents' scores and their child's HbA_1, in agreement with other studies[15–17] which have shown that a good theoretical understanding of diabetes does not indicate practical ability in its day-to-day management. There was an increase in blood testing and in the number of injection sites used while children attended the diabetic club and this may have influenced control. Social contact between families was increased by the club and parents found this helpful. The popularity of the club was demonstrated by the excellent compliance of the families (>80 % attendance at the club and clinic) despite the large time commitment demanded of them (22 h attending club vs 5½ h attending the clinic per year). 'Simple human contact' may be as effective as structured education in improving the ability to cope with diabetes.[18] Small group teaching and semi-structured discussion groups as used in this study have been shown by others to be the most effective way of improving motivation and diabetic control.[19,20] The realization that others are experiencing similar difficulties and the opportunity to discuss problems helps overcome feelings of guilt and isolation. A traditional clinic structure provides contact with the paediatrician but does not facilitate regular contact with other families, and the presence of a child in the interview room may prevent parents voicing their concerns. The staff benefited from more fully understanding the concerns of diabetic families. Diet changed while attending the club with a significant reduction in fat and an almost corresponding increase in carbohydrate, but intake of dietary fibre which may improve blood glucose control in children[21] did not change. The practical, informal approach to teaching diet has been shown to be useful.[19]

No reduction in stress was demonstrated in this study. Dunn has suggested that 'feeling better' about diabetes does not necessarily correlate with improved control.[18] Furthermore, Fonagy *et al.*,[22] using the same measurements as our study, have recently shown that children with the highest anxiety levels may have the best diabetic control.

This intensive educational programme had only a small measurable effect on diabetic control. The children selected for the study were those attending the paediatric diabetic clinic which is well staffed by a motivated team of doctors, dietitian, and specialist nurses, and the children attending this clinic had an acceptable mean HbA_1 at baseline.[1,2,23] Many parents already had sufficient knowledge to adequately manage their child's diabetes at entry to the study. The diet of our children was acceptable at baseline with carbohydrate intake approaching the 50 % and fat only 5 % above the 35 % of energy intake recommended by the British Diabetic Association.[24] It might be expected that it would be difficult to achieve further improvement in diabetic control in such a group of children. Grouping children of similar ages together might have resulted in a greater success in educating the children.

Some beneficial aspects of the diabetic club could easily be implemented cost-effectively into routine clinics, particularly the small group teaching and discussion, and grouping families to visit together thereby increasing helpful social contact. More recently diagnosed families volunteered for the study and it may be worthwhile targeting this group for sustained support.

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Is a specialist paediatric diabetic clinic better?

S Bloomfield, J W Farquhar

Abstract

Diabetic control in 88 children attending three general paediatric clinics was compared prospectively over one year with that of 89 children attending a specialist paediatric diabetic clinic. Glycated haemoglobin (HbA_1) concentration and days admitted were significantly lower in the group attending the specialist clinic. This has implications for the organisation of paediatric diabetic services.

Diabetic control in many children is not as good as it could be.[1] It has been suggested that better diabetic control is achieved in children attending specialist paediatric diabetic clinics,[2] but few objective studies have been done. We have collected, over a one year period, data about diabetic control in children attending a specialist paediatric diabetic clinic in a children's hospital compared with those attending paediatric clinics in three district general hospitals.

Methods

The diabetic clinic at the Royal Hospital for Sick Children (RHSC) acts as a primary referral centre for children under 16 years in south east Scotland. It is staffed by three paediatricians (two consultants and one senior registrar), one adult diabetologist who facilitates gradual transfer of adolescents to the adult clinics, a dietitian, a full time nurse specialist, and a dental hygienist. There is 24 hour access by telephone to medical or nursing staff for advice and the specialist nurse visits at home as required.

Three general paediatric clinics (A, B, and C) in district general hospitals in central Scotland provide care for diabetic children who are seen by a consultant paediatrician or paediatric registrar. A dietitian is available in all these clinics, and a diabetes nurse specialist who is shared part time with the local adult clinics is sometimes available.

Information about children under 13 years of age on 1 October 1985, and with diabetes of more than three months duration, was obtained prospectively for one year as part of a research project concerning diabetes education. Data included a medical and social profile, methods of diabetic care, diabetic events, anthropometric measurements, and measurement of glycated haemoglobin (HbA_1) at each visit. (All blood samples for HbA_1 were analysed at RHSC by a Corning electrophoretic method; the normal reference range is 4·7–7·9 %. Samples were analysed within one week and remained stable.[3])

Data from the three district general hospitals and the RHSC clinic were compared by χ^2 or Kruskal-Wallis tests as appropriate, and associations between quantitative and ordinal variables were tested by Kendall rank correlation.

Results

Comparisons were made at the end of one year (a) between the three general paediatric clinic populations, and (b) for all these three clinics combined (if there was no significant difference between them) with the RHSC paediatric diabetic clinic. Age, duration of disease, age at diagnosis, the number of boys, and social class distribution were similar (table 1). The average time spent with the paediatrician at each clinic visit was 25 minutes at RHSC and approximately 15 minutes in the general clinics.

Children attending the clinic at RHSC were admitted to hospital for significantly fewer days

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Table 1 Characteristics of diabetic children <13 years of age attending paediatric clinics in district general hospitals (A, B, C) and a specialist paediatric diabetic clinic (RHSC)

	A (*n*=40)	*B* (*n*=24)	*C* (*n*=24)	*RHSC* (*n*=89)
Mean (SD) age (years)	10·7 (2·6)	11·1 (1·9)	10·2 (2·4)	10·6 (2·8)
Mean (SD) duration diabetes (years)	4·2 (2·5)	4·9 (2·8)	3·3 (1·7)	4·6 (2·8)
Male/female	16/24	10/14	7/17	39/50
No in social class I and II	13	6	12	32

There was no significant difference between groups for any variable.

Table 2 Comparison of indices of diabetic control between RHSC and three general paediatric clinics over a one year period

	A (n=40)	B (n=24)	C (n=24)	p Value*	RHSC (n=89)	p Value†
Mean (SD) No of days admitted/year	2·7 (6·8)	3·1 (6·0)	2·4 (4·4)	NS	1·2 (5·8)	<0·05
No (%) patients admitted for hypoglycaemia	6 (15)	0	0	<0·05	14 (16)	NT
No (%) patients admitted for hyperglycaemia	7 (17)	8 (33)	8 (33)	NS	3 (3)	<0·001
Mean (SD) HbA_1 (%)	12·0 (2·6)	12·1 (3·0)	11·2 (1·9)	NS	10·3 (1·6)	<0·001
Mean (SD) No of clinic visits/year	5·7 (1·7)	6·1 (2·5)	4·3 (1·6)	<0·001	4·8 (1·2)	NT
Mean (SD) insulin dose (U/kg/24 hours)	0·92 (0·2)	0·95 (0·3)	0·90 (0·2)	NS	0·91 (0·2)	NS
No (%) patients with two injections/day	35 (87)	11 (46)	14 (58)	<0·01	81 (91)	NT
No (%) patients with two insulins/day	32 (80)	8 (33)	23 (96)	<0·01	84 (94)	NT

*Comparison between the three general paediatric clinics.
†Comparison of the three general clinics combined compared with RHSC clinic.
NT=not tested because of a significant difference when comparing A, B, and C.

(table 2) and those admitted for poor control and hyperglycaemia were also significantly fewer. There was a significant difference between the three general paediatric clinics in the number of children admitted with hypoglycaemia. Mean HbA_1 concentration for the year was similar for children attending each of the general paediatric clinics but significantly lower in those attending the RHSC clinic.

Daily insulin dose was similar for all children but methods of administration differed. Two injections per day were used more by children attending clinic A, and two different insulins per day (that is, short and intermediate acting insulin) as opposed to one insulin per day (intermediate acting) were used more often by children attending clinic C. Fewer clinic attendances per year were made by children attending clinic C. Attendance rate at all clinics was greater than 80%. Anthropometric measurements including growth velocities were not significantly different between groups and were within the normal range.

Discussion

We have observed in diabetic children who were similar in age, duration of diabetes, and social class, that diabetic control was better in those attending a specialist paediatric diabetic clinic than in those attending general paediatric clinics. Control in children attending the general clinics was in fact not dissimilar from that reported previously from another specialist centre.[1] The introduction of a specialist clinic in East Birmingham where none previously existed resulted in a dramatic improvement in diabetic control.[2]

What are the possible explanations for the better control achieved by the specialist paediatric diabetic clinic? The number of clinic visits to the specialist clinic at RHSC were significantly fewer and the time spent with the doctor was not significantly different in comparison with the general clinics. Access to a paediatrician with a special interest in diabetes may be beneficial, but the diabetes team he leads might be a more important factor. This includes specialist nurses, both in the ward and clinic, whose roles are supportive and educational, a dietitian with specific expertise in diabetes, and a dental hygienist. All play a part in educating and motivating families towards good control and are often more accessible than medical staff.

The standard of control achieved, however, may not be commensurate with the greater resources available in the specialist centre, but the introduction of some aspects of specialist care into district general hospitals—for example, the specialist nurse—and shared care between centres may produce savings in both hospital admissions and future complications. Thus the specialist clinic can act as an advisory, educational, and training resource for other clinics. The annual incidence of insulin dependent diabetes mellitus has almost doubled in a decade in Scotland,[4] a trend found in most developed countries,[5] and these young people will place an increasing burden on health care resources. The evidence that good control can reduce future complications is growing,[6] and their incidence may be reduced if diabetic children can achieve optimal control.

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