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Psychological, social, and economic aspects of juvenile diabetes which may influence the use of 'self-monitoring of blood glucose' techniques

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A Thesis Submitted to the Yale University School of Medicine in Partial Fulfillment of the Requirements for the Degree of Doctor of Medicine

by

Ira Marc Cheifetz

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ABSTRACT

PSYCHOLOGICAL, SOCIAL, AND ECONOMIC ASPECTS OF JUVENILE DIABETES WHICH MAY INFLUENCE THE USE OF "SELF-MONITORING OF BLOOD GLUCOSE" TECHNIQUES

Ira Marc Cheifetz

This study ascertained whether psychological, social, and economic characteristics of juvenile diabetes correlate with accuracy of "self-monitoring of blood glucose" (SMBG) testing. Each of forty juvenile diabetics and either of their parents/guardians provided information concerning the psychological, social, and economic status of the child and his/her family. Subsequently, each child performed a blood glucose test on him/herself exactly as if he/she were at home. A simultaneous capillary blood sample was sent to the laboratory for an assumed accurate result, and the two results were compared to assess the child's testing accuracy. Seventeen (42.5%) of the children reported SMBG results that differed from the laboratory value by at least 20%. Overall, twenty-one children (53%) committed an obvious error in their SMBG testing routine. A stereotypical inaccurate SMBG tester could not be identified. However, the children who statistically (P less than or equal to 0.10) are more prone to perform blood testing inaccurately include: adolescents, children with mothers who are not available to assist their respective children with SMBG testing and provide a consistent meal schedule, children originally diagnosed with diabetes in the immediate

preadolescent or adolescent years, families in a lower socio-economic class based upon income and occupation, less well-behaved children, the youngest child in the family, children who have only one parent participating in the SMBG testing routine, and children with fathers who work irregular hours/shifts. This information should be used as a guideline to identify those children (1) who are more apt to require additional initial and supplemental education in SMBG techniques and diabetes in general and (2) who may need additional psychological support from child psychiatrists and/or social service workers. Increased SMBG accuracy should lead to improved metabolic control and, subsequently, fewer short-term and long-term complications.

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TABLE OF CONTENTS

LIST OF TABLES

INTRODUCTION

It seems obvious that many psychological, social, and economic factors would generally influence a person's self-care behavior and more specifically a diabetic's care of his/her chronic condition. Studies have already shown that certain economic and social factors, such as age, income, duration of diabetes, and education affect how accurately an adult uses the available "self-monitoring of blood glucose" (SMBG) techniques now available (Fairclough, 1983; Koski, 1969; Amir et al., 1977). Additionally, other studies have strongly implied that psychological factors influence the way in which a diabetic cares for his/her condition (Hauser and Pollets, 1979; Simonds, 1977a; Becker et al., 1972). However, few studies have attempted to relate the above factors, especially psychological factors, to the case of juvenile insulin-dependent diabetes mellitus (IDDM) (Simonds, 1977a; Simonds, 1977b; Baker and Barcai, 1970).

Knutson (1965, p. 212) addresses this psychological and environmental view in a chapter entitled "Motivation Research: An Elusive Challenge." He observes: "Health behavior seems so inseparably linked to motivation that logic impels one to orient any discussion of health practices to human needs and motives.... Unfortunately, an enormous gap exists between knowing that health behavior is motivated and identifying the specific motivation components of any particular act."

Accordingly, I will examine the general hypothesis that specific psychological, social and economic factors, as are described below, affect the amount of care and concern a child displays in the management of his/her diabetes. In order to accomplish this, I will postulate that this resulting care and concern is directly proportional to the

accuracy of the child's home testing, which, in turn, is a specific entity that may be easily determined and quantified.

Based upon this measurement of accuracy, the children in this study will be divided into either an "accurate" or an "inaccurate" group. As these two groups are compared on a continuum with each other, the following specific hypotheses will be tested via questionnaire data and appropriate statistical analyses. Operationally, a child in the accurate group is more likely to be described as: being within grades 2 through 6 at school, having a relatively shorter duration of diabetes as well as a younger age at onset, receiving assistance with the home blood testing and insulin injection routines from both parents, having obtained his/her initial diabetes and SMBG instruction/education from more varied and extensive sources, performing a number of weekly blood tests closer to seven days per week and four tests per day, having a higher family income, having parents with a regular employment schedule and a maximum of a forty hour work week, having parents who report higher satisfaction with their present employment, living in a family with a higher socio-economic status as determined by the Hollingshead Scale (Hollingshead, 1957), living with parents who have not had a prior marriage, experiencing a more stable home life in terms of the marital situation of his/her parents, being exposed to a greater number of diabetic relatives with whom the child can speak, experiencing more open and accepting attitudes towards the insulin injections and blood testing procedures, and being better behaved as viewed by his/her parents in terms of the Achenbach Child Behavior Checklist (Achenbach and Edelbrook, 1981). I also expect to demonstrate that parental age, parental education, the type of blood testing method used, as well as the child's

I.Q., birth rank, number of siblings, and sex will not affect the accuracy of the child's testing.

This study will, therefore, attempt to identify those risk factors involved with the inaccuracy of SMBG use in juvenile diabetes. Knowledge of the more pertinent risk factors will help to identify those current juvenile diabetics who may require additional assistance (psychological, such as counselling, or cognitive and physical, such as additional instruction in technique). It should also help identify those new onset diabetics who should receive additional initial education and support. Knowledge such as this may be incorporated on a more general basis into the present instructional programs and clinics.

Additionally, the patients' and parents' views on the different techniques available to monitor blood glucose levels will be examined.

As a second aspect of the study, I will attempt to determine those steps in the blood testing procedure which are most commonly performed incorrectly. The specific hypothesis is that these steps include inaccurately timing the reaction of the blood with the test pad and incorrectly applying the blood to the test pad. This information may be used to modify the current educational programs to correct for the more frequent errors.

Juvenile Diabetes: An Overview

Insulin-dependent diabetes mellitus (IDDM), a chronic, life-long disorder, afflicts approximately one out of every 1000 children under the age of eleven (Korhonen et al.,

1983) and one out of every 500 children under age eighteen. The incidence has been estimated to be 14 - 16 cases per 100,000 population under age eighteen (Leslie and Sperling, 1986). This disorder is extremely common when compared with the prevalence rates of other endocrine and metabolic disorders. The disease occurs equally in boys and girls over the entire period of childhood and adolescence. However, the sex incidence does vary dependent upon the age of onset (Korhonen et al., 1983).

IDDM usually presents with polydipsia, polyuria, weight loss, and fatigue. Patients are very prone to ketoacidosis both at onset and subsequently.

The possible complications from IDDM later in life are common and severe. Diabetes is a major cause of ophthalmologic disease, renal failure, and cardiovascular disease (Harris and Hamman, 1985). Diabetes is the leading cause of new adult cases of both blindness and end-stage renal disease (Leslie and Sperling, 1986). It is important to remember that the genesis of these complications most probably commences in the early years of the disorder.

Clinical trials have demonstrated that diabetic animals maintained in "strict" metabolic control develop fewer microvascular abnormalities affecting the retina and kidney than do animals in worse control (Engerman et al., 1977). Similar studies in humans have supported this earlier animal data (Rosenstock et al., 1986; Young, 1985; Rifkin and Ross, 1981).

The preliminary evidence that complications may be delayed or even prevented by strict control of blood glucose levels emphasizes the need for the best treatment continuously throughout the person's life (Farquhar and Campbell, 1980). Relatively

tight control appears essential for the maintenance of the person's health and growth. This necessary control involves a fairly rigid diet in terms of type and amount of food consumed, rigid meal times, regular monitoring of blood glucose levels, and regularly scheduled insulin injections (Pond, 1968).

IDDM remains a challenge to the clinician, researcher, and, especially, the patient. Knowledge about the epidemiology, pathogenesis, and natural history of this debilitating disease continues to increase daily. However, treatment options are not keeping pace. The rigorous regulations imposed on daily life, compounded by the threat of blindness, nephropathy, and vascular disease, are still shadows darkening the mind of every juvenile diabetic.

The long-term goals in the treatment of juvenile diabetes are metabolic stabilization, avoidance of hypoglycemic and hyperglycemic symptoms, maintenance of normal maturation and growth, minimizing urinary glucose loss, and, overall, avoidance of diabetic complications (Kaar et al., 1984). The assessment and exact accomplishment of this metabolic control is complex. This assessment is now often accomplished by self-monitoring of blood glucose techniques on a daily basis by juvenile diabetics.

Self-Monitoring of Blood Glucose Testing:

Maintaining euglycemia is beyond the limits of traditional urine testing since glucose does not appear in the urine until the blood glucose is greater than 180 milligram percent. For blood glucose levels between 0 and 180, urine tests will remain

negative. Additionally, the blood glucose measured in the urine is partly dependent upon the concentration of the urine. Without the utilization of a "double-void technique," a correlation between the urine test result and the time of day when tested does not exist. Therefore, urine testing is an inaccurate method upon which insulin adjustments can be made on a daily basis (Connors, 1984).

Self-monitoring of blood glucose was first introduced in 1978 (Sonksen, 1978), and, subsequently, its use has increased exponentially. A debate as to the necessity and usefulness of this technique continues. However, one point has been repeatedly proven: Home glucose monitoring will never lead to better metabolic control unless it is accompanied by intensive support and education (Tattersall, 1984).

The accuracy of SMBG techniques has been extensively studied. Fairclough et al. (1983), in a study of fifty patients, revealed that their performance with the Chemstrip bG, Dextrostix-Dextrometer, and Stat Tek techniques was unacceptable when compared with the accuracy of trained medical personnel. In a study by Jovanovic and Peterson (1980), 31% of the blood glucose measurements by their patients using the Dextrostix-Eyetone technique were in error by greater than twenty percent. Six studies of the performance of patients using the Chemstrip bG technique have shown that over one-third of all blood glucose determinations were in error by over twenty percent (Shapiro et al., 1981; Birch et al., 1981; Kublis et al., 1981; Waalford et al., 1980; Fahlen et al., 1980; Webb et al., 1980). (These studies used a cutoff of twenty percent when determining whether a patient's result compared favorably to a laboratory result. An error, by the patient, of twenty percent or greater will generally lead to an inappropriate adjustment of his/her insulin dosage (Ting and Nanji, 1988).)

The study by Strumph et al. (1988) showed that children misread Chemstrip bG results 51% of the time as compared to analyzing the same strip in two different Accu-Chek bG reflectance meters. Errors were more common at low (less than 80 milligram percent) glucose values with 72% of the readings in error and at high (greater than 240 milligram percent) values with 54% in error. Of note is that this last study employed an error cutoff of fifteen percent instead of the more common twenty percent as described above.

The only exception to the uniformly poor patient performance with SMBG techniques has been reported by Ikeda et al. (1978) in which eight patients performed blood glucose determinations using the Dextrostix-Eyetone system with an error rate of only 4%. However, the small sample size of this study does not lend confidence to their results.

On the other hand, Clements et al. (1981) showed that trained medical personnel were in error by over 20% in less than 11% of the trials using the Chemstrip bG and the Dextrostix-Eyetone systems. Additionally, Schiffrin et al. (1983) showed that twenty highly trained insulin-dependent adolescent diabetics utilizing the Chemstrip bG and Glucometer systems had average results which differed by less than 10% from the laboratory values.

These studies demonstrate that the average diabetic does not accurately test his/her own blood glucose level. However, the problem is not inherent in the testing equipment as is shown by the accuracy obtained by trained personnel. Virtually all of the systems developed for the self-monitoring of blood glucose levels have been shown to be highly accurate when performed by trained medical or paramedical persons (The

Medical Letter, 1988; Fairclough et al., 1983). The study by Strumph et al. (1988) compared two Accu-Chek bG meters each with the same 316 Chemstrip bGs. Only one reading (0.3%) differed by more than 15%, which helps to show that interdevice variance is minimal. Additionally, the specific type of testing equipment used does not appear to correlate with accuracy or inaccuracy.

Sex, Age, and Duration of Diabetes:

Kaar et al. (1984) found that, in general, boys had better metabolic control than girls but was unable to explain this difference. This result was shown to be independent of the child's motivation towards treatment or adherence to the prescribed diet. According to Hamburg and Inoff (1982), boys in poor diabetic control seemed to be more eager to take action to confront their difficulties. On the other hand, girls in poor diabetic control seemed to feel powerless and acted compliant. This sex difference was interpreted as reflecting sex variation in response to stress. However, Koski (1969) and Kirk et al. (1986) found no sex difference between a well controlled group of juvenile diabetics and a poorly controlled group.

Kaar et al. (1984) additionally demonstrated a negative correlation between metabolic control and both the age of the child and the duration of diabetes. Studies by French and Sanders (1969), Koski (1969), and Swift et al. (1967) support this result. In contrast, Hamburg and Inoff (1982) claim that the duration of the disorder is positively related to diabetic control for girls but is insignificant for boys. Thus, for girls, the longer one has had diabetes, the better her control is. Hamburg and Inoff contend that

their results are more significant than those of Kaar et al. since their study accounted for the confounding effect of age at onset and chronological age. Both of these possibilities are opposed by the findings of Kirk et al. (1986), Tietz and Vidmar (1972), and Williams et al. (1967) who found no relationship based on sex and duration of diabetes.

It is easy to understand how studies of the correlation between the duration of diabetes and metabolic control could yield conflicting results. In the case of a positive correlation, skills regarding diabetes management may improve over time, and, additionally, various biologic systems, disturbed at the onset of the diabetes, may reach a new homeostasis over time. Both of these factors would enable the diabetic to control his/her condition more easily.

A negative correlation may be explained by the fact that diabetes is a chronic disease producing a course of increasing levels of damage and complications. The patient may also become "tired" of the diabetic routine and become "lazy" in his/her treatment, especially during adolescence. Allgrove (1988) and Kaar et al. (1984) add that residual endogenous insulin secretion early in the course of this chronic disease facilitates its management. These possibilities could be reflected in a worsening of many of the indices of diabetic control (Hamburg and Inoff, 1982).

Those children with onset around the time of puberty seem to have the greatest difficulty. In general, prepubertal children were shown to be in better control than pubertal children (Kaar, 1984; Mann and Johnston, 1982; Pond, 1968).

It is commonplace in the early adolescent years (approximately ten through twelve years of age) for children to be quite unreliable in their self (urine) testing

(Isenberg and Barnett, 1965). Frequently, these children attempt to fool both parents and doctors into thinking that they have excellent control. This type of deceptive behavior can be understood as an attempt to avoid real or expected punishment or discipline from their parents. There is also the increasing need for the early adolescent as he/she develops to want to separate from his/her parents, to be more similar to his/her peers, and to eliminate testing in order to avoid the constant reminder of being a diabetic. The testing, therefore, becomes an extremely undesirable chore (Isenberg and Barnett, 1965). It has been suggested that an increase in normal life stresses might be at least one factor leading to more frequent episodes of metabolic instability often encountered in adolescence (Bedell et al., 1977; Coddington, 1972).

Onset at this vulnerable and difficult point in their lives means reaching adolescence with the additional shock of a chronic illness and the necessary adjustment to a strict routine of diet, injections, and blood/urine testing. Associated with this is the fear of an unknown future and of feeling somewhat alienated from his/her peers. Worries regarding careers and failure in the "marriage market" have been shown by Pond (1968) to be common in adolescent diabetics. Mann and Johnston (1982) claim that the decrease in metabolic control in adolescent females is secondary to "the normal adolescent-related" psychosocial changes.

It must be remembered that hormonal changes, and not psychological changes, may be the explanation for the worse control (Hamburg and Inoff, 1982). Bloch et al. (1987) demonstrated that puberty is associated with an approximately thirty percent decrease in sensitivity to insulin. Normal teenagers, in contrast to the diabetic adolescent, can compensate for this with increased insulin production.

Emotional and Psychological Characteristics:

Diabetes in a child is more labile and difficult to control than in an adult. This may be related as cause or effect to a problem of temperament or psychological adjustment to the handicap. Additionally, the normal fragility of a child's metabolism may play a role. The mechanisms of control by diet and insulin contribute to emotional difficulties (Pond, 1968). Additionally, in the younger child, the daily pain inflicted by the parent(s), in terms of needle sticks, must resemble punishment.

The emotional trauma of being diagnosed with diabetes as a child is probably greater than for any other chronic disease. Living with diabetes can impose challenges that test the limits of endurance (Korhonen et al., 1983). The child has to accept that he/she has an incurable disease whose treatment requires daily injections, a diet in which many of the usual "choice foods" are excluded, and a rigid schedule of meal times. The child must monitor the effects of treatment with urine and/or blood tests and, therefore, cannot escape confronting his/her own success or failure. The diabetic child will soon learn that although treatment can abolish the symptoms, it cannot guarantee a "normal" life or a "normal" life span (Tattersall, 1981). There is always an aura of danger present.

The emotional problems of the juvenile diabetic have been recognized since the 1920's, but there is no solution in sight for these problems (Tattersall, 1981). This area has tended to be neglected in traditional psychological research. Any attempt to link psychiatry more closely to general medicine might start with diabetes. Diabetes, apart from presenting many practical psychiatric problems, is also a useful paradigm of the

interactions of the emotions with a physical illness.

Psychological forces seem to be a dominant issue in the case of the very poorly controlled, or "brittle," diabetic. These children's lives are continually disrupted by hypoglycemic or hyperglycemic symptoms, which often require hospitalization. This condition has been variably noted to be "a very small percentage" among those with juvenile diabetes (Drash, 1971), 10 - 20% of all insulin-dependent diabetics (Marble, 1961), or even all diabetics under the age of twenty (Knowles, 1964). The diversity of these estimates demonstrates the varying opinions regarding the point at which these patients are labelled "difficult to control" or "brittle."

Unstable diabetes is usually related to either an emotionally disturbed patient or a disturbed environment. It is the opinion of many authors that these are the most common causes of brittleness (Greydanus and Hoffman, 1979; Craig, 1971; Oakley, 1968; Malins, 1968; Joslin, 1959).

Greydanus and Hoffman (1979) have shown that emotion and the person's overall psychological state may influence the course of a person's diabetes. It is also probable that a person's psychological and emotional state may alter how that person cares for his/her diabetes (Kimball, 1971; Baker and Barcai, 1970; Slawson et al., 1963; Danowski, 1963; Treuting, 1962). Diabetes is the best example of a disorder where the patient is expected to be "his/her own physician," and one would expect that his/her ability to concentrate on this job would be impaired by personal or environmental stress (Tattersall, 1981). Although it is difficult to show the role of stress in the precipitation of its onset, it is noted by many that these factors can profoundly affect the subsequent metabolic control of a juvenile diabetic.

At all stages of life, but most obviously in childhood, diabetes affects not only the child but also his/her family. There is little doubt that emotional stability in a home where parents take a realistic view of their child's handicap is the best guarantee of stable diabetic control. Additionally, the child must not manipulate the family and not exploit his/her illness to his/her own ends (Tattersall, 1981).

Tattersall (1981) also believes that the diabetic may utilize the "weapon" closest at hand to relieve any mental anguish at home. He adds that this is "usually more annoying than dangerous and happily tends to die out in the late teenage years." Stearns (1959) emphasized that the motivation for such potentially self-destructive behavior may represent the need for self-punishment, attention seeking, or the urge to punish others.

In a study by Simonds (1976-1977), children in poor diabetic control reported more frequent interpersonal conflicts than those in good control. Their mothers described them as having significantly more behavioral and emotional problems. However, cause and effect are difficult to determine: Did the poor diabetic control cause the behavioral problems or vice versa? A subsequent study in 1977 compared this group to a group of matched non-diabetic children. Children in poor control were not significantly different from their non-diabetic counterparts in either psychiatric status or number of conflicts. However, by mothers' reports, they were more anxious and depressed. Taylor (1985) and Gath (1980) showed that children in poor metabolic control more commonly demonstrated signs of emotional and behavioral difficulties.

Koski (1969) found that aggressive, antisocial, and oppositional (i.e., disobedience and running away) behaviors were found almost exclusively in poorly

controlled juvenile diabetics. On the other hand, anxious and manifestly fearful behaviors were more frequently identified in the cases of well controlled diabetes. The mother of a poorly controlled diabetic is more prone to claim that her child generally has more behavioral problems than would a mother of a well controlled diabetic (Simonds, 1977a). It has also been shown that those children who have better metabolic control and who test more accurately have more introverted personalities (Steinhausen et al., 1977).

Grant et al. (1974) and Bradley (1979) have shown that stressful life events are associated with disturbances in a diabetic's control. The correlations in these studies were not very strong, and they were complicated by methodological problem including the difficulty in assessing a diabetic's control objectively. More specific questions such as which life stresses have the greatest effect on control or which personalities are most affected remain unanswered (Hauser and Pollets, 1979).

Patients react to juvenile diabetes with the personality resources available to them although prior psychological problems may be reinforced or unmasked. Unfortunately, we are left with a vague impression that psychological factors can influence the level of serum glucose in a diabetic and, especially, his/her monitoring of that level, but exactly how accurate this impression is and what its mechanism is, remains to be shown.

Home Life of the Juvenile Diabetic:

The characteristics of each family may also influence the child's blood testing accuracy. The ability of a diabetic child intentionally to utilize poor treatment and testing techniques as an escape from unpleasantness at home or school was first published by Loughlin and Mosenthal (1944). They showed that one-third of the children they studied for frequent hospital admissions for ketoacidosis came from homes broken by divorce, separation or widowhood, or from homes where the mother was out all day and in which meals were haphazard. However, Koski (1969) did not find a significant correlation between the mother's being away from home all day and poor control. Bruch (1949) found the clinical course of a child's diabetes and the way in which the disease and its treatment were accepted were closely related to the psychologic climate of the home. Koski and Kumento (1977) showed conclusively that a stable home life, especially marital stability of the parents, is highly correlated with better control of the diabetes. The study by Simonds in 1977 reported an unusually low rate of divorce in the families of controlled patients as compared to those with unstable diabetes or non-diabetic comparison groups.

Simonds' study (1977a) suggests the interesting hypothesis that good control may be associated with unusually healthy or well-integrated families. Even "normal" family conflicts may be related to poor control in some youngsters. A study by Tietz and Vidmar (1972) is one of the few reporting no significant relationship between family intactness or psychopathology and diabetic control. But, the number of participants in this study was too small to warrant any firm conclusions.

In two parent homes, children in good control have a higher proportion of two parent involvement in all aspects of care. This empirical, age-based evidence suggests that control is enhanced by active participation of both parents in the care of the diabetes, especially during adolescence (Anderson et al., 1983; Lagreca, 1982). The cooperation of all family members in the care of the diabetes is important (Koski, 1969). Fonagy (1987) reported that children under the age of twelve were more likely to demonstrate better control as shown by hemoglobin A_1 concentration if they relied on their parents for help in glucose testing and/or insulin injections. (The concentration of glycosylated hemoglobin [HbA_1] reflects the blood glucose control over the prior six to eight weeks.)

A point worth noting is that the larger a patient's family is, the poorer the control is (Swift et al., 1967). This may involve the concept of the "sick role" (Williams et al., 1967). This study by Swift et al. (1967) also found that the birth rank of the childhood diabetic was significantly associated with diabetic control. In their study, in contrast to a study by Koski (1969), the eldest child in the family had significantly worse control than did children of other birth ranks. According to Koski, the eldest child's diabetes was rarely found to be poorly controlled. The discrepancy may be due to the sample size or cultural factors.

One last correlation involving a juvenile diabetic's home life was found by Farquhar and Campbell (1980). Using HbA_1 values as a measure of metabolic control, their study showed that those children having first degree relatives with insulin-dependent diabetes had worse control.

Socio-Economic Characteristics:

Underprivileged families in the lower socio-economic classes are often less able to cope with the stresses of life both economically and psychologically. It might be expected that these families would have a greater than average difficulty in controlling a child's diabetes. Several studies have found poor control in poor socio-economic circumstances (Becker et al., 1972; Vincent, 1971; Gordis et al., 1969; Koski, 1969; Swift et al., 1967; Knutson, 1965; Bergman and Werner, 1963; Stone, 1961). In some of these studies noncompliance and inaccuracy in urine testing reached sixty percent of the studied clinic populations. However, Kirk et al. (1986), Ludvigsson (1977), and Williams et al. (1967) have demonstrated no correlation between control and social class.

These apparent differences stem from the multiple possible methods of calculating a person's socio-economic status. Those who have measured it purely in terms of income have found no correlation with control. However, when social status is defined in terms of "harmony in the family" or frequency of major problems, there is general agreement that problems in the home usually lead to poor control (Tattersall, 1981).

According to Fairclough et al. (1983), adult diabetics using the Chemstrip bG technique who had an annual family income of less than $10,000 as well as those who had not earned a college degree performed remarkably poorly. Swift et al. (1967) supports this claim that income is positively correlated with well controlled diabetes.

Education and Intelligence:

Educational status had no influence on patient performance with two reflectance meter techniques studied: Stat Tek and Dextrostix-Dextrometer (Fairclough et al., 1983). However, Koski (1969) has demonstrated that a large proportion of children with well controlled diabetes are at the top of their class in school. No reasonable explanation for this was offered since no correlation between intelligence and diabetic control was shown. Steinhausen et al. (1977) confirms this lack of correlation between I.Q. and metabolic control. On the other hand, Swift et al. (1967) found that higher I.Q. was positively related to better diabetic control. They argued that hypoglycemic episodes may lead to a lowered intelligence.

Attitudes Concerning Self-Testing:

Fairclough et al. (1983) asked a group of diabetics whether they believed that SMBG testing is more beneficial than urine testing. The results showed that forty-seven people agreed, one disagreed, one said both were the same, and one did not know. More than half of these patients expressed a preference for the use of a technique involving a reflectance meter if the cost were not a factor. This study indicated that certain patients were either unwilling or unable to afford the cost of a system with which they could perform accurately. Other patients objected to the technical requirements for the calibration and use of a reflectance meter (Fairclough et al., 1983).

The main advantage of a meter is the feeling of security given by the readout of a number. This may be a potential disadvantage if the diabetic puts blind faith in the meters without questioning the results. On the other hand, the lack of a number with the Chemstrip bG may tempt the patients to estimate more acceptable values (Schiffrin et al., 1983).

The Technique of Self-Testing:

Kirk et al. (1986) and Schiffrin et al. (1983) have shown that (1) meticulous attention to obtaining a sufficiently large drop of capillary blood to cover the entire pad of the reagent strip and (2) careful timing of the blood strip reaction are critical in obtaining a high degree of accuracy. A study by Bates and Ahern in 1986 reported that (1) washing or blotting the reagent strip early or excessively hard would lead to incorrectly low results and vice versa, (2) incomplete coverage of the reagent pad with blood would also lead to low results, and (3) if the patient forgot to wash his/her hands, residual sugar on his/her fingertips may lead to inaccurately high results. Using old reagent strips (i.e., two months after opening the vial) also leads to inaccuracies. Wing et al. (1985) found that children and adolescents frequently mistimed the duration of blood exposure to the strip, but the most common error was inadequate wiping of blood from the strips.

Summary:

Since the major goal of SMBG techniques is to reduce the incidence of complications by improving blood glucose regulation, it is important to identify those children who are at increased risk of having difficulties with home monitoring so that more education may be offered to them. However, it is evident that no single factor in the treatment or course of diabetes mellitus determines metabolic control and testing accuracy/inaccuracy. Thus, diabetes has long fascinated physicians from many viewpoints: biochemical, pathological, and psychological.

METHODS

Subject Population:

A total of one-hundred families of juvenile insulin-dependent diabetics, aged six to eighteen years, from the Yale-New Haven Juvenile Diabetes Clinic received a letter from me explaining the goals and design of this study. No additional selection criteria existed except for their prior attendance at this clinic and the child's age being between six and eighteen years. The final study group comprised forty of these families who had a willingness to participate. The study was approved by the Yale University School of Medicine Human Investigations Committee.

The children in this study ranged in age from 6.0 to 17.4 years with a mean of 11.5 years (standard deviation of 3.1). The average age at diagnosis was reported to be 7.2 years old (standard deviation 3.5). The duration of diabetes ranged from 0.4 to 12.4 years with a mean of 4.2 years and a standard deviation of 3.0. The group consisted of 19 females and 21 males.

Patient Evaluation:

Prior to the performance of any blood glucose measurements, each patient and either of his/her parents/guardians provided information concerning the economic, social, and psychological status of the child as well as the family as a whole. The parental questionnaire was designed to gather information concerning: the

parents/guardians with whom the child currently lives, the current marital status of the child's natural parents, the household income, the highest education achieved for each family member, the number and ages of siblings, employment information (job description, hours per week worked, regularity of schedule, usual shift worked, length of time at current job, and satisfaction/dissatisfaction with the current employment) for both parents, the type(s) of SMBG technique(s) used, the age of the child and of each parent/guardian, all sources of diabetes and self-testing education received, the duration of diabetes, the sex of the child, any relatives with diabetes, and to what extent, and by whom, the child receives help with the insulin and SMBG routines. (The parental questionnaire may be found in Appendix I.) Additionally, the child's general behavioral achievements were measured by having the parent/guardian complete the Achenbach Child Behavior Checklist (Achenbach and Edelbrook, 1981). (See Appendix II for this checklist.)

Each child received a questionnaire pertaining to the feelings they experience concerning the blood glucose monitoring and insulin injection routines, how much help they receive as well as who helps them, whether they can predict their glucose values prior to SMBG testing, and how often they use SMBG testing. (A copy of this questionnaire may be found in Appendix III.) All children under the age of 13 were evaluated for I.Q. by means of the Koppitz Human Figure Drawing Test (Koppitz, 1968).

These questionnaires were completed without any intervention on my part with the exception that I did help each of the children under seven years of age read the questionnaire. Whether or not the child received assistance with reading was tabulated along with the remainder of their data.

Study Design:

Following the completion of the questionnaires, each child was requested to perform a blood glucose test on him/herself exactly as if he/she were at home. If the parent typically helped the child at home, then the same was permitted for this study. The results were noted as to whether or not parental assistance was involved. No other assistance was available to the child.

The types of SMBG tests used included the Chemstrip bG, Accu-Chek bG types I and II, Glucometer types I and II, Glucoscan, and Diascan techniques. The actual meters and lancets (manual or automatic) employed belonged to the child. Therefore, the child was very familiar with the exact equipment utilized.

I monitored each child's technique to determine whether any obvious errors had been committed in the testing process. A checklist was used to record these errors. (A copy of this checklist may be found in Appendix IV.) When a self-test which required color matching to charts was employed, color vision was assessed using the Ishihara Pseudoisochromatic Charts.

Immediately subsequent to the child's self-test, I filled a capillary tube with blood from the same finger stick. (In some cases, the same finger stick was unable to provide the necessary blood and a new finger stick became necessary.) This capillary sample was then delivered immediately to the Clinical Laboratory for an assumed "accurate" analysis. (The same technician performed this analysis on the same machine for each sample.) An integral part of this study is that the two samples must be identical with regard to glucose content. That is, it is assumed that the minimal time

delay between samples was negligible as was the occasional need for a second finger stick.

The study was double-blinded in that the Auto-Analyzer laboratory result was not known by myself or the participants at any time prior to the completion of the questionnaires and self-blood test. In addition, the lab technician did not know the child's SMBG result.

Of importance is that the SMBG results obtained are actually whole blood glucose measurements; whereas, the laboratory measurements are blood plasma values. Therefore, the child's value was multiplied by 0.9 to correct for this difference (Villeneuve et al., 1985; Ellenberg and Rifkin, 1983; Tietz, 1970).

The adjusted child's result was correlated with the laboratory result to determine relative accuracy. A twenty percent difference between the two values was used as a cutoff for accuracy. (A relative error greater than or equal to twenty percent will lead to the administration of an incorrect insulin dose (Ting and Nanji, 1988).) This comparison enabled me to divide the original forty children into two groups: 23 were labelled as accurate (Group A) and 17 were labelled as inaccurate (Group I).

Statistical Analysis:

Statistical analyses were performed to determine the possible biographical, economic, social, and psychological factors associated with SMBG accuracy and inaccuracy. Different statistical tests, both parametric and nonparametric, were utilized dependent upon the characteristics of each variable and the distribution of the data.

The analyses were performed on each of the 167 variables independent of the others. Chi-Square or Likelihood Chi-Square Analyses were performed on each of the categorical pieces of data if only two options existed and the expected values were greater than or equal to five. Fisher's Exact Tests were applied to the categorical data when only two choices were possible and the expected values were less than five. T-tests were performed for each continuous set of data which approximates a normal distribution. A Mann-Whitney U-test was used for the categorical data when more than two possible options for the independent variable existed as well as in the case of a continuous independent variable which does not follow a normal Gaussian distribution.

RESULTS

The Population Groups:

Upon comparison of the forty self-monitoring of blood glucose (SMBG) results with the "accurate" laboratory value, 23 (57.5%) of the children are classified as accurate SMBG users (i.e., their SMBG result is within twenty percent of the laboratory value) and 17 (42.5%) are grouped as inaccurate SMBG users (i.e., their SMBG result differs from the laboratory value by twenty percent or more). Throughout this discussion the accurate group will be referred to as Group A, while the inaccurate group will be labelled as Group I.

Within each of these two groups, three of the children (13% of Group A; 18% of Group I) received help with their SMBG test from one of their parents. In addition, three (13%) of the accurate children and two (12%) of the inaccurate children received assistance, from myself, with reading the questionnaires. These latter two points are not statistically significant.

The parental questionnaires for the accurate group were completed by twenty (91%) mothers and two (9%) fathers, while those for the inaccurate group were completed by fifteen (88%) mothers and two (12%) fathers (N.S.). In each case, the parent who completed the questionnaire was the child's natural parent except for one child who was adopted at five weeks of age. Of note is that one patient from the accurate group did not have a parent/guardian complete the corresponding questionnaire. A different patient from this group did not complete his/her

questionnaire. Therefore, for the parents N = 39, for the children N = 39, and for the glucose results and SMBG testing procedures N = 40.

The Glucose Results:

Overall, the laboratory glucose values vary from 74 to 596 mg/dl with a mean of 259.6 mg/dl (standard deviation of 124.1), the children's SMBG results (N = 34) range from 59 to 432 mg/dl (mean 224.6 mg/dl; standard deviation 101.1), and the parents' SMBG results (N = 6) extend from 72 to 360 mg/dl (mean 179.5 mg/dl; standard deviation 103.1). The overall error range (i.e., percent difference between the two values) is 2% to 57% with a mean of 20.9% and a standard deviation of 15.6.

The error range within the accurate group is 2% to 19% with a mean of 9.9% and a standard deviation of 5.1; while the range in the inaccurate group is 20% to 57% with a mean of 35.9% and a standard deviation of 12.1. When the glucose data are further analyzed for each of the two population groups, it is found that a statistical difference with regard to the children's SMBG results exists. The accurate group reported a mean SMBG result of 253.0 mg/dl (standard deviation 98.1) as compared to 183.9 mg/dl (standard deviation 94.0) for the inaccurate group. This corresponds to t-test probability value of 0.048 (t = 2.05, df = 32.0). No other statistically significant differences are noted. The actual data may be found in Table 1.

TABLE 1: Summary of the glucose values (mg/dl) obtained by the laboratory, children, and parents. The probability value listed is based upon a t-test analysis.

GLUCOSE	ACCURACY	N	RANGE	MEAN	STD DEV	PROB
LAB	accurate	23	100 - 400	248.7	96.5	N.S.
	inaccurate	17	74 - 596	274.3	156.1	
CHILDREN	accurate	20	89 - 432	253.0	98.1	0.048
	inaccurate	14	59 - 343	183.9	94.0	
PARENTS	accurate	3	95 - 198	147.3	51.5	N.S.
	inaccurate	3	72 - 360	211.2	144.2	

SMBG Machine Types:

The SMBG machines employed by the participants in this study include: Accu-Chek bG I (10%), Accu-Chek bG II (15%), Glucometer I (17.5%), Glucometer II (10%), Chemstrip bG (32.5%), Glucoscan (12.5%), and Diascan (2.5%). When compared against each other via a Mann-Whitney U-test, no significant difference among the seven methods utilized exists. However, the Accu-Chek bG I technique has four entries in Group A and none in Group I. When this meter is compared to the remainder of the techniques, as considered together, the result is significant with P = 0.097 (one-tailed Fisher's Exact Test). The remainder of the machines are almost equally distributed between the two accuracy groups as is shown in Table 2.

TABLE 2: SMBG techniques utilized by the children while participating in this study

MACHINE	GROUP A (N = 23)	GROUP I (N = 17)
Accu-Chek bG I	4 (17%)	0
Accu-Chek bG II	4 (17%)	2 (12%)
Glucometer I	3 (13%)	4 (24%)
Glucometer II	2 (9%)	2 (12%)
Chemstrip bG	6 (26%)	7 (41%)
Glucoscan	3 (13%)	2 (12%)
Diascan	1 (4%)	0

Of additional interest is that of 39 responses, four (10%) had utilized a different SMBG method before employing the method included in Table 2. All four of these families are members of the accurate group. A one-tailed Fisher's Exact Test yields a probability value of 0.089.

Sex, Age, and Duration of Diabetes:

Neither sex nor duration of diabetes are statistically significant when the two population groups are compared. The overall distribution by sex is 19 (47.5%) girls and 21 (52.5%) boys. Within Group A, 9 (39%) are female and 14 (61%) are male. For Group I, 10 (59%) are female and 7 (41%) are male. The accurate group has a mean duration of diabetes of 4.3 years (standard deviation 3.3), while the inaccurate group represents an arithmetic mean of 4.0 years (standard deviation 2.8).

The mean chronological age at the time of data collection was 11.5 years which separates into a mean of 10.8 years (standard deviation 3.0) for the accurate group and 12.4 (standard deviation 3.0) for the inaccurate group. This is statistically significant with a P value of 0.078 by a Mann-Whitney U-test (S = 413.5, Z = 1.77). The mean age of diagnosis is 6.4 years (standard deviation 3.4) for Group A and 8.4 years (standard deviation 3.3) for Group I. This distribution corresponds to a Mann-Whitney U-test P value of 0.082 (S = 401.5, Z = 1.74).

Home Life:

With regard to the parents currently living at home with the children, the two groups are almost identical. Subsequently, no statistical difference can be established between the two groups in terms of whether they live with two natural parents or with a natural parent and a stepparent/guardian. Each of the children is living with at least one natural parent, except the one child (in Group A) who was adopted at five weeks of age. The distribution of parents/guardians living with the children at the time of data collection can be found in Table 3.

TABLE 3: The parental composition of the households in each of the two groups studied

	GROUP A (N = 22)	GROUP I (N = 17)	PROB
MOTHER			
Natural Mother	21 (95%)	16 (94%)	N.S.
Stepmother	0	1 (6%)	N.S.
Adopted Mother	1 (5%)	0	N.S.
No Mother	0	0	
FATHER			
Natural Father	17 (77%)	14 (82%)	N.S.
Stepfather	3 (13%)	1 (6%)	N.S.
Adopted Father	1 (5%)	0	N.S.
No Father	1 (5%)	2 (12%)	N.S.

When the parental data contained in Table 3 are reanalyzed to compare the situation of a natural parent versus another parent substitute, the difference remains insignificant.

In terms of prior marriages, seven (18.0%) of the mothers had one prior marriage, and none had more than one prior marriage. These women are distributed as three in the accurate group (14% of this group) and four in the inaccurate group (24% of this group). This does not represent a statistical difference.

The situation is slightly different in the paternal case. For Group A, there were no prior marriages reported. However, in the inaccurate group two fathers had one prior marriage each, while a third father had two prior marriages. A Mann-Whitney U-test reveals a P value of 0.043 (S = 3.0, Z = 2.02).

With regard to the length of time each parent has lived with his/her child, the accurate group contains 21 mothers (95%) who have lived with their respective child since the child's birth. The remaining mother has lived with her child for greater than five years. In the inaccurate group, 16 of 17 (94%) mothers have lived with their respective child all of his/her life. Again, the remaining case was greater than 5 years.

The situation differs for the fathers in that only 17 of 22 (77%) in the accurate group have resided with the child since birth. The remaining cases are: two (9%) have lived with the child for greater than five years, two (9%) for three to five years, and one (5%) for one to two years. For the inaccurate group, 14 of 15 (93%) fathers have resided with their respective child since birth with the remaining case being from three to five years. This slight difference is not statistically significant.

In terms of the current marital situation of the patients' natural parents, 19 (86%) of Group A and 12 (71%) of Group I remained married at the time of data collection. No parent in Group A and two (12%) in Group I reported being separated. Two (9%) of the biological parents in the accurate set of children and three (18%) in the inaccurate set are divorced. The only death had been one (5%) of the fathers in Group A. None of these marital differences are statistically meaningful based upon a Likelihood Ratio Chi-Square analysis or a one-tailed Fisher's Exact Test, as appropriate.

Maternal Employment:

Thirteen (59%) of the mothers in Group A reported being employed at the time this information was collected as compared to 14 (82%) of the mothers in Group I (P

= 0.110 by Likelihood Ratio Chi-Square analysis, df = 1, value = 2.53). (Of note is that one additional mother had recently stopped working but did supply details of her recent employment; therefore, the analyses below use N = 15 for Group I.)

When the data are considered in terms of the actual number of months worked during the prior year, a difference becomes more apparent (P = 0.004 by a Mann-Whitney U-test, S = 435.5, Z = 2.91). For Group A, the mean number of months worked over the last year was 6.1 (standard deviation 5.2). On the other hand, the Group I mean was 10.1 months (standard deviation 4.3).

An additional difference is the average number of hours worked per week by the mothers in each group. By Likelihood Ratio Chi-Square analysis, those mothers who work thirty or less hours per week (93% of Group A versus 53% of Group I) are statistically more likely to have a child in the accurate group than mothers who work greater than thirty hours per week (P = 0.013, df = 1, value = 6.2). By t-test analysis, mothers in Group A average 21 hours of work per week (standard deviation 9.9) and Group I mothers average 32 hours per week (standard deviation 12.0) yielding a probability value of 0.011 (t = -2.73, df = 27.0).

The average length of time the mother has held her current job does not vary significantly between the two groups: 73.0 months (standard deviation 66.0) for Group A versus 51.2 months (standard deviation 40.1) for Group I.

The employed mothers in group A more commonly work regularly scheduled hours/shifts (12 of 13; 92%) than the working mothers in the second group (9 of 15; 60%). This represents a P value of 0.039 by Likelihood Ratio Chi-Square analysis (df = 1, value = 4.25). However, whether these hours are divided among the day,

evening, or night shifts does not seem to be a differentiating factor (Mann-Whitney U-test) between the two groups. In Group A, eleven (79%) mothers work primarily days, one (7%) evenings, and two (14%) nights. In Group I, thirteen (87%) work mostly days, two (13%) evenings, and none work nights.

The views of the mothers towards their jobs do not vary significantly between the two groups. The details are shown in Table 4.

TABLE 4: Maternal job satisfaction

	GROUP A (N = 13)	GROUP I (N = 15)
Very Satisfied	9 (69%)	7 (47%)
Somewhat Satisfied	3 (23%)	6 (40%)
Somewhat Dissatisfied	1 (8%)	2 (13%)
Very Dissatisfied	0	0

Paternal Employment:

In contrast to the differences described above for the two accuracy groups in terms of maternal employment, the lone statistically significant difference when paternal employment is considered is the regularity of hours worked. In Group A, 17 of 19 (89%) fathers work regular hours/shifts. In the second group, only 9 of 15 (60%) recorded regular hours/shifts. Likelihood Ratio Chi-Square analysis yields a P value of 0.025 (df = 2, value = 7.38).

Twenty of 21 (95%) and 17 (100%) of the fathers in Groups A and B, respectively, were employed at the time of the data collection. (In several cases, data were entered as "unknown." Therefore, the values used for N do vary among items.)

The mean number of months worked in the prior year was 11.4 (standard deviation 2.7) for Group A and 11.5 (standard deviation 1.9) for Group I (N.S.). Overall, 66.7% of the fathers remain at their place of occupation over 40 hours per week. A mean of 48 hours per week was calculated for Group A and 49 for Group I (N.S.) with a standard deviation of 0.7 in each case. The fathers in Group A had held their current job, at the time of data collection, for an average of 130.9 months (standard deviation 101.0) as compared to 81.9 months (standard deviation 74.9) for their counterpart group (N.S.). All 18 of the working fathers in Group A and 14 of 16 (87.5%) in Group I work day shifts. The remaining two work evenings (N.S.).

The average length of time the fathers in each group have remained at their current place of employment is suggestive, but not conclusive, of a difference in that a t-test reveals a probability value of 0.110 (t = 1.60, df = 33.0). The fathers of the more accurate SMBG testers had held their current job for a mean of 130.9 months (standard deviation 101.0) in contrast to the second group of fathers who reported a mean of 81.9 months (standard deviation 74.9).

Paternal job satisfaction for the two groups may be found in Table 5. This distribution is not significant.

TABLE 5: Paternal job satisfaction

	GROUP A (N = 19)	GROUP I (N = 15)
Very Satisfied	15 (79%)	9 (60%)
Somewhat Satisfied	4 (21%)	6 (40%)
Somewhat Dissatisfied	0	0
Very Dissatisfied	0	0

Socio-Economic Status:

The Hollingshead Socio-Economic Scale (Hollingshead, 1957), based upon parental education and job description, demonstrates a significant difference between the two sets of families. In the accurate group, the mean socio-economic rating is 52.3 with a standard deviation of 11.2. On the other hand, the families in the inaccurate group achieve a rating of 44.2 with a standard deviation of 11.5. This corresponds to a P value of 0.031 by a Mann-Whitney U-test analysis (S = 252.0, Z = -2.15). (The absolute values listed do not carry any inherent significance. Of importance is the relation of the two values to each other.)

The actual income data of the 36 families who completed this question can be found in Table 6.

TABLE 6: Family income

FAMILY INCOME	GROUP A (N = 21)	GROUP I (N = 15)
$10,000 - 19,999	1 (5%)	2 (13%)
$20,000 - 29,999	3 (14%)	0
$30,000 - 39,999	4 (19%)	6 (40%)
$40,000 - 49,999	1 (5%)	3 (20%)
Over $50,000	12 (57%)	4 (27%)

The family income with the overall distribution described in Table 6 does not represent a statistical difference between Groups A and I when compared by a Mann-Whitney U-test. However, the P value does decrease to 0.060 by a Likelihood Ratio Chi-Square analysis (df = 1, value = 3.38) when the "over $50,000" annual income group is compared to the remainder of the income brackets. More detailed information concerning income over $50,000 is not available.

Family Characteristics:

The actual distribution of parental ages may be found in Table 7. No statistical age difference between the two groups can be identified based upon Mann-Whitney U-test analyses.

TABLE 7: Parental ages

		30 - 39	40 - 49	over 50
NATURAL MOTHER	Group A	12	9	1
	Group I	10	6	1
NATURAL FATHER	Group A	10	8	2
	Group I	5	8	3
STEPMOTHER	Group A	1	0	0
	Group I	0	1	1
STEPFATHER	Group A	1	1	0
	Group I	0	0	1

Table 8 summarizes the distribution of siblings for the two SMBG groupings. The only statistically significant distribution occurs in the twelve to seventeen year old age group where P = 0.008 by Likelihood Ratio Chi-Square analysis (df = 1, value = 7.02).

TABLE 8: Number of siblings according to age for each of the two groups analyzed

		0 - 5	6 - 11	12 - 17	over 18
GROUP A	-- 0 siblings	14	12	18	20
	-- 1 sibling	7	9	2	1
	-- > 2 siblings	1	1	2	1
GROUP I	-- 0 siblings	14	12	7	14
	-- 1 sibling	3	3	9	0
	-- > 2 siblings	0	2	1	3
PROBABILITY		N.S.	N.S.	0.009	N.S.

The position of the patients studied in relation to his/her siblings is detailed in Table 9.

TABLE 9: Familial ranking of the patient in relation to his/her siblings

	GROUP A (N = 22)	GROUP I (N = 17)
Only Child	5 (23%)	2 (12%)
Eldest Child	9 (41%)	1 (6%)
Middle Child	4 (18%)	5 (29%)
Youngest Child	4 (18%)	9 (53%)

A Likelihood Ratio Chi-Square analysis on this distribution calculates a probability of 0.017 (df = 3, value = 10.13). Restructuring the data to compare the case of "only children" versus the case of "children with siblings" a statistical difference is no longer evident by the application of the same statistical techniques. However, when only those children with siblings (N = 32) are considered, the distribution described above is consistent with a statistical difference of 0.009 (Likelihood Ratio Chi-Square analysis, df = 2, value = 9.32).

Education:

With regard to the highest education achieved by the mothers and fathers, no statistical difference between the two groups is evident. The average highest maternal

education achieved in Group A is 2.5 years of college (standard deviation 2.2 years of education) with a range of completion of high school through completion of 3 years of post-graduate work. For Group I, the mean is 1.6 years of college with a standard deviation of 2.0 years of education. The range for this group is eleventh grade through completion of two years of postgraduate work.

Paternal education averages 3.6 years (standard deviation 2.7) of college for the accurate group as compared to 2.9 years (standard deviation 3.1). The minimum education level in the accurate group is tenth grade and in the inaccurate group is 8th grade. The maximum education is three or more years of postgraduate training in both cases.

In terms of the children, the accurate testers average having completed 4.5 years (standard deviation 2.9) of school after kindergarten, while their counterparts average 7.4 years (standard deviation 3.4). A t-test generates a probability value of 0.067 ($t = -1.88$, $df = 37.0$). The youngest children in each group were commencing first grade at the time of the data collection. The oldest patient in Group A was entering twelfth grade, and the eldest in Group I was entering the first year of college.

Intelligence:

All of the children under thirteen years of age, who were willing, completed a Koppitz Human Figure Drawing Test (Koppitz, 1968) to grossly determine their I.Q. Twenty-three children are in this subset. Seventeen are members of the accurate grouping and 6 of the inaccurate grouping. The categorical range in Group A is 1

through 6 as compared to 2 through 5 for Group I. The significance of these values is: 6 corresponds to an I.Q. in the "high average to superior" range, 5 equates to an I.Q. of "average to high average," 4 corresponds to "low average to average," 3 equates to a "low average" intelligence, 2 equates to "borderline" functioning, and 1 corresponds to "functionally retarded." The one child who received a score of 1 does carry the diagnosis of "learning disabled." The mean in Group A is 4.8 (standard deviation 1.4), which is similar to the mean of 4.3 (standard deviation 1.2) for the other grouping (N.S.).

Child Behavior:

Based upon a Mann-Whitney U-test analysis of the total score on the Achenbach Child Behavior Checklist (Achenbach and Edelbrook, 1981), as completed by either of the child's parents, a probability value of 0.107 (S = 357.0, Z = 1.61) is achieved. In terms of this checklist, a lower score on a continuum corresponds to less behavioral problems as subjectively seen by the parent. The minimum score in each case is 0. The maximum in Group A is 57 as compared to a maximum of 59 in Group I. The mean for the accurate group of children is 19.8 (standard deviation 16.4) as contrasted to a mean of 29.4 for the alternative group (standard deviation 18.7).

However, no statistically significant distribution was evident for any of the 118 individual test items or groups of items (i.e., social withdrawal, depression, immaturity, somatic complaints, sexual disorders, schizoid/anxious behavior, aggressive behavior, delinquency, obsessive-compulsive behavior, hyperactivity, or communication disorders) between the two groups of children.

SMBG Testing:

The children in Group A had utilized SMBG testing for a mean of 27.6 months (standard deviation 25.7; range 1 to 108 months) as compared to the children in Group I who reported a mean duration of SMBG testing of 28.6 months (standard deviation 19.6; range 3 to 72 months). This was calculated to be statistically insignificant by a t-test analysis.

According to the parents, the children in Group A monitor their glucose levels at home on the average of 2.5 times per day (standard deviation 0.8) and 6.4 days per week (standard deviation 1.6). The ranges are 1 to 4 times per day and 1 to 7 days per week. There is no strikingly significant difference with regard to the second group who average 2.3 (standard deviation 1.1) SMBG tests per day and 5.4 (standard deviation 2.2) testing days per week. The ranges in this latter case are from 1 to 5 times per day and 1 to 7 days per week. A Mann-Whitney U-test does give a P value of 0.121 (S = 296.0, Z = -1.55) for the number of days per week testing is performed.

Of note, the children were asked the same questions concerning the quantity of SMBG testing performed. The mean results compare favorably with those above, but in several cases the individual responses do vary. The children in Group A, on average, claimed to test 6.4 days per week (standard deviation 1.5) and 2.6 times per day (standard deviation 0.7). The children in the other group reported testing 5.0 days per week (standard deviation 2.4) and 2.4 times per day (standard deviation 1.2). The slight differences in terms of the number of days per week testing is performed is significant by a Mann-Whitney U-test analysis (P = 0.044, S = 281.5, Z = -2.01). The difference in the times per day SMBG testing is performed is not statistically meaningful.

Urine Testing:

When the parents were questioned as to whether or not their child had ever used urine testing, 33 of the total 39 (85%) answered in the affirmative. This separates into 18 of 22 (82%) of the accurate group members as compared to a similar 15 of 17 (88%) members of the inaccurate group (N.S.). Of the 18 parents in Group A who have had experience with urine testing, 17 (94%) prefer blood testing. In Group I, 12 of 15 (80%) would rather use the blood testing method. Thus, overall 88% of the parents questioned prefer blood testing over urine testing.

When the children were questioned as above, 36 of 39 (92%) overall report using urine testing at a prior time. This total of 36 can be divided into 19 of 22 (86%) of Group A children and all 17 of Group I children (N.S.). Of these 19 children in the accurate group, 14 (74%) favor blood testing, while a comparable 13 (81%) in Group I also favor this method.

Additionally, both the parents and the children were asked whether they experienced: (1) blood testing to be a painful procedure, (2) blood or urine testing to be more accurate, and (3) blood or urine testing to be easier to perform. This information may be found in Tables 10 and 11.

TABLE 10: Parental views concerning blood and urine testing

PARENTAL OPINIONS	GROUP A (N=18)	GROUP I (N=16)	PROB	OVERALL (N=34)
"BLOOD TESTS HURT"	2 (11%)	2 (13%)	N.S.	4 (12%)
"BLOOD IS ACCURATE"	17 (94%)	14 (88%)	N.S.	31 (91%)
"URINE IS ACCURATE"	0	0		0
"BLOOD IS EASIER"	2 (11%)	2 (13%)	N.S.	4 (12%)
"URINE IS EASIER"	2 (11%)	4 (25%)	N.S.	6 (18%)

TABLE 11: The children's feelings concerning blood and urine testing

CHILDREN'S OPINIONS	GROUP A (N=19)	GROUP I (N=17)	PROB	OVERALL (N=36)
"BLOOD TESTS HURT"	1 (5%)	3 (18%)	N.S.	4 (11%)
"BLOOD IS ACCURATE"	13 (68%)	10 (59%)	N.S.	23 (64%)
"URINE IS ACCURATE"	2 (11%)	0	N.S.	2 (6%)
"BLOOD IS EASIER"	9 (47%)	9 (53%)	N.S.	18 (50%)
"URINE IS EASIER"	5 (26%)	4 (24%)	N.S.	9 (25%)

SMBG and IDDM Education:

The parents were asked: "How were you taught about diabetes in general?" The data collection is described in Table 12. No significant difference between the two sets of children is evident in terms of where the families learned about IDDM. The parents were instructed to select as many options as appropriate.

TABLE 12: Sources of basic diabetes education utilized by the families. (There are no statistical differences between the two groups.)

	GROUP A (N=22)	GROUP I (N=17)	OVERALL (N=39)
INITIAL HOSPITALIZATION	13 (59%)	13 (76%)	26 (67%)
HOSP. BASED IDDM CLINIC	15 (68%)	10 (59%)	25 (64%)
PRIVATE PEDIATRICIAN	6 (27%)	7 (41%)	13 (33%)
BOOKLETS/PAMPHLETS	13 (59%)	6 (35%)	19 (49%)
DIABETES CAMP	0	1 (6%)	1 (3%)
MEDIA	3 (14%)	0	3 (8%)
MEDICAL LITERATURE	3 (14%)	1 (6%)	3 (8%)
NURSING EXPERIENCE	2 (9%)	0	2 (5%)
RELATIVES WITH IDDM	1 (4%)	1 (6%)	2 (5%)

The 39 families with completed parental questionnaires also supplied data as to who recommended their current SMBG method as well as how they were instructed in its use. The varied sources of SMBG recommendations are outlined in Table 13. The different methods of SMBG education are summarized in Table 14. In these cases as well, the parents where allowed to choose more than one option, if indicated.

TABLE 13: References used by the families when selecting their SMBG method. (There are no statistical differences between the two groups.)

	GROUP A (N=22)	GROUP I (N=17)	OVERALL (N=39)
INITIAL HOSPITALIZATION	10 (45%)	9 (53%)	19 (49%)
HOSP. BASED IDDM CLINIC	15 (68%)	8 (47%)	23 (59%)
PRIVATE PEDIATRICIAN	3 (14%)	4 (24%)	7 (18%)
FRIENDS/RELATIVES	0	1 (3%)	1 (3%)
MEDIA	1 (3%)	0	1 (3%)

TABLE 14: Educational resources for SMBG techniques. (There are no statistical differences between the two groups.)

	GROUP A (N=22)	GROUP I (N=17)	OVERALL (N=39)
INITIAL HOSPITALIZATION	7 (32%)	9 (53%)	16 (41%)
HOSP. BASED IDDM CLINIC	15 (68%)	8 (47%)	23 (59%)
PRIVATE PEDIATRICIAN	2 (9%)	3 (18%)	5 (13%)
BOOKLETS/PAMPHLETS	7 (32%)	4 (24%)	11 (28%)

Choosing a SMBG Method:

A seemingly important consideration in the recommendation and choice of a SMBG method is expense. However, when questioned about this topic, only 3 of 17 (18%) members from Group I stated that cost influenced their selection of a SMBG

technique. No member of the accurate group said expense played a role in their choice. This slight difference does prove to be statistically significant with a one-tailed Fisher's Exact Test yielding a P value of 0.074.

A confounding factor is that overall 31 of 37 (84%) parents said insurance pays for at least part of their SMBG expenses, while the remaining two parents did not know what role insurance plays in their situation. More specifically, 18 of 22 (82%) of Group A receives some financial reimbursement for the SMBG meter, lancets, and/or reagent strips. Thirteen of 15 (87%) families in Group I reported at least partial insurance coverage. This is a statistically insignificant difference.

Of the eighteen affirmative answers in Group A, five (29%) have 100% coverage and eleven (65%) have 80%. The remaining two parents did not know the exact percentage. In the inaccurate group, one (8%) has 100% coverage and the remaining twelve (92%) receive 80% insurance reimbursement. A Likelihood Ratio Chi-Square analysis reveals a probability of 0.104 (df = 1, value = 2.64).

The thirteen families who used only a non-meter technique (i.e., Chemstrip bG in this study) were questioned as to whether they would convert to a meter technique if cost were not a factor. Eight responses were obtained: two in Group A and six in Group I. Both of the members in the former group said they would not switch, while all six in the latter group said that they would convert (P = 0.036 by a one-tailed Fisher's Exact Test).

The families currently employing a meter technique were questioned as to whether they believe their current meter method is more accurate than a non-meter technique. Twenty-nine of 31 parents responded (18 in Group A and 11 in Group I).

Seventeen (94%) in the accurate group feel their meter technique is more accurate. All eleven in the second group agree. A Fisher's Exact Test does not indicate any difference.

Help Available to the Child:

According to the parental questionnaire, 24 (62%) children in this study currently receive some degree of assistance with their SMBG testing. This partitions into 14 of 22 (64%) in the accurate testers and 10 of 17 (59%) in the inaccurate group (N.S.). The people who actually help the children in each group are detailed in Table 15. The parents listed more than one source, when appropriate.

TABLE 15: Sources of SMBG help received by the children as reported by the parents

SOURCE OF HELP	GROUP A (N=14)	GROUP I (N=10)	PROB	OVERALL (N=24)
MOTHER	14(100%)	9 (90%)	N.S.	23 (96%)
FATHER	9 (64%)	4 (40%)	N.S.	13 (54%)
STEPMOTHER	0	0		0
STEPFATHER	0	1 (10%)	N.S.	1 (4%)
SIBLINGS	2 (14%)	3 (30%)	N.S.	5 (21%)
GRANDPARENTS	1 (7%)	0	N.S.	1 (4%)
SITTER	1 (7%)	0	N.S.	1 (4%)

The data shown in Table 15 reveal that overall 13 (54%) of the children receive some SMBG aid from both of their parents. This is partitioned into 9 (64%) of the Group A patients and 4 (40%) of the Group I patients (N.S.).

When examining exactly how much assistance the children in each of the two accuracy groups receive, a very similar distribution is found. In Group A, 8 (36%) of the total 22 children receive assistance with SMBG routines "always or almost always," 4 (18%) receive help "sometimes," and 10 (45%) receive assistance "never or almost never." The distribution for Group I in terms of the same categories is 7 (41%), 2 (12%), and 8 (47%). No significant difference exists based upon a Mann-Whitney U-test analysis.

The above series of inquiries were also directed to the children. Of interest is that the results are similar but not identical. Overall, 21 (54%) of the children reported receiving at least some help with their SMBG routine. Twelve of the 22 (55%) children in Group A receive some degree of assistance. Nine of 17 (53%) children in Group I report receiving help. The origin of this assistance can be found in Table 16. Again, some children described more than one source of aid.

TABLE 16: Sources of SMBG help received by the children as reported by the children. The probabilities shown are based upon a Likelihood Ratio Chi-Square analysis.

SOURCE OF HELP	GROUP A (N=12)	GROUP I (N=9)	PROB	OVERALL (N=21)
MOTHER	11 (92%)	8 (89%)	N.S.	19 (90%)
FATHER	11 (92%)	5 (56%)	0.05	16 (76%)
STEPMOTHER	0	0		0
STEPFATHER	0	0		0
SIBLINGS	1 (8%)	2 (22%)	N.S.	3 (14%)
GRANDPARENTS	0	1 (11%)	N.S.	1 (5%)
FRIENDS	1 (8%)	0	N.S.	1 (5%)

In contrast to the results obtained in the parental questionnaire, from the children's point of view a statistical difference between the two groups becomes evident in terms of paternal SMBG assistance available (P = 0.050 by a Likelihood Ratio Chi-Square analysis, df = 1, value = 3.80). Additionally, 16 (76%) of the 21 children who receive some assistance have both of their parents involved. By groups, 11 (92%) in Group A and 5 (56%) in Group I fall into this category. This also corresponds to a Likelihood Ratio Chi-Square probability of 0.050 (df = 1, value = 3.80).

As was described for the parental case, no significant difference can be identified in terms of the quantity of assistance received by the two groups relative to each other. Again, the children's answers are similar but not identical to their parents. In Group A, 7 (32%) receive help "always or almost always," 5 (23%) obtain assistance

"sometimes," and 10 (45%) secure help "never or almost never." For the respective categories, the Group I results are 6 (35%), 2 (12%), and 9 (53%).

Additionally, the children were asked to respond to the same questions in terms of their insulin injections. Twenty-nine (74%) reported receiving at least minimal assistance. This may be partitioned into 18 members of Group A (82%) and 11 members of Group I (65%) (N.S.). The distribution of this aid may be found in Table 17.

TABLE 17: Sources of assistance with insulin injections as reported by the children

SOURCE OF HELP	GROUP A (N=18)	GROUP I (N=11)	PROB	OVERALL (N=29)
MOTHER	17 (94%)	11 (100%)	N.S.	28 (97%)
FATHER	14 (78%)	8 (73%)	N.S.	28 (76%)
STEPMOTHER	0	0		0
STEPFATHER	1 (6%)	0	N.S.	1 (3%)
SIBLINGS	3 (17%)	3 (27%)	N.S.	6 (21%)
GRANDPARENTS	0	1 (9%)	N.S.	1 (3%)
FRIENDS	1 (6%)	1 (9%)	N.S.	2 (7%)
SITTER	1 (6%)	0	N.S.	1 (3%)

In terms of insulin injections, 22 of 29 (76%) of children who receive some assistance have both of their current parents involved. In the accurate subset, 14 (78%) fall into this category. For their counterparts, 8 (73%) are included in this grouping (N.S.).

With regard to the degree of help received, in the accurate group, 11 (50%) receive assistance "always or almost always," 7 (32%) obtain aid "sometimes," and 4 (18%) secure help "never or almost never." These same categories when applied to Group I give results of: 6 (35%), 5 (30%), and 6 (35%), respectively.

Relatives With Diabetes:

Eight children in each group have contact with family relatives who have been diagnosed with IDDM (36% of Group A and 47% of Group I; N.S.). Of these relatives, five (63%) in Group A and three (38%) in Group I use SMBG to regulate their insulin dose. Again, this is not a significantly large difference. Of this remaining set of eight children, only two in Group A and one in Group I speak to these relatives "often or very often." The remaining children speak to their diabetic relatives "occasionally or never."

Recent Complications:

Five (13%) of the 39 participants reported a hypoglycemic or hyperglycemic complication during the prior twelve months. Of these, one is a member of the accurate set (5% of Group A) and four are in the inaccurate set (24% of Group I). Likelihood Ratio Chi-Square analysis calculates a P value of 0.074 (df = 1, value = 3.18). The one representative from Group A and two of the children from Group I were subsequently given further education concerning IDDM and SMBG use.

Children's Attitudes Towards SMBG Testing and Insulin Injections:

Each child was asked: "What do you like the most about blood testing." The results for both groups are very similar, and there are no statistical differences between their respective responses. Twenty-two responses for Group A were recorded as were seventeen for Group I. Fifteen (68%) of the children in the former group reported that they feel SMBG testing is helpful since it is "accurate" and, therefore, helps in adjustment of their insulin dose. Eleven (65%) members of Group I also feel this way. When combined, 67% of all of the children agree with this view.

When questioned as to whether they enjoy any extra attention they may receive from their family due to their SMBG and insulin needs, only two (5%) of the entire 39 children who responded to this question answered "yes." Each study group contains one of these children.

This last question was then rephrased to refer to any extra attention they may receive from their friends. In this case, three (8%) children said they enjoy this attention. Two are in Group A and one in Group I (9% and 6%, respectively; N.S.).

The children were then queried as to whether or not they feel "extra-special" because of their IDDM. Again, three (8%) children answered in the affirmative: one in Group A and two in Group I (5% and 12%, respectively; N.S.).

Within this series of items, the children were given the option of selecting that they did not like anything about the SMBG routine. Overall, only eleven (28%) children selected this choice. Six of these children are in the accurate group and five are not (27% versus 29%, respectively; N.S.).

When the above inquiries were rephrased to ask what the children liked the least about SMBG testing, the following results were obtained. Fifteen (38%) of the 39 children claimed that they dislike the pain involved. This is distributed as ten (45%) in Group A and five (29%) in Group I (N.S.).

Only one child reported disliking the extra attention he/she receives from his/her family. This child is a member of Group I. Two children, one in each set of children, dislike the extra attention they feel they receive from their friends. Two (9%) children in the accurate set report feeling "different" than their friends, while one (6%) child in the second group agrees with this view.

Another popular "dislike" among the children studied in terms of SMBG use is that it became a nuisance to test their glucose levels several times daily. Twenty-four (62%) of all of the children feel this way. More specifically, 14 (64%) children in Group A concur, while a comparable 10 (59%) in Group I agree. Four members of each group of children reported not disliking anything about their SMBG routine (18% of Group A; 24% of Group I; 21% overall).

These children were then queried as to how much they minded their SMBG and insulin injection routines. These results may be found in Tables 18 and 19.

TABLE 18: The children's frequency of disliking their SMBG routine

	GROUP A (N = 22)	GROUP I (N = 17)	OVERALL (N = 39)
"very much--somewhat"	4 (18%)	8 (47%)	12 (31%)
"a little--not at all"	18 (82%)	9 (53%)	27 (69%)

TABLE 19: The children's frequency of disliking their insulin injections

	GROUP A (N = 22)	GROUP I (N = 16)	OVERALL (N = 38)
"very much--somewhat"	4 (18%)	2 (13%)	6 (16%)
"a little--not at all"	18 (82%)	14 (87%)	32 (84%)

A statistically significant difference exists for the distribution described in Table 18 concerning the SMBG procedures. The probability value by Likelihood Ratio Chi-Square analysis is 0.052 (df = 1, value = 3.78). However, no significant difference is evident between the two groups of children in terms of their frequency of disliking their insulin injection routines.

Glucose Predictions:

Each of the children were queried as to whether or not they are subjectively able to describe their blood glucose value as hyperglycemic, euglycemic, or hypoglycemic prior to a SMBG test. Overall, 29 (74%) feel that they are able to make this determination. These 29 children consist of 19 members of Group A (86%) and 10 members of Group I (59%). The difference between these results corresponds to a P value of 0.050 by Likelihood Ratio Chi-Square analysis (df = 1, value 3.84).

<u>The SMBG Testing Procedure:</u>

As is described in the "Methods" section of this paper, each child was monitored in an attempt to identify those steps which were performed incorrectly. In each case, the manufacturer's instructions for the SMBG method employed was the "gold-standard."

Each parent and/or child who utilized a meter technique was questioned as to whether or not the meter had been calibrated, as directed, when the newest supply of reagent strips was started. Overall, only eleven of the twenty-seven (41%) families that used a meter technique were able to answer this question. Of these eleven, seven were assigned to Group A, and each had calibrated his/her meter with the most recent reagent strip supply. The remaining four are, thus, in Group B. Three of them (75%) had not calibrated their machine as directed. A one-tailed Fisher's Exact Test calculates the corresponding P value to be 0.024.

General SMBG education, as well as the individual instructions included with each technique, direct the child to wash his/her hands prior to the start of every SMBG test. Of the 40 children studied, 23 (58%) did wash their hands. Thirteen of 23 (57%) children in Group A followed this instruction, and a comparable 10 of 17 (59%) in Group B were compliant (N.S.).

Following the finger stick itself, which each child accomplished without difficulty, the child should obtain a sufficiently large drop of blood so as to cover the entire reagent pad. Nineteen (70%) of the 27 children who utilized a meter technique appeared to accomplish this step without difficulty. The remaining eight are distributed in a statistically insignificant manner as five in Group A (29% of this group) and three

in Group B (30% of this group).

Of additional importance is the need to place the drop of blood on the reagent strip without excessive "smearing" (i.e., the patient should allow the drop to gently touch the pad). Thirty-five (88%) of the total children applied the blood to the test pad without excess smearing. Of the other five children, two are in the accurate group and three in the inaccurate group (9% versus 18%; N.S.).

An essential step in both the meter and non-meter techniques is the proper timing of the reaction of the blood with the reagent pad prior to wiping off any excess blood. Thirty-three (83%) of the total children timed their procedure correctly. The other seven children are divided as two in Group A and five in Group B (9% and 29% of the two groups, respectively). This corresponds to a Likelihood Chi-square probability of 0.088 (df = 1, value = 2.91).

Accurate color vision is an obvious prerequisite for any non-meter technique. All thirteen of the children who employed the Chemstrip bG technique possess normal color vision as tested by the Ishihara Polyisochromatic Plates.

All of the children cleared the excess blood from the reagent strip appropriately. Additionally, each child using a non-meter technique compared the strip to the reference strip correctly. Each child utilizing a meter technique correctly inserted the strip and read the result without difficulty.

When the above data are encompassed together, 21 (53%) of the total forty children performed their SMBG procedure without an obvious error. Eight (35%) children in the accurate subset of patients performed at least one of the steps in the SMBG procedure incorrectly. In contrast, eleven (65%) of the children in the inaccurate

grouping of patients committed at least one obvious error. Chi-Square analysis calculates a probability value of 0.060 (df = 1, value = 3.51).

DISCUSSION

The data presented support the hypothesis that psychological, social, and economic factors influence the amount of care and concern a juvenile diabetic has in the management of his/her chronic condition.

This study demonstrates a statistically significant (P less than or equal to 0.10) psychological, social, or economic difference between accurate and inaccurate SMBG users in the expected directions in terms of the: age at diagnosis, child's current chronological age, number of prior paternal marriages, current maternal employment status and regularity of hours worked, regularity of paternal hours worked, socio-economic status, child's rank within the family, child's education, general behavior of the child, number of days per week SMBG testing is performed, and participation of two parents in the SMBG testing routine. However, no statistical difference is evident between the two groups with regard to the: duration of diabetes or SMBG testing, child's sex, identity of the parents in the household (i.e., biological parents versus stepparents), prior maternal marriages, parental marital status, parental education, number of times per day SMBG techniques are performed, parental satisfaction with current employment, current paternal employment status, prior use of urine testing, child's subjective feelings and attitudes towards SMBG testing and insulin injections, sources of SMBG and IDDM education, presence of relatives with IDDM, and child's intelligence.

The significance of the above factors is emphasized by the fact that 42.5% of the children studied are inaccurate in their use of SMBG techniques. If this twenty

percent or greater error, committed at the time of this study, is generalized to daily testing habits, it must be assumed that these children are frequently being administered incorrect insulin doses. This result supports earlier work by Fairclough et al. (1983), Jovanovic and Peterson (1980), Shapiro et al. (1981), Birch et al. (1981), Kublis et al. (1981), Waalford et al. (1980), Fahlen et al. (1980), and Webb et al. (1980) who demonstrated the inaccuracy of SMBG use by the average diabetic.

The Glucose Results:

Analyses of the glucose results from the laboratory, parents, and children indicate that a statistical difference between Groups A and I is only evident for the children. The average glucose value reported by the children in the inaccurate group is 183.9 mg/dl as compared to 253.0 mg/dl in the accurate group ($P = 0.048$). This may imply a conscious or unconscious attempt by the children in the inaccurate group to falsify their SMBG reading in a bias towards a more acceptable value. This pattern may become evident for the parents if a larger sample size were used. (Only three children in each of the groups had a parent perform the SMBG ritual.)

SMBG Machines:

Prior studies (Strumph et al., 1988; The Medical Letter, 1988; Fairclough et al., 1983) have demonstrated that the inaccuracy of SMBG use is not secondary to machine error. According to these earlier studies, the machines tested showed similar degrees

of accuracy when used correctly. Compared against each other, the distribution of the seven SMBG techniques utilized in this study (Accu-Chek bG I and II, Glucometer I and II, Chemstrip bG, Glucoscan, and Diascan) is statistically insignificant. However, the Accu-Chek bG I machine does have four entries in the accurate group and none in the inaccurate group. When this machine is compared against the other six, grouped as a whole, a significant difference becomes evident (P = 0.097). A larger sample size is necessary to more reliably assess the possible increased accuracy of the Accu-Chek bG I machine.

All four of the families who utilized a different SMBG method prior to choosing their current technique are assigned to Group A. This suggests that these families may be more concerned with the usefulness and appropriateness of their technique than their counterparts. Again, a larger sample size is necessary to confirm this.

When a child is first diagnosed with IDDM, a SMBG technique that is best suited for him/her must be chosen. Common sense would indicate that cost should be an important consideration. However, no member of the accurate group claimed that cost played a role in the selection process. Eighteen percent of Group I families did consider expense. This difference does prove to be statistically significant, but the small numbers involved makes this result suspect.

The families who use a non-meter technique were asked if they would purchase a meter if cost were not a factor. Two answers were obtain in Group A, and both claimed they would not switch. However, of the six answers obtained from the inaccurate group, all said that they would convert. A confounding variable is insurance reimbursement. However, the insurance data obtained are too variable to offer any

clear explanation. Of those families who rely on a meter technique, 94% (of the 31 patients who responded) reported that they felt a meter technique is more accurate than a non-meter counterpart technique. Whether these families truly believe meters are more accurate or whether they are just placing "blind faith" in a numerical readout can only be hypothesized.

Frequency of SMBG Testing:

When questioned concerning the quantity of SMBG testing performed, the children and the parents offered identical average results. However, the individual data entries vary. This implies that the children and their parents either consciously or unconsciously have different views concerning the same objective action (i.e., the number of times per day and the number of days per week SMBG testing is performed). The significance of this difference remains open for debate.

The only significant (P = 0.044) variation between the two groups in regard to SMBG testing occurs in the children's questionnaire, the accurate group reported testing 6.4 days per week as compared to 5.0 days per week in the inaccurate group.

When the SMBG frequency data are taken as a whole, it becomes obvious that very few children test their blood glucose four times per day seven days per week as is generally recommended. The overall frequency reported was 2.4 times per day and 5.8 days per week.

<u>Sex, Age, Duration of Diabetes, and Duration of SMBG Testing:</u>

The results obtained in this clinical project support earlier studies (Kirk et al., 1986 and Koski, 1969) that failed to demonstrate any difference in accuracy between girls and boys. Kaar et al. (1984) did find that boys were, in general, in better metabolic control than were their female counterparts.

Additionally, the duration of diabetes does not correspond to accuracy of SMBG testing. This variable has been studied by numerous investigators with all possibilities being equally represented in the literature.

However, the inaccurate group of SMBG users are on the average older than their accurate counterparts (12.4 versus 10.8 years; $P = 0.078$). This finding is supported by the earlier work of Kaar (1984), Mann and Johnston (1982), and Pond (1968). Parallel to this finding, the children in Group A were on average younger at diagnosis than were the children in Group I (6.4 versus 8.4 years; $P = 0.082$).

The interpretation of this data is difficult. Several possible explanations exist. First, this data may be explained by the belief that as a child becomes closer to adolescence he/she becomes more rebellious and less caring about his/her testing protocol. This view is supported by Kaar (1984), Mann and Johnston (1982), Pond (1968), and Isenberg and Barnett (1965). Adolescents are more likely to attempt to be independent from their parents and the structure imposed by the insulin injection and blood testing protocols. The diabetic adolescent more often desires to be more similar to his/her "healthy" peer than does a younger child. These findings of greater inaccuracy of SMBG testing in adolescents is supported by the work of Bedell et al.

(1977) and Coddington (1972) who reported worse metabolic control in adolescent diabetics.

A second possible explanation exists. The younger a child is at diagnosis, the more likely he/she is to be in the accurate group of children. Therefore, one may postulate that the difference between the two groups is that if a child is diagnosed with diabetes at a younger age (i.e., less than approximately seven years of age) he/she is more likely to receive a significantly greater amount of help from a parent. The parental help may encourage superior testing habits which carry into later childhood/adolescence. This latter view is supported by the finding that the duration of diabetes does not differ between the two groups. That is the time interval from their initial diabetes education to the present is the same.

In studying the duration of SMBG use, no difference is evident. It would seem possible that with the passage of time a child may become either more or less accurate in terms of SMBG testing. His/her accuracy may improve with practice or may falter as the procedure becomes more of a nuisance or a chore. Unfortunately, no prior studies concerning the association between the duration of SMBG use and accuracy could be found.

Home Life and Family Characteristics:

It would seem intuitively obvious that the amount of stress present in a diabetic's home life would greatly influence his/her care and concern in glucose testing. Of intrigue is that the data presented do not reveal any difference between the two groups

in terms of the marital status of the child's biological parents or the identity of the parents with whom the child is currently living. Since 37 of 39 mothers and 31 of 39 fathers are the child's natural parent, an actual difference may not become apparent due to the small sample size. Studies by Simonds (1977), Koski and Kumento (1977), Bruch (1949), and Loughlin and Mosenthal (1944) indicate that marital stability is associated with improved compliance and metabolic control by the juvenile diabetic. The conclusions by Koski in 1969 support those identified in this study.

However, one finding which may hint at an underlying association between home life stability and better metabolic control is that in Group A no father reported a prior marriage. This is in contrast to Group I where two fathers had one prior marriage and one father had two prior marriages. Although the sample size is small, a Mann-Whitney U-test does give a probability value of 0.043. This same distribution does not exist for the mothers; a similar percent in each group had one prior marriage.

The ages of the two groups of parents are very similar on average. Of significance is the age distribution of the children's siblings. The children in the accurate group are much less likely ($P = 0.008$) to have a brother or sister aged twelve to seventeen years than is a similar child in the inaccurate group. The significance of this is uncertain. Assistance received by the children from siblings in terms of SMBG testing and insulin injections is similar between the two groups and, therefore, would not account for the above difference. However, it may be hypothesized that when a diabetic child does have an adolescent sibling he/she is more likely to mimic the older brother/sister and attempt to achieve independence from his/her parents and subsequently from the testing routine. This is in agreement with the conclusion that

diabetic adolescents are, in general, less accurate SMBG testers than are their younger colleagues. Groups A and I are very similar in terms of the presence of siblings from birth through eleven years of age or over seventeen years of age.

The child's birth rank is an important factor in SMBG accuracy. Considering those children who have siblings, ninety percent of first born children were classified as accurate testers, while 69% of last born children are inaccurate testers. These differences are statistically significant (P = 0.009).

Society often grants the eldest child more responsibility and/or higher expectations in everyday life than children of other birth ranks. This general association with the eldest child may carry over to accuracy of SMBG testing. This is in agreement with the study by Koski (1969) who found that the eldest child's diabetes was usually very well controlled. In direct contrast, the study by Swift et al. (1967) claimed that the eldest child usually had worse control as compared to children of other birth ranks. Cultural differences as well as sample size may be compounding factors. There was no difference noted when children with siblings were compared to children without siblings.

Maternal Employment:

With regard to maternal employment several differences between the two subsets exist. These differences may be expanded into an indication of the stability of the home life in the mind of the child (i.e., "Is there always someone at home to help me with my diabetes?").

Fifty-nine percent of the mothers of the accurate children reported being employed at the time of data collection. This compares to eighty-two percent of the mothers in the inaccurate set (P = 0.110). Although this difference is not strikingly significant, a large discrepancy does exist when the actual amount of time worked is analyzed. For the mothers in Group A, the average number of months worked in the last year was 6.1 which is in contrast to the average of 10.1 months by their counterparts (P = 0.004). Furthermore, those mothers who work thirty or less hours per week are more likely to have a child in the accurate group (P = 0.013). The mothers in Group A remain at their place of employment, on average, 11 hours per week less than their counterpart group.

These results indicate that maternal employment itself does not adversely affect the child assuming the mother remains able to devote "a substantial amount of time" to her diabetic child. The stability of having a maternal figure at home for, at least, the purpose of ensuring regular meals times as well as compliance with SMBG testing and insulin injections seems to increase testing accuracy. Loughlin and Mosenthal (1944) agreed that in homes where the mother was out all day and where meals were, thus, haphazard, the diabetic children were generally in worse metabolic control. The study by Koski (1969) disagrees with these findings.

Additionally, mothers who reported regular hours/shifts more commonly have a child who performs SMBG testing accurately. This, again, is presumed to be secondary to a perceived sense of stability and support as viewed by the child. The actual shifts worked do not vary between the two sets of mothers. However, the numbers are too small to make any firm conclusion. (Only three mothers in Group A work evenings or

nights, and only two mothers in Group I work evenings.) Maternal employment satisfaction is similar between the two groups.

Paternal Employment:

Thirty-seven of thirty-eight fathers for whom information was obtained were employed at the time of this study. Based upon the number of hours worked per week, the number of months worked during the prior year, the average length of time they have been at their current employment, and the satisfaction with their current job, the groups are almost identical.

The only significant difference in terms of paternal employment is that 89% of the fathers in Group A reported working regular hours/shifts. In contrast, 60% of fathers in Group I work regularly scheduled hours/shifts. This represents a probability value of 0.025. The more stability the children experience in terms of parental availability to help with SMBG testing and insulin injections, the more likely they are to have increased care and concern for their chronic condition. In turn, this is manifested as increased accuracy of blood glucose testing.

Help Available to the Child:

The children and their parents were independently questioned as to the extent of help the children receive with SMBG testing. The average results are similar. However, the actual data show variability between the two sets of questionnaires. The

significance of this is uncertain, but it does illustrate that the children, whether accurate or inaccurate testers, differ as to the help they perceive themselves receiving in comparison to the amount of help that is believed to be offered to them.

According to the parents, 64% of the children in Group A receive at least some assistance with their blood testing. This is similar to 59% in the inaccurate set of children. These data subdivide to show that 100% of the children in Group A receive aid from their mother as compared to 90% in Group I (N.S.). In terms of paternal assistance, 64% of the fathers in the accurate group help as compared to 40% in the inaccurate group. Although no significant difference in paternal aid can be shown due to the small sample size of children receiving parental assistance (N = 14 for Group A and N = 10 for Group I), it can only be suggested that the involvement of a father figure in the testing procedure leads to improved accuracy. A larger sample is needed to confirm this belief. The involvement of both parents may reflect greater family cohesion and, thus, greater SMBG accuracy.

When the data collection is reorganized, 64% of the patients in Group A receive SMBG assistance from both parents as opposed to 40% in Group I. Although in the current study the difference does not prove to be significant secondary to the small numbers involved, studies by Anderson et al. (1983), Lagreca (1982), and Koski (1969) show that the participation of both parents in the diabetes routine leads to improved compliance and metabolic control.

When these same analyses are applied to the data supplied by the children, maternal help is almost identically involved in the two groups. The difference that becomes evident is the difference suggested above: 92% of the fathers in Group A

help their respective child with SMBG testing as opposed to only 56% of the fathers in Group I. This corresponds to a probability value of 0.050. The same data apply to the children who obtain both parents' help (i.e., all children who have a father helping them also receive maternal assistance). From a child's point of view, the involvement of both parents may signify family stability and increased support available to him/her.

In terms of assistance with insulin injections, an almost similar distribution of help received is reported in the two groups. The remaining sources of help with both SMBG testing and insulin injections are also approximately equally reported in the two groups. These sources include: siblings, grandparents, sitters, and friends.

Intelligence and the Child's Education:

Intelligence was approximated for the children under thirteen years of age by the Koppitz Human Figure Drawing Test (Koppitz, 1968), which does not reveal any difference between the groups in terms of I.Q. This is in agreement with the published data from Steinhausen et al. (1977) and Koski (1969). Swift et al. (1967) did demonstrate a positive correlation between intelligence and good diabetic control.

The average education of the children in the accurate group at the time of data collection was 4.5 years after kindergarten. Their counterparts had averaged 7.4 years of schooling after kindergarten (P = 0.067). This, most probably, is not the result of the education difference but rather is secondary to the age difference as described above.

Child Behavior:

Many studies link different aspects of child behavior to SMBG accuracy and/or inaccuracy. This study attempted to investigate this area as well. Based upon analysis of the Achenbach Child Behavior data (Achenbach and Edelbrook, 1981), which may be used to describe whether children are well or poorly behaved in relation to their peers, a difference between the two groups is evident with a probability value of 0.100. Those children with a lower score on the Achenbach test (i.e., less well behaved) were shown to be less accurate with their SMBG testing. This supports the results of Simonds (1976-1977) who reported that children in poor diabetic control were more likely to have behavioral problems as reported by their mothers.

However, on a test such as this where a parent is completing the data, a confounding variable of the parent's bias is encountered. A parent with a less well behaved child may be less honest in completing the checklist despite being assured of confidentiality. On the other hand, a parent who is very compliant with the SMBG testing protocol may be more apt to be very critical in completing the checklist. This area can be more accurately assessed in future studies by having an impartial observer, such as a teacher, complete the checklist.

Within the checklist results, there are no characteristics which could be more often associated with children in either of the two accuracy groups. This may simply be an artifact of the use of a checklist with over one hundred items and a study containing only forty participants.

Socio-Economic Status:

The Hollingshead Socio-Economic Scale (Hollingshead, 1957) classifies families into socio-economic groupings based upon parental education and current employment data. If both parents are employed, an average between their two ratings is utilized. If only one parent is employed, that parent's information is used alone.

A significant difference between the two accuracy groups was identified with Group A receiving a rating of 52.3. On a continuum, the families in Group I received a rating of 44.2. It should be emphasized that these numbers do not carry any inherent significance, but the difference on a relative scale is important and yields a P value of 0.031. The data imply that a lower socio-economic status is more likely to be positively correlated with worse accuracy in terms of home blood testing. The explanation for this remains subject to debate. The inherent difference between socio-economic classes in terms of stress coping skills may play a role. This result confirms earlier work by Becker et al. (1972), Vincent (1971), Koski (1969), Gordis et al. (1969), Swift et al. (1967), Knutson (1965), Bergman and Werner (1963), and Stone (1961).

When the income data are analyzed independent of employment status or education, the distribution of income is insignificant. However, if the families who earn over $50,000 per annum are compared to the remaining income brackets, the probability value does become significant at 0.060.

The highest education received by parents in both groups is almost identical. Parental education does not influence the child's SMBG testing accuracy.

Relatives with Diabetes:

The study by Farquhar and Campbell in 1980 found that those children with first degree relatives with IDDM were in worse metabolic control than children without insulin-dependent relatives. The data obtained in the current study does not offer any clear relationship concerning this point. Only three children were identified who spoke with SMBG-using relatives "often or very often." This number is too small to warrant further discussion.

Recent Complications:

Four of the five children who had experienced a hypoglycemic or hyperglycemic complication within the prior year are in the inaccurate group of children. This represents a statistically significant difference (P = 0.074) and supports the underlying assumption that children who test inaccurately have worse metabolic control. These five children who experienced a "short-term complication" of their diabetes represent only thirteen percent of the total group studied. However, the number of children experiencing subclinical hypoglycemic and hyperglycemic episodes, predisposing to "long-term complications," may be postulated to be significantly greater given the presence of 42.5% of the children in the inaccurate SMBG group as well as the overall 53% error rate in the testing process.

Urine Testing Versus Blood Testing:

Overall, eighty-five percent of the children used urine testing at some prior time. Eighty-eight percent of these families prefer blood testing. No significant difference between the two accuracy groups exists. These results are consistent with those of Fairclough et al. (1983).

When the parents and children were questioned as to their respective feelings towards blood and urine testing, several interesting points became evident as are outlined below. For all of the items studied in this subsection, the data distribution between the two accuracy sets of children are almost identical. Therefore, only the overall results will be discussed in detail.

A common view by the non-diabetic person is: "The worst aspect of daily blood testing would be the pain of the needle sticks." However, only twelve percent of the parents feel that the needle sticks were painful to their children. The children are in agreement; only eleven percent feel that SMBG is a painful procedure. Ninety-one percent of the parents believe blood testing is accurate. This is in slight contrast to sixty-four percent of the children.

The medical community teaches that urine testing is not acceptable since the blood glucose must be greater than 180 milligram percent to produce a positive urine test. Most of the parents seem well educated in this regard since no parent believes urine testing is accurate.

<u>Children's Attitudes Towards SMBG Testing and Insulin Injections:</u>

In preface, the attitudes of the children in the two groups towards the SMBG testing and insulin injection routines are very similar. Therefore, only the overall results will be discussed in detail.

The major complaint by the children (62% overall) concerning SMBG testing was that it became a nuisance to test blood glucose levels on a regular basis. However, these children were almost equally distributed between the two accuracy groupings. Therefore, whether or not a child views the testing routine as a nuisance or not does not appear to affect his/her testing accuracy. A larger sample size is required to confirm this surprising result.

Overall, two-thirds of the children feel that SMBG testing is accurate and, therefore, helpful. Sixty-nine percent of the children studied reported disliking their SMBG "a little to not at all." Eight-four percent reported disliking their insulin injections "a little to not at all." The remaining children in both cases reported their dislike of the procedures as "somewhat to very much."

Given this general acceptance of SMBG testing and insulin injections in comparison to the 42.5% inaccuracy rate, it may be postulated that the education and support processes are faulty and not the individual child's care and concern for his chronic condition.

SMBG and IDDM Education:

In terms of the sources of initial diabetes and SMBG education, no apparent difference between the two groups of children is identified. Only 67% of the families reported being taught about diabetes during their initial hospitalization. This percent is unacceptable and must be increased if compliance with and understanding of the necessary testing protocols is to be accomplished. Even more distressing is that only 41% of the families reported being instructed in SMBG use during the child's initial hospitalization. It seems obvious that SMBG instruction should be instituted while in the hospital to stress the importance of this practice.

The child's private pediatrician provided early IDDM education in only one-third of the cases studied. Only 13% of the children received initial or supplemental SMBG instruction from their private pediatrician. Again, if the children are to perform SMBG testing accurately, reinforcement of the techniques is necessary by both hospital based specialty clinics as well as by the general pediatrician.

The SMBG Testing Procedure:

In terms of the actual testing procedure, several important differences between the two groups were identified. With regard to calibration of the meters, 100% (N = 7) of the members of Group A had calibrated their machine with the start of their current supply of reagent strips. Only 25% (N = 4) of the Group I members had been compliant with the calibration step. Of greater importance is that only eleven of the

twenty-seven families that used a meter technique could remember if they had calibrated their machine.

The steps most commonly reported in the literature (Bates and Ahern, 1986; Kirk et al., 1986; Wing et al., 1985; Schiffrin et al., 1983) as being performed incorrectly are: (1) failure of the child to wash his/her hands, (2) failure to completely cover the reagent pad if using a meter technique, (3) placing the drop of blood on the reagent pad by "smearing" it, and (4) incorrectly timing the reaction of blood with the reagent.

The general theory behind the requirement of hand washing is that any glucose on a child's hand may be transferred onto the reagent strip, thereby, falsely increasing the SMBG result. No difference between the two groups is evident in this study. However, only 58% of the children did comply with this step.

All of the meter techniques employed in this study are reflectance meters (i.e., they measure color). Therefore, any white, the original color of the reagent strip, which remains visible will alter the meter's ability to interpret the glucose content. (Incomplete covering of the reagent pad with blood will result in an inaccurately low reading.) Seventy percent of the children who utilized a meter technique accomplished this step correctly. The distribution of the children in error between the two groups studied is not statistically meaningful.

Smearing of the blood on the reagent strip may interfere with the chemical reaction as well as deposit any glucose from the child's fingers onto the strip, as discussed above. Eighty-eight percent of the children performed this step without error. Again, the distribution between the two groups is not significant.

Allowing an excessive or an inadequate amount of time for the blood to react with the reagent strip will alter the completeness of the chemical reaction and, therefore, will alter the glucose result obtained. Eighty-three percent of the children timed their procedure correctly. These children who timed the procedure incorrectly are more likely to be in the inaccurate group as shown by a Fisher's Exact Test ($P = 0.100$).

Although the only statistically differentiating characteristics between the two accuracy groups in terms of individual testing errors are in calibrating the meter and timing the reaction, 65% of the children in Group I performed at least one step incorrectly as opposed to only 35% of Group A members. The overall error rate was 53%. These error rates are unacceptable. The use of a larger sample size may better indicate differences between accurate and inaccurate groups of children with regard to the individual steps in the SMBG testing process.

CONCLUSION

This study has demonstrated that certain psychological, economic, and social characteristics of juvenile diabetics are correlated with decreased accuracy of SMBG testing. A stereotypical inaccurate tester could not be identified. However, the children who are more likely to perform blood testing inaccurately include adolescents, children with mothers who are not available to assist their respective children with SMBG testing and provide a consistent meal schedule, children with fathers who work irregular hours/shifts, children originally diagnosed with diabetes in the immediate preadolescent or adolescent years, families in a lower socio-economic class based upon income and occupation, less well-behaved children, the youngest child in the family, and children who have only one parent participating in the SMBG testing process. This information should be used as a guideline to identify those children (1) who are more apt to require additional initial and supplemental education in SMBG techniques and diabetes in general and (2) who may need additional psychological support by child psychiatrists and/or social service workers.

The data presented demonstrate that children and their parents, for the most part, realize that SMBG testing can be accurate and very beneficial. However, this cannot be generalized to indicate that these children are compliant with all SMBG recommendations. It does imply that they may understand the importance of SMBG testing and may simply require intermittent reinforcement from juvenile diabetes specialty clinics and private pediatricians. The private pediatrician must become more active in diabetes and SMBG education, both initially and subsequently.

Although only inaccuracies in meter calibration and timing could be singled out as inherent to the Group I children, this group did have, on the whole, significantly more SMBG errors identified. Reinforcement educational sessions should be offered to all children in order to help prevent errors from being committed and to improve upon the overall 53% error rate. Increased SMBG accuracy should lead to improved metabolic control and, subsequently, fewer short-term and long-term complications, which is the ultimate goal.

This study may be viewed as a screening project on a generally middle-class group of families in an attempt to identify those psychological, economic, and social aspects of juvenile diabetics that are more likely to lead to inaccurate SMBG use. Further studies involving a wider socio-economic population base and a larger population sample are needed to further refine and expand upon the results presented in this study.

APPENDIX I

PARENT'S QUESTIONNAIRE: I.D. Code: __

Follow the directions included with each question. Whenever choosing the answer "OTHER" please describe your answer in the space provided.

1. What are your child's initials? ________

2. Who is filling out this form? (CIRCLE ONE NUMBER)

    1. Mother
    2. Father
    3. Stepmother
    4. Stepfather
    5. Other (Please specify: ______________________)

3. a. Which MOTHER or MOTHER substitute now lives in your child's household? (CIRCLE ONE NUMBER)

    1. Natural mother
    2. Stepmother by a new marriage
    3. Other mother substitute (Describe: ____________)
    4. No mother/mother substitute

   b. How long has this MOTHER lived with your child? (CIRCLE ONE)

    1. All child's life (i.e., since child's birth)
    2. More than 5 years
    3. 3-5 years
    4. 1-2 years
    5. Less than 1 year

   c. How many PRIOR marriages has this MOTHER had? (CIRCLE ONE)

    0 1 2 3 more

4. a. Which FATHER or FATHER substitute now lives in your child's household? (CIRCLE ONE NUMBER)

   1. Natural father
   2. Stepfather by a new marriage
   3. Other father substitute (Describe: ______________)
   4. No father/father substitute

   b. How long has this FATHER lived with your child? (CIRCLE ONE)

   1. All child's life (i.e., since child's birth)
   2. More than 5 years
   3. 3-5 years
   4. 1-2 years
   5. Less than 1 year

   c. How many <u>PRIOR</u> marriages has this FATHER had? (CIRCLE ONE)

   0 1 2 3 more

5. What is the present situation of the BIOLOGICAL parents? (CIRCLE ALL THAT APPLY)

   1. Married (and not separated)
   2. Separated
   3. Divorced
   4. Father deceased
   5. Mother deceased
   6. Father remarried
   7. Mother remarried

6. a. What is the PRESENT employment status of the MOTHER living with the child (or natural mother, if no mother lives with the child)? (CIRCLE ONE NUMBER)

   1. Neither employed nor looking for work
   2. Looking for work
   3. Employed
   4. Student

b. During the past 12 months, for how many months was the MOTHER employed or attended school? (CIRCLE ONE)

0 1 2 3 4 5 6 7 8 9 10 11 12

IF THE ANSWER TO #6b IS 0, THEN SKIP TO QUESTION #7.

c. In a typical week, how many HOURS PER WEEK were spent by the MOTHER either at work or at school? (CIRCLE ONE)

1. 1-10
2. 11-20
3. 21-30
4. 31-40
5. 41-50
6. more than 50 hours/week
7. Unknown

d. For what type of firm/industry does the MOTHER work? (ENTER DESCRIPTION, "UNKNOWN", OR "STUDENT")

Firm/industry: ______________________________

e. What is the MOTHER's job title? (ENTER DESCRIPTION, "UNKNOWN", OR "STUDENT")

Title: ______________________________

f. What are the MOTHER's job duties? (ENTER DESCRIPTION, "UNKNOWN", OR "STUDENT")

Duties: ______________________________

g. How long has the MOTHER had this position? (ENTER NUMBER OR "UNKNOWN")

YEARS ______ OR MONTHS ______

h. What is the MOTHER's usual work/school schedule? (CIRCLE ONE)

1. Regular--same days and hours each week
2. Rotating shifts
3. Irregular days or hours
4. Unknown

i. When does the MOTHER usually work (or go to school)? (CIRCLE ONE NUMBER)

1. Days
2. Evenings
3. Nights
4. Unknown

j. All in all, how does the MOTHER feel about her present job/school? (CIRCLE ONE NUMBER)

1. Very satisfied
2. Somewhat satisfied
3. Somewhat dissatisfied
4. Very dissatisfied
5. Unknown

7. a. What is the PRESENT employment status of the FATHER living with the child (or natural father, if no father lives with the child)? (CIRCLE ONE)

1. Neither employed nor looking for work
2. Looking for work
3. Employed
4. Student

b. During the past 12 months, for how many months was the FATHER employed or attended school? (CIRCLE ONE)

0 1 2 3 4 5 6 7 8 9 10 11 12

IF THE ANSWER TO #7b IS 0, THEN SKIP TO QUESTION #8.

c. In a typical week, how many HOURS PER WEEK were spent by the FATHER either at work or at school? (CIRCLE ONE)

1. 1-10
2. 11-20
3. 21-30
4. 31-40
5. 41-50
6. more than 50 hours/week
7. Unknown

d. For what type of firm/industry does the FATHER work? (ENTER DESCRIPTION, "UNKNOWN", OR "STUDENT")

Firm/industry: ______________________________

e. What is the FATHER's job title? (ENTER DESCRIPTION, "UNKNOWN", OR "STUDENT")

Title: ______________________________________

f. What are the FATHER's job duties? (ENTER DESCRIPTION, "UNKNOWN", OR "STUDENT")

Duties: ____________________________________

g. How long has the FATHER had this position? (ENTER NUMBER OR "UNKNOWN")

YEARS ______ OR MONTHS ______

h. What is the FATHER's usual work/school schedule? (CIRCLE ONE NUMBER)

1. Regular--same days and hours each week
2. Rotating shifts
3. Irregular days or hours
4. Unknown

i. When does the FATHER usually work (or go to school)? (CIRCLE ONE NUMBER)

1. Days
2. Evenings
3. Nights
4. Unknown

j. All in all, how does the FATHER feel about his present job/school? (CIRCLE ONE NUMBER)

1. Very satisfied
2. Somewhat satisfied
3. Somewhat dissatisfied
4. Very dissatisfied
5. Unknown

8. What are the ages of these people? (CIRCLE THE NUMBER UNDER THE APPROPRIATE AGE CATEGORY FOR EACH PARENT OR PARENT SUBSTITUTE THAT APPLIES.)

	< 20	20-24	25-29	30-39	40-49	over 50
Mother	1	2	3	4	5	6
Father	1	2	3	4	5	6
Stepmother	1	2	3	4	5	6
Stepfather	1	2	3	4	5	6
Guardian	1	2	3	4	5	6

9. NOT COUNTING THIS CHILD, how many OTHER children of each age group live in your child's household? (WRITE IN NUMBER. IF NONE, ENTER 0.)

a. How many children aged birth to 5 years? ____
b. How many children aged 6 to 11 years? ____
c. How many children aged 12 to 17 years? ____
d. How many children aged 18 years or older? ____

10. What is your child's position in the family? (CIRCLE ONE)

1. Only child
2. Eldest
3. One of the middle children
4. Youngest

11. What is the education of the parents living with your child? (CIRCLE THE HIGHEST YEAR OF SCHOOLING EACH OF THESE PARENTS COMPLETED OR GOT CREDIT FOR IN REGULAR SCHOOL OR COLLEGE.)

    a. MOTHER/mother substitute:

    (grade school) (high school) (college)
    1 2 3 4 5 6 7 8 9 10 11 12/GED 13 14 15 16 17 18 19+

    b. FATHER/father substitute:

    (grade school) (high school) (college)
    1 2 3 4 5 6 7 8 9 10 11 12/GED 13 14 15 16 17 18 19+

12. What will be the school grade of your child in Fall 1986? (CIRCLE GRADE)

    K 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15+

13. What is the total income (BEFORE TAXES) of the parents with whom the child lives? (CIRCLE ONE)

    1. under $10,000
    2. $10,000 - 14,999
    3. $15,000 - 19,999
    4. $20,000 - 24,999
    5. $25,000 - 29,999
    6. $30,000 - 34,999
    7. $35,000 - 39,999
    8. $40,000 - 49,999
    9. over $49,999

14. How old was your child when FIRST diagnosed with diabetes? (CIRCLE AGE)

    <1 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16+

15. How long has your child been using blood testing?

    _____ YEARS OR _____ MONTHS

16. How many DAYS PER WEEK is blood testing done at least once? (CIRCLE ONE)

0 1 2 3 4 5 6 7

17. How many times per day is blood testing done (when it is done)? (CIRCLE ONE)

1 2 3 4 more

18. Has your child used urine testing? (CIRCLE ONE)

YES NO

IF YES,

a. Which do you prefer? (CIRCLE ONE NUMBER)

1. Blood
2. Urine

b. Why? (CIRCLE ALL THAT APPLY)

1. The blood test hurts your child.
2. The urine test is less painful.
3. The blood test is more accurate.
4. The urine test is more accurate.
5. The blood test is easier to do.
6. The urine test is easier to do.
7. Other (Please describe: ________________)

19. What type(s) of blood testing do you use? (CIRCLE ALL THAT APPLY)

1. Accu-Chek I
2. Accu-Chek II
3. Glucometer I
4. Glucometer II
5. Chemstrips
6. Glucoscan
7. Visidex/Glucostix
8. Other (Please identify: ____________________)

IF YOU HAVE CIRCLED MORE THAN ONE TYPE, which one is used the most often? (ENTER THE ABOVE CHOICE NUMBER)

Choice #:____

NOTE: ALL QUESTIONS BELOW THAT REFER TO "YOUR BLOOD TESTING METHOD" REFER TO THIS TYPE WHICH IS USED MOST OFTEN.

20. How were you and your child instructed in its use? (CIRCLE ALL THAT APPLY)

    1. Medical staff at hospital (other than diabetes clinic)
    2. Medical staff at a diabetes clinic/class
    3. Family doctor
    4. Instruction booklets or pamphlets
    5. Other (Please describe: ______________________)

21. a. Who recommended your present blood testing method? (CIRCLE ALL THAT APPLY)

    1. Medical staff at hospital (other than diabetes clinic)
    2. Medical staff at a diabetes clinic/class
    3. Family doctor
    4. Friends or relatives
    5. Media (advertisements, articles, TV, radio)
    6. Other (Please describe: ________________________)

    b. Was cost a significant factor in your selection of your blood testing method? (CIRCLE ONE)

    YES NO

    c. Does your insurance cover blood testing costs? (CIRCLE ONE)

    YES NO

    IF YES, how much coverage is provided? (CIRCLE ONE)

    1. 80%
    2. 100%
    3. Other (Please list amount: _____%)

22. **Answer only part a or b as appropriate.**

    a. IF YOU USE A TEST **WITHOUT** A METER, would you switch to a method with a meter if both cost the same? (CIRCLE ONE)

    YES NO

    b. IF YOU USE A TEST **WITH** A METER, do you feel that it is more accurate than the tests without meters? (CIRCLE ONE)

    YES NO

23. Does anyone help your child use blood testing? (CIRCLE ONE)

    YES NO

    IF YES,

    a. Who? (CIRCLE ALL THAT APPLY)

    1. Natural mother
    2. Natural father
    3. Stepmother
    4. Stepfather
    5. Siblings
    6. Grandparent, aunt, or uncle
    7. Other (Please describe: ________________)

    b. How often does someone help your child? (CIRCLE ONE)

    1. Always or almost always
    2. Sometimes
    3. Never or almost never

24. How were you taught about diabetes in general? (CIRCLE ALL THAT APPLY)

1. Medical staff at hospital (other than diabetes clinic)
2. Medical staff at a diabetes clinic/class
3. Family doctor
4. Instructional booklets or pamphlets
5. Diabetes camp
6. Media (advertisements, articles, TV, radio)
7. Other (Please describe: ________________________)

25. Do you or any of your child's relatives have diabetes for which insulin injections are required? (CIRCLE ONE)

YES NO

IF YES,

Do these people use blood testing? YES NO

IF YES,

How often do you or your child talk with this person about diabetes and blood testing? (CIRCLE ONE)

1. Very often
2. Often
3. Occasionally
4. Never

26. Has your child had any complications due to diabetes DURING THE PAST YEAR? (CIRCLE ONE)

YES NO

IF YES,

a. What was the complication? __________________

b. In which month did it occur? (CIRCLE ONE)

Jan Feb Mar Apr May Jun Jul Aug Sep Oct Nov Dec

c. Was additional blood testing instruction given? (CIRCLE ONE)

YES NO

SECTION (II): CHILD BEHAVIOR CHECKLIST

Below is a list of items that describes children. For each item that describes your child NOW or WITHIN THE LAST 12 MONTHS, please circle the 2 if the item is VERY TRUE or OFTEN TRUE of your child. Circle the 1 if the item is SOMEWHAT OR SOMETIMES TRUE of your child. If the item is NOT TRUE of your child, circle the 0. Please answer every item.

Item	NOT TRUE	SOMEWHAT/SOMETIMES TRUE	VERY TRUE/OFTEN TRUE	
1. Acts too young for his/her age.	0	1	2	3 (08)
2. Allergy........................ (please describe: ______________________)	0	1	2	
3. Argues a lot..................	0	1	2	
4. Asthma.........................	0	1	2	
5. Behaves like opposite sex......	0	1	2	
7. Bragging, boasting.............	0	1	2	
8. Can't concentrate, can't pay attention for long............	0	1	2	
9. Can't get his/her mind off certain thoughts; obsessions.. (please describe: ______________________)	0	1	2	
10. Can't sit still, restless, hyperactive..................	0	1	2	
11. Clings to adults, too dependent	0	1	2	
12. Complains of loneliness........	0	1	2	
13. Confused, seems to be in a fog.	0	1	2	(20)
14. Cries a lot....................	0	1	2	
15. Cruel to animals...............	0	1	2	
16. Cruelty, bullying, meanness to others........................	0	1	2	
17. Day-dreams, gets lost in his thoughts......................	0	1	2	
18. Deliberately harms self or attempts suicide.............	0	1	2	
19. Demands a lot of attention.....	0	1	2	
20. Destroys his/her own things....	0	1	2	
21. Destroys things belonging to his/her family or other children......................	0	1	2	
22. Disobedient at home............	0	1	2	
23. Disobedient at school..........	0	1	2	(30)
24. Doesn't eat well...............	0	1	2	
25. Doesn't get along with other children......................	0	1	2	
26. Doesn't seem to feel guilty....	0	1	2	
27. Easily jealous.................	0	1	2	
28. Eats or drinks things that are not food (please describe:.... ______________________)	0	1	2	
29. Fears certain animals, places, or situations................. (please describe: ______________________)	0	1	2	
30. Fears going to school..........	0	1	2	
31. Fears he/she might think or do something bad.................	0	1	2	
32. Feels he/she has to be perfect.	0	1	2	
33. Feels or complains that no one loves him/her................	0	1	2	(40)
34. Feels others are out to get him	0	1	2	
35. Feels worthless or inferior....	0	1	2	
36. Gets hurt a lot, accident-prone	0	1	2	
37. Gets in many fights............	0	1	2	
38. Gets teased a lot..............	0	1	2	
39. Hangs around with children who get in trouble................	0	1	2	
40. Hears things that aren't there. (please describe: ______________________)	0	1	2	
41. Impulsive, acts without thinking......................	0	1	2	
42. Likes to be alone..............	0	1	2	
43. Lying or cheating..............	0	1	2	(50)
44. Nailbiting.....................	0	1	2	
45. Nervous, highstrung, tense.....	0	1	2	
46. Nervous movements, twitching... (please describe: ______________________)	0	1	2	
47. Nightmares.....................	0	1	2	
48. Not liked by other children....	0	1	2	
49. Often constipated, doesn't move bowels..................	0	1	2	
50. Often fearful or anxious.......	0	1	2	
51. Often feels dizzy..............	0	1	2	
52. Often feels guilty.............	0	1	2	
53. Overeating.....................	0	1	2	(60)
54. Overtired......................	0	1	2	
55. Overweight.....................	0	1	2	
56. Physical problems without known medical cause:				
a. Aches, pains...............	0	1	2	
b. Headaches..................	0	1	2	
c. Nausea, feels sick.........	0	1	2	
d. Problems with eyes......... (please describe: ______________________)	0	1	2	
e. Rashes, skin problems......	0	1	2	
f. Stomachaches or cramps.....	0	1	2	
g. Vomiting, throwing up......	0	1	2	(70)
h. Other (please describe:.... ______________________)	0	1	2	

(Please continue on next page)

Item	NOT TRUE	SOMEWHAT/SOMETIMES TRUE	VERY TRUE/OFTEN TRUE	4
57. Physically attacks people......	0	1	2	(08)
58. Picks nose, skin, or other parts of body.................	0	1	2	
61. Poor school work...............	0	1	2	
62. Poorly coordinated, clumsy.....	0	1	2	
63. Prefers playing with older children......................	0	1	2	
64. Prefers playing with younger children......................	0	1	2	
65. Refuses to talk................	0	1	2	
66. Repeats certain acts over and over; compulsions............ (please describe: ______________________)	0	1	2	
67. Runs away from home............	0	1	2	
68. Screams a lot..................	0	1	2	
69. Secretive, keeps things to him/herself..................	0	1	2	(20)
70. Sees things that aren't there.. (please describe: ______________________)	0	1	2	
71. Self-concious, easily embarrassed...................	0	1	2	
72. Sets fires.....................	0	1	2	
73. Sexual problems................ (please describe: ______________________)	0	1	2	
74. Showing off, clowning..........	0	1	2	
75. Shy, timid.....................	0	1	2	
76. Sleeps less than most children.	0	1	2	
77. Sleeps more than most children during day and/or night....... (please describe:	0	1	2	
79. Speech problem................. (please describe: ______________________)	0	1	2	(30)
80. Stares blankly.................	0	1	2	
81. Steals at home.................	0	1	2	
82. Steals outside the home........	0	1	2	
83. Stores up things he/she doesn't need..........................	0	1	2	

	Item	NOT TRUE	SOMEWHAT/SOMETIMES TRUE	VERY TRUE
	84. Strange behavior............... (please describe: ______________________)	0	1	2
	85. Strange ideas; delusions....... (please describe: ______________________)	0	1	2
	86. Stubborn, sullen, irritable....	0	1	2
	87. Sudden changes in mood or feelings.....................	0	1	2
	88. Sulks a lot....................	0	1	2
(40)	89. Suspicious.....................	0	1	2
	90. Swearing, obscene language.....	0	1	2
	91. Talks about killing self.......	0	1	2
	92. Talks or walks in sleep........ (Please describe: ______________________)	0	1	2
	93. Talks too much.................	0	1	2
	94. Teases a lot...................	0	1	2
	95. Temper tantrums, hot temper....	0	1	2
	96. Thinks about sex too much......	0	1	2
	97. Threatens people...............	0	1	2
	98. Thumb-sucking..................	0	1	2
(50)	99. Too concerned with neatness or cleanliness................	0	1	2
	100. Trouble sleeping.............. (please describe: ______________________)	0	1	2
	101. Truancy, skips school..........	0	1	2
	102. Underactive, slow moving, lacks energy........................	0	1	2
	103. Unhappy, sad, depressed........	0	1	2
	104. Unusually loud.................	0	1	2
	105. Uses alcohol or drugs.......... (please describe: ______________________)	0	1	2
	106. Vandalism......................	0	1	2
	107. Wets self during the day.......	0	1	2
	108. Wets the bed...................	0	1	2
(60)	109. Whining........................	0	1	2
	110. Wishes to be of opposite sex...	0	1	2
	111. Withdrawn, doesn't get involved with others..........	0	1	2
	112. Worrying.......................	0	1	2
	113. Has trouble getting along with teachers.....................	0	1	2
	114. Please write in any problems your child has that were not listed above:			
	______________________.....	0	1	2
	______________________.....	0	1	2
(67)	______________________.....	0	1	2

(Please be sure you have answered all items)

APPENDIX III

CHILD'S QUESTIONNAIRE: I.D. Code: __

Follow the directions included with each question. Whenever choosing the answer "OTHER," please describe your answer in the space provided.

1. What are your initials? __________

2. How many DAYS PER WEEK is blood testing done at least once? (CIRCLE ONE)

   0 1 2 3 4 5 6 7

3. How many times per day do you use blood testing (on those days when it is done)? (CIRCLE ONE)

   1 2 3 4 more

4. Have you ever used urine testing? (CIRCLE ONE)

   YES NO

   IF YES,

   a. Which test do you like better? (CIRCLE ONE)

      1. BLOOD
      2. URINE

   b. Why? (CIRCLE ALL THAT APPLY)

      1. The blood test hurts.
      2. The urine test doesn't hurt.
      3. The blood test is more accurate.
      4. The urine test is more accurate.
      5. The blood test is easier to do.
      6. The urine test is easier to do.
      7. Other (Please describe: ________________)

5. a. What do you like the most about blood testing? (CIRCLE ALL THAT APPLY)

   1. "It is helpful to me since the test is accurate."
   2. "I like the extra attention I get from my family because of my use of blood testing."
   3. "I like the extra attention I get from my friends because of my use of blood testing."
   4. "It makes me feel extra special."
   5. Nothing
   6. Other (Please describe: ____________________________)

   b. What do you NOT like about blood testing? (CIRCLE ALL THAT APPLY)

   1. "It hurts me."
   2. "I do NOT like the extra attention I get from my family because of my use of blood testing."
   3. "I do NOT like the extra attention I get from my friends because of my use of blood testing."
   4. "It makes me feel very different from everyone else."
   5. "It gets to be a pain or a drag testing."
   6. Nothing
   7. Other (Please describe: ______________________________)

6. Do you mind the insulin injections? (CIRCLE ONE NUMBER)

   1. Very much
   2. Some
   3. Just a little
   4. Not at all

7. Do you mind the blood testing? (CIRCLE ONE NUMBER)

   1. Very much
   2. Some
   3. Just a little
   4. Not at all

8. Does anyone help you with your blood testing? (CIRCLE ONE)

YES NO

IF YES,

a. Who? (CIRCLE ALL THAT APPLY)

1. My mother
2. My stepmother
3. My father
4. My stepfather
5. My brother(s) or sister(s)
6. My grandparent, aunt, or uncle
7. Other (Please describe: ____________)

b. How often does someone help you? (CIRCLE ONE)

1. Always or almost always
2. Sometimes
3. Never or almost never

8. Does anyone help you with your insulin? (CIRCLE ONE)

YES NO

IF YES,

a. Who? (CIRCLE ALL THAT APPLY)

1. My mother
2. My stepmother
3. My father
4. My stepfather
5. My brother(s) or sister(s)
6. My grandparent, aunt, or uncle
7. Other (Please describe: ______________)

b. How often does someone help you? (CIRCLE ONE)

1. Always or almost always
2. Sometimes
3. Never or almost never

9. Can you ever predict your glucose levels accurately before testing your blood? (CIRCLE ONE)

YES NO

APPENDIX IV

ASSESSMENT OF BLOOD TESTING TECHNIQUE I.D. Code: __

1. TECHNIQUE USED:

1. Accu-Chek I	2. Accu-Chek II
3. Glucometer I	4. Glucometer II
5. Chemstrips	6. Glucoscan
7. Visidex/Glucostix	
8. Other: ______________	

2. GLUCOSE VALUES:

Lab result: ____
Child's result: ____
Child's % difference: ____
Parent's result: ____
Parent's % difference: ____

3. STEPS

		NO	YES	NA
A.	Has meter been calibrated recently?................	0	1	9
B.	Washes hands or uses alcohol wipes?............	0	1	9
C.	Loads injector device without assistance?........	0	1	9
D.	Obtains a large drop of blood?........................	0	1	9
E.	Places drop on entire pad?..............................	0	1	9
F.	Times test with a timer or second hand?........	0	1	9
G.	Washes/wipes pad using correct technique?..	0	1	9
H.	Places strip in machine correctly?..................	0	1	9
I.	Records results on a chart?.............................	0	1	9

4. Color vision normal? YES NO NA

5. Child's date of birth? __________

6. Child's age? ________

7. Child's sex? M F

8. Were there any difficulties with the procedure? YES NO
IF YES, describe.

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