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AN EXPLORATORY INVESTIGATION OF ADOLESCENT DIABETES MELLITUS: PATIENT AND PHYSICIAN ATTITUDES TOWARD DISEASE AND TREATMENT

By

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ABSTRACT

AN EXPLORATORY INVESTIGATION OF ADOLESCENT DIABETES MELLITUS: PATIENT AND PHYSICIAN ATTITUDES TOWARD DISEASE AND TREATMENT

By

Robert John McCormick Shaffer

A review of the psychological literature on adolescent diabetes led to hypotheses predicting that disease-related information would link to patient's age, disease duration, Health Locus of Control, IQ, familial experience with diabetes, and evaluation of the doctor/patient relationship. Discrepancies between patient's regimen behaviors and health attitudes also seemed likely to relate to age, disease duration, information level, doctor/patient relationship, and doctor/patient agreement with treatment goals. Questionnaires and interviews with selected patients and their physicians provided pertinent data.

The sample was recruited through MSU's Pediatric Endocrine Clinic, private physicians, and from diabetic camp personnel. Of 100 targeted patients, 83 returned questionnaires. There were 27 males (aged 11 to 20 years) and 56 females (aged 11 to 22 years). These volunteer subjects were generally from higher SES families, and had been exposed to more sophisticated caregivers. The questionnaires covered SES, regimen, information, attitudes toward diabetes and perception of physician's views. On the basis of age, sex, information, and perceived congruity of patient/physician attitudes about disease management, 16 patients were selected for interviews that included measures of vocabulary, Health Locus of Control, medical history, health values, and patient satisfaction. Physicians of interviewed patients were separately interviewed about similar issues, including their accessibility, and their patient's disease control.

The questionnaire data were analyzed using correlations, multiple regressions, and ANOVAs. As expected, information levels correlated positively with age. Substantial positive linkages were also found between information and strict regimen behaviors, attitude/behavior congruity, and femaleness. The interviews suggested that role models had influenced patient's information. Patients whose health attitudes and behaviors were congruent had greater information. Other predictions were not confirmed, but high attitude/behavior congruity correlated with femaleness, and with strictness of attitudes and regimen. Most interviewed patients described their physicians as accessible, and expressed satisfaction with these relationships. That differences were found in this relatively homogeneous sample between patient's attitudes and perceived physician attitudes, suggested that adolescent patients may also misperceive the views of their physicians.

Issues of methodology, links to prior work such as the Health Belief Model, and applications to clinical practice were discussed. Suggestions for future research were also made.

DEDICATION

This dissertation was made possible by the patients
who offered their time and efforts to this project.
I wish to thank them, their parents and their
health providers.

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INTRODUCTION

Illness is the first whisper of our mortality. In the event of chronic illness in children, this whisper may become a background noise against which personalities are formed, major life events are interpreted, and social relations are carried on. Chronic illness can add its tonal color to all of life. Thus, disease is more than a process of physiological events and tissue damage. Illness and its treatment has effects upon cognitive, affective, familial and social spheres. In some chronic diseases the so-called "secondary processes", or "psycho-social overlay" can assume etiological significance, or at least greatly influence the course of the illness.

This research will investigate the attitudes and perceptions of adolescent patients and their physicians about the experience of chronic disease.

Chronic disease in children

It must be noted that the term "chronic illness" is quite encompassing. Incurable diseases strike numerous zones of the body, restrict various activities, are disfiguring or invisible, can be successfully managed or not, are affected to greater or lesser extents by psycho-social factors, and, of course, affect life spans to differing degrees. Thus all chronic illness is not the same. While it may be the legitimate goal of psychological science to seek the broadest generalizations, it would be a mistake to ignore the differences among chronically ill populations.

In recent years psychological researchers have taken cognizance of the fact that approximately 10 percent of all children will have experienced a chronic disorder before the age of 18 years (Pless & Douglas, 1971). This increased awareness has led to more investigations of this population.

Possibly the most economical way to examine disease and adaptational processes is through the use of one carefully selected disease as a "model". There are several characteristics that should be included in any model disease studied from a socio-psychological perspective:

1) It should have minimal physiological effects on cognitive capacity. Psychological coping strategies would otherwise be unduly limited and thus compromise generalizability.
2) It should permit a lifespan into at least middle adulthood. This gives a perspective on the course for an extended period of time and through several phases of the life-cycle.
3) It should affect a relatively large number of children. This would ease subject selection, but of more importance, would permit broader utilization of the findings.

4) There should be a moderate degree of stress: enough to evoke coping responses, but again, not so much as to severely limit the means of coping.
5) It should permit a moderate degree of self-treatment. The bulk of treatment for most chronic diseases of children (e.g., cystic fibrosis, juvenile diabetes, asthma, etc.) is done at home by parents or by the children themselves. Patients solely under the care (and control) of physicians or expensive life-saving machines are more rare. The passivity of this situation may promote important but differing coping-styles. Self-treatment provides both a "press" of sorts, an imposed task, as well as serving as an arena in which the patient can perform, achieve, and be assessed.

Juvenile diabetes mellitus (Type I diabetes)

A disease that fits the above criteria is juvenile diabetes mellitus; now termed "Type I diabetes". Estimates of incidence and prevalence vary widely. Of the 4.5 to 10 million diabetics in the United States, perhaps as many as 1.5 million suffer from the more aggressive "juvenile" type (Jackson & Guthrie, 1975). From 1 in 2,500 to 1 in 600 school-aged children are living with diabetes (Kohrman, 1979).

The adjective "juvenile" is something of a misnomer in that not all its victims are children, or even stricken as children. Rather, the term is usually applied to those diabetics dependent on exogenous insulin injections (or by some definitions, those with no remaining endogenous insulin production), and not merely dietary therapy.

Diabetes results from the lack or relative insufficiency of, or difficulty in utilizing the pancreatic hormone insulin. The cause is unknown, but speculations include viral infection theories, genetic predisposition, autoimune reactions, or interactions between the above (Notkins, 1980).

One of the major functions of insulin is to facilitate the use of glucose as a fuel for all cells. In the absence of insulin, cells obtain fuel from stored fat and protein reserves. This breakdown of stored materials may result in toxicity as the result of free fatty-acids (ketone bodies) released into the blood serum by the process (Lilly, 1967). The glucose released from food digestion is unable to enter the cells. It flows through the blood stream in excessive concentrations and is ultimately excreted by the kidneys. Severe thirst motivates drinking the large amounts of water necessary for this excretion. In some patients with severe cases of diabetes acidosis ("ketosis" or "diabetic coma") may develop. This toxic condition may be fatal if untreated with insulin, fluids and electrolytes.

The treatment of Type 1 diabetes

The principal treatment of juvenile diabetes consists of one to four injections of insulin preparations per day. Meals and physical activities must be balanced and timed to coincide with the action of the exogenous insulin.

Degree of "control" or management of the disease has traditionally been determined by multiple fractional daily urine tests for glucose and periodic blood-serum glucose assays. The reliability of these measures, particularly that of fractional urines done in the home, has been questioned (Malone, Hallrang, Malphus, Rosenbloom, Grgie & Weber, 1976). Other measures include growth and development, urinary ketone output, and 24 hour collections of urine checked for both volume and glucose content (Weil & Kohrman, 1980).

Skeletal growth can be greatly inhibited by the poor control of juvenile diabetes during the years of most rapid growth (Jackson, et al., 1978). It would appear that excessive doses of insulin and too limited a number of calories, or conversely, more calories than can be utilized by a given dosage of insulin, can both deprive the diabetic child of the requisite sustenance with which to grow to his/her full potential.

The treatment of juvenile diabetes is a dilemma. One school of thought (typified by Jackson & Guthrie, 1975) maintains that strict attempts at control of blood glucose will result in optimal growth and development, and delay in long-term complications (i.e., blindness, kidney failure, occlusion of small and perhaps large arteries, damage to peripheral nerves, in some cases, gangrene and amputation of extremeties, etc.). Other physicians (Weil & Kohrman, 1980) believe that such strict control is difficult to obtain with common insulin delivery mechanisms (i.e., one to four injections daily). Such attempts may in fact lead to markedly increased risks of "insulin reactions" (a state of hypoglycemia in which insufficient glucose is present in the brain. This may result in weakness, unconsciousness, and possible convulsions. Its onset is sudden, there is a lethal potential, it may stunt growth and hamper the child's development of autonomy from his/her parents. This school adds that no long-term human studies have yet demonstrated the benefits claimed by strict-control advocates, and propose that the rigors and deprivations of such regimes are both psychologically damaging and uncalled for in the absence of proof of their efficacy. They note, however, that there are serious dangers from either too loose or too strict management, and future technology may make better control feasible.

According to Ack, Miller and Weil (1961) IQ is not limited by diabetes if onset occurs after five years of age. Prior to that age, it is difficult for parents or children to recognize potentially brain-damaging effects of hypoglycemia. Gans and Deutch (1962) propose that brain damage from such incidents and from prolonged coma is more frequent than had been believed. The data on subtle neurological degradation as a sequela of hypoglycemia is mixed but suggestive. Further, its sudden onset and consequent incapacitation may lead the diabetic to a state of increased sensitivity to all potential loss of control (Kimbal, 1971). Clearly the complications of diabetes are severe. The treatment itself is highly dangerous. Thus great importance is placed on the success of whatever treatment regimen is undertaken.

As stated, the evidence for either position is sketchy, anecdotal, or based on a small number of animal or short-term human studies. Most pediatricians fall somewhere along a continuum between extreme positions. Their views are determined more by training and personal values than by clear-cut evidence (Kohrman, 1979). Whatever attitude is taken by the physician, it is clear that the treatment is an onerous one for both family and patient.

The investigation of those factors that contribute to successful management is important not only to people afflicted with Type I diabetes, but to the health care community that is partially responsible for the treatment, initial instruction, and control of juvenile diabetes and other chronic diseases.

Several processes that occur in a treatment regimen are amenable to study. First, basic information about the disease and its treatment must be transmitted from health care providers to patients and family. Second, attitudes toward the strictness or looseness of a regimen may differ among medical personnel, parents and patients. The congruence or disparities of these views may affect the quality of care and success of information transmission. Finally, actual disease control is determined by many investigatable psychosocial and physiological factors.

The exploration of these questions should illuminate areas of compliance or management difficulty and help health care providers appreciate the role of attitudes and communication in their practice.

LITERATURE REVIEW

This study falls partially under the shadow of that large umbrella termed "compliance research". Systematic compliance studies are relatively recent additions to the fields of medical, clinical, ecological and social psychology. As is common with relatively new areas of research, both issues of methodology, e.g., variable selection and definition, construction of testable hypotheses, postulation of causal processes, and tie-ins to established theories remain unsettled.

In its simplest sense, "compliance" means adhering to a prescribed medical regimen (Vincent, 1971). If compliance is defined in this way, what are the findings about compliance and treatment outcome in diabetic populations?

A number of studies have examined these questions in one form or another since the late 1940s. Dahlberg, Jorpes, Kallner and Haefner (1947) obtained self-reports from 5,207 diabetic patients. Only 30% of this sample reported following the strict diets prescribed at that time, 54% adhered to a "loose" diet, and 11% admitted to following no particular diet at all. Eighty-three juvenile diabetics were studied by Gabrielle and Marble (1949). While 51 did not adhere to a prescribed diet, 52 did conduct urine tests at home. Of these, 21 reported "high" levels of glucosuria (excess glucose in the urine). Tunbridge (1953) asked 94 diabetic patients to compile 24 hour diet recalls for one week. Reported adherence to prescribed diet was "accurate" in 15, "fair" in 44 and "hopeless" in 34.

More recent studies have begun to examine short-term outcome, e.g., control of glucosuria, number of insulin reactions and ketosis episodes as well as the patient's adherence to management advice. Stone (1961) studied the incidence and causes of poor control in 160 insulin dependent diabetic patients. The subjects ranged in age from 18 to 70 years of age. The modal duration of diabetes was between 5 and 10 years. There were 62 men and 98 women. Each subject was seen four times. At the first session patients were evaluated for diabetic control on the basis of diet, urine testing, insulin shots and ketoacidosis. Twenty-one percent were found to be in what they termed "good" control, 17% in "fair" control and 62% in "poor" control. The next session investigated the reasons for poor control through patient interviews, and then provided information about proper self-care procedures.

While causes for poor control overlapped, the leading problem seemed to be ignorance of proper daily treatment (found in 83 subjects). Loosely defined "emotional problems" were also common causes of poor control, particularly when they led to overeating, found in 37 subjects. Social/environmental difficulties influenced the care of 18 subjects, while dogged refusal to attempt to manage the disease was found in only four subjects. There was no connection between age, sex, race, religion, duration of disease or job and the control of diabetes.

Stones' (1961) subjects were re-evaluated between 22 and 28 months after first being seen. At this time, 53% were under "good" control, 11% under "fair" control and only 36% still in "poor" control.

Williams, Martin, Hogan, Watkins and Ellis (1967) focused on the determinants of "good control" in four populations of adult insulin-dependent diabetics. The 213 subjects were selected from two university clinics, one private practice and one pre-paid health maintenance group.

Control was measured by the amount of glucose found in periodic blood and urine samples, the number of episodes of keto-acidosis and insulin reactions, and nearness to ideal body weight. According to these criteria, 71% of these subjects were in "poor" or "very poor" control, while 29% were in "fair" or "good" control. Of the subjects under "poor" control, 42% of the total were having difficulties with insulin reactions or body weight, while 29% of the total sample were having multiple difficulties.

An early age of onset, and stressful living conditions correlated significantly with poor control. Large households and, surprisingly, higher SES; tended to correlate with poor control. Having a physician with strict attitudes toward control highly correlated with good control, as did overall patient satisfaction with the physician. As expected, there was a significant positive correlation between knowledge of the regimen and performance (i.e., "compliance") but a negative correlation with good control. The authors suggest that subjects with control problems are required to learn more about their disease, but owing to other factors (e.g., life stresses, etc.) are unable to effect a change. They also suggest that the continuing emotional support of the health care team may be more important in achieving compliance and control than strictly educational sessions.

Watkins, Williams, Martin, Hogan and Anderson (1967) studied in depth the 60 subjects from the above sample who were patients at university clinics. Their ages ranged from 16 to 81 years, with a mean of 44. They were generally poorly educated and of low SES. This investigation made an attempt to relate knowledge with actual demonstrations of self-care competence in the home and degree of control. Home care practices were disturbingly poor in that 80% used improper insulin administration technique, over 50% administered the wrong dosage, 67% tested urine incorrectly, and only 10 of 60 subjects reported reasonable scheduling and amount of food intake. Nevertheless, almost half of the subjects were in "good" or "fair" diabetic control. Again, there was a positive correlation between knowledge and management ($\underline{p} < .01\%$), but there was no correlation between management per se and control. The correlation between knowledge and control was again negative. The authors suggest that subjects' knowledge of management may in fact be limited to rote responses and lack a conceptual basis. The lack of relationship between management and control may call into question the quality of advise given by physicians.

A prerequisite for any sort of compliance behavior on the part of patients is effective communication with the physician.

Hulka, Kupper, Cassel and Fitzhugh (1975) studied the relationship between doctor-patient communication and diabetic control. Their subjects included 42 physicians and 242 adult patients with diabetes. The average patient/doctor ratio was 5.8, the mean patient age was 63 years. Twenty-two were insulin dependent, 164 used oral medication and 56 were managed by diet alone. Slightly over 50% of the subjects were female, and almost 75% were in the middle or working classes. Communication scores were determined by a ratio of information items recalled by patients, divided by the number of items the physician had attempted to communicate. The mean communication score was .67. There was a tendency for those pairs trying to transmit and receive larger numbers of items to have higher scores. Those patients requiring medication, especially insulin, were the most successful. Duration of disease was also a significant predictor of high communication scores. However, number of physician visits, duration of care with doctor, age, sex, SES or marital status were not significant variables. There was no relationship between communication score and appointments kept or medication compliance. A trend between good communication and high patient satisfaction did exist, however. Hulka used Williams' (1967) criteria to determine diabetic control. Omitting 29 subjects owing to insufficient data, 125 subjects were in "very poor" or "poor" control, and 88 in "fair" or "good" control. There was no evidence suggesting a relation between communication and control. Hulka's data indicated that when communication was effective, compliance was high. This result is in accord with Stone's (1961) findings that ignorance was a prime determinate of poor compliance.

The particular problem of compliance and control in children with diabetes has been an area of intense interest due to differing treatment approaches. Jackson, Holland, Chatman, and Guthrie (1978) provided growth and control data from 252 diabetic children under treatment for 3 to 16 years. Their prescribed regimen was strict and fairly uniform for each child. Ratings of overall diabetic control based mostly on amount of glycosuria were made. Control was "good" for 20%, "fair to good" for 64% and "fair" for 16% of the sample. No growth retardation was found in those children in the two better controlled groups.

Perhaps the most frequently cited and controversial report in this literature is Swift, Seidman, and Stein (1967). Their sample consisted of 50 male and female children with diabetes (mean age 11.7 years, range 7-17 years), a matched control group from public schools, and their parents. Subjects were matched for sex, race, SES, and childrens' IQ. The researcher's evaluation included a comprehensive psychiatric interview (including self-concept, affect modes, independence, maturity, etc.), psychological testing (house, tree, person; WISC, general anxiety scale, and Rorschach), interviews with parents about the child's developmental history, parental acceptance of the disease, demographic data, and a rating of diabetic control.

Diabetic control was significantly related to the following psychosocial variables: adequate self-concept, normal independence/

dependence balance, and high IQ. Later onset of diabetes and shorter duration of the disease were also related to better control.

The diabetic sample exhibited more extreme independence/ dependence balance, poorer self-perception, more latent and manifest anxiety, constriction, hostility and oral preoccupation on the interview data. The psychological testing revealed more depression, constriction, dysphoria, latent anxiety and pathological body image. At home interviews found poorer home/peer adjustment and emotional tone, as well as more extreme maternal protection/neglect and parental domination/submission. The authors made several suggestions to alleviate some of these problems: Self-care procedures should be encouraged as soon as children can understand the concepts behind them, but not sooner, honest discussions about the child's fears should occur, and physicians must pay attention to the emotional tone of the home.

Bruhn (1977) presented the viewpoint that the diabetics' self-concept is important in determining the degree of his or her control over the disease. He argued that a negative self-concept (e.g., as "ill", "different", "obese", etc.) will be reflected in the quality of self-care. Poor self-care may lead to poor control and exacerbated illness, thus reinforcing the poor self-concept and resulting in a vicious cycle. Bruhn suggested that self-concepts can be determined by the expectations of parents and responses of peers. Some children may also exploit the benefits for secondary gain. Bruhn presented little data to support his clinical observations.

Simonds (1977) has produced data correlating good diabetic control in children with absence of psychological symptoms. Forty male and female diabetic children ranging in age from 6 to 18 years were selected for study from a clinic population. Twenty-two percent of the entire clinic population were judged to be in "good" control, 27% "good to fair", 14% in "fair", 32% in "fair to poor" 5% in "poor" control. Those children in "fair" control were eliminated from study. The remainder were formed into two groups, matched for age, sex and duration of diabetes. Each child was given a 44 item semi-structured interview by an examiner blind to control status. This interview explored interpersonal and intrapsychic conflicts. Mothers completed a behavioral/emotional symptom checklist for their children.

In contrast to Swift et al. (1967), Simonds found an overall rate of "diagnosable" maladjustment of only 7.5%, no higher than that of the healthy samples. Nevertheless, those children in "poor" control had significantly greater interpersonal problems, and three times as many reported a "different" self-image due to their disease. Mothers of children in "poor" control also reported more behavioral problems in their children than did those of children in "good" control. Simonds suggested that parental tensions, and anxiety over diabetes may have been responsible for some of the interpersonal difficulties as well as for the poor control. He proposed that a closely supportive relationship between patients and staff within this sample helped to reduce the incidence of maladjustment.

Koivukangas (1977) also suspected that physical distance, and, as one would assume, a concomitantly more remote personal relationship between patient and medical personnel, results in poorer metabolic control. There was no independent rating of compliance, however. Koivukangas reported on the control status of 60 Finnish children with diabetes. They were of both sexes, averaging 12 years old, and had had diabetes for an average of five years. Subjects were divided into two groups, one received home visits, the other were controls and did not.

Metabolic control was determined on the basis of grams of glucose per 24 hours, urine output and frequency of ketoacidosis. Home visits were made every three months for nine to 12 months. The results were as follows (see Table 1).

TABLE 1.--Home Visits and Control of Diabetes

Level of Control	Home Visits		Controls	
	Start	9-12 Months	Start	9-12 Months
Good	11	12	7	6
Fair	8	3	11	4
Poor	8	12	10	18
Total Number of Patients	27	27	28	28

Source: Modified from Koivukangas, (1977).

As can be seen from these figures, control generally worsened over time for both groups. Koivukangas felt that this was due to the ending of "remission", or "honeymoon" period among those subjects recently diagnosed.

Ludvigssen (1977) corrected this procedural error by studying only children past the remission stage. His sample consisted of 58 Swedish diabetic children 6 to 17 years of age with the duration of diabetes ranging from 3 to 14 years. Age at onset varied from 1 to 13 years. Thirty-six percent were post-pubertal, 41% pre-pubertal and 22% were currently in puberty.

Ludvigssen's approach was to correlate a number of psychosocial and physiological variables with metabolic control. The variables included the following:

1) Familial social situation measured through questions about income and education.
2) Knowledge about diabetes and treatment in parents and children, measured by a questionnaire similar to that of Etzwiler's (1963).
3) Patient attitudes toward diet and treatment: measured by interviews and questionnaires.
4) Psychological assessment measured through "interviews and school contacts".
5) Diet quality, physical exercise and insulin dosage were measured.

6) Physiological measures included anti-insulin and c-peptide antibodies.
7) Diabetic control was measured by daily urinalysis records for one year.

In general, control decreased until age 14, then increased, but increased until 10 years duration, then decreased. That is, regression curves for age and duration of control crossed. There was no correlation between SES and control. One quarter of the parents and 2/3 of the patients over 12 had inadequate knowledge of diabetes. Knowledge was negatively correlated with control, but when attitudes toward treatment were taken into account, the correlation was positive. Only a weak correlation was found between diet and control. The research found that physical exercise was the most potent variable influencing diabetic control. Attitudes seemed to be important mediating variables, in that they correlated with active exercise and good dietary habits.

Summary

The majority of studies cited above are actuarial in nature. That is, they have postulated categories of diabetic control, or psychological symptoms, and have recorded the number of people fitting in or exhibiting them. For the most part they have only hinted at the causes underlying good or poor metabolic management and psychological adjustment. Criteria for control ratings was variable. Several articles have relied strongly on clinical observations and "semi-structured" psychiatric interviews (e.g., Simonds,

1977) rather than on standardized tests. The lack of rater "blindness" in some studies may have led to biased results.

Most clearly lacking, however, is any theoretical grounding in psychological theory. Most studies have selected a series of variables from prior research, thrown them together and found individual correlations with management success (Ludvigsson's, 1977 multiple regression methodology is an exception).

Models of Health Behavior

The Health Belief Model

The outstanding attempt to apply social science theory to the complex area of health behavior has been made by Becker and his colleagues with the evolving "Health Belief Model" of patient behavior. This is perhaps the most thoroughly researched and developed model of patient behavior, including "compliance". The Health Belief Model (HBM) is theoretically grounded in the work of cognitive and behavioral decision making processes under conditions of uncertainty. Feather's (1959) work predicted individual behavior from an assessment of a) the individual's valuation of an outcome, and b) the exception that a given action will bring about the desired outcome.

Becker has applied this perspective to health behavior by examining:

a) Motivation to avoid illness or to get well

b) Desire for a particular level of health

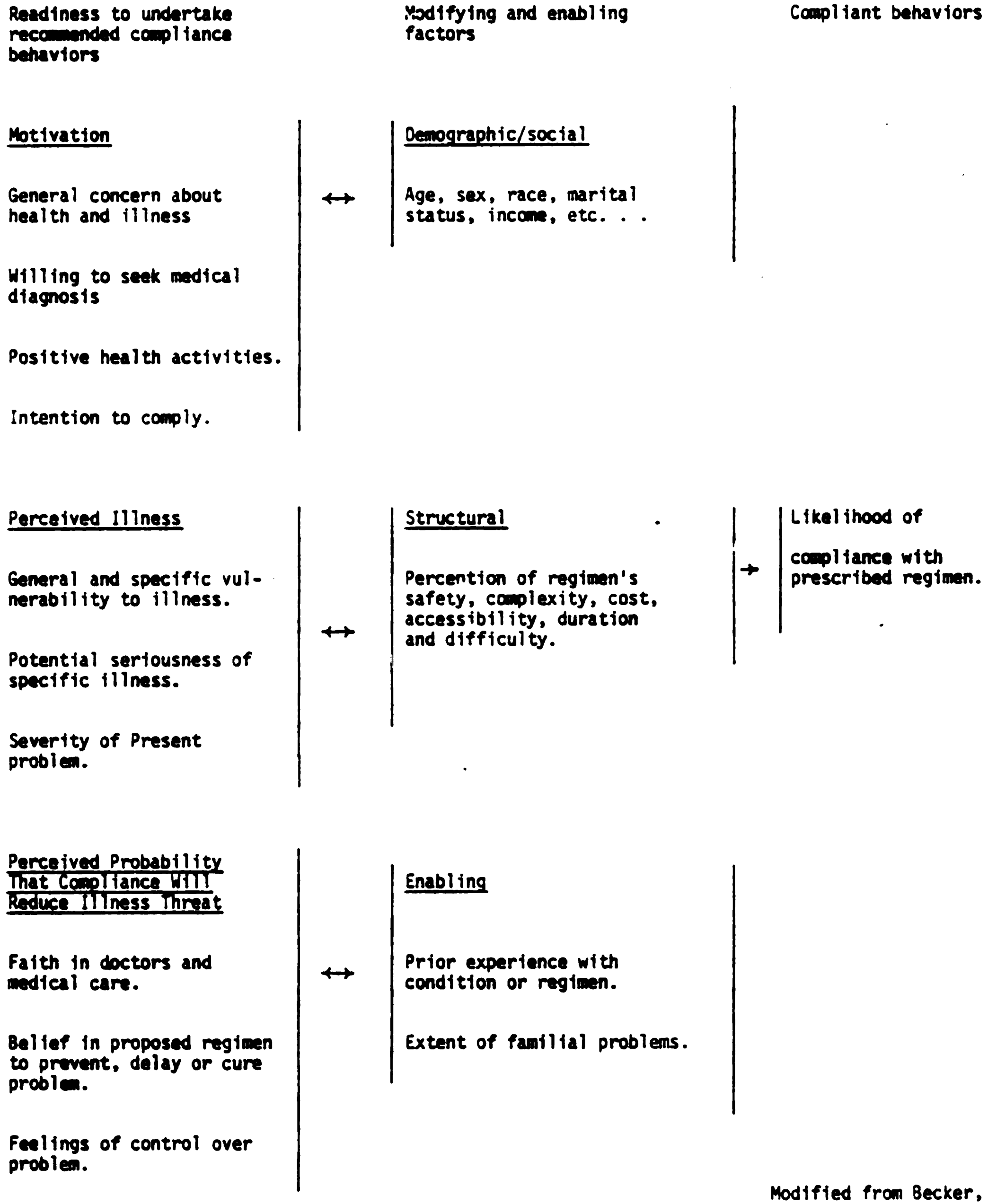
c) Belief that a particular action will improve health (Becker, Maiman, Kirscht, Haefner & Dreckman, 1977).

These elements have been incorporated into the comprehensive model of health behavior that follows (see Figure 1).

One of the most important features of the HBM is the hypothesized interrelationships between major variable categories. That is, the "motivation" variable (e.g., intention to comply) is influenced by, and influences, the "demographic/social" variables (e.g., ethnic group, etc.). This is a decided theoretical advantage over simply assessing motivation or scoring levels of SES and relating them separately to an outcome measure. Further, it is theoretically possible to assign standardized values to each cluster of variables and arithmetically arrive at a probability score for "compliance" that is comparable with other scores. For example, the weighted sum of benefits of "preventive action" minus "perceived barriers" to "preventive action" equals the likelihood of "preventive action".

Becker et al. (1977) have used the HBM to predict the dietary compliance of obese children. One hundred and eighty-two mothers of children diagnosed as obese were interviewed for approximately one hour about concerns, beliefs, motives related to health and to obesity. The women were mostly Black and of lower SES. The questions were designed to operationalize elements of the HBM.

The subjects were administered a) a high-threat message about the dangers of obesity, b) a low-threat message, or c) no



Modified from Becker, et al. (1977).

Figure 1.--The Health Belief Model

messages at all. Outcome measures were number of follow-up visits completed and a ratio of initial weight/weight loss.

Children in the high threat conditions lost the most weight over four follow-up periods within two months. Controls lost the least weight and low-threat subjects an intermediate amount. Separate correlations between predictive items and weight loss per follow-up and appointment keeping ratios were made. Under the category of parental concerns; general concerns regarding the childs health, special health procedures (e.g., vitamins) and belief that weight could be lost were significantly correlated. Severity of obesity was significantly related to outcome measures under "susceptibility" variables, while maternal beliefs similar to Locus of Control (LOC) and belief in the benefits of dietary therapy were significant. The main barrier to treatment success was "family problems", but this variable lost significance after the first follow-up visit. Only marital status and age of child were predictable sociodemographic variables. Older children and intact families were the most successful in treatment.

The authors conducted a multiple-regression analysis on nine variables regressed against weight/loss per follow-up visit and appointment return. The variables accounted for 17% of the variance of appointment kept ratio, and 44% of the weight lost at the first follow-up visit. This impressive figure declined to 22% at the fourth follow-up visit. These are relatively strong correlations when the multiply determined nature of appointment keeping behaviors is considered and the possibility of plateau effects, and increased homogenity of sample over time is kept in mind.

Similar trends occurred throughout all treatment groups. At the risk of being redundant, however, it must be pointed out that the model was not fully explored in this study since the relationships between the major variable categories were not tested. Thus the causal paths between categories presented earlier remain theoretical, while the importance of the categories themselves has been supported.

Further, the nature and the sophistication of the attitude measures used is unclear. Items designed to tap maternal beliefs in an interview were created with an undetermined amount of validation. The Pandora's Box of unrealiability, interviewer bias and other destabilizing elements may well have limited the significance of their results.

To some extent, it is possible to assess these variables with already validated instruments. Specifically, "perceived threat" could be approached with modifications of state-trait measures of anxiety (e.g., Spielberg, 1977), in that one of the results of the type of threat studied is anxiety. "Feelings of control over disease" could be investigated with a health locus of control scale (Wallston & Wallston, 1978). Finally, there are a number of measures of marital and family functioning that systematically and psychometrically assess these areas.

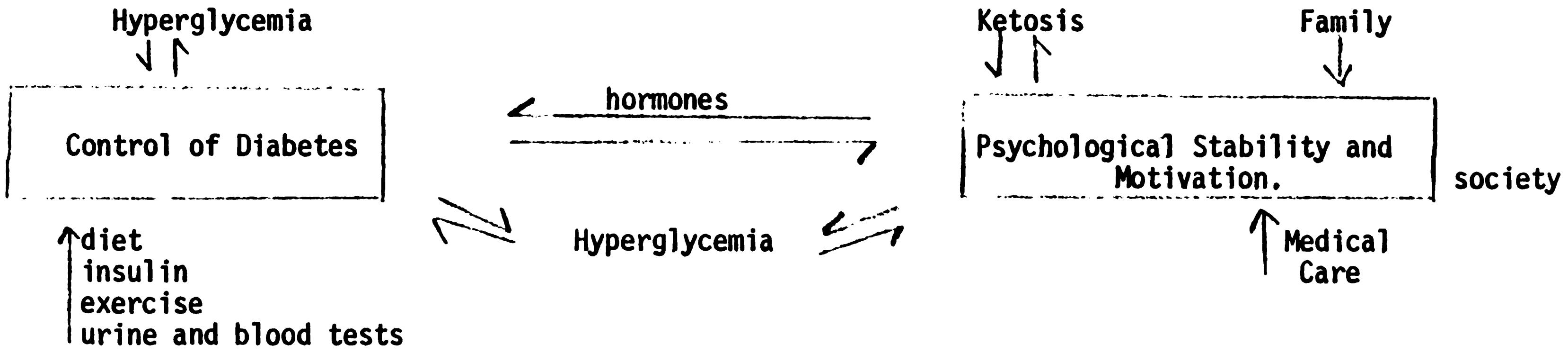
Models of diabetes

Laron (1977) has proposed two simple models of the factors affecting control of diabetes, and of the influence of parental attitudes on the psychological stability and control of the diabetic child. They are reproduced in Figures 2 and 3.

These models, though simple, and provided with no quantitative data in their support, are based on rich clinical observations and are sophisticated enough to suggest feedback-type relationships between social, psychological and physiological processes. Nevertheless, they are relatively broad in their suggestions of causal pathways, and fail to account for some of the logically obvious steps necessary for the establishment of such variables as "control of diabetes". Kohrman (1978) has proposed another simple model designed to elucidate some of the possible steps and gaps in securing patient compliance (see Figure 4). Kohrman points out that interference with any of these processes can interfere with the desired outcome. That is, even total education cannot ensure motivation, nor can complete compliance necessarily lead to maximum control.

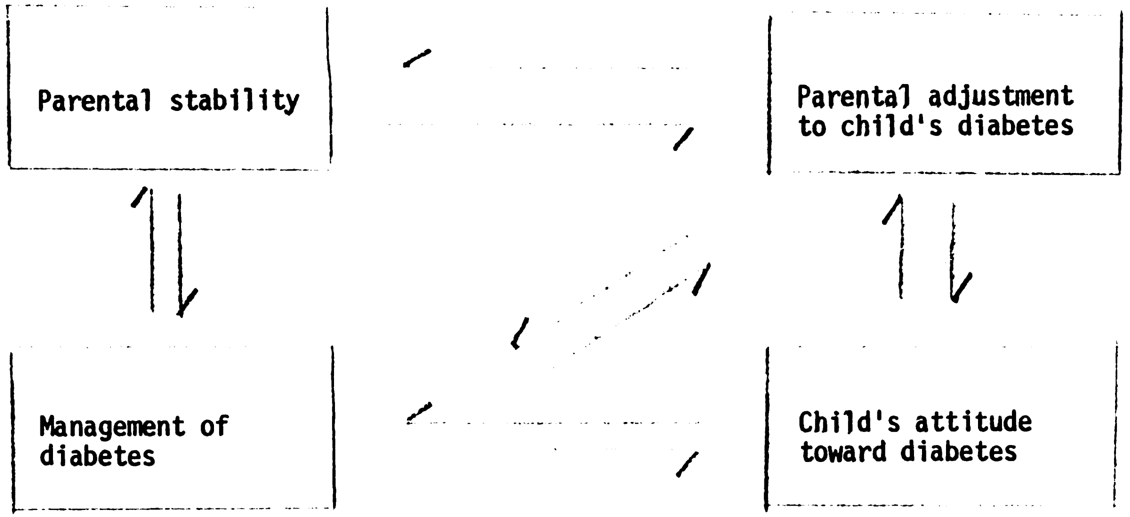
Despite the difficulties present in these models, there are several logically necessary and empirically determined variables that deserve further investigation if the optimum approaches to the treatment of chronic disease are to be determined. They include:

1) Patient information/education levels. While compliance is not always necessary for successful control, an understanding of the regimen has been shown useful in



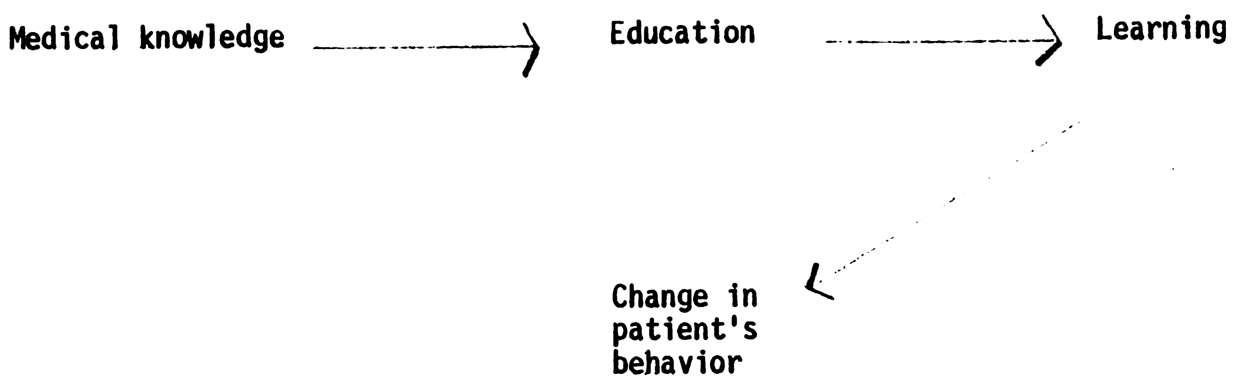
Modified from Laron (1977).

Figure 2.--Laron's Diabetic Control Model.



Modified from Laron (1977).

Figure 3.--Laron's Model of Psychological Aspects.



Modified from Kohrman (1977).

Figure 4.--Kohrman's "Elements of Compliance".

many cases (Watkins et al., 1967; Stone, 1961). Both information and communication patterns require communication.

2) Attitudes of patients, parents and physicians toward treatment. Attitudes are fundamental elements of motivation, in that they help to define the goals toward which patients strive (Bruhn, 1977).
3) Social and familial stability. A number of studies have found that these environmental factors are related to the successful management of diabetes (Simonds, 1977; Swift et al., 1967).
4) Intrapsychic patient variables. Variables such as Locus of Control and IQ can contribute to the determination of attitudes, and the capacity of an individual patient to reach his or her treatment goals. Affects, possibly mediated by the family, may also be influential.

These four variables and their relationship to diabetes will now be addressed.

Information

Because of the importance, complexity and potential danger of treatment, diabetes presents an especially interesting area in which the attitudes, beliefs, and knowledge of patient and family can be studied. A number of studies mentioned above have found inadequacies in adult patients' knowledge about their treatment (Williams et al., 1967; Watkins et al., 1967). The most systematic investigations of the knowledge of childhood diabetics and their parents have been undertaken by Etzwiler and his colleagues.

Collier and Etzwiler (1971) used a 34-item questionnaire to study knowledge of diabetes and its treatment. It was administered to 129 diabetic children of junior and senior high school age and to their parents. They found deficiencies in knowledge about diet, ketoacidosis and modification of regimen required by activity and illness. Parental knowledge correlated with that of their children. Family income, grade level, duration of the disease and maternal education had no bearing on the knowledge scores. Children with a diabetic parent scored lower than the mean. Most parents and children reported that their main source of education was their family physician. Etzwiler's results questioned the efficacy of the physician as educator.

In an earlier study, Etzwiler (1967) used the same instrument to evaluate the knowledge of dietitians and nursing students. Again, serious gaps of knowledge concerning vital information were discovered. Clearly, reliable sources of information for the juvenile diabetic and his or her family are lacking.

A study conducted by Davis, Shipp, and Pattishall (1965) offers some support for the above. Fifty-eight diabetic children attending a summer camp especially designed for such children were interviewed about their attitudes toward diabetes. Their ages ranged from 8 to 15 years, 31 were male, 27 female. The average duration of diabetes was 5.1 years. The overwhelming majority of these children reported that diabetes did not adversely affect their plans concerning education, occupation, marriage or childrearing. It is of interest to note that 20% of these children could think of nothing "bad" about diabetes, and that 47 of 54 children responding would prefer diabetes to a bad case of pimples! The authors suggested that the subjects did not comprehend the seriousness of their condition. Very likely this is true due either to ignorance, or denial of threatening communication. These results however, must be interpreted in the context of the atmosphere of a summer camp. Selection bias, peer solidarity, and high spirits may well have influenced their answers and aspirations.

Thus there is evidence that children with diabetes, their parents, and nursing students and dietitians all show remarkable ignorance about diabetes, its treatment, and prognosis. The following diagram will summarize a common and simplified information transmission pattern (see Figure 5).

Collins and Etzwiler, 1971; and Etzwiler, 1967, have suggested that the bulk of diabetic knowledge is transmitted through the physician. Auxiliary transmitters include nurses and dietitians. This is overlayed upon the prior beliefs and societal attitudes already incorporated. In some cases, the doctor speaks primarily to the parents and through them to their children. In others, both parents and child are informed simultaneously. The family structure

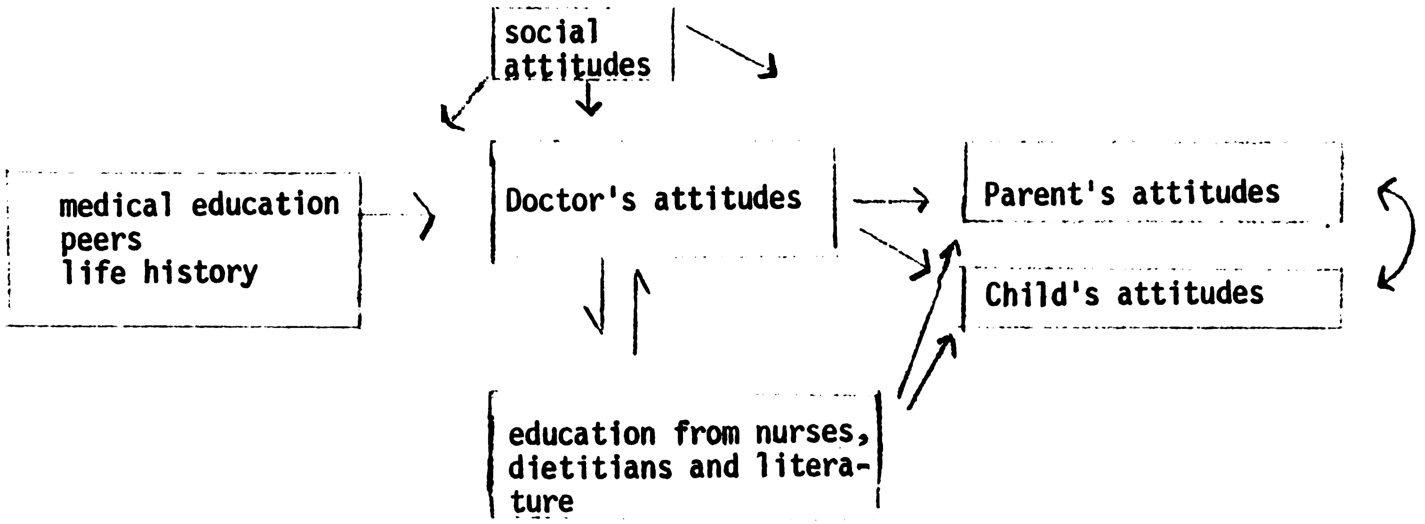


Figure 5.--Attitude and Information Transmission Pattern.

will influence the inter-familial communication. Collier and Etzwiler (1971) suggested that the greatest weakness in this pattern is the link between physician and familial unit.

In summary, the logical bedrock upon which a home-care regimen is based is information about one's disease and its treatment. There may be numerous sources for this information, and a number of mediating variables determining its retention. Nevertheless, there is evidence that the physician is the single most important source of information about diabetes. Therefore, both the level of patient/parent information and the success of information transmission deserve investigation.

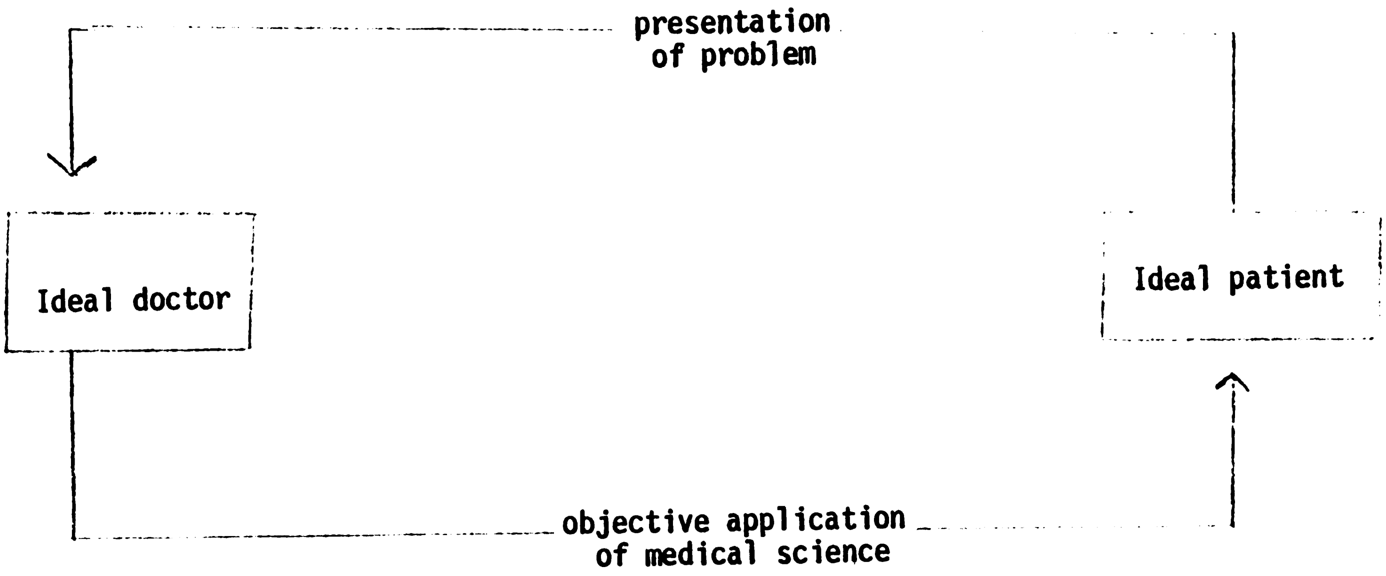
Doctor/patient communication and compliance studies

There have been some initial attempts to develop theories of doctor/patient communication. Many of these attempts incorporate the assumptions of Talcott Parson's (1951) "sick role". In brief the patient is:

1) Not responsible for his illness
2) Exempt from normal responsibilities
3) Obligated to attempt recovery
4) Obligated to seek and comply with medical help

Bloom (1963) presents these assumptions in the following simplified model (see Figure 6).

Clearly, matters are not this simple. Bloom recognized two types of doctor/patient communication:



Modified from Bloom (1963).

Figure 6.--Bloom's Idealized Medical Interaction Model.

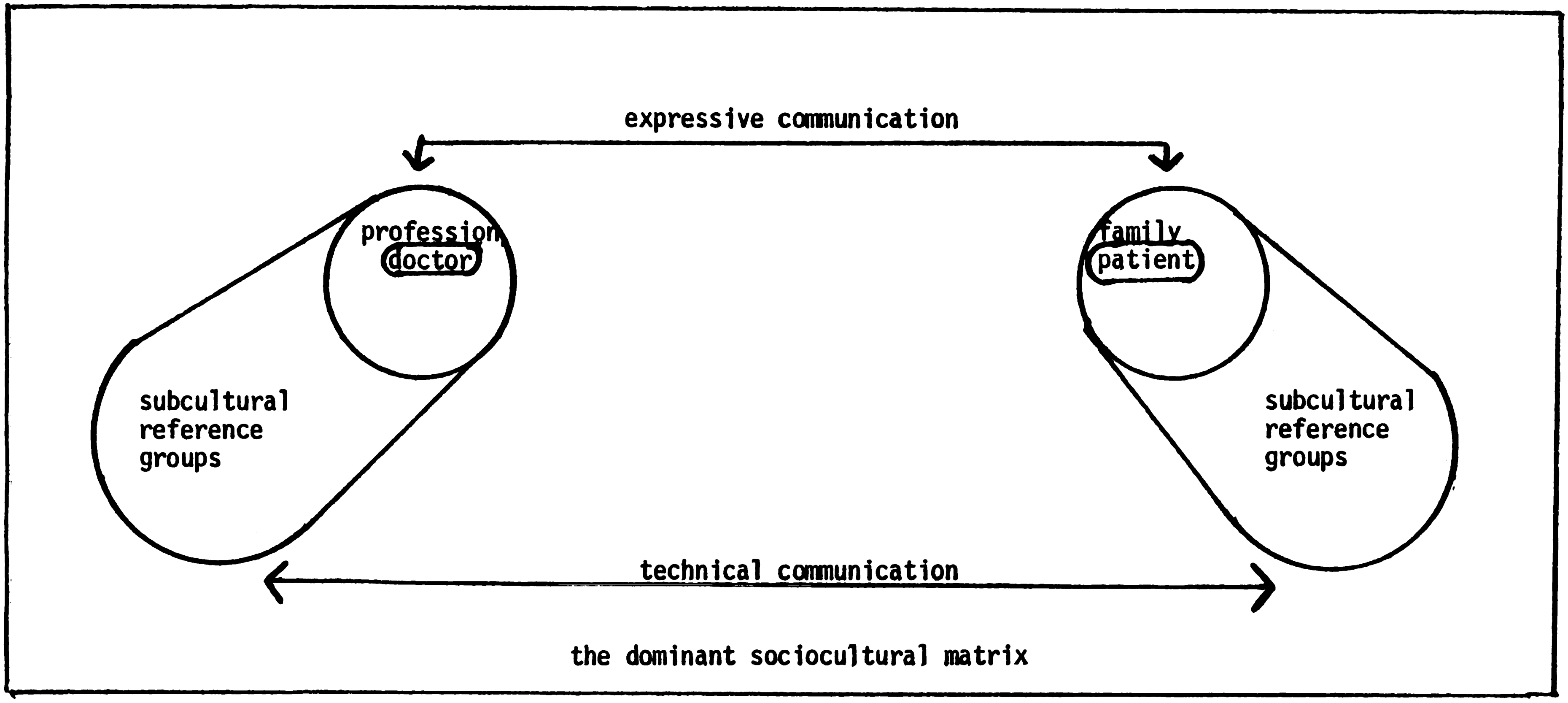
a) "Technical" (objective) and b) "expressive or affective." Both participants are influenced by usually differing subcultural reference groups, and by the larger socio-cultural matrix. This model is presented below (see Figure 7).

The theories of Szasz and Hollender (1956) include the elements hypothesized by Bloom, and further divide the communication process into three types:

1) Active-passive; in which the doctor acts on a passive patient, e.g., surgery.
2) Guidance-cooperation; in which the doctor instructs a willing patient, e.g., acute infection.
3) Mutual participation; in which doctor and patient collaborate in reaching mutual goals, e.g., psychotherapy and chronic disease.

The authors note that all three patterns can occur in the case of diabetes. Acute management of ketoacidosis and coma is active-passive; initial teaching and instruction is a guidance-cooperation process and long-term planning and life style issues demand mutual-participation. Wilmer (1968) adds that these higher levels of communication are hindered by the doctor's "pity" (condescending) but often helped by physicians "sympathy" and "empathy", (e.g., the ability to identify with the patients feelings, yet maintain an appropriate distance).

There have been a number of empirical studies exploring some of these issues. The work of Hulka and her co-workers has been



Modified from Bloom (1963)

Figure 7.--Bloom's Modified Interaction Model.

cited (1975). Children's understanding of basic facts about health would seem to begin in the latency years. Blos (1955) studied 42 healthy children ranging from 5 to 10 years. They were asked to respond to pictures depicting health and disease related situations. Children of 9 and 10 years were able to supply causal explanations. These findings are in accord with those of Gelkert (1962) who asked children to point to various body parts on an outline of the human body. Latency-aged children had acquired a rudimentary anatomical knowledge. But Boyle (1978) and Pratt, Seligman, and Reader (1957) have found that adult patients and the general public are lacking in basic information about common medical terms. Sub-cultural differences are revealed by the fact that many patients are reluctant and embarassed to ask for clarification, doctors assume that patients should know more, but in practice actually underestimate their knowledge.

Davis (1968) examined the process of communication between 154 patients and 154 doctors with the Bales' observational rating scale. He found that doctors asking questions without explaining why, unreleased tension, and passive physicians paired with assertive patients, all reduced patient compliance.

Francis, Korsch, and Morris (1969) also studied the relationship between doctor/patient communications and compliance. The compliance of 800 pediatric outpatients was affected by a lack of physician "warmth" and unmet expectations regarding causes and diagnosis on the mothers' part. Other variables included the mothers' attitudes toward the disease (c.f., the Health Belief Model), and the complexity of the regimen.

On the basis of results obtained from 25 female voluntary psychiatric patients and three residents, Sapolsky (1965) concluded that those patient-therapist pairs forming complementary dyads of the Fundamental Interpersonal Relations Orientation Behavior scale, Schultz, (1958), (e.g., mutual compatibility for "inclusion, control and affection") were most successful in psychotherapy. Patients with similar perceptions as their therapists (measured by semantic differential) were also more successful in therapy than those who were noncompatible or felt dissimilar.

In summary, while children of late latency and early adolescence understand basic facts about their bodies, many diabetic patients, both adults and children, appear to have significant gaps in their knowledge about diabetes. Logically, at least some knowledge is required for successful treatment at home. The empirical support for any contention linking high knowledge with good outcome or compliance is mixed. There is some evidence that the physician's style of intervention, including "warmth", activity, and manner of inquiry and education affect the patients' compliance. Francis, et al. (1969) suggested that for pediatric populations, these influences are mediated by the family.

Affective influences

Environmental effects on diabetes have been suggested:

> Experimental evidence indicates that stressful life situations may lead to important metabolic changes in persons with diabetes mellitus, and that those may be accompanied by changes in behavior. Ketonemia and an increased excretion of water, glucose and chlorides were observed as well as alternations in fasting blood sugar which led to either hyper-or hypoglycemia. Study of the life histories and daily experiences of persons with diabetes mellitus indicates that many of the apparently spontaneous fluctuations in the syndrome are the result of life stress (Treuting quoting Hinkle, et al., 1962, p. 97).

"Stress", however, is a vague term. Treuting (1962) observed that emotional destabilizers are specific to the individual, yet conflict with significant others, especially parents, in the case of children, or the threatened loss of such persons, often precedes recurrent ketoacidosis. Increases in insulin requirements were associated with loneliness, dejection or a chronic resentment focused on family members.

One attempt to scale stressful events and thereby permit at least crude comparisons between individuals was through the use of Holmes and Rahe's (1967) "Schedule of Life Events". This device is a checklist of positive and negative life events weighed for their relative impact on the individual and the amount of re-adjustment that they would require.

Grant, Kyle, Teichman and Mendels (1974) used this approach in comparing the clinical course of 37 adults with diabetes with their life stresses. A positive correlation between metabolic upset and life events was found for their subjects over a period ranging from 8 to 18 months.

Holmes and Masuda (1974) suggest that simple stressful events rarely alter disease courses to any great degree. Rather, a culmination of events or a large number of "life stress units" are apt to have a deleterious effect.

After reviewing the literature on stress and the course of diabetes, Houser and Pollets conclude:

> . . . the published empirical research in this area certainly supports that view that psychological factors and the surrounding social-emotional context, need to be considered in understanding fluctuations that occur in diabetic control. Specifics such as which are key aspects of the environment, and what are the relevant personality dimensions remain unclear (Hauser & Pollets, 1979, p. 338).

Many years earlier, Benedek (1948) believed that frustrated aggressive or sexual conflicts were the key stresses leading to increased glycosurea. However, in a system as complex as the human endocrines, proving a direct causal relationship without controlling many variables is impossible. Further, glycosurea (sugar in the urine) is only one measure of diabetic management. It may not be the best (Malone, et al., 1976).

Other authors, notably Cohen (1960), Peck and Peck (1956), Rosen and Lidtz (1959) and Starns (1959) report evidence of diabetics deliberately omitting insulin or sabatoging their diets in efforts to induce coma and enter the hospital, thus temporarily escaping from seemingly intolerable emotional situations. While such instances of voluntary mismanagement do occur, the preponderance of evidence indicates that they do not account for all cases of "idiopathic" ketoacidosis or hypoglycemia.

Kimball (1971) made use of recent work exploring the conditioning of the autonomic nervous system (DiCara and Miller, 1968; Miller, 1969) to explain these "idiopathic" metabolic changes. Stressful events and related cues (affective and cognitive reactions) that once served as unconditional stimuli to the infant or child, could, through generalization, become conditional stimuli for similar physiological dysfunction (the conditional response). For example, if a child exhibited a violent autonomic upset, releasing stress hormones and altering temporarily the metabolic situation when the parents left the child alone, it is conceivable that similar though modulated reactions to threatened loss of parental support or security in general could occur in later years. If a similar hormonal reaction also occurred, ketoacidosis would be possible.

In summary, certain affects are associated with metabolic changes in at least some people with diabetes. They may act by leading to the conscious abandonment of the treatment regimen in order to escape into illness, or they may exert their influence without conscious mediation, presumably through the autonomic nervous system. While the stresses inducing these emotions are idiosyncratic, familial relations and threats to security are often mentioned.

Familial reactions

The psychological effects on care givers and family can be disruptive (Greenberg & Blain, 1953). Case studies and clinical experience highlight two common parental responses: anxiety and guilt (Kimbal, 1971; Zeidel, 1973). Zeidel (1973) notes a progression in the parents of his patients similar to that of people facing death or other great losses. It includes initial reactions of anxiety, often evoking denial, mourning reactions (over the loss of a healthy child) and guilt. The latter may stem from their feeling responsible for any genetic component of the disease, or from feelings resulting from anger at the child for being ill. Guilt may lead to self-sacrifice, over-solicitiousness and neglect of the rest of the family. In some situations, parents may become severely over-controlling of their child.

Schiff's observations (1964) reveal a complex of possible familial reactions to diagnosis. Again, guilt and self-blame (or anger directed outward: blaming the doctor, spouse, or God) are seen. Denial is not uncommon: "The doctor made an error". "My child will outgrow it", etc. . . .) Rejection and resentment of the child can surface. Occasionally, overprotection and overbearing control are forms of resentment. Over-solicitiousness may also, as noted above, be related to parental guilt. Schiff noted that denial may lead to poor or careless treatment; rejection to battles within the family, including manipulation of the disease by the patient; over-solicitiousness to a crippled, inadequate self-image, and over-protection to either a passive ineffectual personality, or sullen rebelliousness.

After the initial shock of onset, daily stresses present themselves to the family. These include the patients' moodiness and emotional lability resulting from blood sugar variations, and under some regimens, the extreme regimentation necessary to conform to treatment. Often, the entire family will submit to a diabetic diet in order to aussuage their guilt feelings (or simplify meal preparation, improve their own health, etc.) However, such moves are frequently resented by siblings. Parents are also subject to the stresses of dealing with what has been called "manipulation" of the disease, e.g., eliciting various types of secondary gain: "I'm too sick to go to school"; guilt-inducing threats: "Buy me this 'cause I gotta get shots", or even actual sabotaging of the treatment. Moreover, babysitters, school officials, peers and neighbors are often misinformed about the relatively few special needs of the diabetic child. Tunbridge (1953) adds self-pity to the woeful list of parental responses. Most of the conclusions cited above stem from clinical observations and case studies. Some work, however, has taken a more controlled and systematic course. Swift, et al. (1967) as cited above, found diabetic families to exhibit greater extremes of domination-submission behaviors, and mothers to show extremes of protection-neglect. Degree of diabetic control was related to these psychological-familial variables. The better control, the more normal the psychological balance.

Crain, Sussman and Weil (1966a) determined that diabetic children experienced a closer, warmer and more expressive relationship with their mothers than did their non-diabetic siblings. In a later report they found:

> The presence of diabetes mellitus in a child is related to lower marital integration, less agreement on how to handle the child and greater marital conflict (Crain, Sussman and Weil, 1966b).

They conceptualized the presence of diabetes as an "intrafamilial crisis" for which there is no ready solution available. No data relevant to the effect of marital disharmony on diabetic control was mentioned.

Certainly among the most imaginative and useful work in this area is that of Salvador Minuchin and his colleagues at the Philadelphia Child Guidance Clinic. They did not present data on differences between diabetic and non-diabetic families, but rather, gave their attention to that sub-group of diabetics with "idiopathic" (or "psychogenic") ketosis (Minuchin, Baker, Rosman, Liebman, Milman & Todd, 1975). They presented a conceptual model of psychosomatic processes in children that is based on three assumptions:

1) A type of family organization that encourages somatization.
2) The child's involvement in parental conflict.
3) Physiological vulnerability.

The structure of families at risk includes four elements:

1) Enmeshment - In which interpersonal boundaries are fluid, little autonomy exists, and parent/child roles are not well differentiated.

2) Overprotectiveness - As a familial style, extending beyond the sick child.
3) Rigidity - Such families have difficulty in going beyond old ways of coping when new solutions are called for.
4) Lack of conflict resolution - While their thresholds for conflict are very low, open confrontations are rare. Clear resolutions don't occur, and problems return (Baker, Minuchin, Milman, Liebman, & Todd, n.d.).

The Philadelphia group has reported great success in treating patients with juvenile diabetes, anorexia nervosa, and intractable or "psychosomatic" asthma. Their approach has been to involve all members of the family in "Structural Family Therapy". Their goal is to alter those features of pathological family functioning mentioned above. In a dramatic demonstration Baker et al., (n.d.) correlated the increase in free fatty acids (a precurser to ketoacidosis) of the identified diabetic patient with family stress in a laboratory situation. A diabetic sibling, performing a different role in the family, also showed rises in free-fatty acids (as did her healthy parents), but a normal drop-off absent in the psychosomatic patient. In this instance, "idiopathic" ketoacidosis served as a pathological psychosomatic stress response to maintain a pathological familial equilibrium. The patient was saying, in effect: "How can my parents fight when I'm sick and need so much care? I'll create a diversion and they won't hurt each other". It would appear that such processes can operate within a family system, each member making a contribution, with no member consciously aware of the process.

In summary, researchers have begun to examine in detail the "process" of living with the disease, and the socio-familial millieu in which the disease occurs. Onset of disease strikes families with already established "structures" of power and communication. How a family typically copes with stress reflects this "structure" and bears on the child's response to, and course of, diabetes (Minuchin et al., 1975). The disease onset is a familial "crisis" with many parallels to loss and grieving experiences. How the grief is resolved, how the family copes with the daily stress, and of great importance, what the disease means and what function it plays in family dynamics is determined in great part by the families "structure" and the child's coping mechanism. These, in turn, may relate to the course of the disease, which can affect level of familial stress, and so on in a cycle.

Attitudes toward the disease

The use of whatever information is transmitted and the readiness to follow a regimen are deeply influenced by the patient's attitudes toward the disease and its treatment. Certainly the patient's attitudes are affected to some extent by the information (both technical and expressive) given by the physician and the salient environmental influences such as parental behaviors, and peer group responses.

Just what is known about the attitudes of juvenile diabetics toward their disease and regimen? To recapitulate: Davis et al. (1965) found that children attending a summer camp for diabetic children did not feel put upon by their diabetes, preferred it to less serious disorders and seemed to underestimate the seriousness of the disease. Possibly the group solidarity of a camping situation, as well as elements of denial and lack of information account for their findings.

Using a similar camp population, Khurana and White, (1970) asked 144 diabetic girls (years 10 to 15) to write answers to "What does your diabetes mean to you?" Sixty-nine replied that they were not bothered by the disease, only 37 children said it interferred with eating, 27 felt slightly different from other children, 42 were aware of taking better care of themselves, 16 admitted objections to insulin shots, and 4 "hated being diabetic". Fifty campers were interviewed individually. One-third were unaware of potential complications, but the remaining 2/3 were fearful of blindness and amputations.

Seventy nine parents of 80 children were interviewed about their reactions to their child's diabetes. Twenty one were considered to be "overanxious", two "overindulgent", ten "perfectionist", seven "indifferent" and 39 "apparently normal". In general, these children tended to either model or react against their parents responses, e.g., children of anxious parents tended to be anxious themselves, others were dependent, defiant or depressed. Those children with "indifferent" parents had the least controlled diabetes. The authors concluded that children's attitudes are closely related to those of their parents, and both parents and children are poorly informed about this condition. Partridge, Garner, Thompson, and Cherry (1972) eliminated the camp bias by selecting 54 children 14 to 18 years of age, from a large group practice and 200 healthy adolescents as controls. The subjects first completed a questionnaire concerning the actual and ideal ages at which children should become responsible for such things as use of money, choice of clothes, etc. Both groups report similar actual ages for independence and a similar sequence for the ideal state. However, the diabetic sample preferred earlier ages for responsibility. In general, the healthy group felt they were given freedom too soon, the diabetic group, too late.

The diabetics believed that 12.5 years was the appropriate age for total control of their disease. This is in accord with Etzwiler's (1962) earlier findings regarding necessary information levels, but later than some physicians recommend. It was also found that the average diabetes information score was higher for adolescents than for their fathers, but lower than their mothers' scores. The authors believe that it is in fact too low to permit total responsibility at 12.5 years.

A final interesting twist to this study was an effort to validate diabetics' own estimates of disease control. Information from hospital records (urine and blood glucose, coma, etc.), was collapsed into a global 5-point control rating. A Chi-Square test found the patients to be in agreement with these ratings at the $\underline{p} < .05$ level of significance. Without access to charts, the patients' physicians were also able to rate control at a significantly successful level. However, another study, (Thompson, Garner & Partridge, 1969) found that children over-estimated their control when compared with objective means.

Sullivan (1979a and b) devised a 37-item questionnaire entitled the "Diabetic Adjustment Scale". It was an attempt to measure adolescent girls attitudes toward diabetes, family and peer relationships, school adjustment, independent-dependent conflicts and body-image concerns. This true-false written questionnaire was given to 105 diabetic girls ranging in age from 12 to 18 years, on the first day of a diabetic summer camp. These subjects were also given the Beck Depression Inventory and the Rosenberg Self-Esteem Scale.

Sullivan found that "attitudes toward diabetes" (e.g., feel that diabetes is a serious disease, feel that it is getting worse, etc.) were significantly correlated with the other areas of adjustment: peer and family relationships, school adjustment, independence-dependence conflicts, body image, and overall adjustment. Even though these six elements were "factor analytically derived", "attitudes toward diabetes" was correlated with the "total adjustment score" with a correlation of .75, the highest in the matrix. Thus, these girls' attitudes toward their disease may have been a key to their overall adjustment and performance in other important areas of their lives. Of course, these correlations do not imply that dysphoric attitudes toward diabetes led to difficulties in other areas. Sullivan (1979b) notes that diabetes may well be the scapegoat upon which the frustrations of adolescence are heaped.

In relation to self-esteem, Sullivan found that girls with poor adjustment in peer relations and poor total adjustment scores had significantly lower self-esteem scores than girls with better adjustment. This was also true for negative attitudes towards diabetes, independence/dependence conflicts and poor family relationships. No relationships between self-esteem and body-image or school adjustment appeared.

Depression scores were correlated ($\underline{p} < .001$ level) with poor total adjustment scores, negative attitudes towards diabetes and poor peer relationships. Girls with poor adjustment in family relationships, independence/dependence conflicts, and body-image problems were more depressed ($\underline{p} < .01$ level) than girls with higher adjustment scores. The diabetic girls were significantly more depressed than a control group of 100 healthy adolescent girls (Sullivan, 1978).

An ANOVA found that severity of depression affected peer adjustment scores, attitudes towards diabetes, and family and total adjustment scores. While self-esteem did not seem to affect adjustment to diabetes, it was correlated with depression and may have thus indirectly influenced adjustment (Sullivan, 1979b). An analysis by t-tests found no differences in total adjustment, depression or self-esteem between those definitely educated and managed by a strict regimen (44%) and those of indeterminant regimens.

It appears from this brief review that when research is directed at the "attitudes about juvenile diabetes" the questions are essentially directed at the diabetic state itself. Some studies have found surprisingly high levels of acceptance of the condition along with gross ignorance of potential problems. This of course, occurs most commonly among younger children. These results are likely influenced by the frequent use of summer camp populations. These groups are biased first by selection, and secondly by the feelings generated by a camping situation. Other work found close ties between positive and negative attitudes towards diabetes and adjustment in many other important areas of adolescent girls lives, as well as self-esteem and depression. The direction of causality is uncertain. Some mixed evidence suggests that non-camp children can sometimes successfully estimate their own levels of control, as could their physicians. A somewhat superficial examination of "strict" vs. unknown regimens found no differences. One important type of attitude has been relatively neglected: What are the views of diabetics towards their particular treatment regimens? How do they correspond with the attitudes of their care-givers?

Locus of control

Whatever belief about one's level of control over reinforcements that has been achieved can be readily undermined when an illness is present. The patient is confronted by his powerlessness to have prevented the disease and perhaps, uncertainties about his role in effecting a cure (Shontz, 1975).

The construct "Locus of Control" (LOC) was formulated by Rotter (1954) in his theory of social learning. A response, in Rotter's view, is not conditional merely on the actual probability of reinforcement, but rather on the subject's assessment of that probability and on the subjective value of the reinforcement itself at that time. Thus reinforcement strengthens not behavior but beliefs about reinforcement in similar situations in the future.

One is said to be relatively "internal" in regard to LOC when one believes that the outcome of some effort is within the power of the individual to influence. When one believes that effort is irrelevant to outcome, when fate, luck, God, other people or forces determine the outcome, one is considered to be "external" in orientation. Such generalized orientations come about through experiences that differentiate cause and effect in particular situations. From beliefs about particular situations, beliefs about one's capacities in general develop.

Gender differences seem to have little effect in adults (Rotter, 1966), but the findings with children present an extremely varied pattern (Rotter, 1970). Higher social class has been found to significantly and positively correlate with internal LOC (Franklin, 1963). This relationship is strongest with general measures of LOC. Crandall, Katkovsky, and Crandall (1965) found that first-born children were somewhat more likely to be internal than their latter-born siblings, as were children from smaller families. There was a moderate positive correlation between chronological age in children and internality. This relation was minimized, however, when mental age was controlled (Crandall et al., 1965). Thus, within certain limits, chronological age cannot predict LOC. IQ does correlate positively with internal beliefs about LOC (Bailer, 1961).

Medical aspects of LOC

Since health and illness are potent reinforcers for many people, it may be presumed that individual variations in LOC will commonly be reflected in behaviors affecting health and illness. These behaviors may be divided into illness prevention or health maintenance, and illness adaptation, including information seeking and compliance.

A replication of Straits and Sechrest's (1963) work by James, Woodruff, and Werner (1965) corroborated their findings that non-smokers were more internal than smokers. They also found that males who believed the first Surgeon General's report on smoking were more likely to quit if they were internal in their orientation. However, Best and Steffy (1971) and Lichtenstein and Keutzer (1967) were unable to show a correlation between internality and smoking.

Review articles by Strickland (1978) and Wallston and Wallston (1978) report suggestive relationships between LOC and birth control use, weight loss, influenza innoculations, dental care and seat belt usage. While not all studies were significant, there were general trends for internally oriented individuals to take greater precautions in these areas.

LOC evidently plays a role in sick-role behaviors as well. An early study by Seamen and Evans (1963) found that tuberculosis patients matched for occupational status, education, and ward placement, but differing in LOC, were more knowledgable about their condition, asked more questions of staff and were less satisfied with the amount of information that they received when they were internally oriented.

A series of reports by DuCette and Lowery (Lowery, 1974; Lowery & Ducette, 1975) found that Black male diabetics knew more about their condition at diagnosis if they were internal. There were no significant differences in information levels between the two groups at 3 and 6 years duration. Nevertheless, "internals" had significantly fewer disease management problems at three years, but significant more at six years duration. DuCette suggested that years of fluctuating course, independent of information or control efforts, may have discouraged efforts at control in this particular area.

Mixed results were also obtained in investigations of complicance. Weaver (1972) found internals undergoing kidney dialysis to be more adherent to dietary restrictions and more regular in keeping appointments. Key (1975), on the other hand, found that a sample of Black hypertensive external women were more compliant with diet and medication than internals. Kern (1974) found more outpatient usage among a sample of elderly externals. No LOC relationships at all were discovered by Marsten in her report of work with myocardial infarction patients (1970).

Wallston and Wallston (1978) echo Rotter (1975) in suggesting that such discrepancies are due to omission of measures of the perceived value of health for subjects. Some evidence has accumulated to support their criticism. Kaplan and Cowles (1978) examined both health LOC and value of health in a group of 35 adults in an anti-smoking project. After approximately six months post-treatment, the high value, internal-subjects were significantly more successful than other groups. An equally interesting finding was that internals with low health values were the least successful at follow-up.

Lewis, Morisky, and Flynn (1978) studied a sample of Black hypertensive women similar to Key's (1975) subjects. However, in this study both LOC, health value, and perception of support from significant others was assessed. A two-way interaction between Health LOC and perceived support was significant. There was a greater likelihood for these subjects to report continued use of medication.

A dissertation by Rutter (1970) was designed to explore the relationship between Type I diabetes and LOC belief in children. Rutter speculated that responsibility for becoming ill is felt to be internally located (feelings of guilt, remorse and responsibility, etc.), while treatment of illness is left to others (passive, apathetic behaviors), and is thus felt to be an externally controlled situation generating, external attitudes. Rutter studied LOC in 263 healthy children, 50 children with diabetes, and 20 girls with scoliosis (curvature of the spine). Her subjects were between the ages of 11 and 13. Measures included the Bailer LOC scale for children and a "Responsibility in Illness Test" (RIT), specially devised by Rutter to measure LOC beliefs in illness situations. This instrument provided separate scores for responsibility in positive and negative events in illness.

Relevant findings included:

1. Children felt greater self-responsibility for negative than for positive events.
2. LOC and RIT were positively correlated for boys with diabetes.
3. Gender, age, and SES were unrelated to scores.
4. Diabetic children expressed greater self-responsibility for positive events in illness, and were more internal in their LOC beliefs in general.

Rutter's results indicate that children with a chronic disease requiring self-care apparently differ from healthy children and children with a more "passive treatment regimen".

In summary, LOC, particularly when measured with instruments focusing on health related situations, plays some role in information seeking and compliance behaviors. Ambiguous or contradictory findings in some studies may have been the result of failure to assess the reinforcement value of a particular outcome, that is, the value of "health" in a given environmental context. LOC seems to be a meaningful concept for pubertal and near pubertal children. Some ill children, especially males with diabetes, are evidently higher in internality than other children. The relationships between LOC and information levels, attitudes towards their regimens, and successful disease management in children with diabetes, remain to be explored.

Measures of diabetic management

It was previosly stated that diabetic regimens vary widely depending on the goals and beliefs of the particular physician. Many physicians insist on strict chemical control of the disease. Others believe that a normal social adjustment with a minimum of hinderance from either illness or stringent treatment is the desirable course. It is very probable that the majority of doctors treating juvenile diabetics hold to some middle course, and are likely to modify their prescriptions based on the needs and desires of the patient and family. Whatever the approach to treatment, some measures of successful diabetic management must be made. As treatment attitudes vary, so do measurement techniques, ranging from psychological development to esoteric chemical analyses.

A number of clinicians and researchers have proposed goals and measures for diabetic management (Jackson, 1978; Weil & Kohrman, 1980; Williams et al., 1967). There is universal agreement on the avoidance of acute symptoms of diabetes: large urine volumes, ketoacidosis, and hypoglycemia. Methods of measurement used to prevent these problems vary, however. Weil and Kohrman (1980) suggest that a 24 hour collection of urine containing fewer than 5% of the day's calories as glucose is good management. Other authors rely heavily on periodic blood tests, sometimes several daily (Petersen, Forhon & Jones, 1980); yet others on several daily measures of glucose in the urine or some combination of the above.

Unfortunately, a study by Malone et al. (1976) on diabetic campers found no correlations between childrens' urine test results and those performed on the same specimens by technicians. Further, children determined to be in "good control" by blood testing in the morning were often in "poor control" later in the same day. The authors conclude that such day to day measures were unreliable in assessing "metabolic control" (blood, urine), but had some use in charting general "management" success, that is, preventing acute symptoms.

The traditional approach to this problem has been to collect data from these daily measures over a period of time, average and give them weights to form an index. Unfortunately, this solution has frequently failed to systematically differentiate between poor management due to high vs. low blood sugar.

A recent innovation was the use of hemoglobin A_1C measures in diabetic patients (Cole, 1978). Diabetes leaves indications of high blood sugar in red blood cells. Since these cells exist for several months, it was hoped that they would reveal the state of control for that period. However, a study by Ainsle and Etzwiler (1978) found that, while hemoglobin A_1C did differentiate between diabetics and controls, it did not distinguish between different levels of control in diabetic children. While the uncertainties inherent in such fine-scale measures have led a number of clinicians to focus on broader criteria, new technologies may yet increase the reliability of A_1C.

Weil and Kohrman (1980) and Drash (1976), among others, placed emphasis on rates of growth and development that were consistent with familial patterns. Growth can be plotted an standardized growth grids for accurate comparison of velocity and absolute height and weight. Less easily measurable but equally important was their stress on normal physical activity and minimal social disruption. This would include the absence of the acute symptoms of diabetes. Social isolation, obviously poor self-image, and frequent school absences are signals of problems in this area.

This brief review suggests that there is no commonly agreed upon criteria for diabetic control other than the absence of acute symptoms. Chemical and blood analyses seem to have some value in making management decisions but include great variability. General physical and psychological growth and development are judged to be important variables by many physicians, and are measured in some fashion by a few of them.

The main points of the literature review may be summarized as follows. Juvenile diabetes is a common and serious disease of children and adolescents. The regimen is complex, onerous, controversial, and home-based. Knowledge of many aspects of treatment is poor among both patients and many professionals. Knowledge would not seem to guarantee compliance, nor does compliance always lead to a stable course.

Variables that have been listed by several theoretical and empirical attempts to explain health and illness behavior include: demographic factors, intelligence, LOC, health care accessibility, health care evaluation, perception of symptoms, knowledge of disease and social and familial network characteristics.

The selection of those variables has at times been a priori, based on unilateral, nonsystematic clinical observations, or applicable only to acute illnesses. There is a need to examine the problems of chronic medical regimens in adolescent populations from a broader viewpoint. This attempt to broaden the focus can succeed only if both patients and their physicians are each given opportunities to express their opinions on issues such as education, doctor-patient communication, "compliance" and regimen values, and success criteria.

Statements of problems and hypotheses

It must be clear that the purpose of this dissertation is to gather and examine data in a richer context than has been done in earlier work with diabetes, i.e., from the perspectives of both patient and physician. This attempt may or may not replicate previous findings, but is likely to begin the process of elucidating the interactional causes for such results.

When a comprehensive approach is taken, there is a certain arbitrariness in differentiating between dependent and independent variables. This is because cause and effect are interrelated. The effect of one cause may well be the cause of another effect.

"Good outcome," in its most inclusive definition, is the ultimate dependent variable. Unfortunately, this project cannot be so exalted and will confine its "dependent" variables to patient knowledge levels and discrepancies between physician and patient attitudes toward diabetes, its treatment, and its successful management.

Patient information was chosen as a dependent variable because it is a logical *sine qua non* for compliance and to some extent, to outcome as well, and because it is a frequent independent variable in many studies that have taken it for granted and failed to investigate its antecedents in a thorough way.

Discrepancies between patients' ideal and reported treatment practices were selected as a dependent variable because discrepancies in certain directions, e.g., reports of high ideals with low performance, may indicate poor compliance, possibly poor physician-patient relationships, and/or a complex of effects such as guilt and inadequacy that will result in lowered self-esteem (Bruhn, 1977). Such as state of illness-related low esteem may be either a reflection of pre-existing problems, or may have begun with the disease and spread into other areas of the patient's life. In either case, it bodes ill for a good disease course.

The formal hypotheses are stated below:

Hypothesis 1:

It is predicted that high information levels will be related to:

a) greater age
b) longer duration of diabetes
c) internal health locus of control (HLOC)
d) higher IQ
e) more familial experience with diabetes
f) higher evaluation of education and physician accessibility from the patient.

Hypothesis 2:

It is predicted that greater discrepancy between patients' reported and ideal practices will be related to:

a) lesser age

b) shorter disease duration

c) lower information levels

d) lower patient satisfaction with physician accessibility

e) higher discrepancies between physician and patient treatment goals.

Hypothesis 1, parts "a" and "b", and Hypothesis 2, parts "a" through "c", will be tested with statistical methodology, Hypothesis 1, parts "c" through "f", and Hypothesis 2, parts "d" and "e" will be examined with case study data.

The formal hypotheses provide a framework in which the complex questions raised here can be most clearly seen, addressed and answered. However, there are other, somewhat broader questions that require attention if greater clinical understanding and more comprehensive health behavior theories are to result. These supplementary questions are:

1. What do patients confidentially report they actually do to care for their disease?
2. What do patients know about their disease?
3. What do patients feel about their disease and its treatment?
4. Do patients perceive any differences between their own views and those that they attribute to their physicians?
5. How do familial or environmental factors influence the patient's attitudes toward disease and treatment?

6. How do patients remember and evaluate their education experiences? How do these reports compare with those of their physicians?
7. How do patients define, evaluate, and value their health status? Are their physicians in agreement?
8. How do patients characterize and evaluate their relationships with their physicians?
9. Do patients and physicians agree on treatment goals and evaluation criteria?
10. To what extent are the opinions of practicing physicians about regimen-success predictors in accord with those in the literature?

To reiterate, the relationships between these variables are complex and interlocking. The methodology that follows will be an attempt to integrate these complex variables into a comprehensible picture, as well as, no doubt, raising additional questions.

METHODS

Subjects

The subjects of this study were adolescents with Type I diabetes mellitus of greater than six months duration, and a group of their physicians. The names of potential subjects were solicited and received from the Pediatric Endocrinology Clinic of Michigan State University, the staff of a camp for diabetic children (Camp Midicha), a number of private physicians, and Juvenile Diabetes Foundation groups. Approximately 100 questionnaire packets were sent to all potential subjects. Eighty-three were completed and returned. Ages of the 27 males ranged from 11 to 22 years, and those of the 56 females from 11 to 21 years. Because of probable sex and age effects, the sample was median split to form four groups: younger females from 11 to 15, older females from 16 to 22 years, younger males from 11 to 15, and older males from 16 to 20 years.

Sixteen subjects, four from each group, were selected for interviews on the basis of their questionnaire scores. Eleven consented. The physician or nurse nominated by each interviewee was also interviewed. Data from, and descriptions of the 16 potential interviewees and their physicians is presented in the Results section.

Variables

In order to adequately examine the formal hypotheses and supplementary questions, a comprehensive set of variables must be specified. They are listed below:

1. Patient's age
2. Patient's sex
3. Duration of disease
4. Perceived severity of disease
5. General demographic data
6. Patient's IQ (vocabulary score)
7. Patient's health specific LOC
8. Patient's social network including familial experiences with diabetes
9. Patient's evaluation of education process
10. Patient's evaluation of physician's accessibility
11. Physician's evaluation of education process
12. Physician's evaluation of own accessibility
13. Discrepancies between physician and patient evaluations of education and accessibility
14. Discrepancies between patient's and physician's treatment goals.
15. Patient's information about diabetes.

The instruments that follow were selected or designed to measure these variables.

Instruments

Eight questionnaires or assessment instruments were administered to various subsets of the subject sample.

The "Diabetic Treatment Questionnaire" was a 27-item yes-no and multiple choice device which asked patients for confidential reports of their self-treatment. Topics included urine testing, insulin dosages and injection techniques, diet, emergency treatment, exercise, and a self-rating of management success. Topic areas were culled from the diabetic education literature and from a report conducted by the Rand Corporation on patient compliance (Marquis & Ware, 1979).

A 33-item multiple choice questionnaire was used to assess knowledge about diabetes. The nature of the disease, treatment and diet information were covered. This questionnaire is a modification of the one developed by Etzwiler (1963). The author has given permission for its use with the changes.

An "Attitudes Toward Diabetes" scale was developed for this study. The resultant 22 items, in five-point Likert format, were selected from educational materials and from experienced endocrinologists. Criticism of the items was solicited from nine experts in diabetic management and from psychologists familiar with test construction to strengthen their face validity. Subjects completed the attitude scale with their own views as well as with their estimation of their physicians' views.

The attitude scale was weighted with 2 points for the most conservative answers, 1 for moderately strict, 0 for uncertainty and -1, -2 for the more liberal or less demanding responses. For example, testing urine four or more times daily would earn "+2", never testing, would earn "-2". By summing all responses, a single score summarizing the trend of opinion was calculated. In addition, a discrepancy score was calculated between the two summed attitude scores by subtracting the patients' attitude score from the perceived physicians attitude score, e.g., if the physician's score totaled 0, and the patient's score was +4, then the discrepancy equalled 4, or if the doctor's score was -9, patient's = +5, then the discrepancy would equal 14, and so forth.

To further illustrate the scoring system, a pilot case is presented. The knowledge and attitude instruments were used with a 23 year-old female diabetic patient and her diabetologist. Both were in complete agreement on information items. The patient's attitude score was -1 (slightly liberal) and her physician's score was -5 (more liberal), yet the patient's impression of her doctor equalled +7 (rather strict), and the doctor's estimate of her view totaled a -4. Therefore, the <u>actual</u> discrepancy was merely 4, but the patient's view of her doctor erred by 12 points, and his of her by 5. Thus, while there was rather little real difference in their opinions, the patient seemed to misperceive her physician more than he did her, believing that he was more strict than he reported.

Patients selected for interviews also completed measures of verbal IQ and health related LOC. The final 31 words of the WISC-R vocabulary subtest were used to estimate the verbal IQ of subjects 16 years old and under, while those 16 and older were given the vocabulary subtest from the WAIS. The vocabulary subtest for both these instruments is a test of word knowledge designed to tap learning ability, fund of knowledge, richness of ideas and concept formation (Sattler, 1974). This subtest is stable over time, and is relatively unimpaired by some neurological diseases or psychological disturbances. It is considered to be a good measure of "g" (general intelligence factor) and thus an excellent estimate of overall IQ (Blatt & Allison, 1968; Cohen, 1959).

The Multidimensional Health Locus of Control scale (MHLOC) was given to those subjects with normal verbal IQ (i.e., eighth grade reading ability). This instrument is a revision of Wallston, Wallston, and Kaplan's (1976) Health LOC scale. The device has been modified to account for individual LOC (I), and control exerted by chance (C), or by powerful others (P). It is in true/false format with six items each for the I, P, and C scales. Two forms (A and B) are available, though only one form (A) was used in this study.

Items were developed with a sample of 115 subjects who were 16 years of age and older. The mean age was 42 years, 49% were male. Reliabilities of combined A and B forms gave alphas of .859 for I, .830 for P, and .841 for the C scale. There were significant positive correlations between each MHLOC scale and corresponding scales for Levenson's general LOC instrument I: $\underline{r}$ = .58, P: $\underline{r}$ = .28, c: $\underline{r}$ = .80. As might be expected, the MHLOC I scale correlated negatively with the C scale, while the P and C scales are positively correlated. The only MHLOC scale to correlate with social desirability was the C-scale when forms A and B were combined. In this case, the shared variance was only 6%. Good health was associated with higher I scores, poor health with higher C scores.

Those children with reading ability below the eighth grade level or with vocabulary scores below 1 SD for the mean were given Parcel and Myer's (1978) Children's Health LOC scale (CHLOC). The refined version of this scale is a 20-item yes/no questionnaire. The instrument was designed for elementary school aged children and older. Findings revealed an increase in internality with age, no gender effects, but some variation by ethnic group.

The Kuder-Richardson formula yielded moderately high internal consistency ($\underline{r}$ = .72, .75). Test-retest reliability over six weeks time was a fair $\underline{r}$ = .62, which is on par with other such instruments. Construct validity was determined to be .41 with the Bailer-Cromwell scale of general LOC for children, and .31 with the Intellectual Achievement Responsibility Scale, which measures academic LOC. Factor analysis procedures uncovered three factors similar to those of Levenson (1974) and the MHLOC: control by powerful others, internal control, and chance.

The last data-gathering instrument used with patients was an interview. It was designed to explore the reasons behind the responses given in the previous questionnaires with particular attention paid to some of the six major theoretic variables used by models to explain health behaviors (Cummings, Jette, Brock, & Haefner, 1980). These variables are:

1. Accessibility of health services
2. Attitudes toward health care
3. Threat of illness
4. Knowledge about illness
5. Social interactions, norms, and structures
6. Demographic characteristics

Its 40-items include questions about diabetic history of the patient as well as open-ended questions about the variables listed above. The interview schedule was built for this study from salient elements of the literature reviewed above, and expert review. A small pilot test of this device with two subjects revealed no problems with comprehension. Due to economic limitations, patients were interviewed either at home or in their clinic by the researcher. All patients were given assurances of anonymity, and if interviewed in a clinic, were given a room separate from that which was used by their physician. Simple demographic data were collected via questionnaire from the parents of all patients. Included were questions about parental income, education, and the name of the physician treating their child's diabetes.

The final element of this study was an interview with the physician of those patients who were interviewed. There were 21 items designed to parallel the questions asked of the patient sample. They included the physician's education program, views of his/her accessibility, attitudes toward treatment issues, and evaluation of the patient's success. This was also pilot-tested with one nurse practitioner without apparent problems.

Procedures

Subject selection.--Subjects were selected as described above. Letters describing the research goals, nature of the instruments, assurance of annonymity, and release forms were sent to patients and their parents in separate letters.

Letters of explanation similar to those of the parents were delivered to the physicians nominated by parents. All subjects were offered a general abstract of research results if desired (please refer to Appendices A and B for copies of letters and instruments).

Administration.--There were three phases to this study. The first phase was a mass mailing of approximately 100 copies of the Diabetes Treatment questionnaire, the Information questionnaire, and the Attitudes Toward Diabetes questionnaire Parts I and II, to the adolescent patients. A brief demographic questionnaire was also sent to their parents. Each subject was paid one dollar upon return of the completed questionnaire.

The second phase involved selection of a representative group for intensive study. A 2 (high/low information) x 2 (high/low discrepancy) x 2 (age: 11-15 and 16-22) x 2 (male/female matrix was created.

Anton (1978), Kiesler (1971), and Miller and Warner (1975) all discuss the usefulness of intensive, small population studies. This research design is particularly well-advised when the questions are complex, experimental manipulation is impossible or unethical, the subjective experience is an issue, and when "process" or changes over time are investigated. This research conforms with the first three points.

As mentioned, a total of 16 patients were selected for the interview matrix, through the above procedures and offered $5.00 upon completion of the second phase interviews. The subjects were met in their homes, or their clinic by the researcher, given the vocabulary sub-tests, and the MHLOC or CHLOC, depending on their vocabulary scores. The interview schedule completed the session. The interviews ranged from about 20 minutes to 2-1/2 hours, with 1/2 hour being average. Records were made by tape recorder and written notes.

The final phase included the brief office interviews with the physicians nominated by the parents of the interviewed subjects.

RESULTS

The results of this investigation are presented in two sections. The first section, Part I, is concerned with the statistical treatment of the questionnaire data, while the later, Part II, discusses findings from the case studies.

Part I

Questionnaire Data

The statistical analysis of the questionnaire data began with a brief summary of the statistical approach, then the descriptive findings about the sample, the demographic variables and the scales constructed from the questionnaires were reviewed. The variables were intercorrelated and presented in a Pearson Product Moment correlation matrix, and the hypotheses reviewed and discussed. From the intercorrelation matrix, several variables were selected for inclusion in multiple regression analyses. The final level of statistical analysis presented was a series of ANOVAs.

The traditional approach to the statistical analysis of data has been to determine a probability for the rejection of the null hypothesis. However, sampling error becomes a major problem for significance testing when sample sizes are smaller than 4,000. Sampling error is not a bias in sampling, but rather chance variations between sample and population values. Only larger samples will reduce sampling error.

The major problem with using statistical tests with small samples is the insensitivity of the testing procedure in uncovering the true relationships among variables in the population studied. Under these circumstances, most true relationships among variables will never be discovered, i.e., The Type II error is committed.

There is unfortunately, an additional problem with the statistical test when used with small samples. This is concerned with the interpretation of less than significant findings. As noted small samples generate large sampling errors. This means that when studies are replicated, correlations between given variables will vary over a wide range of values. Since the power of a statistical test is very low for small samples, many of the sample correlations will not be significant. Frequently, non-significant correlations never get published, due to the researcher's reluctance to report "poor" relationships and to editorial policies which inhibit reporting of non-significant findings. Since replications will also uncover many large correlations generated by sampling variability, the larger correlations will begin to appear in the literature. Researchers, anxious to consolidate knowledge and to generalize findings, will therefore get a very biased estimate of the true correlation between variables, for many of the non-significant sample correlations were never published.

This bias in the test of significance, when using small samples, has led a number of researchers to look for alternative statistical procedures which avoid some of the pitfalls of statistical testing. One approach is to utilize meta-analytic techniques (see Hunter, Schmidt, & Jackson, 1982), which combine independent studies to obtain a larger sample size. However, for single studies with small samples an alternative to the test of significance is to form confidence intervals. The confidence interval gives much more information concerning the effects of sampling variability, and in particular, the effect of sample size on estimating the value of the correlation.

For the 95th confidence level, the interval for the Pearson Product-Moment correlation coefficient takes the following form:

$$\text{Conf } [r - (1.96 * SE) \leq p \leq r + (1.96 * SE) = .95] \qquad (1)$$

where

$$SE = \frac{1 - r^2}{\sqrt{N - 1}} \qquad (2)$$

The upper and lower bounds of this confidence interval are a function of the standard error of the correlation coefficient, SE. This in turn is a function of the sample size, N. Confidence intervals may be used to estimate the effect of sample size on sampling error. For example, Stoffelmayr, Dillavou, and Hunter (1983) present the following cases: At the 95th confidence level, a sample size of 400 with a sample correlation of .40 would generate a lower bound of .32 and an upper bound of .48. Using equations (1) and (2), it would require at least <u>685</u> more subjects to reduce the size of the interval so that the estimate of the population coefficient would lie between .35 and .45. These two sample sizes are relatively large in comparison to most psychological studies. The authors point out that the average sample size in employment test validity studies is 68. For a sample correlation of .40, with such an _N_, the sampling variability would be quite large. The quantity, 1.96*SE would equal .20 rather than .08 and .05 calculated in the previous examples (400 and 1,084 subjects respectively). This would give a lower estimated correlation of .20 and an upper estimated correlation of .60, a moderately high correlation.

As can be seen, the size of _N_ has a profound effect on sampling variability. Levine and Hunter (1983) suggest reporting all correlations, the sample size, and confidence values rather than merely reporting results of significance tests. First, sample correlations will be useful for future meta-analytic studies which may find use for those sample correlations, even when low. Second, by reporting confidence limits, one can, if it were desired, test the null hypothesis. If the interval includes zero, then the null hypothesis would not have been rejected. Levine and Hunter (1983), when discussing this use of the confidence interval, also hasten to add that any interval that includes zero (e.g., -.08 to .38) also includes many other values which are likely. Thus in the above example, .38 is as possible as zero.

Due to the problems of using small samples, the confidence limit approach was followed in the analysis presented here. The intervals will indicate the effect of sampling variability on these results. In addition, the confidence interval approach also gives the researcher information concerning what would happen if tests of significance were to be made.

Scales

In a descriptive study of this kind, demographic variables assume great importance, and are discussed in detail below. As mentioned earlier, two-thirds of the sample was female, one-third male. This varied somewhat from the population prevalence (Jackson & Guthrie, 1976). Ages ranged from 11 to 22 years, the mean ($\bar{X}$) age for this sample, was 15½ years with a standard deviation (SD) of 2.8 years. There was a slight skew toward the younger ages. Due to an error on the questionnaire, there were only 64 valid duration reports. They ranged from 6 months to 19 years. The mean for these cases was 6 years with a SD of 3.6 years. There was a slight skew toward the briefer durations.

Socio-economic status (SES) was assessed on a seven point scale 1 high to 7 low. The modal score was 2, with a mean of 3.1, and SD of 1.7. The sample was skewed toward higher SES.

Patients reported that five types of physician treated their diabetes: the MSU Pediatric Endocrine Clinic pediatricians, general practitioners, internists, and adult endocrinologists. Thirty-five patients reported pediatricians, 31 reported pediatric endocrinologists as their physicians. Only nine adult endocrinologists, two internists, three general practitioners were named.

There is a discrepancy in that the Pediatric Endocrine Clinic is underreported, e.g., patients of the clinic reported pediatricians or general practitioners as their physicians for their diabetes.

A number of scales were constructed from the four questionnaires, from various items therein, or from interactions between the questionnaires. The information scale (INFO) was a sum of correct answers from the knowledge questionnaire. The potential range was 0 to 33. Obtained range was 16 to 33. The mean was 28, mode = 31; *SD* = 4.2. Cronbach's $\underline{\alpha}$ = .801, standardized item $\underline{\alpha}$ = .804. Self-appraisal of control status (S-APP) was a seven-point scale ranging from "very bad" to "excellent." The mean was 5.2 ("very good") with a *SD* of 1.1. Thus the curve slightly favored the higher values.

Patient attitudes toward treatment were measured with the 23-item Patient's Attitudes Toward Diabetes questionnaire (ATT-Self). Negative and relatively low values indicated looser, or undemanding views, positive and relatively higher values indicated more demanding or strict attitudes toward care. Three items could not be clearly weighed as "liberal" or "strict", and were thus omitted. The scores ranged from -14 to +29, $\underline{\bar{X}}$ = 8.11, *SD* = 8.22. The distribution was fairly normal.

Patients' perceptions of their physician's beliefs about the same questions were measured with the 22-item (utility of long and short term compliance was condensed into one question). Perceived Physician's Attitudes Toward Diabetes questionnaire (ATT-DOC).

The nature of the scoring, loose/tight, was similar to the Patients' Attitude questionnaire. Scores ranged from -7 to +36, the mean was 13.23 with a SD of 8.67 there was again, a moderately normal distribution with slightly greater kurtosis than there was found in the Patients' Attitude scale.

The different scores on patient attitudes (ATT-Self) and perceived doctor's attitudes (ATT-DOC) suggested that the patients viewed their physicians as asking somewhat more or being more strict then they themselves were. This was tested with $\underline{t}$ test ($\underline{t} = 5.37$, $\underline{81} = \underline{p} < .001$) and found to be the case.

Of special interest is the relationship between the patients' perceptions and physicians' actual views. A representative of the MSU Pediatric Endocrine Clinic completed this questionnaire (ATT-Self) and obtained a score of -10, over 2 SDs below the mean, and lower than any patient's score (ATT-DOC). In general, the patients believed their doctors to be stricter about urine testing, diet and compliance with the regimen. In fact, the clinician was more demanding about urine test recording, but more liberal about the other topics.

Two factor analysis programs were used with the attitude scales, SPSS (Nie, Hull, Jenkins, Steinbrenner & Bent, 1973) and PACKAGE (Hunter & Gerbins, n.d.). Both were principle factor approaches with a Kaiser normalization and varimax rotation. Convergence on three factors from ATT-Self with the SPSS program required 13 iterations, using all items. Factors 1, 2 and 3 had Eigen values of 2.37, 1.26 and 1.19. The exploratory factor analysis, PACKAGE, also found three factors. Their Eigen values were: 3.08, 2.03 and 1.08, and they accounted for .13, .09 and .06 percent of the variance.

The same factor-analysis programs were used with the Perceived Physician's Attitude scale. Nine iterations led to convergence on two factors in the SPSS program. Factor 1 had an Eigen value of 2.28, and Factor 2 had an Eigen value of 1.21. However, the PACKAGE program formed three factors of 10, 8 and 4 items. Their Eigen values were 2.95, 1.97 and 1.06. After varimax rotation, .13, .08 and .06% of the variance was accounted for.

While there was some item overlap in factors between the SPSS and PACKAGE programs, none of the factors were readily interpretable.

The two Attitude scales were combined into a 45 item group and subjected to the PACKAGE and SPSS principal components factor analyses. The PACKAGE procedure found 12 factors, the SPSS, 16. Due to the large number of factors, interpretation was judged to be too complex to be worthwhile.

The final factor analysis to be reported was of the a priori, type, using the two scales as pre-determined factors. PACKAGES' multiple groups subprogram found standard score coefficient alphas of .67 and .75 for ATT-SELF and ATT-DOC, respectively. After partialling, the coefficient between scales was .83. It is notable that the greatest correlations were consistently between parallel items on the scales, not for items clustering within either scale.

Several other scores were derived from the interaction of the two attitudes scales, Perceived Attitude Agreement (DOC-AG) simply summed the raw number of total item agreements between the scales. Of a potential 22, patients ranged from 3 to the maximum, 22. The $\underline{\bar{x}}$ was 11.9, SD 3.6 in a relatively normal distribution.

Another simple raw score summary is Attitude Uncertainty (DOCS?), the number of instances in which patients were uncertain what their own attitudes or their physician's attitudes were. Naturally, the potential range was again 0 to 22. The range obtained was 0 to 10, in a bi-modal distribution, $\underline{\bar{x}} = 3.51$, SD = 2.48. Twelve percent of the patients expressed no uncertainties and scored 0.

A more complex score was derived from a summary of Attitude scale item by item differences (e.g., ATT-DOC item 1 score — ATT-Self item 1 score) + (ATT-DOC item 2 score -- ATT-Self item 2 score) + . . ., = Doctor/Patient Attitude Discrepancies (DOC-PAT DISC). The potential range was from -88 to +88, obtained range, -13 to +25, the $\bar{x} = 4.00$, SD = 6.55. This reinforces the finding that doctors are seen by patients as more conservative than patients see themselves.

One other weighted score attempted to scale patients on how seriously and strictly they followed a regimen. Twenty items were selected from the Diabetic Treatment questionnaire and reweighted to reflect liberal vs. strict behaviors (-2 to +2). This sum forms the score Regimen Behaviors (COMPL). Potential range = -40 to +40, obtained range = -14 to +25, $\bar{x}$ = 7.55, SD = 8.95, α = .52.

The final constructed scales were attempts to gauge discrepancies between regimen standards or attitudes, and behavior regimen, i.e., ATT-Self and ATT-DOC minus COMPL. Thus, COMPL scores were subtracted from ATT-Self and ATT-DOC scores to form COMPL/DISC-Self and COMPL/DISC-DOC. Scores on these two scales that are close to the zero mark indicate little discrepancy, compliance and attitudes may be high (strict) or both low or negative, (looser) but congruent. Positive scores, on the other hand, imply higher standards than behavior, e.g., doing less than one feels one should, negative scores, the reverse, e.g., doing more than one thinks one ought. As the number of items and shape of the distributions for the COMPL and attitudes scales were reasonably similar, they were not standardized. The range of COMPL/DISC-Self extended from -21 to +33, with a $\bar{x}$ of 1.32, with SD of 10.17. The range of COMPL/DISC-DOC extended from -25 to +40 with a $\bar{x}$ of 5.83, SD of 11.87. Thus, generally patients feel that they are rather close to their ideal, but that they are doing less than they assume their physicians would want.

Please refer to Tables 2 and 3 for a summary of these scales.

Correlations

The next level of analysis produced a 14 x 14 Pearson Product Moment Correlation matrix and variable clustering (see Table 4 and Figure 8). Demographic variables (sex, age, duration,

TABLE 2.--Description Statistics for Major Variables.

	Range	Mean	Mode	Median	S.D.	Skew	Kurtosis	Alpha α
Age	11-22	15.54	14.00	15.16	2.83	.19	.87	
Dur*	1-19	6.03	3.00	5.25	3.63	1.21	1.77	
SES	1-7	3.15	2.00	2.75	1.65	.51	- .88	
INFO	16-33	27.76	31.00	29.00	4.18	-1.03	.44	.80
S-APP	2-7	5.22	5.00	5.21	1.14	- .59	.91	
ATT-Self	14-29	8.77	11.00	8.00	8.22	.21	.16	.68
ATT-DOC	-7-36	13.23	7.00	13.00	8.67	.07	.21	.75
DOC-PAT	3-22	11.42	12.00	12.17	3.64	- .08	.06	
DOCS?	0-10	3.57	5.00	3.80	2.48	.28	- .55	
Compl	-40-40	7.55	0.00	0.00	8.95	.00	.00	.52
DOC/PAT-DISC	-13-25	4.00	0.00	3.36	6.55	.25	1.78	.32
COMP/DISC-Self	-21-33	1.32	4.00	1.00	10.17	.43	.55	.43
COMP/DISC-DOC	-25-40	5.83	6.00	6.49	11.87	- .05	.28	.60

_N_ = 82.
*_N_ = 64.

TABLE 3.--Descriptive Statistics by AGE and SEX Groupings.

	young females *n* = 32		older females *n* = 24		young males *n* = 14		older males *n* = 13	
	Mean	S.D.	Mean	S.D.	Mean	S.D.	Mean	S.D.
Dur	5.44	2.55	6.75	4.87	5.50	3.32	6.91	4.11
SES	3.52	1.95	2.61	1.31	2.93	1.39	3.46	1.56
INFO	26.88	4.30	30.54	1.91	25.64	5.032	27.08	3.73
S-APP	5.09	1.20	5.13	1.04	5.43	1.34	5.46	0.97
ATT-Self	9.47	8.61	7.96	6.74	7.93	9.29	9.46	9.20
ATT-DOC	14.22	9.42	10.65	8.11	12.86	3.46	15.92	8.20
DOC/PAT-DISC	3.81	5.50	3.44	8.07	3.64	4.33	5.85	8.21

TABLE 4.--Pearson Product Moment Correlation Matrix

	Sex	Age	DUR	SES	INFO	S-APP	ATT-Self	ATT-DOC	DOC-AG	DOCS?	DOC-PAT/ DISC	COMPL	COMPL/ DISC-Self	COMPL/ DISC-DOC
Sex	--	-01±20	23±20	02±20	24±19	14±19	01±20	08±20	07±20	13±19	08±20	-22±19*	18±19	23±19*
Age	-01±20	--	23±14	-12±20	48±15*	01±20	01±20	7±20	-14±19	-10±20	- 3±20	11±19	-01±20	-15±19
DUR	24±20	23±19	--	01±20	-01±20	-04±20	01±20	-05±20	11±20	01±20	-09±20	-01±20	-01±20	-04±20
SES	16±20	-12±20	01±20	--	-18±18*	-02±20	13±20	23±19	02±20	15±19	07±20	04±20	05±20	13±20
INFO	-24±19	48±15	-07±20	-18±19	--	11±19	01±20	-07±20	02±20	-19±19	01±20	37±17*	-31±18	-33±18*
S-APP	-14±19	01±20	-04±20	-02±±0	11±19	--	24±19	07±20	22±19*	-14±19	-05±20	38±17	-15±19	-25±19*
ATT-Self	01±20	01±20	01±20	13±20	01±20	24±19	--	58±13*	41±17*	-32±18*	-33±18*	30±18*	54±14*	18±19*
ATT-DOC	08±20	07±20	-05±20	23±19	-07±20	07±20	58±13*	--	-05±20	-21±19*	47±16*	08±20	39±17*	65±11*
DOC-AG	07±20	-14±19	11±20	02±20	02±20	22±19*	41±17*	-05±20	--	-42±16*	-46±16*	35±17*	02±20	-30±18*
DOCS?	13±19	-10±20	02±20	15±19	-19±19	-14±19	-32±18*	-21±19*	-42±16*	--	-03±20	-23±19*	-07±20	01±20
DOC/PAT-DISC	08±20	-03±20	-09±20	07±20	01±20	-05±20	-33±18	47±16	-46±16*	-03±20	--	-20=19*	-10±20	48±15*
COMPL	-22±19*	11±19	-01±20	04±20	37±17*	38±17*	30±18*	08±20	35±17*	-23±19	-20±19	--	-63±12*	-68±11*
COMPL/DISC-Self	18±19	-01±20	-01±20	05±20	-31±18	-15±19	54±14*	39±17*	02±20	-07±20	-10±20	-63±12*	--	75±9*
COMPL/DISC-DOC	23±19*	-15±19	-04±20	13±19	-33±18*	-25±19	18±19	65±11*	-30±18*	01±20	48±14*	-68±11*	75±9*	--

*Interval does not include zero.

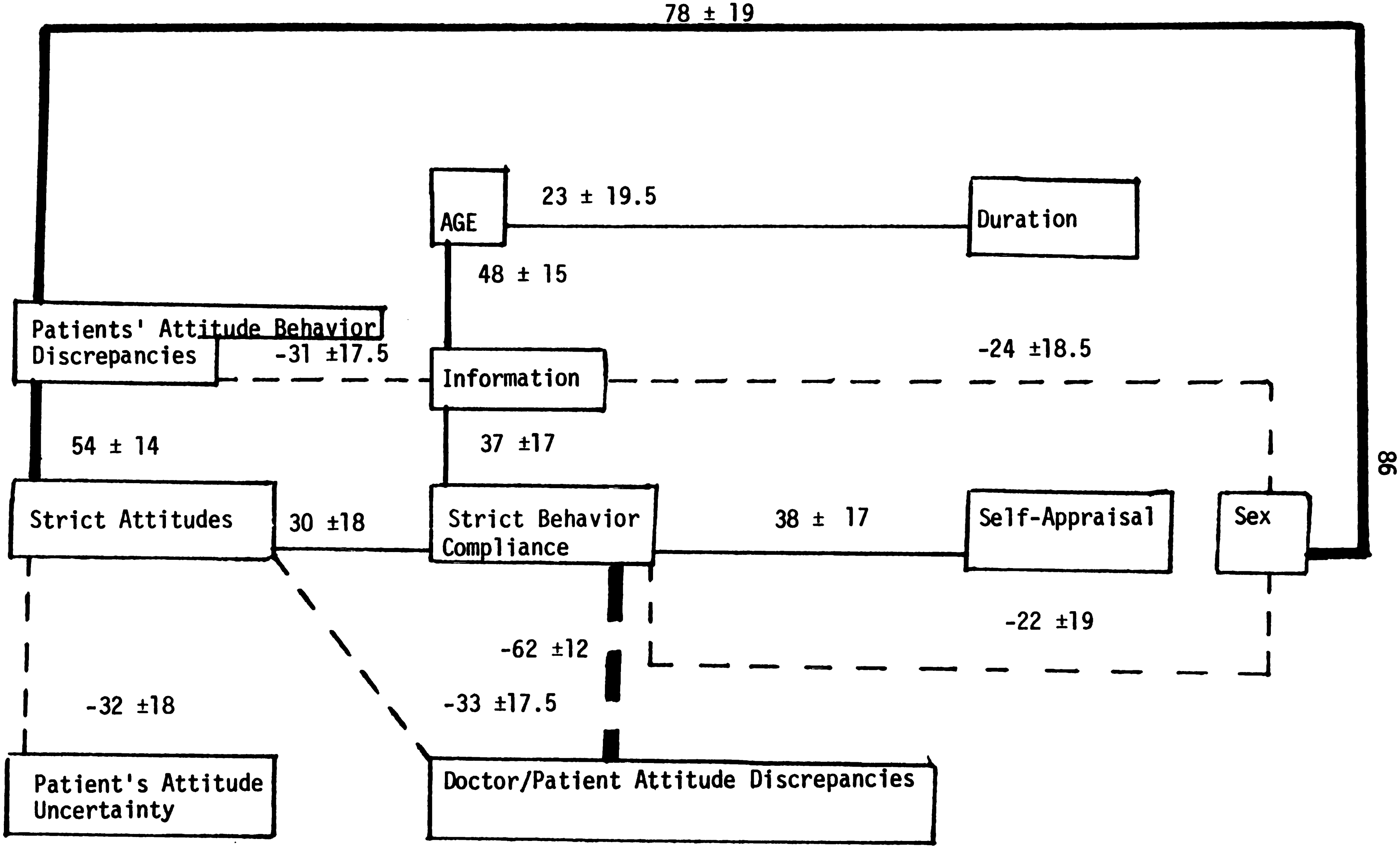


Figure 8.--Variable Interrelationship.

SES) and constructed scales scores, information level, self appraisal of control status, patient and perceived physician attitudes toward diabetes, etc., (INFO, S-APP, ATT-SELF, ATT-DOC, DOC/AG, DOCS?, DOC/PAT DISC, COMPL, COMPL/DISC-Self, and COMPL/DISC-DOC) provided the variables for the correlations. Type of physician was not correlated because of nominal measurement levels. Means were used to replace missing values.

The strongest relationships between key variables are summarized in graphic form in figure 8.

Strict regimen behavior (COMPL) was associated with: 1) high self appraisal (S-APP) 2) high information 3) Strict Attitudes 4) femaleness) fewer self Attitude/Behavior discrepancies (some common items).

High Information (INFO) levels were associated with: 1) greater age 2) strict regimen behavior (COMPL) 3) femaleness 4) fewer attitude/behavior discrepancies.

Strict attitudes toward diabetes (ATT-Self) were associated with: 1) little confusion about own or doctor's attitudes 2) fewer DOC/PAT attitudes discrepancies 3) higher or stricter regimen behavior 4) higher ATT-SELF/Behavior discrepancies (COMP/DISC-SELF)

High patient Attitude/Behavior discrepancies (COMP/DIS Self) were associated with: 1)low information 2) maleness 3) looser regimen behavior 4) strict attitudes.

As the figure shows, information levels (INFO), patient attitudes toward diabetes (ATT-Self), and regimen behaviors (COMPL) have both the strongest and most frequent intercollelations. Below are the statistically-based hypotheses and their acceptance, or rejection on the basis of these correlations.

Hypotheses

Hypothesis I: higher information levels will be associated with:

a) Greater age - confirmed by Pearson correlation (r = .48 ± 15)

b) Longer duration of disease (DUR) - not confirmed by Pearson (r = .07 ± .20)

Hypothesis 2: patient attitude and regimen behavior discrepancies correlate with:

a) Younger age - not confirmed (r = -.09 ± .20)

b) Shorter disease duration - not confirmed (r = -.001 ± 20)

c) Lower information levels - confirmed by Pearson correlation (r = -31, ± .18)

These results led to reasonable empirical and theoretical choices for variable inclusion in the third analysis of this section, namely a series of multiple regressions. Multiple regression equations were formed in order to select the variables that best predicted patients' scores on several important and practical scales. Four variables were selected as dependent variables: information levels (INFO), regimen behaviors (COMPL), physician/

patient attitude discrepancies (DOC/PAT-DISC) and patients' attitude/ behavior discrepancies (COMPL/DISC-Self). These variables are of theoretical interest because they represent knowledge, admitted basic compliance, discrepancies between own attitudes and perceived physician attitudes, and discrepancies between the patients' attitudes and their behaviors. It was important to predict these four variables in particulr because the former provide useful "hard" data (patient information, compliance) for clinical applications and the latter may explicate the complex attitudinal relationships (DOC/PAT-DISC, COMPL/DISC-Self) that underlie or lead to overt behaviors such as "compliance". The correlations indicated that a sufficient number of other variables were related to these four to permit further analysis. A frankly empirical approach was used to form the simple multiple regression equations. Means were substituted for missing values. The first procedure with each dependent variable formed regression equations with the demographic variables. The second step formed equations based on selected constructed scales. Those independent variables with the greatest betas were retained for the third set of regressions. The results from this last step are presented below.

Information (INFO)

AGE, Duration, Perceived Physician's Attitudes (ATT-DOC), and regimen behavior (COMPL) were the independent variables in the third stage regression for INFO. The Multiple R = .60 ± .14. The beta confidence intervals for AGE and COMPL did not include zero.

Regimen behavior (COMPL)

Sex, information, self-appraisal (S-APP), patient attitude (ATT-Self), and doctor/patient attitude discrepancies (DOC/PAT-DISC) were the independent variables in the third regression for COMPL. The multiple R = .59 ± .14. The beta confidence interval for information and self-appraisal did not include zero.

Physician/patient Attitude Discrepancy (DOC/PAT-DISC)

Duration, patient and perceived physician attitudes (ATT-SELF, ATT-DOC), attitude uncertainty (DOCS?) and agreement with physician (DOC-AG) were the independent variables retained from previous regressions. The Multiple R = .88, ± .05. The beta confidence intervals for both attitude scales (ATT-SELF; ATT-DOC) and patient attitude uncertainty did not include zero. However, the high correlation between the attitude scales (_r_ = .58) was a major influence on the high R.

Patient Attitude/Behavior Discrepancies (COMPL/DISC-SELF)

The independent variables selected for COMPL/DISC SELF included: information, both attitude scales (ATT-DOC; ATT-SELF), self-appraisal (S-APP), regimen behavior (COMPL), attitude uncertainty (DOCS?) agreement with physician (DOC-AG), and physician/patient attitude discrepancies (DOC/PAT-DISC). Multiple R = .99 Regimen behavior and patient attitudes were highly correlated with the dependent variable and may have masked contributions from other independent variables. These two variables were dropped from the analysis to allow other variables to contribute. Multiple R dropped to .62 ± .14. Beta confidence intervals for information, perceived physician's attitudes, physician/patient attitude discrepancies did not include zero. Please refer to table 5 for a summary of these data.

ANOVAs

The final level of questionnaire analysis was a series of ANOVAs. Dependent variables selected were Information level (INFO), regimen behavior (COMPL), and physician/patient attitude discrepancy (DOC/PAT-DISC). Variables were divided by median splits. Information by age and sex yielded a significant main effect for age only ($\underline{F} = 12.97$, $\underline{p} < .001$). There were no two-way interactions. Regimen behavior by age, sex, and information yielded significant main effects for information only ($\underline{F} = 3.73$, $\underline{p} < .05$). No two-or three-way effects were found. When information level was co-varied out, information level was again significant ($\underline{F} = 12.05$, $\underline{p} < .001$), but there were no main effects for sex and age. There were no significant effects for physician/patient attitude discrepancy by age, sex, or information level, or with information co-varied. Please refer to table 6 for detailed results.

The statistical treatment of the questionnaire data confirmed the predicted relationships between higher information and greater age, (through correlations, regressions, and ANOVAs) and High Attitude-regimen behavior discrepancies and low information (through correlations, and regressions). Expected relationships

TABLE 5.--Multiple Regression for Information, Compliance, Doctor/Patient Attitude Discrepancies and Regimen Behavior

Variable Entered	Beta	Confidence Interval
A. Information, Age, Duration, Regimen Behavior, Physician/Patient-Attitude discrepancies		
Multiple R = .60 ± .14		
AGE	.48	.29 to .67
ATT/DOC	-.075	-.26 to .11
COMPL	.32	.13 to .50
DUR	-.18	-.37 to .01
B. COMPL with Information, Sex, Self-Appraisal, Patient Attitudes, and Physician/Patient Attitudes-Discrepancies		
Multiple R = .59 ± .14		
Sex	-.18	-.38 to .01
INFO	.29	.09 to .48
ATT/Self	.18	-.02 to .39
S-APP	.33	.13 to .53
DOC/PAT-DISC	-.11	-.31 to .09
C. Physicians/Patient Attitude-Discrepancies with Duration, Self-Appriasal, Physician-Attitude, DOC?, and DOC-AG		
Multiple R = .88 ± .05		
DUR	-.03	-.14 to .08
ATT-Self	-.87	-1.0 to -.71
ATT/DOC	.93	.78 to 1.1
DOCS?	-.17	-.29 to -.04
DOC-AG	-.12	-.26 to .02
D. COMPL/DISC-SELF with Information,Self-Appraisal, Attitude Uncertainty, Perceived Physician Attitude, Agreement and Physician, and Doctor/Patient Discrepancies		
Multiple R = .61 ± 14		
INFO	-.27	-.47 to -.81
S-APP	-.16	-.35 to .03
DOCS?	-.10	-.32 to .12
ATT-DOC	.56	.34 to .78
DOC-AG	-.16	-.40 to .09
DOC/PAT-DISC	-.45	-.69 to -.20

TABLE 6.--ANOVAs for Information, Regimen Behavior and Doctor/Patient Attitude Discrepancies

Source of Variation	Sum of Squares	DF	Mean Squares	f	Significance of F	ETA^2
A. Know by Sex, Age						
Main Effects	241.587	2	120.794	7.96	.001	.167
Sex	93,166	1	53,166	3.51	.065	.937
Age	196.698	1	196.698	12.097	.001	.135
2-way interactions	23.560	1	23.560	1.56	.216	.016
Sex/Age	23.560	1	23.560	1.55	.216	.016
Explained	265.148	3	88.383	5.83	.001	
Residual	1183.242	78	15.170			
Total	1448.390	81	17.881			
B. COMPL. Age, Sex and INFO						
Main Effects	771.198	3	237.066	3.31	.025	.119
Sex	107.024	1	107.024	1.38	.244	.017
Age	44.231	1	44.231	.57	.453	.087
INFO	442.844	1	442.844	5.71	.019	.068
2-way interactions	28.090	3	9.803	.12	.948	.004
Sex/Age	17.214	1	17.214	.22	.639	.003
Sex/INFO	1.116	1	1.116	.01	.905	.001
Age/INFO	13.991	1	13.991	.18	.672	.002
3-way interactions	85.608	1	85.608	1.10	.297	.013
Sex/Age/Know	85.608	1	85.608	1.10	.297	.013
Explained	884.897	7	126.414	1.63	.141	
Residual	5584.966	72	77.569			
Total	6469.862	79	81.097			
Covariates	851.442	1	851.442	12.06	.001	.132
INFO	851.442	1	851.442	12.06	.001	.132
Main Effects	300.118	2	150.059	2.13	.127	.046
Sex	143.897	1	143.897	2.04	.158	.022
Age	117.466	1	117.406	1.66	.201	.018
2-way interactions	21.217	1	21.217	.30	.585	.003
Explained	1178.778	4	293.195	4.15	.004	
Residual	5297.084	75	70.628			
Total	6469.862	79	81.897			

Table 6 (Continued)

Source of Variation	Sum of Squares	DF	Mean Squares	F	Significance of F	ETA^2
C. DOC/PAT-DISC by Age, Sex and INFO						
Main Effects	64.838	4	16.210	.376	.825	.019
Sex	16.263	1	16.263	.377	.541	.004
Age	8.317	1	8.317	.193	.562	.002
Know	26.324	2	13.162	.305	.738	.008
2-way interactions	232.363	5	46.473	1.077	.381	.071
Sex/Age	116.241	1	116.241	2.694	.105	.035
Sex/INFO	181.005	2	90.502	2.098	.131	.055
Age/INFO	23.582	2	11.791	.273	.762	.007
3-way interactions	20.627	2	20.627	.478	.492	.006
Sex/Age/INFO	20.627	1	20.627	.478	.492	.006
Explained	317.828	10	31.783	.737	.688	
Residual	2977.160	69	43.147			
Total	3294.988	79	41.709			
Covariates	.537	1	.537	.012	.912	.001
INFO	.537	1	.537	.012	.912	.001
Main Effects	37.989	2	18.944	.440	.646	.012
Sex	16.188	1	16.188	.375	.542	.005
Age	16.876	1	16.876	.391	.534	.005
2-way interactions	15.395	1	15.395	.356	.552	.005
Sex/Age	15.395	1	15.395	.356	.552	.005
Explained	53.921	4	13.480	.312	.869	
Residual	3241.066	75	48.214			
Total	3294.988	79	41.709			

between information and disease duration, and attitude/behavior discrepancies and age, and duration were not found. However, several other findings of importance emerged. These included ties between female sex and strict regimen behavior and high information; strict regimen behaviors and high self appraisal and strict attitudes toward diabetes; and a tendency for patients to perceive their physician's attitudes as being more strict than their own. This perception was not always accurate. Further, older males displayed the greatest perceived differences, and older females the least.

Part II

Interview data

This portion of the results section reviews data gleaned from the patient and physician interviews. It is presented on a case-by-case basis with mention of any relevant scores from the questionnaire scales. All subjects are referred to by pseudonyms. Trends and patterns are discussed at the end of this section.

Five people who had completed questionnaires refused interviews: one young female (INFO = 33, DOC/PAT-DISC = 13), two older females (INFO = 26, 25; DOC/PAT-DISC = 13, 9) and two older males (INFO = 20, 24 DOC/PAT-DISC = 6, 20). Mean compliance scores (COMPL) equalled 1.6, self appraisal (S-APP) = 5.2, SES = 2.8. All were patients of private physicians.

The physicians interviewed included: One adult endocrinologist, university based, with a large number of diabetic patients, one university-based family practice physician, one year post residency, who sees only one Type I diabetic, one community-based pediatrician, whose high INFO/high DISC patient refused an interview, one professor of pediatrics with an international reputation for his work in diabetes and metabolism, and one well-trained pediatric nurse practitioner with several years experience in managing diabetes. All are MDs with the exception of the nurse, who has an MSN degree.

"Tina"

Tine was a 14 year-old white female, the youngest daughter in an intact, middle-class, Italian-American family. She has had diabetes for ten years, yet achieved one of the lowest information scores (18). Her own opinions about treatment and her perceptions of her physician's corresponded exactly, and fell 1/2 a standard deviation below (more loose) the mean for all patients. Her "compliance" score (COMPL) fell one SD below the group mean. Consequently her treatment ideal and her physician's expectations were evidently not met. In confirmation of this, her self-appraisal was one SD below the group mean (S-APP = 4).

One possible reason for her lower information level may be that her vocabulary scaled score was also lower, 9. Her health locus of control (MHLOC), scores also showed greater than usual levels of externality (10/8), for this sample, especially on "chance" and "powerful others", both 3/3.

The onset of diabetes occurred at such an early age that Tina recalls little of the experience, and of course, had no preconceptions about the disease. Most of her education was filtered through her mother and two aunts.

She reported that "health" was her most important value, followed by "happiness" and "beauty". Tina believed that diabetes need not threaten her health, as it was felt to be "OK" to have it (1 on 7-point scale).

Both short-and long-term compliance were important to her. Following the regimen was rated 4 on a 7-point scale of difficulty. Injections were the hardest part of the treatment for Tina. Tina's case of diabetes is of average severity, in her opinion, but others her age do more to treat the disease. She believes that her disease control is average, that of others is slightly better. Tina found no barriers preventing access to her physician, but her mother still makes all disease-related telephone calls. Her physicians understand her and accept her views, she believed, and she tended to feel that they care for her as a person.

Tina's nurse practitioner stated that she was poorly informed about diabetes due to her early diagnosis and had never been directly taught about diabetes. She also believed that this patient was embarrassed when in the clinic and overly dependent on her mother. Her control was viewed as "moderate" because of consistent injections and dietary adherence (though for cosmetic, not health reasons). Several sources form a coherent pattern; lower information, regimen behavior, and self appraisal.

It is likely that three factors were important in this course to date:

1) early diagnosis, too young to be directly taught,
2) education mediated by her mother and other family members, possibly not accurately,
3) modest intellectual capacities.

"Tammy"

Tammy was a 12 year-old white female whose diabetes was diagnosed when she was three years old. She was the only, and adoptive, child of an older rural family of lower SES. Her father had a heart condition, and her mother is confined to a walker or wheelchair. There is a possibility that Tammy may also have a very mild case of neurofibromutosis. This was not confirmed at the time of the interview.

Her information score was among the lowest in the sample, 18, below two *SDs* below the mean. Her own attitudes toward diabetes and its treatment were one *SD* more liberal (lower) than the sample, she believed that her doctors were closer to the group mean, and thus more demanding than she was. Her actual compliance rating was only slightly below the mean, suggesting that she felt compelled to do more than she believed was necessary.

Her scaled vocabulary score was "10", giving her a normal rating for intellectual (verbal) ability. Given the unusual amount of illness in her small family, her CHLOC scores were of great interest. There were 15 internal responses, 5 external, 4 of which concerned "powerful others" (including doctors and nurses) and 1, "chance".

Naturally, due to her young age, she had no prior expectations or recollections about diabetes or her early experience with it. She felt that her parents learned the most from their general practitioner, and she, in turn, learned the most from them. There have been occasional supplements from magazines, the diabetes association and the diabetes camp.

Tammy believed that the most important points to be taught include the following:

1) "what it's (i.e., diabetes) about,"
2) how to "cope with it"
3) what to expect, e.g., "reactions",
4) injection techniques, and
5) urine sampling.

She said that it is not really possible to have diabetes and be healthy, yet "health" is her first value, followed by "happiness" and "beauty".

Having diabetes is intermediate between "OK" and the "worst thing in the world". Both short and long-term compliance were important to her, while actually caring for it is mid-way between "easy" and "really impossible". The hardest parts are giving shots and testing urine. "Facing having it" is the most embarrassing aspect. She feels that she was forced to give up some school activities, sports in particular, because of her diabetes.

Tammy stated that people her age treat their disease about as she does, but her case is "easier" to care for then was theirs. Nevertheless, both she and they rate a "5" on a 7-point scale of control. Thus all are better than mediocre.

She rated access to her physicians as very good, but believed that they did not share her feelings about diabetes, nor her views. Despite their disagreements, she felt cared for as a person, and made an effort, with varying success, to follow their advice.

Her clinic nurse practitioner agreed that the clinic is easily accessible, but mistakenly believed that this patient "probably" agreed with the clinic's treatment goals. This appeared to be an overestimate of agreement.

The nurse also rated Tammy as a "5" on a 7-point scale of information, again, perhaps an over-estimate. Finally, at the time of the interview, this nurse rated Tammy's disease control as a "6" on a 7-point scale, based on "fairly" good 24 hour urine tests, and rare bouts of ketoacidosis. However, at a later date, she expressed the view that dietary patterns were a major problem, and thus in fact, prevented good control.

Tammy was quite clear in her disagreements with her doctors, without disliking them. It may be her ingenuous nature which led her caregivers to overestimate her knowledge and control. It's possible, too, that her elderly and infirm parents have tended to indulge, protect and even slightly "infantilize" her, thus impairing her compliance and knowledge about diabetes. While Tammy's regimen adherence and self-appraisal were at the mean, her lower information and higher perceived attitude discrepancies fit the patterns established by the correlational analysis.

"Ashley"

Ashley is a 13 year old white female from an upper SES background. Her diabetes was diagnosed when she was 7 years old. She has an intact family with one older brother. Her information score (32) was one point below its ceiling. She expressed little difference between her own views and those she attributed to physicians. Both were roughly 1-1/2 SDs more liberal (lower) than the group mean, and incidently, quite close to her doctor's actual views. Nevertheless, Ashley reported that her behavior was more strict than the mean (1/2 SD). Her self-appraisal slightly exceeded the mean.

Surprisingly, her scaled vocabulary score was a low 6. Ashley's Health Locus of Control score (HLOC) allowed no influence from "chance" but "powerful other's" influence was equally divided between internal and external control (3/3).

Ashley knew a friend of her brother who had diabetes, who had dieted and required injections. While very ill at diagnosis, she recalled being angry about the hospitalization, shots and double-voided urines. She said that she learned more during her initial hospitalization, particularly from a teaching nurse who also provided emotional support. Family, books, "Diabetes Forecast" and her clinic have also been instructive.

Her three most important values were "health", "happiness" and "beauty". Ashley saw diabetes as being equally between "OK" and "very bad". She believed that long-term compliance is more important than short-term because of the likelihood of complications. Ashley rated the prescribed regimen as almost "easy", the most difficult parts being injections and the occasional embarrassment of eating in school. Other people with diabetes treat it about the same as she does, but since her case was easier to care for ("in good health and not bothered by it"), she rated her control as a "5", 2 points from "excellent", others only, "4". She found her physicians easy to reach, empathetic and caring.

Her clinic nurse practitioner was in general agreement, though gave her control an even higher rating, indeed, believed that Ashley may have been too vigilent about her diet, and urine spillage. The clinics' goal, at that time, was to maintain reasonable metabolic control (then measured with urine glucose tests); prevent seizures and permit a "normal lifestyle". These goals required some negotiation between patient, family and physicians. At the time of the interview, the staff felt that the patient may have been overly compliant.

The triad of high information, regimen adherence and self-appraisal again emerged illustrating the correlational findings. High information-low attitude discrepancies were also typical.

Perhaps the most salient contributing factor to this patient's course was the influence of her family. Their financial resources, and intellectual and cultural values have been invested in helping their children reach their potentials. Thus diabetes, like school work or violin lessons, was simply one more area in which to exercise whatever talents may exist. That this state of affairs was still in balance in late pre-adolescence is suggested by her low attitude discrepancies, adequate perceptions and high compliance. Adolescence may alter this balance. A secondary factor that may have exerted long term influence was the impact of initial hospitalization and teaching. The emotional support of the staff may well have reinforced the attitudes they transmitted.

"Jennifer"

Jennifer was a 17 year old upper social class white female whose diabetes was diagnosed 11 years ago. She was an only daughter with older brothers. Her situation was remarkable not only for the long duration of her diabetes but for her perfect information score (33). Both her own attitudes and her perceptions of physicians' views toward treatment were more liberal than the group means. Her adherence score (COMPL = 4) was below the group mean ($\underline{\bar{x}}$ = 7.6, $\underline{SD}$ = 9), and consistent with her attitudes. While she rated her overall control as "very good", she still said that it was slightly below her own treatment ideals.

Jennifer's verbal intelligence was average to above, (11) and her Health Locus of Control scales (MHLOC) were heavily internal (15/3). The majority of the external items were associated with "powerful others" (4/2).

She was so young at diagnosis that she did not understand what was occurring, and can only remember feeling "scared". Understandably, she did not recall her initial hospitalization. Most of her information has come from books, "Diabetes Forecast" and a physician at her clinic. She believed that 1) diet, 2) exercise, 3) "having a good time" were the most important points to teach.

"Health", "happiness" and "wealth" were her principal values. Having diabetes is rated "3" on a 7-point scale of discomfort, a "2" on a 7-point scale of difficulty of care.

Jennifer admits to sometimes taking "a vacation" from her treatment regimen, but "hopes" that compliance will be helpful over time. Her experience with different physicians had led her to believe that their recommendations can sometimes be in error. She felt that her parents, as well, were not always helpful. While her care is a little "easier" to manage then most, in her opinion, she does about the same as most people. In addition, both she, and most others, are exactly between "awful" and "excellent" in their control of diabetes. She was pleased with her physicians' accessibility, their goals as understood, and their concern for her.

Jennifer's nurse practitioner stated that her compliance and metabolic control have recently improved considerably, due to increased maturity and independence from her family. Her major problems remain psychological adaption to illness, and metabolic control. The most difficult area of compliance is her diet, which is alternately too strict, then too lax. Her intellectual grasp is good, but emotional lability remained a problem. It is believed that her social/familial environment is important (there is some "trianglation" in the family's structure) in determining her control and compliance. Her high information and lower regimen scores were not typical of the statistical findings, but her perception of her physicians attitudes as stricter than hers was consistent.

In general, Jennifer had an excellent understanding of general diabetes knowledge, and her perceptions of her physicians were accurate. Nevertheless, her familial environment and only slowly increasing maturity, especially in independence from her parents, are still delaying more stable control.

<u>"Jean"</u>

Jean was a 20 year old white female who was diagnosed with diabetes when 5 years old. She was the second youngest child with three sisters and one brother. At the time of the interview her father had recently died from heart disease, possibly associated with long standing insulin-dependent diabetes. Her family is middle class. She was student-teaching in her final year of college.

Jean's information score reached the top of the scale. Her own attitudes toward treatment were slightly more conservative than the mean, she perceived her physicians to be slightly more liberal than the mean. The "compliance" score, however, was outstandingly high: over two <u>SD</u>s above the mean. The score was raised by her use of a portable insulin pump, recommended because of cutaneous and retinal complications. Also outstanding were her Health Locus of Control scores (HMLOC): all items were answered in the internal direction. Vocabulary scores were also well above average, though possibly inflated by her teaching experience.

As with most children diagnosed at such an early age, she had no peers with the disease, and was more frightened by the hospitalization than diabetes. She had, moreover, exposure to her father's diabetes. Again, due to her age she learned little from her initial hospitalization. Only when hospitalized a second time in the 7th grade was she able to assimilate much information. It was at this point too, that she began to read on her own, and attend a summer camp for diabetic children. Prior to this point, a series of physicians were consulted, and, in Jean's opinion, she had her father's poor example to guide her. In her opinion, the most important thing to teach is the necessity of self-care and independence. Clearly, this view is reflected in her HLOC scores.

"Happiness", "health", and "beauty" were her first three primary values. Having diabetes was not far from being "OK", but caring for it was one point more difficult (3 on a 7-point scale). The difficulty arises from the time demands of the regimen, while the most difficult parts overall are the psychological aspects. Both short- and long-term compliance were important to her. While she believed that her diabetes was no more difficult to manage than others, she believed that she did more to care for it then they. Consequently, her control was mediocre, (with "much to improve"), theirs was one point from "awful" (4 vs. 2 on a 7-point scale).

When discussing her physicians, Jean generally split responses between her new doctor, seen positively, and his predecessor, seen negatively. She stated that her current physician is accessible, shares her views and cares for her as a person.

This physician, a nationally recognized authority, also believed that he was accessible, but a busy schedule prevents him from spending as much time with her as he would prefer. He believed that she shares his attitudes completely intellectually and about "65% emotionally". Her compliance is "75%", since realistic life-style situations interfere. It is his belief that he must treat her disease in the context of other aspects of her life and its demands on her time and resources. He rated her control one point higher ("5") than she, stating that her blood sugars were still high 25% of the time and she recklessly risked her eyes in sports. His goals for treatment stressed metabolic control and psychological growth, quite in keeping with her own perceptions.

Once again, high scores on information and regimen adherence coincide. Rather strict attitudes toward care and relatively low perceived attitude discrepancies conformed with the statistical findings.

The interview with this woman suggested that her relationship with her father was a key to her outstanding scores. There was a very strong bond between the family's two diabetics, he constantly placed demands on her that he himself failed to meet, often bragged about her to others, but never praised her directly or verbally expressed his love. His death, related to diabetes, must have been highly traumatic and anxiety arousing. Thus, a demanding achievement drive was developed in an attempt to gain his approval. Her recklessness may be a form of denial, stemming from her fears. Her active medical coping may also be fueled by her anxiety about complications and death.

"Kurt"

Kurt was a 15 year old white male who has had Type I diabetes for two years. His knowledge score was one of the highest for the young male group. Kurt's SES was low, due in part to his father's chronic illness. This young man has taken responsibility for maintaining his family's home and farm and has expressed upwardly mobile career aspirations. His self-appraisal was high and reflected a higher than average "compliance" (COMPL) score. His own and presumed physician's attitudes were precisely at the full-group mean. Kurt believed that he could do only a little more to meet his own standards, and is even closer to his physician's perceived requests.

His scaled vocabulary score equaled 13 (range 0-19) and was the highest of the young males. His health locus of control scores (MHLOC) were: Internal = 8 External = 10; Individual = 5/1 Powerful Others = 0/6 Chance = 3/3 (internal direction/external direction).

As mentioned, his father was seriously ill with heart disease, a grandfather had cancer and adult onset diabetes. Kurt had little knowledge of diabetes before onset, had initial teaching from a local hospital at diagnosis. He has learned the most from his visits to the MSU Pediatric Endocrinology Clinic and little from other sources.

"Health" and "happiness" were his first and second most important values. Having diabetes was a "3" on a 7-point scale of distress (low to high) and it is rather easy for him to follow his regimen, the only difficulties being minor dietary indiscretions. He viewed his disease control as "excellent", that of others his age as much poorer, because they seem to care less than he does. He was also confident in the efficacy of the treatment in both the short- and long-term. Kurt stated that his physicians are easy to contact, share his views toward treatment and care for him as a person.

The nurse practitioner at his clinic agreed with his own assessment of excellent control and very good compliance.

In Kurt, the statistical complex of high information, regimen adherence, and self-appraisal along with strict attitudes and low perceived attitude discrepancies appears again.

Salient points were high IQ, reliance on powerful-others (i.e., doctors), family history of illness, familial work-oriented values, and early responsibility. These features combined to form a patient with a sense of responsibility and the competence and motivation to manage his own disease.

"Jerry"

From a number of aspects, Jerry is very similar to Kurt. Both are white males of 15 years with diabetes of relatively short duration (2 and 3 years). Further, Jerry also scored very high on the information test. Jerry's social class was in the middle of the scale, but below the sample's mean. From there, the similarities diminish. The most striking difference between them is his own regimen attitudes (very slightly conservative) and those he presumed his physicians hold (much more conservative). He was fairly close to his own adherence and treatment success ideal, but actual regimen behaviors were scored below the group mean (COMPL = 5).

Jerry's vocabulary scaled score equaled "11". Health locus of control (MHLOC) showed a little more internality or "chance" reinforcers, and while less than Kurt, still considerable influence from "powerful others" (I = 5/1, P = 2/4, C = 4/2).

Jerry had an aunt with Type II diabetes, but knew no one with Type I before his diagnosis. He felt "pretty upset" at the diagnosis. Partially due to other misdiagnoses, his father initially refused to believe it. At the time of the interview, (perhaps to impress the interviewer), he claimed not to be bothered by diabetes at all ("1/2" on a 7-point scale).

Jerry learned most about diabetes during his initial hospitalization, and had returned several times for hyper- or hypo- glycemic episodes. He stated that the most important thing doctors should teach is that diabetics are no different than anybody else. Social aspects (e.g., social acceptance or competence) entered the conversation a number of times, clearly, they were of concern to Jerry.

"Happiness" was his most important value, followed by "health" and "handsomeness." He believed that long-term regimen adherence was more important than short-term, and that the only difficult part of the treatment was the diet.

Jerry rated his disease control exactly in the middle of the range (4) while others were one point lower. He was consistent in feeling that his case was a little easier to treat, and most people do about as much as he does to treat it.

Jerry said that he saw physicians frequently--perhaps too frequently, and that access to them was easy to obtain. Most contacts were made by his mother. He believed that physicians understand his feelings, and that <u>he</u> agrees with <u>their</u> views about treatment. They also care for him as a person, he attempts to follow their advice with helpful prodding from his mother.

These views were in marked contrast with those of the nurse clinician at his clinic. She rated his control as very poor, and his compliance equally bad. She believed that Jerry's psychological problems were too severe to permit anything but emphasis on basic care, that he frequently used his condition to manipulate his parents, teachers and physicians, and indeed, was highly self-destructive. She felt that he also resented his father's skills and economic achievements. It should be noted that this subject suffered a closed head injury, an arrest for theft and a suicide threat between his interview and his nurse clinicians'.

On the statistical indices Jerry differed from Kurt in his lower regimen adherence and greater perceived attitude discrepancies.

This implies that these variables may be useful in differentiation.

In summary, despite reasonable intelligence and high information scores, this man's diabetes care was rated very poor. Evidence suggests that this is due to psychopathology. No clear picture of this state emerged during his interview, but rather was suggested by the great discrepancies in his questionnaires and confirmed by his clinical course. His difficulties with his father may be reflected in his relationships with medical authority figures.

"Terry"

Terry was selected as a pilot subject and is presented here as a case study because his inclusion increases the sample size and gives an insight into a patient with moderate information scores. He is a 15 year old white male with diabetes of 5 years duration. It is of interest to note that his one sibling, a younger sister, also has diabetes. Almost all important variables (duration of disease, attitudes and treatment, self-appraisal and attitude of discrepancies) were less than one S.D. below the group mean. The information score, however, was closer to the mean for young males.

His vocabulary scaled score (11) was slightly above average, the multi-dimensional health locus of control (MHLOC) was generally on the internal side (13/4), but admitted influence from both "powerful others" and "chance" (4/2, 5/1 respectively). When diagnosed, he knew no peers with diabetes but did have a maternal grandmother with the disease. His reaction to his diagnosis was fear of the hospital and a desire to run away.

Terry learned about diabetes during his first hospitalization in a class with his parents and other adults. He remembers mostly facts about diet and "keeping control". He has not been to the diabetic camp, and believed he has not learned much since his first hospitalization. He has had several hospitalizations for diabetes since his diagnosis.

"Health", "happiness" and "riches" were his first three values. He believed that "health" is possible to achieve "when in good control". Nevertheless, diabetes is "the worst possible thing in the world". Both short- and long-term regimen compliance were important, in his opinion. Yet, actually following a regimen was difficult for him ("5" on a 7-point scale), especially so for the dietary aspects. Further, he believed that diabetes had also prevented him from playing football. While his care of diabetes is the same as others, most people his age eat fewer sweets, and thus achieve better control ("5" vs, "6"). Terry was pleased with the accessibility, empathy and attitudes of his current clinic physicians.

His clinic nurse predicted that he was satisfied with the time spent in clinic, but she was not, believing that he needed more time for education and discussion of social problems. Her goals were to prevent his frequent major blood sugar swings, raise his self-esteem and give him more control over his health. Although

Terry expressed concern about long-term outcome, she felt his major goal was to simply "feel good". She also felt that his compliance behavior was only "fair", his major problems being "binging and cheating".

The generally lower scores of this subject well reflect his less than average adjustment to the disease. It appears that his perceived lack of new learning post-diagnosis may be due to his desire to "escape" from awareness of diabetes, just as he wished to run away from the hospital. His failure to adhere to a diet (however ambivalent his feelings about following a prescribed regimen are) was associated with his lower self-esteem. Finally, many of his views seemed to be fixated at the time of his diagnosis. Possibly, his anxiety was so high at that time that it could be lowered by adapting the teaching nurse's attitudes, regardless of his capacity to carry them out, or of any later teaching.

"Peter"

Peter was an 11 year old white male with a diagnosis of diabetes of 3 years duration. He was from an intact upper middle class nuclear family which included one older brother.

His information level was over two S.D.s below the group mean (INFO = 18). His own attitudes toward diabetes were very close to the mean, but his view of his physician's attitudes was over 1/2 S.D. above the mean. His admitted regimen adherence is very typical for the whole group, and his self appraisal one point better ("very good").

The scaled vocabulary score on the WISC-R was 9, average or low average. The locus of control (CMHLOC) scores were strongly internal, and 18/2 ratio, with one external response for "powerful others" and "individual responsibility" respectively. As with most subjects, Peter could say little of his awareness of diabetes prior to his diagnosis, he recalled getting progressively "sicker" and feeling "bad" about "all parts of it". He had had one hospitalization for hyperglycemia since diagnosis, and in general, "just feels better" about it.

He was taught about diabetes and its treatment during the diagnostic hospitalization by his own doctor. He does not recall the experience well, nor know where his parents were taught. He has learned more about the disease from his visits to his current physician, and from "Diabetes Forecast" magazine.

Peter stated that he has never had any difficulty in learning what he wanted to know about diabetes. There are two points he believed physicians should teach: 1) injections, and why they must be taken, 2) diet, and why it's required.

Being "healthy" was his foremost value, "happiness" and "handsomeness" following. He stated that it was possible to be healthy with diabetes if one is in "good shape". Having diabetes is precisely midway between being "OK" and the "worst possible thing in the world".

His treatment of his diabetes rated a "3" on a 7-point scale of difficulty, with "shots" being the hardest part of the regimen. Following the regimen, especially in the long run, is important to avoid "getting sick". There are no parts of the disease or treatment that are now embarrassing to him, and his parents do not "bug" him about his care. His particular case was no more or less difficult to treat then others, he felt most people do about the same as he, and thus all achieve control that rates a "6" on a 7-point scale.

Peter sees his physician monthly, and is in telephone contact as well. He found him to be accessible, empathic, and in agreement about treatment.

In the lapse of time between the questionnaire and interview, this patient began to use home blood glucose monitoring, and may have been in more frequent contact with this doctor. This may account for the apparent decrease in attitude discrepancy between the questionnaire and interview responses.

The young family practice physician seen by Peter was extremely invested in his care. He saw Peter's mother as well and was frequently consulted by the family. Peter was the only Type I diabetic now being treated by this physician. The regimen prescribed by the doctor was accurately described as demanding, even idealistic, thus Peter's views were corroborated. This physician saw Peter's knowledge and compliance as slightly better than average. Possibly this view reflects frequent office visits, outside contact (he coached Peter in soccer) and telephone calls. It may be somewhat optimistic, though the physician admits that he must frequently return to previously discussed topics to ensure Peter's understanding. He believed that Peter's occasional lapses or regressions were due to a fluctuating emotional acceptance of the disease, and unrelated parental problems.

In Peter, young age, low information and high attitude discrepancies fit the statistical pattern. His greater adherence, did not, but may have been a reflection of his physicians effects.

Both doctor and patient agreed that there was good rapport and excellent communication between them.

"Mark"

Mark was an eleven year old white male whose diabetes developed in his sixth year. He was the youngest member of a middle class family with two healthy older siblings and a working mother separated from his father, living in another state.

His information scale (22) was roughly one SD below the full group mean, but close to the mean for young males. Both attitude scales (ATT-Self and ATT-DOC) were one SD below the mean, thus more lax or liberal. There was very little discrepancy between his attitudes toward diabetes and those he presumed were held by his physicians (DOC/PAT-DISC = 0). However, his actual regimen was looser, approximately two SDs below the group mean. Consequently, it is suggested that he may be far from meeting his own standards. Nevertheless, his self appraisal (S-APP = 5, or "very good") was at the group mean.

On the 20-item "Children's Health Locus of Control" scale (CHLOC), Mark presented a highly internal pattern, 18 to 2, the two external responses to "powerful others" items. His vocabulary scaled score, "12" was also high, suggesting a person with high intelligence and a strong sense of internal locus of control.

Mark was one of the few interviewed with some exposure to diabetes before his diagnosis. The father of a playmate had the disease and was helpful in reducing his anxiety at its onset. It is interesting to note that in contrast to other subjects diagnosed at an early age, this subject expressed, <u>in recollection</u>, more fear about the disease and his future with it, than about the hospital and separation anxiety.

He said that he learned most from his first hospitalization and the teaching nurse there (at the time of the interview, he had had no subsequent hospitalization for diabetes). His parents and diabetic neighbor were also helpful, but camp was not.

Among the things he believed doctors should tell their patients are: 1) it's not contagious, 2) it can be treated, and 3) one should strictly follow the regimen. Clearly, the most important elements involve anxiety reduction.

"Happiness", "health" and "handsomeness" were his first three values. "Health" is possible to achieve with diabetes if one does not "eat too much". Having diabetes is precisely intermediate between "OK" and "the worst thing in the world".

Both short- and long-term compliance were important for him, but the regimen was somewhat difficult to follow (4-5 on the 7-point scale). The most difficult part was "not eating sugar", and the most embarrassing part was receiving "shots in the butt."

He believed that his case is "about the same" as others and most people his age treat it about as he does. His control was a good "5" on a 7-point scale, his peer's between "4" and "5".

Access and empathy were good with his physician, partly because his feelings were "sort of common". Yet he rated their caring for him as a person as only between "3" and "4" on a 7-point scale. He felt that "they should" care for him. Finally, he stated that he tried "pretty much" to follow his doctor's advice, but still had difficulty in not eating sugar.

His nurse practitioner saw Mark as more successful than he saw himself. She rated his control as a "7" on a 7-point scale and comprehension a "6", with very good compliance. She believed that his metabolic control (measured by urine tests), psychological adjustment and knowledge were all exceptionally good.

The problematic aspects of this case were the lower information score, lower questionnaire rating for compliance, especially in the light of his clinicians' glowing report. Two reasons for a lower knowledge level suggest themselves: 1) his age at 11 years, placed him among the youngest subjects in the sample, 2) his incorrect answers were to items about ketones and diets, the former he rarely experienced (at that point) the latter he was not taught by the Endocrine Clinic. The low compliance score was based mostly on his admittedly few urine tests, and his admitted duplicity in reporting them to his doctors.

It appears that his nurse, who is fond of him, was deceived by the data he supplied to her. It is suggested that higher standards, especially his internality, and desire for the high regard of his physicians, compelled him to lie about his compliance. Yet he evidently did not lie to the investigator, nor, for the most part, has he had great difficulties with his disease.

The role of family dynamics, and parental separation is unclear. Possibly the key to this subject's contradictions lies there.

"John"

John was a 20 year old white male who has had diabetes for 9 years. He was the only child of a middle class, older couple living in northern Michigan.

His information score (33) was the highest among the males. John's attitudes toward diabetes score was about 1/2 SD above the patient's mean (more conservative), while his views of his physician's attitudes were very close to the estimated physician's attitude mean. This pattern resulted in a very low discrepancy (DOC/PAT-DISC = 0).

The compliance score for this young man was an outstanding two SDs above the group mean (COMPL = 21). Not surprisingly, his self-appraisal was also above the mean (S-APP = 6).

One important factor in permitting such a high level of knowledge was his WAIS vocabulary score, scaled to 15, clearly above average. Less obvious, and contrary to hypothesis, was the pattern of Health Locus of Control (MHLOC) responses. The overall ratio between internal and external responses was 13/5, but four of the external responses were for individual responsibility items, one for powerful others. This implies a lower sense of personal influence than others in the sample. However, it may be a much more realistic view.

John stated that he began his experiences with diabetes with "a clear slate", i.e., knew little or nothing about it. It is very important to note that his private physician was himself diabetic, and ensured an especially complete education. This included a "well organized" class in the hospital with both parents and physician, and 2-3 weeks of outside classes as well. He has also learned from his own questions, books, pamphlets and training as a counselor at the diabetic camp. He emphasized that he learned little as a camper. He has learned psychological coping from friends with diabetes, but believes that he learned most from his mother. This was because she attempted to make the regimen "fun" made use of new information, and was a helpful cook. There appear to have been salubrious effects from these efforts, as he has never been hospitalized from his diabetes, and indeed, had only one episode of pronounced hypoglycemia.

For John, there were two important points that physicians should discuss with their patients:

1) what diabetes is
2) the reasons for treatment, including psychological aspects.

He consistently returned to the importance of including parents during the early stages of education and treatment.

John's definition of "health" included both physical and psychological well-being, both possible with diabetes. "Health" is his first value, followed by "happiness" and "handsomeness".

John gave a 2.5 value to both the dysphoria of diabetes and difficulty in caring for it, i.e., not too bad to have, and rather easy to care for. Following all of his doctor's advise would leave him feeling "more unhappy-not better!" essentially because he knew more about his unique reactions than did the physician. Long term compliance was probably beneficial, but there was "no proof" of it, he believed.

The most difficult aspect of the regimen is "avoiding somogyi phenomena". This was a very sophisticated response, suggesting very tight control. There were no embarrassing parts, but urine tests in high school once were.

He perceived his parents as "guiding", "not harping" about his diabetes. John felt that they "learned together". He felt that his case of diabetes was not more or less difficult to manage than any other that was also free of complications. However, his control rated a 5.5 vs. a 3.5 (on a 7-point scale) because "in general" he did more to care for his diabetes than others, except at camp. In particular, he did occasional blood sugar tests on his own.

Although he spent enough time with his doctor during his quarterly appointments, he never calls for advice, and rates the physician as difficult to contact. Again, he felt that both he and his physician understand each other and agree on treatment goals. The physician was given only a 4 on a 7-point scale of personal caring, since they had only met once. Evidently this perception is both accurate and mutual, since neither of the two university-based adult endocrinologists could recall this patient at all.

Along with Jean, John represents the highest level of knowledge and regimen adherence in the sample. Like her, he is older, intelligent, had diabetes for a long period, served as a counselor at the diabetic camp, and had a close personal relationship with an adult with diabetes (her father, his general practitioner).

Since a number of other subjects had enough intelligence to comprehend diabetes and its various regimens, why had he done so well? He himself emphasized the importance of his family. He mentioned their interest, lack of coercion and efforts to follow the regimen humanely. He also had a very successful role model, his physician. On the other hand, his female counterpart, with equal understanding, has had many complications. Her level of control has varied drastically. Her family life was less stable, role model much less positive and successful, and of course, gender and genetic endowment were different.

"Tom"

Tom was a 16 year old white male whose diabetes was diagnosed four years ago. He lived in an intact lower middle class nuclear family with one older brother and two younger sisters.

He was selected as a case study because of his high information score (31) and high doctor-patient discrepancy (DOC/PAT-DISC = 25). While his physician's perceived attitude rating was very close to the group mean, his own score was almost two _SD_s below (more liberal) the mean. This was one of the few cases in which the patient was more liberal than the clinic's actual score (measured by the nurse clinician's response). His compliance behavior was consistent, also nearly two _SD_s below the mean. Possibly reflecting this behavior, his self-rating was one _SD_ below the group mean.

Tom's vocabulary score was scaled at 11, a bright average. As with the other volunteers, there were more internal than external responses on the Locus of Control scales (MHLOC) (15/3). However, one external response was given for a "powerful other" item.

While he was relatively old at diagnosis (12 years), Tom had had no experience with diabetes, nor held any preconceptions that he could articulate. Nevertheless, he found that the regimen is "less hard" than he had suspected, specifically, the diet is "less strict", and the shots have become "routine". He has never been hospitalized for diabetes after the first hospitalization, where he received initial instruction from a nurse. A secondary source of information was the clinic he currently attends (MSU), where he learned that diabetes was "not as hard as it seemed at first" (e.g., in the hospital). However, the single most potent source of information about diabetes was his mother, who attended classes and retained and translated what she had learned from physicians.

According to Tom, the most important things doctors should teach are: 1) diabetes should "not be a hassle", and 2) "one shouldn't listen to school friends" (e.g., their information may be incorrect, inapproprite or meant to tease).

Tom believed it was possible to be healthy with diabetes, and placed "health" just behind "happiness" and before "handsomeness" in his value hierarchy. Having diabetes is precisely in the middle of a 7-point scale of unpleasantness. He contradicted his earlier views on the questionnaire by saying that both short- and long-term compliance do make a difference.

He rated compliance difficulty as a 3 on a 7-point scale (7 = impossible). The most difficult part of the regimen for him to follow was the urine testing. Consistent with most other people interviewed, he stated that his parents do <u>not</u> bother him about his way of treating diabetes. He believed that his diabetes is no more or less difficult to control then others, but, they do more urine testing than he does. He claimed that he is equal to them in his actual control, (5 on a 7-point scale), which is higher than his questionnaire rating.

Despite his earlier responses implying attitude discrepancies with his doctors, he rated their accessibility and empathy as high. His attempts to follow their advice are "not exceptional, I take it as it comes".

There are a number of points of agreement between his perceptions and those of his clinic nurse practitioner. She agreed that her accessibility is high. She rated his knowledge as a 5.5 on a 7-point scale and a 5 on a 7-point scale of actual control. One of her principal goals for him is increased independence, especially from his mother, and feels that his primary goals is a "normal" life, with as little interference from diabetes as possible.

This case demonstrates that a high knowledge level certainly does not guarantee a high level of compliance, nor a high level of perceived agreement with physicians. Very probably, his mother's interest was responsible for Tom's high information level, as his general approach to care has been casual, with her intervention when needed. While he frequently referred to the clinic's more liberal advice, he did not rate them as being so. Perhaps because he felt his original teaching was much more strict. Finally, his interview responses were somewhat more strict and compliant than his questionnaire responses. It is unclear whether this was an actual change in view over time or a reaction to the vis-à-vis situation.

Interview summary

There are several common characteristics of the five subjects who refused interviews: the majority were older with low information, higher discrepancy scores. Their self-appraisals and

SES were both high, but reported compliance was low. Perhaps the most important characteristics was that they were all non-MSU Clinic patients, and thus had no personal relationships with the researcher.

Although the sample size was too small for statistical treatment, some suggestive trends in interviewees were found. Most high-information volunteers had high verbal scores, but so did a number of lower-information scorers. It cannot be confirmed that knowledge about diabetes and verbal IQ are related in this small group.

The locus of control (MHLOC and CMHLOC) scores were strongly skewed toward internality, only one person's external responses were greater in number than the external. Notably, the "powerful others" category had the most external responses of the three categories. Physicians and nurses are considered "powerful others", on this scale. The value hierarchy presented by these patients placed health first, happiness second, and beauty third. The prominent role given to health suggests that the health locus of control scores should predict behavior.

As in the questionnaire analysis, there is a general correspondence between high "compliance" and high information scores, and between higher self-appraisal and self-reported regimen adherence.

In the interviewed subsample, there was a small tendency for greater perceived doctor-patient attitude discrepancies among the high information subjects. Overall, the older males had the largest perceived attitude differences, being more "loose" in their views than in their views of their doctor's opinions. The older females were apt to be more demanding or strict than they believe their doctors to be.

The interviews uncovered several commonalities that began to etch a picture of these patients' experiences. Generally, patients recalled little of their pre-diagnosis ideas or experiences with the disease. This is due in part to memory lapses, but also because of their young ages at onset. Those exceptions, i.e., with close family members or significant others with diabetes, had exceptional courses as well. There is a, perhaps coincidental, correspondence between the quality of the role models and outcomes to date.

In keeping with the early age of onset, many children expressed greater fear of hospitalization and parental separation than they did of any aspects of the disease (some however, were aware of injections and diet). Most believed that this initial hospitalization provided the bulk of their education. The important role of a teaching nurse was mentioned. However, those with the highest information used other sources: magazines, books, and outpatient visits in particular.

Surprisingly, few gave the diabetic camp much credit for education, except in psychologic coping. Yet, in other settings, parents frequently comment on the camp's role, particularly in teaching injection techniques.

One would assume that parents must play a major role in education, particularly with very young children. The oldest high information/high compliance male and female patients both reported the importance of parental instruction, but two lower scoring patients did as well. One girl with low information scores was subject to her aunts' as well as her mother's efforts at education. Unfortunately, it was not feasible to formally interview parents to determine their educational experiences and attitudes.

The effectiveness of out-patient post-hospitalization education is ambiguous. Some high-information patients made such use of specialty care clinics and evidently benefited from them. Several low-information patients were given the same clinic education program yet claimed, (and showed) little evidence of its success. In general, patients expressed no complaints or problems with the education they received.

The dysphoria of diabetes was usually rated as only moderate, as was the difficulty of caring for it. Urine tests, diet and injections were the worst parts. Apparently these children and adolescents were not badgered or "bugged" by their parents, and did not find diabetes to be embarrassing. As these are highly socially-desirable responses, they are perhaps questionable.

Data from the interviews suggests a large role for parental influence in patients' information levels and treatment behaviors. Some (John, Tom) had very supportive parents who helped them learn and follow a regimen. Other well-meaning, but over-indulgent parents supported, but have not channelled their love into regimen adherence (Tammy). Paternal illness (Jean and Kurt) was associated with a sense of personal responsibility and high information and compliance levels. Familial conflict (either between parents of between parents and children) was associated with either poor or greatly fluctuating compliance.

For most, following the prescribed regimen, both short- and long-term, was highly desirable. Older, sophisticated patients knew that some latitude existed, and believed they often knew more about their idiosyncratic reactions than their doctors.

Many believed that their disease and their control of it was similar to their diabetic peers. Again, older, more sophisticated patients felt they did better than most other similar patients. This is probably correct, and at least, reflects the actual variance between cases.

Almost all patients found their doctors easy to reach and empathetic. One exception was an older male seeing an adult endocrinologist. Evidently little patient-physician "bonding" occurred. To summarize the results in terms of the hypotheses, the following is presented:

Hypothesis 1, Information Levels:

a) AGE (questionnaire): confirmed by Pearson correlation
b) Duration: not confirmed, negative correlation
c) Internal LOC (interview): not supported, most patients were "internal", insufficient variance
d) Verbal IQ (interview): not confirmed, small sample
e) Familial experiences (interview): partially confirmed, role models important

f) Evaluation of physicians accessibility (interview): not supported, almost all doctors were seen as accessible, insufficient variance

Hypothesis 2, Discrepancy between patient attitudes and patient behaviors:

a) AGE (questionnaire): not significant

b) Duration (questionnaire): not significant

c) Information (questionnaire): confirmed by Pearson correlation

d) Physician accessibility satisfaction (interview): not supported, insufficient variance, most patients were highly satisfied with education and accessibility

e) Treatment goal discrepancy satisfaction: not supported insufficient discrepancy

TABLE 7.--Case Study Review.

	Subject Name	SEX	AGE	Dur	SES	Phy	INFO	DOC/PAT-DISC	ATT-Self	ATT-DOC	COMPL	S-APP	Verb IQ	I/E
Young Female	Tina	F	14	10	3	P.End.	18	0	5	5	-10	4	9	10/8
	Tammy	F	12	9	5	P.End.	18	3	0	7	5	5	10	15/5
	Ashley	F	13	5	2	P.End.	32	1	-3	-4	12	6	6	13/4
	22*	F			2	Ped.	33	13	4	26	7	5		
Older Females	Jennifer	F	17	11	1	P.End.	33	7	-2	2	4	5	11	15/3
	Jean	F	20	15	3	P.End/ A.End	33	-1	11	10	27	5	19	18/0
	33*	F	18	8	4	?	26	-13	25	9	-8	4		-
	35*	F	16	7	2	Ped.	25	9	-3	7	13	6		-
					6									
Young Males	Kurt	M	15	2	6	P.End.	31	2	11	13	14	6	13	8/10
	Jerry	M	15	3	3	P.End.	31	16	4	18	5	5	11	11/7
	Terry	M	15	5	5	P.End.	25	3	3	6	5	4	11	13/4
	Peter	M	11	3	2		18	7	7	19	8	6	9	18/2
	Mark	M	11	5	3	P.End.	22	0	1	2	-8	5	12	18/2
Older Males	John	M	20	9	3	A.End	33	0	12	12	21	6	15	13/5
	Tom	M	16	4	5	P.End.	31	25	-14	12	-7	4	11	15/3
	25*	M	16	13	2	A.End	20	6	13	18	-7	5	-	-
	81*	M	19	6	4	Ped.	24	20	14	36	3	6		-

*Refused interview.

DISCUSSION

One purpose of this dissertation was to investigate adolescent patients' knowledge, attitudes, and perceptions of physicians' attitudes toward their chronic disease. An additional purpose was to use those findings to formulate more concise and testable questions about disease management, education, and quality of care. This study has obtained information from multiple sources (patients, their parents, and physicians) and through multiple instruments (questionnaires, standard tests, and interviews). In brief, the study found positive correlations between high information levels and greater age, female sex, strict regimen adherence and low attitude/behavior discrepancies. Role models may have also influenced information levels. Variables correlated with high attitude/behavior discrepancies included low information levels, lax attitude and male sex. Patient satisfaction and health locus of control were generally high, and thus did not corroborate the hypotheses. Additional findings included a tendency for patients to perceive their physicians as asking for tight control and a suggestion that both initial diabetes education and familial factors were influential in determining attitudes, information, and possibly, disease course. Before the results can be fully interpreted, the representativeness of the sample must be examined. This is particularly critical because several hypotheses were not confirmed, perhaps partly due to insufficient variation of independent measures.

Sample description

The basic demographics of this sample (age, sex, SES, etc.), were reported in the results section. There were several aspects that contributed to subject homogeneity: the majority of volunteers were patients of a university-based pediatric endocrine clinic. Thus, they were exposed to relatively sophisticated caregivers, a multidisciplinary staff, and this researcher, who is also diabetic. Other subjects were contacted through physicians active in diabetic associations or camps, or through diabetic groups. Therefore, many patients in this sample likely had, at least at some point in their disease course, above average education and care. As noted previously, this sample's SES was skewed toward the higher levels. These factors: sophisticated physicians, higher SES, and exposure to the researcher, likely contributed to the high (83%) questionnaire return rate. On the other hand, these same factors also limited the number of patients with poorer care, lower SES, information and compliance, and greater patient/physician disagreement or misunderstanding. A more representative sample would have led to greater spread in the scores and increased the possibility of a greater number of confirmed hypotheses.

Comparisons With Prior Research

Information

A second test of sample representativeness and, of course, an important question in itself, is the degree of correspondence of this studies' findings with prior literature. Comparisons between different instruments and samples are often difficult to interpret. However, as noted in the Methods section, Etzwiler's work (Collier & Etzwiler, 1971), used a very similar information questionnaire, thus allowing more direct comparisons. The mean number of correct responses in their junior and senior high school age sample was 22.5 (on a 34-item version with two items deleted through error), versus 27.8 for children of the present sample (based on 33 items). Collier and Etzwiler found that upper income mothers and daughters obtained higher scores, while the present study found a slight positive correlation between SES and information ($\underline{r}$ = .18, ± .19) across all subjects.

Collier and Etzwiler also found that patients made more errors on questions about diet and ketoacidosis, as did this study. This finding appears reliable across samples. The poor scores on diet and ketoacidosis items may be due to the use of "free" diets, and the fact that a certain proportion of Type I diabetics are not subject to ketoacidosis, or have not yet experienced it. Etzwiler reported that diabetic children of diabetic parents scored lower than the mean. In this study, the single patient with a diabetic parent achieved the maximum score. She was older, very intelligent, and considerably more compliant than her father. This information was derived from her mother, physicians' and her own questions, not directly from her diabetic father. Indeed, she gave the impression that she learned in spite of him. Likely, his role was important, but not as a direct educator.

Williams et al. (1967) obtained positive correlations between information levels and compliance, but negative correlations between information and disease control. However, general medical knowledge seems unrelated to compliance (Haynes, 1976). In hypertension (Kirst & Rosenstock, 1977; Sachett et al., 1975) rheumatic fever (Gordis, Markowitz & Lilienfeld, 1969b), and contraception (Siegel, Thomas, Coulter, Tothill & Chipman, 1971), general knowledge about the specific condition also appeared to be unrelated to adherence among adults (Kirst & Rosenstock, 1980). Yet, information specific to the performance of a regimen does seem positively correlated (Kirst & Rosenstock. 1980).

This study found positive correlations between information about diabetes and its regimen, and with strict regimen adherence. Thus, those patients with the most information claimed to exert great effort to care for their disease. No clear relation between information and disease control was established through the interviews. Swift et al. (1967) discovered a positive correlation between IQ and disease control. Among the small set of present interviewees ($\underline{N}$ = 12), verbal IQ did not predict either disease control or information, yet several of the brightest interviewees also had very high information scores. Perhaps a larger sample would have uncovered clearer linkages between IQ, information, and compliance. The relationship between compliance, information, and disease control may be quite complex. It is possible that poor control, from any cause, leads to greater educational efforts by physicians, and improved information levels in patients, thus yielding negative correlations between disease control and information. Very probably, distinctions between Type IA and IB diabetes (in which there is some residual endogenous insulin production and resistance to ketoacidosis) influence disease control and confound the results of studies examining compliance and control.

Attitudes toward diabetes

There is only sparse literature on attitudes toward diabetes and its treatment. Most studies have used children at diabetic camps (latency age to mid-adolescence) and have generally found few complaints about the disease, as well as underestimates of its seriousness (Davis et al., 1965; Khurana & White, 1970). The present sample, slightly older and uninfluenced by the peer support and social environment of a camp, tended to rate the dysphoria of diabetes and its care as more severe when interviewed. Virtually all patients were aware of the possibility of serious complications. Sullivan (1978, 1979a, 1979b) obtained correlations between negative views toward diabetes, poor overall adjustment, self-image and peer relations in female adolescent diabetics. She was reluctant to attribute causality to the disease, suggesting diabetes may be "scapegoated", or blamed for problems with causes elsewhere. Jerry, the present interviewee having the most psychosocial problems, claimed to have the fewest problems living with and controlling his diabetes. This seems to be a reflection of two factors: his rather primitive defense mechanisms; and his extreme attempts to maintain self-esteem, including efforts to obtain the researcher's approval through socially desirable answers. Thus, the present sample seemed better informed than those in prior research. In general, these patients were realistic in their assessment of the disease's impact, but in extreme cases, distortions were present.

Literature addressing physicians' beliefs about diabetes is even scarcer than that for patients. Cohen, Mozzuca, Vinicor and Clark (1980), found that family practice residents who thought themselves more aggressive in treating diabetes than their peers, believed that they would take more complete histories and use more follow-up therapies. There was no difference in intentions based on beliefs about prevention of complications in diabetic patients. These authors were unable to replicate these findings with another physician sample. The present study investigated only physician beliefs, not intentions. In general, physicians attributed much of the course of diabetes to genetic predisposition interacting with treatment or regimen type to variable degrees. Frequent urine or blood testing and accurate records of the results were more important to physicians, but specific diets, and foot care were given less importance than their patients' gave them. All interviewed physicians mentioned the importance of psychological variables (e.g., familial stability and various stresses on the patient). The least experienced physician undertook the most vigorous treatment plan. While this may be due in part to his image of himself and beliefs about treatment (Cohn et al., 1980), it may also be related to the fact that he had treated only one Type I diabetic and thus had more time to spend, more naive optimism, or more investment in a learning experience.

Locus of control

For the most part, prior studies of LOC have found positive correlations between internality and information levels, and individual responsibility and health status (Wallston & Wallston, 1978). This study found overwhelming internal, "individual" LOC, that is, patients believed that they were responsible for the outcome of events. This may also be associated with Partridge et al.'s (1972) findings that diabetic children express a desire for control of their regimen at early ages (12 years), and Rutter, (1970) that children accept credit for positive outcomes, but not blame for negative ones. Indeed, most patients in the present sample thought that their control was "good" or "very good", which could be interpreted as positive outcome in their eyes. Most interviewees believed that "chance" played only a small role, or none at all, in health, but many, especially some with high information levels, felt that "powerful others" (including doctors and nurses) were influential. This may be due to their frequent contacts with medical professionals. It will be interesting to see if these findings hold for larger samples. It is probable that accurate information, nature and number of physician contacts, and possibly actual outcomes or disease experiences will be factors. Very possibly, internality would present a bell-shaped curve as a function of knowledge levels, thus those with the most knowledge may be more realistically pessimistic.

The interviewees placed high value on health, thus adding credence to their health LOC scores.

Doctor-patient relations

In a series of explorations of doctor-patient communication, Hulka (Hulka et al., 1975) found positive correlations between effective communication and patient satisfaction, and patient compliance, but not with disease control. Present sample patients expressed great satisfaction with their learning, i.e., only the most sophisticated and informed patients felt that their questions were unanswered, or that their doctors were inaccessible. In short, there was a high level of patient satisfaction with their physician's communication. That this communication was effective is suggested by the relatively high mean information scores. Yet the apparent discrepancies on the more subtle attitude questions imply problems in communicating (transmitting or receiving) basic approaches, and concepts. Two facts imply that a problem existed. The first is that the attitude score of the MSU Clinic nurse-educator was more "liberal" than any patients' projected physician attitudes (ATT-DOC), the second, is the differences in attitudes, and perceived attitudes between age and sex groups, for example perceived physician/patient-attitude discrepancy (DOC/PAT-DISC) for the older females was 3.4, for older males, it was 5.6. Thus, in general patients misperceive their caregivers' views, but do so differentially according to age and sex. Interpretation of the magnitude or numbers of patients misperceiving their doctor's view is clouded by some MSU patients naming private practitioners as their physician. This may be because they actually follow their private physician's advice more than their clinic doctor's, or because they simply felt that the clinic would not require a release form for this researcher. Age/sex attitude differences could be due to physicians actually making different demands upon different classes of patient, or to patient age/sex groups differentially perceiving their doctors views for some reason characteristic of the particular age/sex group itself (e.g., identification with the physician, rejection of authority, etc.). In any case, it may be that the teaching of facts needed to roughly control diabetes is effective and readily retained, but that many patients would simply prefer not to learn too much about an unpleasant and restrictive disease. Thus, their satisfaction may stem from <u>not</u> learning too much. An alternate possibility may be that patients are "projecting" stricter attitudes on their doctors because doctors are parental extensions, surrogates, or external "consciences" of some variety. A further aspect of this hypothesis is that these young patients may "need" to believe that their physicians are strict or demanding, analogous to parents, teachers and other authority figures. Doctors must be "ogres" in order to justify "rebellion", which serves to help define the self for the adolescent. As Erickson states:

> In their search for a new sense of continuity and sameness, adolescents have to refight many of the battles of earlier years, even though to do so they must artificially appoint perfectly well-meaning people to play the roles of adversaries; . . . (Erickson, 1963, p. 251).

Ferguson (1970), in discussing the work of Douvan and Adelson (1966), reported that females generally achieve greater levels of personal autonomy earlier than boys, hence have less need to rebel. They also retain closer ties to the family and its values than do boys. These findings may explain the older males' greater attitude discrepancy in the present sample.

Williams et al. (1967) cited some evidence that "emotional support" may be more important than teaching, *per se*, in improving patients' health. Nearly all patients interviewed in the current study reported that they believed that they were highly "cared for as a person". Several recalled the importance of their doctors and teaching nurses when first hospitalized upon diagnosis. The young patients appeared to be less afraid of the disease than of the hospital experience. The support of the staff seems to have both allayed their fears and been remarkably effective in inculcating broad attitudes e.g., "Watch your diet closely!" rather than concepts, explanations or reasons for "watching your diet closely". This finding may relate to patients recalling basic facts, but missing more subtle aspects of their physicians' teaching approaches.

Familial aspects

Several studies and models (Swift et al., 1967; Becker et al., 1977; Laron, 1977; and Minuchin et al., 1975) have addressed the importance of the family in the course of chronic disease. Unfortunately, the only data on present patients' families was from familial SES and interviews with selected patients and their medical advisers. Family structure, functioning and attitudes toward diabetes were not directly examined. Nevertheless, some tantalizing, if sketchy, observations were made. Only Jennifer's family contained elements of Munichins' structural model. Rather than exhibit idiopathic ketoacidosis, she was greatly, obsessively, concerned about her weight and diet. Her illness control fluctuated with her binges and "fasts". Remarkably, Minuchin has also studied anorexia nervosa in "psychosomatic" families. Jennifer clearly showed some symptoms of the latter disorder, thus supporting Minuchin's theories.

Other patients whose families seemed to have had a negative influence included Tammy. She had frail, elderly, adoptive parents who have sheltered her from the disease and plied Tammy with too many lovingly home-baked pastries; Peter, whose mother's periodic, mild depressions were reported to hamper his disease control; and Jean whose demanding, withholding, diabetic father indirectly stimulated her to learn much about the disease, but at great psychic cost. Finally, Jerry's damaged self-image continued to erode in the shadow of his father's driving ambition and unattainable example. He chose to "act out" in school, his neighborhood and against his diabetes.

On the other hand, several families had evidently been crucial in smoothing the course of the disease. The mothers of John and Tom had helped teach their sons in ways that were either gentle but firm, and not overbearing, or "fun". Ashley's diabetes was treated not as a stigma, but as another area in which she could excel. In Kurt's case, middle-class rural values toward achievement, work, and self-value, in combination with his father's incapacity, spurred him to learn about the disease and treat it successfully.

Several generalizations may be derived from these interviews. All parents were reported to be deeply invested in their children and their health, and virtually all families were intact. Possibly, much more difficult courses would have resulted had this been untrue. Parental overindulgence (Kuhrana & White, 1970), and familial pathology (Minuchin et al., 1975), appeared to negatively influence the course of diabetes. Further, it would seem that the care of diabetes was closely related to a families' style of coping, values, and overall level of functioning. Indulging families will indulge more, achievement-oriented families will have another arena in which to strive, and so forth.

Health Belief Model

Probably the most successful overall model of health behavior is Becker's Health Belief Model (HBM; Becker et al., 1977), see Figure 1, p. 21. The present study was not intended to match or duplicate the HBM, but it does touch upon variables representing each category of this model. Figure 9 presents data from the present study in the form of the HBM (see Figure 9).

It is frustrating that the variables in the present study have not yet been standardized or weighted correctly to use the HBM mathematically. As is, data from case studies and clinical cases can still be used in a rough fashion. This study has, however, uncovered some areas that the HBM should address. The HBM is literally one-sided in that only the patients' processes are examined. The work of Hulka and others clearly shows that the physicians' behavior, what and how he or she demands or requests, has an influence on patient behavior. More than merely "faith in doctors" is involved. Demographic variables, such as age and sex, can be of critical importance. Perhaps age of onset or duration will also prove significant. Role models may in some ways substitute for prior experience. Finally, how are acute and chronic illnesses similar or different? What is the effect of knowing that there is currently no cure? Very likely, depression and defense mechanisms would require incorporation in future models.

Summary of Findings

Another critical question to be put to the data from this study is: can a coherent picture of the diabetic experience be made? The typical patient in the questionnaire sample was a 15.5 year-old upper-middle class female. Her disease developed when she was 9.5 years old. She was the patient of a university pediatric endocrine clinic. She had a very good grasp of the basic facts

Readiness

Motivation

1. General concern about health: high in this sample (inter)
2. Willing to seek medical diagnosis: unknown-parental behavior.
3. Positive health activities: unknown-or variable (Quest)
4. Intention to comply: generally high in this sample (Quest/inter)

Perceived Threat of Illness

1. Faith in doctors: generally high (Quest/inter)
2. Belief in regimen: high for most parts (Quest/inter)
3. Feelings of control over disease: generally high (MHLOC)

Modifying factors

Demographic

1. Age, sex, race, marital status, income etc.: age, sex, income related to information level (Quest)

Structural

2. Perception of regimen: variable, generally seen as moderately difficult-more than some physicians demand.

Enabling

3. Prior experience: Role models influential (inter)
4. Extent of familial problems: generally influential (inter)

Behavior

Compliance

1. Likelihood variable (Quest)

Figure 9.--Data Correspondence with the Health Belief Model.

about diabetes, but misperceived her physicians attitudes. She is slightly conservative or strict in her views toward treatment and believed that her doctors were more so. In fact, however, they were often less strict and less optimistic about treatment. Her own appraisal of diabetic status was that it is "good to very good". She expressed only a slight discrepancy between what she believed about her treatment and how she actually treated the disease, but presumed a greater discrepancy between her behaviors and her doctors' perceived demands.

When the correlations between variables were examined, several relationships stood out, particularly scores on information and regimen behavior. Those who knew the most about diabetes (INFO) were older females, they, by their own admission, did more to treat it (COMPL), had fewer uncertainities about their views of their doctors (DOCS?), and expressed the least discrepancy between their own attitudes and the perceived views of their doctors, and between their attitudes and their actions in treating the disease (COMPL-DISC-Self and DOC). Aside from knowing more (INFO), those who claimed to treat most rigorously (COMPL) also gave themselves credit for it, as their self-appraisal of control status (S-APP) was higher. Their own attitudes were more strict (ATT-Self), but their doctors' (ATT-DOC) may not be, as they tended to agree with their perceptions of their doctors views (DOC-AG) and had few attitude discrepancies (DOC/PAT-DISC) or uncertainties (DOCS?).

Since these relationships are correlational, their mirror image applies for those low in information and strictness of regimen behavior. Also, no causal direction can be inferred, e.g., strict compliance does not necessarily lead to high self-appraisal of disease control or vice versa.

Finally, the interview findings suggested additional, specific commonalities. Several patients, diagnosed in the pre-adolescent years, expressed more anxiety about the hospital and separation, than about the nature of the disease. Indeed, few had any but the sketchiest impressions about diabetes. Most did not recall the details of their diagnostic hospitalization, nor, as far as could be ascertained, many of the concepts underlying their treatment. Yet some seemed to retain a certain vague "conservatism" that has not altered much with subsequent education.

It was not too surprising that mothers were often mentioned in interviews as primary educators. The familial situation was evidently critical. This included structure and functioning, social values, and physical health. The influence of role models was evident, though not simple, since one "poor" role model was associated with a highly knowledgeable and usually compliant patient, but with severe physical and psychological complications. While some of the best-informed patients also had high verbal IQs, the relationship between these two variables was not simple. This was also the case for health locus of control (MHLOC). Generally, patients were internally oriented, but several showed fair degrees of external orientation in regard to "powerful others". Of course "powerful others" included the nurses and physicians who treated these patients. Only the eldest and most sophisticated patients complained about their physicians' accessibility, empathy, or attitudes. Even those patients with the least information were satisfied. Perhaps they knew all that they could comfortably tolerate. Notably, most patients were from a group of specialists, and had consulted several physicians in the course of the disease. Several patients, low in information, from private physicians refused to be interviewed. Their experiences with their disease and treatment may well have been quite different.

The physicians and nurse practitioners generally agreed with their patients assessments of their condition. In one case, however, the nurse thought that a patient was in a much worse condition than he admitted, and in another was receiving inaccurate data. As mentioned numerous times, the caregivers were typically less demanding about some aspects of care (e.g., diet, foot care), and more dubious about the efficacy of conventional treatment than the patients. The least experienced physician was the most demanding, but there was a trend toward intensive regimens for older, or at-risk patients among all providers.

Methodological Comments

The conclusions of this study are limited by several aspects of the methodology. Perhaps the most glaring problem is the homogeneity of the sample. A more random sample would have been very difficult to obtain, but may ultimately have been more fruitful. A related problem is prior interviewee exposure to the researcher. Due to economic constraints, this was a necessity, but may have biased the data obtained.

The basic design, case studies selected from a larger, already studied sample, was somewhat unusual. Generally, case studies have preceeded work with larger samples and more precise or more experimental questions. However, this study was exploratory, designed to raise questions, and note trends for later work. Cronbach's notion of "intensive local observations" is in accord with this goal:

> As results accumulate, a person who seeks understanding will do his best to trace how the uncontrolled factors could have caused local departures from the modal effect. That is, generalization comes late and the exception is taken as seriously as the rule (Cronbach, 1975, p. 125).

Most of the present measures (INFO, ATT-Self, etc.) rest primarily on their face validity. Their usefulness can only be established through further refinement and reliability and validity studies. This is especially true for scales using weighted items (e.g., ATT-Self, etc.). For other measures (COMPL-DISC/Self), scales were manipulated using raw scores because of similar item numbers and curve shapes. Some form of standardized scores may have modified results, yet some authors (Keppel, 1973) warn that automatic data transformations can sometimes be deceptive. Several constructed scales (COMPL-DISC/Self, DOC) were highly correlated with their elements (COMPL, ATT-Self, -DOC), thus giving artifactual multiple regression results. Thus these scales were given less weight or consideration in the discussion.

"Difference" or "discrepancy" scores have great intuitive appeal, but many statistical pitfalls (Nunnally, 1978). Crano and Brewer (1973) discussed some of these difficulties, relying in part on Cronbach's (1958) well-known paper. Yet it is significant that several problems deal with accuracy of ratings. These included: dyadic ratings which are compared to other measures or scores that are based on the same or related data; monadic effects marked as dyadic; response sets, i.e., "leniency", and "assumed similarity"; and "regression phenomena" artifacts such as "regression toward the mean". The present study may well have been subject to response set artifacts, particularly assumed dissimilarity. However, the aim of this portion of the study was not to determine the accuracy of judgements, but rather to record the process of perception. Thus, any misperceptions by patients yielded useful data.

Three large and important areas were only superficially examined. The literature and the data from this study point to the importance of the family. A questionnaire exploring the information and attitudes of parents of diabetic children is sorely needed. This is especially important for young children and for those who were diagnosed at an early age. A measure of family functioning would also have been useful. A rough measure of regimen adherence was developed (COMPL), but it was both a self-rating and only a general measurement of diabetic treatment, not a direct correspondence between requested and achieved care. The caregivers interviewed were helpful in assessing their patients' diabetic control, but their estimates were rather subjective. A more rigorous and multidimensional measure of success is required. However, if the regimen was altered to gather more data, this might well alter the patients' attitudes and actual control as well.

Future Research

As mentioned above, another purpose of this exploratory study was to raise more precise and informed questions. What are they?

There are three areas that deserve further exploration: a) populations, b) methodologies, and c) special issues.

It has been mentioned several times that broad patient sampling was important. Replications should be attempted with wider age and SES ranges. Families should be included, with special attention paid to structural variables (one parent, extended family, etc.). Finally, more types of physicians and nurses must be included in future projects. When exploring caregiver attitudes, it will be necessary to explore their education and experience with diabetes, as well as those of their patients.

The methodologies for future studies have also been alluded to. The foremost need is more work on reliability and validity of instruments. It would be particularly desirable to have standardized scores across scales, when possible. Non-invasive measures of diabetic control would be useful. It is now possible, to obtain accurate long-term assessments with specially treated hemoglobin Alc (Daneman, Wolfson, Becker & Drash, 1981). Proper classification of diabetes type is a necessity for any control estimates. Thus, c-peptide excretion, a measure of residual pancreatic function, could be used. Some regimens are simply inappropriate. A team of expert diabetologists might be used to rate prescribed regimens.

When instruments are refined, and patient and disease categories are accurately assigned or measured, it will be possible to examine the interactions of the variables with some assurance of reliability and validity. This can be done with techniques such as path analysis (Heise, 1975) and modelling. Through these techniques and with computer simulation, the effect of changes in one or more variables on the others can be predicted. These predictions can then be tested in clinical populations and a model produced. A viable model would greatly facilitate the training of patients and physicians, as well as provide a basis for further research.

Below are two examples of projects that could be done with the tools and approaches presently used. One is long overdue, the other is on the cutting-edge of medical technology. A controlled investigation of the newly-diagnosed patient has been needed for years. A critical practical question is what type of education (and support) is best for which patient. The extreme cases range from an intense educational bombardment during the diagnostic work-up, to no, or very brief, hospitalization with education spread out over weeks and months. Follow-up interviews, attitude-perception and information scales could be used to select the optimal patient/ program fit.

The second example is the increasing use of high-technology treatments in diabetes. This includes home blood glucose monitoring, intensive multiple injection regimens and electronic insulin pumps. Put quite simply, who will do best with which new approach? Clinical experience has taught that age and intelligence alone are insufficient to predict success with these devices. No doubt, attitudes, comprehension, and patient/physician communication will prove to be factors in successful use.

Clinical implications

Several findings from this study raise tentative suggestions for clinicians. First, whatever the type of initial therapy undertaken, attention must be paid to the anxiety of the child. Second, families should generally be involved in education, and family therapy undertaken if indicated. Third, education must procede interactively, that is, not merely as a process of giving out information, or bold facts, but inquiring into the patients' grasp of concepts and reasoning methods. Finally, education must be tailored for different ages and sexes.

In summary, this work has explored an approach to the study of chronic disease. The most important elements of this approach include examination of the attitudes and knowledge about health and treatment, and a recognition of the interacting nature of patients and caregivers. Possibly the most important finding from this approach was the discovery of patient misperceptions of their doctors' attitudes and expectations. These misperceptions occurred even in well-informed patients with sophisticated medical care, and varied with patient's age and sex. This must be regarded as a challenge to the health-care professions.

Some of the earlier literature was supported, particularly the importance of the patient's family on his or her adaptation to the disease. Further findings supported a connection between disease knowledge and regimen adherence, and between regimen behaviors and attitudes toward disease and treatment. Of potential practical importance was the evidence for the influences of role-models and initial teaching of diabetic children.

That these results were obtained from a sample with particularly thorough patient-education implies that the adolescent diabetic population in general, and possibly, other chronically ill groups, are focusing on inappropriate elements of their regimens and that communication between patient and physician is inadequate. These findings suggest that there may be more common ground shared between doctor and patient than the patient is aware of, and that if additional efforts to communicate are undertaken the burden of both parties may be lessened.

APPENDICES

APPENDIX A

Letters and Consent Forms

Michigan State University
Department of Psychology
Snyder-Phillips Hall
East Lansing, MI 48823

Dear

My name is Bob Shaffer. I have been working as a psychological consultant at the Pediatric Endocrine Clinic at Michigan State University for about 4½ years. During that time I've met and talked with many children and teenagers who have diabetes. Our patients have come from different parts of the country and have been taught about their diabetes and its care in various ways. I've found that people with diabetes don't all do equally well in following the treatments suggested by their doctors. This is because patients, doctors' views and methods, and even the treatments themselves are different. With your help, I plan to study ways to make diabetes and its treatment easier for patients to understand, and easier for doctors and nurses to teach.

I am asking you to fill out a very brief questionnaire about your education and income levels, and your child to complete a number of questionnaires concerned with how he/she treats his/her diabetes and and what is known and felt about its treatment. If you permit your child to help with this study, please complete the parents' questionnaire, sign the parents' consent form and allow your child to fill out the questionnaires in private. When I receive the completed forms and questionnaires, I will send your child a check for $1.00.

There is a second part of this study for which I will contact a small number of people who helped with the first part described above. In the second part, I'll ask patients questions about their diagnosis, how they learned about diabetes, more about their feelings about treatment and how its teaching could be improved. There will also be a brief word knowledge test, and a questionnaire asking your child's opinions about non-diabetic health care issues. With parental permission, and that of the patient, I'll ask the physician for his/her beliefs about treatment, treatment success standards and teaching methods.

If your child is asked, and decides to participate in the second part, he/she will be given an additional $5.00 fee. This part can take place in your home at a time convenient to you and your child. It should take between 45 minutes and an hour and a quarter. Please note that completion of the first part of the study implies no obligation to help with the second part.

All answers to both parts will remain strictly confidential, that is, no one--doctors, patients or parents, will know anyone elses answers. Overall results, or averages from the entire study, will be sent to you if you wish. A letter similar to this will be sent to your child.

I sincerely hope that you can help me with this study. I believe that the findings will be of use to both physicians and their current and future patients. If you have any questions, please call me at (517) 351-0736 or write me c/o the Department of Psychology, Snyder-Phillips Hall, Michigan State University, East Lansing, MI 48824. Thank you very much.

Sincerely yours,

Bob Shaffer, M.A.
Department of Psychology
Pediatric Endocrine Clinic
Michigan State University

Michigan State University
Department of Psychology
Snyder-Phillips Hall
East Lansing, MI 48823

Dear

My name is Bob Shaffer. I'm a graduate student and researcher and have been working with the Pediatric Endocrine Clinic at Michigan State University for about 4½ years. During that time I've met many children and young adults who have diabetes. They have come from several parts of the state and have been taught how to care for their diabetes in different ways.

I've found that people with diabetes don't all do equally well in following the treatment suggested by their doctors. This is because patients, doctors and even the diabetic treatments themselves are all different. With your help, I plan to study ways to make diabetes and its treatment easier for patients to understand and easier for doctors and nurses to teach.

I am asking you to fill out a number of questionnaires concerning what you do about your diabetes as well as what you know and what you feel about it and its treatment. When I receive your signed consent forms, your parents forms if you are under 18 years of age, and the completed questionnaires in the mail, I'll send you a check for $1.00.

There is a second part of this study that you may later wish to help with. In this part, I'll ask a small number of people with diabetes questions about their diagnosis, how they learned about diabetes, more about their feelings about treatment and their doctor, as well as their opinions on how the treatment or teaching could be improved upon. There will be a brief word knowledge test, and a questionnaire asking your beliefs about non-diabetic health issues. With your permission and that of your parents, I'll ask the doctor or nurse who is now treating your diabetes for his/her viewpoints on treatment and teaching methods. If you are asked and you decide to participate in this second part, you will be paid an additional $5.00 fee. This part can take place in your own home at any time you and your family select. If you decide to fill out the first group of questionnaires, you are under <u>no obligation</u> to help with the second part.

All of your answers will remain strictly confidential. That is, no one; doctors, parents or patients will know anyone else's answers. Overall results or averages from the entire study will be sent to you if you wish. A letter similar to this one will be sent to your parents if you are under 18 years old.

I sincerely hope that you can help with this study. If you have any questions, please call me at (517) 351-0736. Thank you.

Sincerely,

Bob Shaffer, M.A.
Department of Psychology
Pediatric Endocrine Clinic
Michigan State University

PATIENT'S CONSENT FORM

Michigan State University
Department of Psychology

1. I have freely consented to take part in a scientific study being conducted by: R. J. Shaffer, M.A. under the supervision of Professors J. Hurley, Ph.D. and R. Levine, Ph.D.
2. The study has been explained to me and I understand the explanation that has been given and what my participation will involve.
3. I understand that I am free to discontinue my participation in the study at any time without penalty.
4. I understand that the results of the study will be treated in strict confidence and will remain anonymous. Within these restrictions, results of the study will be made available to me at my request.
5. I understand that my participation in the study does not guarantee any beneficial results to me.
6. I understand that, at my request, I can receive additional explanation of the study after my participation is completed. General findings of this study will be made available, although individual results will not be released.
7. I authorize ______________________________ to release
   (Physician's name)
   to Robert Shaffer information about my medical treatment which will be helpful for this study.

Signed ______________________________

Date ______________________________

PARENT'S CONSENT FORM

Michigan State University
Department of Psychology

1. I have freely given my permission for my child to take part in a scientific study being conducted by: R. J. Shaffer, M.A. under the supervision of: Professors J. Hurley, Ph.D. and R. Levine, Ph.D.
2. The study has been explained to me and I understand the explanation that has been given and what my child's participation will involve.
3. I understand that I am free to discontinue his or her participation in the study at any time without penalty.
4. I understand that the results of the study will be treated in strict confidence and will remain anonymous. Within these restrictions, results of the study will be made available to me at my request.
5. I understand that participation in the study does not guarantee any beneficial results to my child.
6. I understand that, at my request, I can receive additional explanation of the study after participation, although individual results will not be released.
7. I authorize ______________________________ to release
   (Physician's name)
   to Robert Shaffer information about my child's medical treatment which will be helpful for this study.

Signed ______________________________

Name ______________________________

Michigan State University
Department of Psychology
Snyder-Phillips Hall
East Lansing, MI 48823

Dear

Thank you again for your help with the first part of my study. Your cooperation was greatly appreciated.

You may recall that there is a second phase of this study in which patients and their physicians will be interviewed in person. In this way, they can express their ideas more completely. I plan to ask questions of patients about non-diabetic health care beliefs, experiences around diagnosis, how treatment procedures were learned, care received from physicians, ideas for improvements in teaching and treatment, and a brief word knowledge test for patients.

This interview can take place at home nearly anytime that is convenient, for example, after school, in the evening, or during the weekend. It should last between 45 minutes and one and one quarter of an hour. Answers will be tape recorded but no names will be used. As before, anonymity will be carefully guarded.

I hope that you will again give your permission for your child to help complete this study if he/she wishes. Patients' opinions are very important to me and may assist the treatment of other people with diabetes in the future.

If you decide to give permission, please fill out, with your child, the card he/she received. I'll need the name, telephone number and address of the doctor or nurse who is currently most responsible for your child's diabetic care and a convenient time for the interview. If you or your child would prefer that the interview be held elsewhere, such as in our clinic, please let me know.

All patients who help with this part of the study will be given a $5.00 fee for their time and effort. Again, if there are any questions, please call me at (517) 351-0763. Thank you.

Sincerely yours,

Bob Shaffer, M.A.
Department of Psychology
Pediatric Endocrine Clinic
Michigan State University

Michigan State University
Department of Psychology
Snyder-Phillips Hall
East Lansing, MI· 48823

Dear

I have been working with Michigan State University's Pediatric Endocrine Clinic as a psychological consultant for the past 4½ years. In that time, I've encountered patients with diabetes taught to follow a number of different treatment regimens. Naturally, there are great differences in patient knowledge, compliance and disease course. As a part of my doctoral research in clinical psychology at M.S.U. I am conducting a study of the knowledge, practices, and attitudes toward disease and regimen of adolescents with juvenile diabetes. I believe that it is important to tap the experience and obtain the perspective of these patients. If this study is successful, we will learn more about the relationships between patient compliance, patient characteristics, education, and patient/physician attitudes toward diabetes and its treatment. It is hoped that this data will facilitate education and treatment for future patients and physicians.

A large group sampling of adolescents with diabetes has been completed. I am now attempting to interview patients and physicians in more detail. I will see your patient, ______________________ in his/her home. This interview will center on family/social history, diagnosis, and attitudes about their education process and regimen. I would also like to telephone you in order to obtain your answers to 21 brief questions concerning patient education, accessibility and treatment evaluation. I've enclosed a copy of this questionnaire for your reference, a consent form, and a card asking for convenient times for the call.

While your patient and his/her parents know that I am contacting you, all responses and opinions of <u>every</u> party will remain strictly confidential and coded for anonymity. An abstract of the general findings, however, will be sent to you if you wish.

I sincerely believe that this study will yield data useful to physicians and their patients and hope that you can help me to complete it. Thank you very much.

Sincerely yours,

Bob Shaffer, M.A.
Department of Psychology
Pediatric Endocrine Clinic
Michigan State University

Enclosures

PHYSICIAN'S CONSENT FORM

Michigan State University
Department of Psychology

1. I have freely consented to take part in a scientific study being conducted by: R. J. Shaffer, M.A. under the supervision of: Professors J. Hurley, Ph.D. and R. Levine, Ph.D.
2. The study has been explained to me and I understand the explanation that has been given and what my participation will involve.
3. I understand that I am free to discontinue my participation in the study at any time without penalty.
4. I understand that the results of the study will be treated in strict confidence and will remain anonymous. Within these restrictions, results of the study will be made available to me at my request. I understand that any relevant medical data I provide will be kept confidential from my patients.
5. I understand that my participation in the study does not guarantee any beneficial results to me or my patients.
6. I understand that, at my request, I can receive additional explanation of the study after my participation is completed. General findings of this study will be made available, although individual results will not be released.

Signed ______________________________

Date ______________________________

APPENDIX B

Instruments

Parent's Questionnaire

Socio-Economic Information

Husband's work is ______________________________________

Wife's work is ____

I. The main source of our family's income is: (circle one)

1 - Inherited money or investments
2 - Returns from earned money that has been invested
3 - Profits and fees from business or profession
4 - Salary, commissions or regular income paid on a monthly or semi-monthly basis
5 - Wages: hourly wages, piece work, or weekly pay check
6 - Odd jobs or seasonal work
7 - Social Security, welfare, or unemployment insurance

II. The person who contributes the largest share of our family income is: (circle the category number which contains jobs similar to the main "breadwinner's" if the actual job does not appear.)

1 - A lawyer, judge, doctor, or other highly trained professional (more than college educated)
- The owner of a business valued at over $250,000
- A top executive in a large corporation or bank
  A CPA or head of a high status organization
- Gentleman farmer or landowner (does not work the land, but collects rents, etc.)

2 - Nurse, teacher, librarian, or other professional with college degree
- The owner of a business values at $100-250,000
- Manager of a store or business, or department in a larger corporation
- Accountant, sales agent for insurance, stock, real estate
- Farmer who supervises a large farm operation

3 - A professional who has a technical degree
- The owner of a business valued at less than $100,000
- The manager of a small store or branch store, sales person for established products
- A bank clerk, auto salesman, postal clerk
- Small contractor who works or supervises jobs
- Farmer who operates medium sized farm with some "hired help" or supervisor of leased land

Parent's Questionnaire (Continued)
Socio-Economic Information

4 - The owner of a business valued at less than $50,000
  - A secretary, bookkeeper, salesperson in a large department store
  - A foreman or master carpenter, electrician, etc.
  - Police captain, tailor, skilled repairman
  - Small landowner or operator of rented land who hires seasonal labor

5 - The owner of a business valued at less than $25,000
  - A dime store clerk, grocery clerk, hair dresser, telephone operator
  - A medium skilled worker or apprentice
  - Policeman, barber, Licensed Practical Nurse
  - A tenant on a good farm, or a small farmer who supplements income by "hiring out"

6 - The owner of a business valued at less than $10,000
  - A factor production worker
  - A taxi or wage earning truck driver, or waitress, gas station attendant
  - Share cropper, farm laborer

7 - Unskilled laborer
  - Domestic laborer
  - Migrant worker

III. Draw a circle around the number of years of schooling <u>husband</u> has completed

Grade School	High School	College	Graduate School
1 2 3 4 5 6 7 8	9 10 11 12	1 2 3 4	1 2 3 4

Draw a circle around the number of years of schooling <u>wife</u> has completed

Grade School	High School	College	Graduate School
1 2 3 4 5 6 7 8	9 10 11 12	1 2 3 4	1 2 3 4

Parent's Questionnaire (Continued)
Socio-Economic Information

Please name the doctor or nurse who you currently consult about your child's diabetes.

Name ____

Address ______________________________________

____

Telephone ____________________________________

Please circle the medical degree and any titles that are applicable.

M.D. D.O. R.N. Other

General Practitioner Pediatrician Internist

Endocrinologist Other

QUESTIONNAIRE DIRECTIONS

The purpose of this questionnaire is to help me learn what people with diabetes actually do, know, and feel about the disease and its treatment.

There are four parts. The first part ("treatment") asks what you actually do to treat your diabetes. Your answers may or may not be what you think you ought to be doing, or were told you ought to be doing. Please don't be concerned if your treatment is different than prescribed. For this part of the study, it is only important to know what you do. Neither your parents or your doctors will ever see your answers.

The second ("information") part will ask what you know about diabetes. Some questions are the true--false type. Just check what is true for you. Other questions are multiple choice. Just circle or check the answer that is most true. None are meant to be "trick" questions.

The third part ("attitudes") is different. I want to know what you think and feel about some questions and statements about diabetes. For these you have a choice of five answers from "strongly agree" to "strongly disagree". Again, just put a check or circle on your answer. If you aren't sure, you may mark "uncertain". Please use this answer only if you really can't decide.

Finally, for the last part, the same questions used in part three will be repeated, but instead of answering for yourself, answer as you think the doctor who treats you for diabetes would answer.

Please read each question carefully, but the first answer that comes to mind is often the best answer.

Your answers will be secret, only I will see them, not your parents or doctors. So please be as honest as you can be. Some of your answers may be different from what you were taught. Your ideas are most important to me.

DIABETES TREATMENT QUESTIONNAIRE

In the first section we are interested in some of the things that some people with diabetes do, while others do not. To begin with:

1. How often, if ever, do you usually test for glucose (sugar) in your urine?

    ______ Never
    ______ Only when ill
    ______ Once a month
    ______ Once a week
    ______ Once a day
    ______ Twice a day
    ______ Three times a day
    ______ Four or more times a day

2. If you ever test for sugar in your urine, what test do you usually use?

    ______ Clinitest 2-drop
    ______ Ketodiastix
    ______ Clinitest 5-drop
    ______ Testape

3. How often, if ever, do you test at school?

    ______ Never
    ______ Only now and then
    ______ Sometimes
    ______ Often
    ______ All the time

4. Do you keep records of the test results?

    ______ Always
    ______ Often
    ______ Sometimes
    ______ Seldom
    ______ Never

5. If you show these test results to your doctor, are they always accurate?

Treatment Questionnaire (Continued)

6. How often does your doctor ask you to collect urine for 24 hours?

______ Never
______ Seldom
______ Sometimes
______ Often

7. Does your doctor ever draw blood for tests?	7a. Do you?
______ Never	______ Never
______ Seldom	______ Seldom
______ Sometimes	______ Sometimes
______ Often	______ Often

8. What is your usual insulin dose?

	A.M.		P.M.	
Type(s)	______	______	______	______
Amount(s)	______	______	______	______

9. How many of your insulin injections do you give yourself?

______ None
______ Some
______ Most
______ All

10. Are your injections usually given at the same time each day?

______ Yes
______ No

11. If your insulin dose is ever changed, who changes it?

______ Doctor
______ Nurse
______ Parents
______ Self

12. How often have you taken a extra dose of Regular insulin on your own (without asking or telling anyone)?

______ Never
______ Seldom
______ Sometimes
______ Often

Treatment Questionnaire (Continued)

13. How often have you forgotten any injections in the last 12 months?

______ Never
______ Once or twice
______ Occasionally
______ Often
______ Very Often

14. Do you follow any particular diet or meal plan?

______ Yes
______ No

15. If yes, how would you describe it?

______ a) "exchange list" (for example, a certain number of break, meat exchanges per day or meal).
______ b) calorie limited (for example, 2,000 calories per day).
______ c) a "free diet" with limitation on concentrated sweets.
______ d) whatever the rest of the family eats.

16. If you are on a restricted diet ("a" or "b" in question 16 above), do you ever eat things not on it?

______ Never
______ Rarely
______ Often
______ Daily

17. Do you have "free days" when you may eat whatever you want?

______ Yes
______ No

18. Do you eat at the same time every day?

______ Never
______ Rarely
______ Often
______ Always

19. Do you carry any emergency food or sugar source?

______ Never
______ Rarely
______ Often
______ Always

Treatment Questionnaire (Continued)

20. When you are vomiting due to the flu or some similar illness, do you:

______ a) cut your insulin dose
______ b) call your doctor
______ c) use only regular insulin and drink pop or fruit juices
______ d) it's never happened to me

21. If you did not have diabetes, would you exercise:

______ More
______ Less
______ The same amount

22. Do you do about the same amount of exercise eacy day, in any given season?

______ Yes
______ No

23. Do you eat an extra snack when you exercise?

______ Never
______ Rarely
______ Often
______ Always

24. Do you change your insulin dose because of exercise?

______ Yes
______ No

25. Are there any activities (e.g., sports, eating with friends, etc.) that you would do <u>more</u> of if you did <u>not</u> have diabetes?

______ Yes
______ No

26. Do you usually weak a necklace or bracelet that says you have diabetes?

______ Yes
______ No

27. Do all of your friends know that you have diabetes?

______ Yes
______ No

Treatment Questionnaire (Continued)

28. Do all of your teachers know that you have diabetes?

______ Yes
______ No

29. Overall, how would you rate your control of your diabetes?

______ Very bad
______ Bad
______ Poor
______ Fair
______ Good
______ Very good
______ Excellent

INFORMATION QUESTIONNAIRE

Now we would appreciate your answering some questions about what you know about diabetes. For each question, please mark the space in front of the answer you think is the correct one.

1. The usual cause of diabetes is:

______ a. Eating too much sugar, candy or desserts.
______ b. Failure of the pancreas to make enough insulin.
______ c. Failure of the kidneys to control sugar in the urine.
______ d. I don't know.

2. In uncontrolled diabetes the blood sugar is:

______ a. Normal
______ b. High
______ c. Low
______ d. I don't know

3. You can "catch" diabetes from another person.

______ True
______ False

4. Insulin causes blood sugar to:

______ Go up.
______ Go down.
______ Become just like normal.
______ I don't know

5. All people with diabetes are treated with insulin.

______ a. True
______ b. False

6. Insulin should only be given in the arms and legs.

______ a. True
______ b. False

Information Questionnaire (Continued)

7. Lente and NPH insulins act:

______ a. Quickly, between 1 and 6 hours.
______ b. Slowly, for about 24 hours.
______ c. I don't know.

8. Regular insulin acts:

______ a. Slowly, for about 24 hours.
______ b. Quickly, between 1 and 6 hours.
______ c. I don't know.

9. One-half C.C.'s of U-100 insulin contains:

______ a. 20 units of insulin.
______ b. 50 units of insulin.
______ c. 100 units of insulin
______ d. I don't know.

10. Diabetic coma (ketoacidosis) is caused by too much insulin.

______ a. True
______ b. False

11. Which two feelings might you have with ketoacidosis?

______ a. Chest pain
______ b. Rapid breathing.
______ c. Nausea.
______ d. I don't know.

12. Which two of the following may lead to ketoacidosis or coma?

______ a. Illness.
______ b. Too much insulin.
______ c. Too little insulin.
______ d. I don't know.

13. Which two of the following might you feel with an insulin reaction?

______ a. Weakness.
______ b. Hunger.
______ c. Chest pain.
______ d. I don't know.

Information Questionnaire (Continued)

14. An insulin reaction is caused by:

_____ a. Too much insulin.
_____ b. Not enough insulin.
_____ c. Not enough exercise.
_____ d. I don't know.

15. When a person with diabetes begins to have an insulin reaction he or she should:

_____ a. Take some extra insulin.
_____ b. Lie down and rest.
_____ c. Eat some carbohydrate (such as sugar).
_____ d. I don't know.

16. You may need an extra snack before any unusually strenous exercise.

_____ a. True
_____ b. False

17. Urine tests should usually be made:

_____ a. Just before a meal.
_____ b. One hour after a meal.
_____ c. Anytime.
_____ d. I don't know.

18. When urine is tested with <u>Clinitest</u> tablets, a blue color means:

_____ a. Lots of sugar in the urine.
_____ b. Little or no sugar in the urine.
_____ c. The tablets are too old.
_____ d. I don't know.

19. When urine is tested with <u>Testape</u>, a dark green color means:

_____ a. Lots of sugar in the urine.
_____ b. Little or no sugar in the urine.
_____ c. Testape never turns green.
_____ d. I don't know.

20. The presence of acetone in the urine is:

_____ a. O.K.
_____ b. Sign of a possible problem.
_____ c. A usual feeling
_____ d. I don't know.

Information Questionnaire (Continued)

21. Acetest or Keto-diastix give the following color when acetons (ketones) are present in the urine:

______ a. Green
______ b. Red
______ c. Purple
______ d. I don't know

22. If acetone (ketones) are found in your urine, you may need which two of the following:

______ a. More insulin.
______ b. Less insulin.
______ c. Lots of liquids.
______ d. I don't know.

23. The number of calories (Kcals) in most diabetic diets are:

______ a. From 200 to 800.
______ b. From 1,000 to 3,500.
______ c. From 10,000 to 35,000
______ d. I don't know.

24. Foods like breads, cereals and fruit contain only protein.

______ a. True
______ b. False

25. The break exchange list contains many similar foods, and one clide of break may be exchanged for:

______ a. ½ cup of corn flakes.
______ b. 4 graham crackers.
______ c. 1 small potato.
______ d. I don't know.

26. Fruits contain mainly carbohydrate and one organe may be exchanged for:

______ a. 1 medium banana.
______ b. 1 cup of orange juice.
______ c. 1 small apple.
______ d. I don't know.

Information Questionnaire (Continued)

27. When a person using insulin become ill and can't eat his usual diet, he should:

______ a. Stop taking insulin.
______ b. Continue taking insulin.
______ c. Take oral medication instead (e.g., Diabinase).
______ d. I don't know.

28. Which two of the following problems are sometimes found in older diabetics?

______ a. Changes in blood circulation.
______ b. Changes in the lungs.
______ c. Changes in vision.
______ d. I don't know.

ATTITUDES - PART I

I want to know what you think or feel about some questions and statements about diabetes. For these you have a choice of five answers from "strongly agree" to "strongly disagree". Again, just put a check or circle your answer. If you aren't sure, you may mark "uncertain". Please use this answer only if you really can't decide.

1. It is important to test urine four times a day.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

2. A person with diabetes should try to keep his or her urine completely free of sugar:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

3. It is important to keep records of every urine test.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

4. Sticking to a prescribed diet or meal plan is a very important part of treatment.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

Attitudes (Continued)

5. It's all right to skip a meal once in a while.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

6. Doctors should discuss possible future diabetes related problems with their teenaged patients.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

7. It is very important for young people with diabetes to take special care of their feet.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

8. A person with diabetes should not have children of his or her own.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

9. It's probably not necessary to carry a diabetic bracelet or necklace.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

Attitudes (Continued)

10. Only your doctor should change your inculin dose.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

11. Fasting blood tests are the best way to measure the control of diabetes.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

12. My main goal in regard to diabetic treatment is to:

______ a. Keep my blood sugar as normal as possible.
______ b. Avoid insulin reactions and acidosis while permitting normal activities.
______ c. I don't know.

13. If a person with diabetes does everything that their doctor tells them to do, they will have few complications when they are older.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

14. It's important to test urine at school.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

Attitudes (Continued)

15. It's very difficult for me to do everything my doctor says I should do.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

16. Whether I follow my Doctor's advice or not will make no difference -

a. Day to Day:	b. In the long run:
______ Strongly agree	______ Strongly agree
______ Agree	______ Agree
______ Uncertain	______ Uncertain
______ Disagree	______ Disagree
______ Strongly disagree	______ Strongly disagree

17. A 24-hour urine collection for sugar content is more useful than blood sugar tests.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

18. It's best to use food exchange lists when making a meal plan.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

19. A person with diabetes should not eat sweet foods at parties or on holidays.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

Attitudes (Continued)

20. A person with diabetes should eat:

______ a. Only "dietetic" foods.
______ b. The same foods at the same time each day.
______ c. Different foods chosen from the exchange lists.
______ d. The same foods as the rest of the family.
______ e. The same foods as the rest of the family except for concentrated sweets.

21. A person with diabetes should exercise about the same amount at the same time each day.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

22. Just about everybody who knows me will (friends, teachers and relatives) should know that I have diabetes.

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

ATTITUDES - PART II

This is the last part. The same questions used in part two will be repeated but instead of answering for yourself, answer as you think the doctor who you see for care of your diabets would answer.

1. It is important to test urine four times a day.
   My doctor:

   ______ Strongly agree
   ______ Agree
   ______ Uncertain
   ______ Disagree
   ______ Strongly disagree

2. A young person with diabetes should try to keep his or her urine completely free of sugar.
   My doctor:

   ______ Strongly agree
   ______ Agree
   ______ Uncertain
   ______ Disagree
   ______ Strongly disagree

3. It is important to keep records of every urine test.
   My doctor:

   ______ Strongly agree
   ______ Agree
   ______ Uncertain
   ______ Disagree
   ______ Strongly disagree

4. Sticking to a prescribed diet is the most important part of treatment.
   My doctor:

   ______ Strongly agree
   ______ Agree
   ______ Uncertain
   ______ Disagree
   ______ Strongly disagree

Attitudes - Part II (Continued)

5. It's all right to skip a meal once in a while.
   My doctor:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

6. Doctors should discuss possible future diabetes related problems in an honest way with their teenaged patients.
   My doctor:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

7. It is very important for young people with diabetes to take special care of their feet.
   My doctor:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

8. A person with diabetes should not have children of his or her own.
   My doctor:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

9. It's probably not necessary to carry a diabetic bracelet or necklace.
   My doctor:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

Attitudes - Part II (Continued)

10. Only your doctor should change your insulin dose.
My doctor:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

11. Fasting blood tests are the best way to measure the control of diabetes.
My doctor:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

12. My doctor's main goal is to:

______ a. Keep my blood sugar as normal as possible.
______ b. Avoid insulin reactions and acidosis while permitting normal activities.
______ c. I don't know.

13. If a person with diabetes does everything that their doctor tells them to do, they will have few complications when they are older.
My doctor:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

14. It's important to test urine at school.
My doctor:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

Attitudes - Part II (Continued)

15. It's very difficult for me to do everything my doctor says I should do.
My doctor:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

16. Whether I follow my Doctor's advice or not will make no difference.
My doctor:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

17. A 24-hour urine collection for sugar content is more useful than blood sugar tests.
My doctor:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

18. It's best to use food exchange lists when making a meal plan.
My doctor:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

19. A person with diabetes should not eat sweet foods at parties or on holidays.
My doctor:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

Attitudes - Part II (Continued)

20. A person with diabetes should eat (according to my doctor):

______ a. Only "dietetic" foods.
______ b. The same foods at the same time each day.
______ c. Different foods chosen from the exchange lists.
______ d. The same foods as the rest of the family.
______ e. The same foods as the rest of the family except for concentrated sweets.

21. A person with diabetes should exercise about the same amount at the same time each day.
My doctor:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

22. Just about everybody who knows me well (friends, teachers and relatives) should know that I have diabetes.
My doctor:

______ Strongly agree
______ Agree
______ Uncertain
______ Disagree
______ Strongly disagree

INTERVIEWS

This section includes the interview schedule that will be used in the homes of the adolescent subjects selected from phase I.

It is intended to determine the reasons for the answers given in phase I, and explore some of the six major theoretic variables used by major models to explain health behaviors. These variables are (Cummings, et al., 1980):

1. accessibility of health services
2. attitudes toward health care
3. threat of illness
4. knowledge about illness
5. social interactions, norms and structures
6. demographic characteristics

PATIENT'S INTERVIEW

I. Establishing rapport

- A. Ice-breaking with subject and family
- B. Brief review of study's purpose and its parts.
  - 1) Reiterate confidentiality.
  - 2) Invite any family members to leave.

II. Basic diabetic history

- A. Onset
  - 1) Age, year and circumstances.
- B. Significant post-onset events
  - 1) Hospitalizations.
  - 2) Major hypo-, hyper- or ketotic episodes.
- C. Familial history
  - 1) List immediate family members.
  - 2) Any members with diabetes? nature of relationship.
  - 3) Any other major diseases?

III. Diabetic education

- A. Pre-education
  - 1) Did you know anybody in your school or neighborhood who had diabetes before you developed it? (if so, follow up nature of relationship and feelings toward)
  - 2) Do you remember what you felt about or knew about diabetes before your diagnosis?

Interviews (Continued)

3) What were your feelings when you first learned that you had diabetes?

4) Concerning questions 3 and 4, have any of these ideas changed? If so, how?

B. Education format

1) Were you taught about diabetes and its treatment? e.g.:

   a. Did anyone teach you in the hospital? (Example: a class with a nurse, your own doctor, a doctor from the hospital, phamphlets or books, etc.)

   b. Do you remember any of this experience?

   c. How did your parents learn about diabetes (as far as you know)?

2) Post-diagnosis/hospitalization education

   a. What have you learned or been taught outside of the first hospitalization? How, where, and from whom? (Example: your doctor's office (doctor or nurse) telephone them, books, pamphlets or magazines, later hospitalizations, etc.)

   b. Have you been to the camp for diabetic kids (Camp Midicha, or others)? Did you learn anything from the staff, doctors, or other kids there? (If so, what and how).

Interviews (Continued)

c. Have you learned from other family members or friends who have diabetes?

d. How or from whom do you think that you've learned the most? Why?

e. What are the most important things doctors should tell people with diabetes?

f. Have you had any problems in learning about diabetes or its treatment? (If yes, explore).

IV. Attitudes toward diabetes and its treatment

A. Health values

1) What does being "healthy" mean to you? (e.g., is it possible to be healthy and have diabetes)?

2) How important is being healthy (or doing well with diabetes, depending on response to the above) to you?

Please arrange the following cards in order from most to least important to you:

beautiful/handsome; famous; healthy; happy; rich

3) How bad is having diabetes?

1	2	3	4	5	6	7
OK						worst possible thing in the world (why)

B. 1) If or when you did everything your doctor asks you to do, would you feel better than if you did not? (why)

Interviews (Continued)

2) Do you think that following your doctor's advice will make any difference in your health in 10 or 20 years? (why)

C. 1) How hard is it to care for your diabetes as you've been told to?

1 2 3 4 5 6 7

easy really impossible (why)

2) What is the hardest part? (why)

3) Is there any part of having diabetes that is embarrassing to you? (why)

4) Is there any part of the treatment that is embarrassing? (why)

5) Is there anything that you have stopped doing because of diabetes? (why)

6) Do your parents ever "bug" you about the way you treat your diabetes? (if yes, how?)

D. 1) Do you think that most people your age with diabetes treat it as you do? That is, do they do more, less, or about the same? (why)

2) Is your particular case of diabetes harder, easier or about the same? (why)

3) How would you rate your control of diabetes?

1 2 3 4 5 6 7

awful excellent

4) How well do most other people your age do?

1 2 3 4 5 6 7

awful excellent

V. Relationship with physician

A. Access

1) How often do you see your doctor?

2) When you see him or her, do you think that he or she spends enough time with you?

3) Do you ever telephone your doctor or nurse?

4) How easy is it to reach your doctor when you want to?

1 2 3 4 5 6 7

easy very difficult

5) How well does your doctor understand your feelings about having diabetes and its treatment? (what makes you say that?)

1 2 3 4 5 6 7

very well very poorly

6) Do you think that your doctor agrees with your views about treatment?

7) Do you feel that your doctor cares for you as a person?

1 2 3 4 5 6 7

very much not at all

8) What makes you feel that is the case?

Interviews (Continued)

9) Do you try very hard to follow all of your doctor's advice?

If "no" - why not?

If "yes" - in what ways?

	7. VOCABULARY Discontinue after 5 consecutive failures.	Score 2, 1, or
	1. Knife	
	2. Umbrella	
	3. Clock	
[illegible]	4. Hat	
	5. Bicycle	
[illegible]	6. Nail	
	7. Alphabet	
[illegible]	8. Donkey	
	9. Thief	
	10. Join	
	11. Brave	
	12. Diamond	
	13. Gamble	
	14. Nonsense	
	15. Prevent	
	16. Contagious	
	17. Nuisance	
	18. Fable	
	19. Hazardous	
	20. Migrate	
	21. Stanza	
	22. Seclude	
	23. Mantis	
	24. Espionage	
	25. Belfry	
	26. Rivalry	
	27. Amendment	
	28. Compel	
	29. Affliction	
	30. Obliterate	
	31. Imminent	
	32. Dilatory	
	Total	Max.=6

From the Weschsler intelligence test for children.

MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL (MHLOC) SCALES

1. If I get sick, it is my own behavior which determines how soon I get well again.
2. No matter what I do, if I am going to get sick, I will get sick.
3. Having a regular contact with my physician is the best way for me to avoid illness.
4. Most things that affect my health happen to me by accident.
5. Whenever I don't feel well, I should consult a medically trained professional.
6. I am in control of my health.
7. My family has a lot to do with my becoming sick of staying healthy.
8. When I get sick I am to blame.
9. Luck plays a big part in determining how soon I will recover from an illness.
10. Health professionals control my health.
11. My good health is largely a matter of good fortune.
12. The main thing which affects my health is what I myself do.
13. If I take care of myself, I can avoid illness.
14. When I recover from an illness, it's usually because other people (for example, doctors, nurses, family, friends) have been taking good care of me.

MHLC (Continued)

15. No matter what I do, I'm likely to get sick.
16. If it's meant to be, I will stay healthy.
17. If I take the right action, I can stay healthy.
18. Regarding my health, I can only do what my doctor tells me to do.

CHILDREN'S HEALTH BELIEFS
(Children's Multidimensional Health Locus of Control Scale)

Read each statement. After reading each statement, circle YES if you agree, circle NO if you disagree. Then go on to the next statement.

YES NO 1. Good health comes from being lucky.

YES NO 2. I can do things to keep from getting sick.

YES NO 3. Bad luck makes people get sick.

YES NO 4. I can only do what the doctor tells me to do.

YES NO 5. If I get sick, it is because getting sick just happens.

YES NO 6. People who never get sick are just plain lucky.

YES NO 7. My mother must tell me how to keep from getting sick.

YES NO 8. Only a doctor or a nurse keeps me from getting sick.

YES NO 9. When I am sick I can do things to get better.

YES NO 10. If I get hurt it is because accidents just happen.

YES NO 11. I can do many things to fight illness.

YES NO 12. Only the dentist can take care of my teeth.

YES NO 13. Other people must tell me how to stay healthy.

YES NO 14. I always go to the nurse right away if I get hurt at school.

YES NO 15. The teacher must tell me how to keep from having accidents at school.

YES NO 16. I can make many choices about my health.

CHMLC (Continued)

YES NO 17. Other people must tell me what to do when I feel sick.

YES NO 18. Whenever I feel sick I go to see the school nurse right away.

YES NO 19. There are things I can do to have healthy health.

YES NO 20. I can do many things to prevent accidents.

PHYSICIAN'S INTERVIEW

This is the final element of the study. Telephone interviews will be arranged with the physicians named by the 20 subjects selected for vis à vis interviews. I have tried to make these questions streamlined and concise in order to ease the work required by the physicians. Please make any comments that you can to simplify them.

PHYSICIAN'S INTERVIEW

I. Education/knowledge issues

1) How are adolescent patients in your practice taught about their diabetes? (For example, are they taught mostly during their initial hospitalization, by the house staff? In your office during follow-up?)

2) How does this education program differ with age and personality?

3) Are the parents involved? How?

4) What are the facts or skills that you most want your patients to know?

5) Do you have a way of measuring your patient's knowledge?

6) How well do you think __________________________ understands what you are trying to teach?

	1	2	3	4	5	6	7	
Not at all								completely

II. Accessibility issues

1) In what ways do patients contact you most often? e.g., telephone consultations, office visits with you or your nurse, etc.?

2) How often do you expect to see __________________ per year?

Physician's Interview (Continued)

3) In your opinion, how accessible are you to ___________?

1 2 3 4 5 6 7

very hard to reach very easy to see

4) If you see ______________________ less often than you would like, or feel that you are less accessible that you would prefer, what are the major reasons?

5) Do you feel that the time you spend with ______________ is sufficient?

6) In your opinion, would __________________ agree with your assessment?

7) Do you ever see _____________________ too often? That is, are you sometimes consulted inappropriately?

III. Attitude and evaluation issues

1) What are your treatment goals for ___________________?

2) What are the most important elements in the treatment regimen you recommend? Why?

3) Do these priorities ever vary over time or with different patients?

4) From your own observations of ______________________, would you say that he/she shares your treatment goals and priorities? If not, what are the differences?

5) Again, judging from your observations, how successfully is ________________ adhering to your treatment recommendations? If there are any problems, what are they?

Physician's Interview (Continued)

6) How successfully is ________________ actually managing or controlling the disease? (independent of compliance)

1 2 3 4 5 6 7

awful excellent

7) What are your criteria for this judgment?

8) What influenced you to emphasize these aspects of management?

9) Considering the many potential variables that affect the course of diabetes (e.g., heredity, social environment, type of treatment, etc.), what factors do you believe predict the best outcome?

IV. Demography

1) Are you a general practitioner or a specialist? If the latter, what is your specialty?

2) How long have you practiced?

3) How many patients with insulin dependent diabetes are you now seeing?

Thank you very much for your time and cooperation.

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