ASSESSMENT OF FACTORS WHICH INFLUENCE COMPLIANCE TO DIET REVISION THERAPY FOR FOOD ALLERGY IN A PEDIATRIC POPULATION

by

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ABSTRACT

Failure to comply with prescribed regimens is a major reason for the failure of treatment programs. This study investigated factors which are related to compliance with prescribed diet revision therapy for food allergies in school-aged children. Forty-five children, aged 6 to 12 years, who were under a physician's care for food allergies, formed the sample.

The Health Belief Model was used as the basis for a questionnaire devised to measure these factors. The development of the Diet Revision Therapy Parent Questionnaire involved a pilot test and revisions; the resulting instrument consists of 38 items organized into 4 subtests, of which one 7-item subtest is to be considered optional. The 38-item DRTPQ has a full scale internal consistency reliability of .87, and a composite reliability of .61 for the four subscales.

The canonical correlation between 3 types of subjective ratings of compliance and the 4 subtests is .80, with 64% shared variance between these sets of variables. A discriminant function of 3 subtests of the DRTPQ proved capable of discriminating diet therapy dropouts from continuing subjects with 88.9% accuracy. These three subtests measured:

- 1. Parent and family life factors, such as the amount of perceived interference in normal routines,
- 2. Child's attitudes to the treatment and his/her normal behavior with respect to cooperation with parental demands, and
- 3. Belief in the benefits to be derived from the treatment.

A fourth category of items measured perceived severity of the condition and perceived susceptibility to illness but proved not to predict compliance in this sample, although it may be useful in clinical practice.

Suggestions for interventions to aid compliance are outlined.

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I. INTRODUCTION

Keep a watch also on the faults of the patients, which often make them lie about the taking of things prescribed. For through not taking disagreeable drinks, purgative or other, they sometimes die. (Hippocrates, "On Decorum", cited in DiMatteo & DiNicola, 1982)

If the participants don't like the treatment then they may avoid it, or run away, or complain loudly. And thus society will be less likely to use our technology no matter how potentially effective it might be. (Wolf, 1978)

A. BACKGROUND TO THE PROBLEM

Whereas the problem of compliance to prescribed regimes has concerned medical science since Hippocrates (Gordis, 1979; DiMatteo & DiNicola, 1982), behavioral scienctists have only recently become concerned about the acceptance of treatments by the consumer of psychological services (Garfield, 1983).

Estimates of failure to comply with health care advice range from 15% to 93% (Rapoff & Christopherson, 1982). The consequences of noncompliance to health care recommendations are potentially serious. Recurring and resistant infections frequently result when antibiotic treatments are not completed (Mattar & Yaffe, 1974). The cost to the health care system of missed appointments, repetition of tests and treatments, and unused medication is high (Becker & Maiman, 1975). In a research project, failure to comply complicates the procedure of determining a treatment's effectiveness immeasureably. Unless a researcher can be sure that the treatment was followed, and followed as prescribed, he cannot be sure that post-treatment effects, or lack of them, can be attributed to the treatment. When

attempting to prove treatment efficacy through treatment outcome, it is crucial that treatment compliance is proven (DiMatteo & DiNicola, 1982).

The term "compliance" is defined as "the extent to which a person's behavior (in terms of taking medications, following diets, or executing lifestyle changes) coincides with medical or health advice." (Haynes, 1979, p. 2) DiMatteo and DiNicola (1982) describe compliance as "the goal of the practitioner-patient influence process" (p. 8), implying that responsibility for compliance is shared between the health care giver and the patient. Dracup and Meleis (1982) add to their conceptualization of compliance a requirement that the regimen must be derived through negotiations between the health care professional and patient and that compliance reflects "the extent to which an individual chooses behaviors that coincide with a clinical prescription" (p. 31).

Often in recent literature, the term "adherence" has been substituted for "compliance" as it is felt to have a less judgmental connotation. "Patient cooperation" is yet another term frequently used in the literature. In this research, "compliance" and "adherence" will be used interchangeably. Specific behaviors described by these terms include taking medication, following a diet or exercise plan, attending appointments, restricting previous behaviors such as smoking, etc.

DiNicola and DiMatteo (1984) describe a noncomplier as one who "purposely or not" ignores, forgets, or misunderstands the clinical prescription. Haynes (1979) also includes as noncompliers patients who choose a different regimen or amend the prescribed regimen, including the choice of no treatment.

Reimers, Wacker, and Koeppl (1987) state that both compliance and the eventual success of a treatment are directly influenced by the acceptability of that treatment. Acceptability is defined by them as "the likelihood of a recommended

treatment being attempted" and as such is clearly a prerequisite to compliance.

Kazdin (1981, p. 493.) refers to acceptability as "judgements by lay persons, clients, and others of whether treatment procedures are appropriate, fair, and reasonable for the problem or client."

Although most acceptability literature refers to behavioral interventions in clinical settings or in school settings, its application to medical recommendations is appropriate. The issue of treatment selection which the concept of acceptability embodies (Elliott, 1986) is inherent in the problem of compliance. Traditionally, the selection of a medical treatment has been felt to be the province of the health care professional. However, when a patient chooses to comply with a prescribed regime, totally, partially, or not at all, he is involved in fact, in treatment selection.

Witt and Elliott (1985) theorize a sequential but reciprocal relationship between acceptability, use, integrity, and effectiveness, in which acceptability determines use, use is prerequisite to integrity (how closely the treatment plan is followed), which in turn influences the treatment's effectiveness.

Compliance, therefore, includes elements of acceptability, use, and integrity and is a determinant of effectiveness.

B. RESEARCH CONTEXT

The present study involves assessing the factors which influence compliance with a medically prescribed diet revision therapy for children who are suspected of being sufferers of food allergies. Subjects were drawn from among those children whose parents responded to a newspaper article describing a proposed research project in which the relationship between food allergies and learning difficulties or behavioral difficulties was to be investigated (Mullens, 1986). (This article is

presented in Appendix I.) The children were evaluated by a physician specializing in food allergies and a thorough medical history was taken. All subjects who met the physician's symptom criteria indicating probability of food allergy were eligible.

The treatment consisted of revising the child's diet by eliminating all common allergy provoking foods until symptomatic remission was obtained, then gradually reintroducing foods as long as symptoms did not return. The early stages of this diet are very restrictive, consisting of rice, poultry, fish, and a limited selection of vegetables. For most subjects, some dietary restriction will be necessary lifelong (Gislason, 1986b).

Symptoms of food allergy vary widely from person to person, and from allergen to allergen within each person. Common reactions are gastrointestinal distress, headaches, rhinitis and otitis media, muscle pain, fatigue, rashes, behavioral and emotional disturbance, and an inability to concentrate and learn efficiently (Gislason, 1986a). Reactions vary from imperceptibly mild to fatally severe and can be either chronic or acute.

Although all subjects suffer from the same condition, food allergy, each has an individual pattern of symptoms and sensitivity: individually prescribed diets are required. Each subject comes to the physician with his own pattern of symptoms -- both type and intensity -- and is found to be allergic to a particular array of foods. When he ingests a food that is an allergen for him, he will react in a unique way.

Determination of each subject's "safe" food list is a matter of carefully calculated trial and error. Symptoms are initially cleared through a two to three week period of strict adherence to the "core diet" described above. At this point, new foods are added and symptoms are carefully monitored. Those which provoke

a reaction are considered allergens and placed on the "unsafe" food list for that subject; those which create no symptoms are considered "safe". The physician guides the subject and his parent through this systematic trial procedure in a series of regularly spaced clinic appointments. Throughout this procedure, the subject's nutritional status is monitored through blood tests and food diaries, and supplements are prescribed as necessary.

Support for the family was provided by regular contact with the graduate student researcher responsible for assessment of the child's learning and behavioral status and by two parent meetings which included educational and feedback components.

Because the issue of compliance to treatment regimens, especially with children, is important in determining whether remission of symptoms is due to the treatment or to some other factor, it is important to undertake some assessment of the degree to which each subject maintained compliance with the treatment. Also important is the identification of those patients for whom compliance to therapy presents difficulties, in order to provide intervention designed to assist them on this diet. By determining the factors which are contributing to these difficulties, it is possible to design a compliance enhancement program which will address these factors.

The elements of this treatment, which must be considered in designing an assessment of compliance, are:

 This is a pediatric population so the treatment is largely administered by others. The behavior of the parents of the actual subjects must be surveyed, and the subject child must be viewed in terms of his membership within a family.

- 2. This is a long term chronic condition requiring a change in family eating behaviors.
- 3. There is no generalizable, reliable, and direct link between treatment and condition for all subjects. Consequences of noncompliance vary widely from subject to subject. A subject may comply with his diet and still experience symptoms by discovering a new allergen among foods previously considered "safe".
- 4. It is not possible to infer compliance to this treatment by physically measurable means as there are no laboratory tests which will indicated whether a patient is compliant with diet revision therapy.

C. STATEMENT OF THE PROBLEM

The present study investigated the factors influencing the degree to which families complied with an individually prescribed diet revision therapy for suspected food allergy. This was done through the development of an instrument based on factors derived from a review of the literature. Such an instrument would enable a health care professional to predict whether or not a particular patient would be likely to comply with treatment, thereby facilitating an appropriate and early intervention program to aid and encourage compliance.

II. REVIEW OF THE LITERATURE

A. INTRODUCTION

The following chapter describes literature which pertains to the assessment of compliance in this research context. The literature on compliance falls into two divisions. In the first section, methods used to assess compliance are reviewed with a view to selecting the most appropriate technique for this project. The structure of the assessment instrument is then derived. The second section is concerned with the factors which have been found to influence compliance, and their organization into general theories. The content of the assessment instrument is derived from this literature.

B. MEASUREMENT OF COMPLIANCE

A variety of measurement techniques is commonly used to assess the degree to which patients' behavior coincides with medical recommendations.

1. Types of Measurement

In cases of medication prescribed to be taken by a patient, it is possible to estimate compliance in a number of ways. These can be categorized into direct and indirect methods.

Direct methods include:

- Measuring the amount of medication present in a subject's body using a variety of laboratory tests.
- 2. Directly observing the patient taking the medication.

Indirect methods include four techniques:

- 1. Physically counting the amount of medication left and comparing to what should be left at that time in the treatment.
- 2. Measuring the treatment outcome.
- 3. Using clinical judgment.
- 4. Self-report of the patient.

2. Sources of Error

All the above methods of compliance assessment are subject to multiple sources of error. Some methods are more appropriate for particular patient groups and regimens than others. In general, direct methods may yield somewhat more accurate results, but indirect methods are often more practical (Gordis, 1979).

a. Laboratory Tests

Physiological tests, such as drug assays, are appropriate when the presence of drugs in the patients' bodies can be used to infer that they have taken prescribed medication. Error can result because the metabolism of drugs varies among individuals. The amount of drug found in blood or urine can also vary with the amount of time elapsed since the drug was taken, and is also affected by intervening factors such as food, exercise and stress. (Epstein & Cluss, 1982; Gordis, 1979: Olson, Zimmerman, & de la Rocha, 1985).

Laboratory tests are not applicable to the present research as no drugs are prescribed and biochemical assessment cannot reflect dietary compliance.

b. Direct Observation

Direct observation of patient behavior is an obtrusive procedure and may influence compliance. Gordis (1976) has commented on the reactivity to direct methods, where the patient becomes aware that his compliance is being assessed and changes his behavior in order to *appear* compliant. Since compliant behavior in this study involved daily eating habits, direct observation would have to have entailed unannounced visits to families timed to coincide with meal times. This was impractical.

c. Pill Count

The pill count, while easily quantifiable, simply proves that the medication is not in the bottle; it does not prove that it was taken as directed. Gordis (1979) points out that this information does little to pin down patterns of noncompliance, and is subject to falsification. Norell (1979) devised a mechanical medication dispenser which records the time of each use of an eyedropper in order to monitor compliance to a medication regime for glaucoma. Epstein and Cluss (1982) comment that, as sophisticated as this method appears, it actually measures use of the dispenser rather than use of the medication.

d. Treatment Outcome

Measurement of treatment outcome is a highly suspect method of measuring compliance. When there is a direct and proven connection between treatment and outcome, compliance with treatment can be inferred, but not proven, by successful treatment outcome and this inference must be interpreted with caution (DiNicola & DiMatteo, 1984). It should be noted that a high degree of correspondence between

treatment and outcome is rare, and even then, intervening variables must be ruled out to prove compliance.

Epstein and Cluss (1982, p. 968) note that "many patients who adhere are not under clinical control, and some who are under clinical control do not adhere."

Taylor (1979) found that 88% of controlled hypertensives were compliant with their regimes and that 34% of uncontrolled hypertensives were also compliant. Therefore, positive outcome should not be used as a compliance measure; rather, negative outcome can be used as an indication that compliance needs to be investigated.

e. Clinical Judgment

Clinical judgment has also proven to be a somewhat unreliable estimator of compliance. Physicians have been shown to regularly overestimate patient compliance, and in some cases, to be no better than chance (Blackwell, 1973; Charney et al, 1967; Caron & Roth, 1968; Norell, 1981). Witenberg, Blanchard, McCoy, Suls, and McGoldrick (1983), in their study of renal dialysis patients, found that clinical impressions (subjective ratings) of compliance were significantly higher than laboratory results (objective ratings) of compliance would suggest. Caron and Roth (1968) found that 22 of 27 doctors overestimated the compliance of their patients to an antacid regimen, and that there was a median correlation of just .01 between physicians' judgments of compliance and an objective measure of compliance (pill count).

However, Cummings, Kirscht, Becker and Levin (1984) found that when nurses were provided with results of patients' lab tests, they were able to predict compliance with more accuracy than either biophysical assessments or self-report.

f. Self-Report

Self-report of compliance to a medical regime is subject to all the sources of unreliability inherent in self-report of any behavior. The patient is likely to over-report the degree to which he is compliant and to under-report noncompliance (Gordis, 1976; Yoos, 1984). Norell (1981) found that patients who report noncompliance are usually at least as noncompliant as they report and that the actual proportion of noncompliant patients may be as much as two or three times higher than reported. Cummings et al. (1984) found patient self-report to be the least valid of the three methods of assessing compliance they investigated. Olson, Zimmerman, and de la Rocha (1985) refer to self-report as the least consistently reliable method of assessing adherence to a medical regime.

Gordis (1979) makes the point that when considering the inaccuracy of patient interview data, there is no evidence to suggest that there has been a deliberate attempt to mislead on the part of the patient. It could be the result of lack of memory for past actions, or because the patient actually thinks he has been compliant when in fact he has not clearly understood the regime.

On the positive side, Taylor (1979) in his study of compliance in hypertensive steel workers, found that self-report explained 52% of the variance in compliance measured against pill count. This is compared to 15% of variance explainable through other sources.

Radius et al (1978) report a correlation of .91 between parental report of drug administration and blood tests revealing the presence of that drug in asthmatic children.

Dunbar and Stunkard (1979, p. 415) feel that, when compared with other prediction techniques, "The best method currently is still to simply ask the patient

what he or she expects to do." As support for this, they cite Davis' (1968) study, which revealed that when patients were asked whether they intended to follow the advice of their doctors, 70% of them did as they predicted they would. Of his sample of 154 clinic patients, 55% said they would comply and did, while 15% said they would not comply and did not. A total of 77% said they would comply, while 23% said they would not. In both cases, congruent subjects outnumber noncongruent subjects approximately two to one.

Becker, Maiman and Kirscht (1977) found that, by asking mothers if they thought they would be able to keep their obese children on their diets, they were able to significantly predict weight loss.

g. Summary

The implication of this review of compliance measurement techniques, is that, with the sources of error inherent in all the techniques presented, the way to combat the unreliability of each of the above methods of assessing compliance is to use multiple methods. This is supported by major writers in the field (Cummings et al, 1984; Dunbar & Agras, 1980; Gordis, 1979; Marston, 1970; Rapoff & Christophersen, 1982; Sackett, 1979).

3. Selection of Methods

Although all methods of assessing compliance are subject to error, it is possible to select methods more appropriate to a particular project than others by considering the characteristics of the population being studied, the condition for which they are being treated, and the treatment regimen itself.

a. Population Characteristics

The present study involves a treatment applied to a pediatric population in their homes. The problem of estimating compliance in a pediatric population is quite different from estimating compliance in adult populations. For children, as for other dependent populations such as the elderly or the disabled, the behaviors, attitudes, and beliefs of "responsible others" are often the major determinants of patients' compliance (Becker & Green, 1975). Research has demonstrated that patients at the extremes of age are at greater risk for noncompliance (Blackwell, 1973; Haynes, Taylor & Sackett, 1979). We must also consider that children may not be cooperative with their parents' efforts at diet revision therapy, and may obtain 'unsafe' foods away from the home. The children's attitudes must also be considered.

Witenberg et al (1983) studied compliance in home-based vs. hospital clinic renal dialysis patients. They found that, despite the prevalent feeling that home-based patients were "doing better," the objective data showed that their compliance level was lower than that of patients who received their dialysis treatment in the clinic. The estimation of compliance with home-administered treatments is subject to error because of a lack of frequent and regular contact between the patient and the staff.

To determine the factors which influence a child's compliance to a medical regime, one must survey the characteristics of the person who is responsible for administering that regime. This is usually the child's parent and most often the mother (Litman, 1974). Cuskey and Litt (1980) describe the parent as mediating the doctor-patient relationship.

Deaton (1985) has found that the parents of asthmatic children make

compliance decisions based on their expert knowledge of their children's conditions and abilities, and that noncompliance is not always maladaptive. Her suggestion is that parents' expertise and awareness regarding their children's conditions be considered in compliance research.

b. Condition Characteristics

Characteristics of the condition for which a treatment is prescribed influence the methods that can be applied to measure compliance to that treatment. Chronic conditions which have no cure (asthma, diabetes, food allergy) require a different sort of compliance than acute conditions for which the treatment is direct, short term, and reliably results in positive change in that condition: otitis media, for example (Deaton, 1985; Becker et al, 1978). Chronic conditions require long term lifestyle changes, whereas treatment for acute conditions require short term behavior change. Assessment methods must be designed to reflect this difference by addressing the family lifestyle and the long term nature of the treatment.

Conditions in which the patient feels essentially symptom-free, such as hypertension, present a compliance problem different from conditions in which noncompliance results in swift and often severe negative consequences. The patient is not receiving direct feedback for compliance (or noncompliance) in asymptomatic conditions (Blackwell, 1973). The design of a compliance instrument must take into account the way in which the patient experiences the effects of compliance or noncompliance to his regimen. In the case of antibiotic medications, which must be taken over a seven to ten day course in order to be maximally effective, many parents of patients cite remission of their children's symptoms as the reason for prematurely discontinuing treatment. (Cuskey & Litt, 1980; Mattar & Yaffe, 1974;

Yoos, 1981, 1984). Charney et al (1967) report that a child who is asymptomatic has a less than 50% chance of completing the prescribed course of antibiotic.

c. Characteristics of the Regimen

Perhaps the single most important determinant of compliance is the regimen itself (Dunbar & Agras, 1980; Dunbar & Stunkard, 1979). Complex or long term regimes are shown to increase noncompliance (Epstein & Cluss, 1982). Treatments which necessitate the least amount of change in a patient's life are most often complied with (Davis, 1967; Haynes, 1979). It follows that it is more likely that a regime which requires adding a behavior, such as taking medication, is more easily complied with than a regime that requires restricting a previous habitual behavior -- diet change, for example. Hingson (1977) notes that a "prescription is easier than a proscription," and that regimens should be designed to fit within a patient's established routine, a point echoed by Padrick (1986). It is necessary to assess the degree to which patients have been able to incorporate the regime into their daily lives in order to truly assess compliance.

4. Conclusion

Several methods of compliance assessment were examined and considered for use in this research. Because each technique has its flaws and benefits, it was concluded that a combination of methods would produce the most valid and reliable estimate of a patient's level of compliance.

Direct observation, laboratory tests, and pill count are methods which had to be ruled out for this treatment. Treatment outcome cannot be used to estimate compliance, as the treatment procedure is diagnostic and designed to establish whether the subject is allergic to a variety of foods. Treatment is therefore not directly linked to symptom patterns as a reaction is possible to a newly discovered allergen. A patient might comply strictly yet still experience negative treatment outcome.

Remaining are indirect measures involving self-report and clinical judgment.

The self-report assessment was accomplished by questioning the parent responsible for administering the treatment, and was a combination of direct and indirect means for assessing factors which have been found to influence compliance.

The self-report assessment was treated in combination with estimates of compliance derived from clinical judgment. The physician estimated each patient's compliance as did the graduate student researcher who worked with the family. There were no restrictions on the information each rater could use in coming to their estimates.

C. FACTORS WHICH INFLUENCE COMPLIANCE

In this section of the review, literature reporting general studies of compliance with medical regimens was outlined, and integrated with factors found to influence the acceptability of behavioral treatment programs. In addition to these general factors is a series of factors concerned with patients' perceptions of their condition. These factors have been organized into a model, the Health Belief Model. This model and and its research literature will be reviewed, and discussed relative to this research.

The catalogue of variables which have been found to influence compliance to medical regimes is lengthy and overlapping (Cummings, Becker, & Maile, 1980). In general terms, three groups of variables can be said to determine how well a

particular treatment is carried out:

- 1. The nature of the patient population,
- 2. The nature of the condition for which the treatment was prescribed, and
- 3. The nature of the treatment prescribed.

a. Population Variables

Demographic variables such as education, income, marital status, and age have proven to be surprisingly uninformative in predicting a patient's compliance to a medical regime (Davis, 1967, 1968; Dunbar & Stunkard, 1979; Olson et al,1985).

Age is predictive of compliance only so far as extremes of age are concerned. Blackwell (1973, p. 250) reports that noncompliance is more common when the patient is "extremely young or extremely old." This may be influenced by the likelihood that the treatment will have to be administered by a third party as discussed previously. Cuskey and Litt (1980) agree that pediatric noncompliance is more common than adult noncompliance, but Mattar and Yaffe (1974) disagree. They posit that pediatric compliance is high, as parents value the health of their children more than they value their own health. Adolescents have been demonstrated to be less likely to comply than other young patients (Litt & Cuskey, 1980).

Since the subjects in this research are all between the ages of six and twelve, age is not likely to predict compliance in these subjects, but it would be necessary to survey the parents of these subjects regarding factors which influence their children's adherence to the treatment.

Education level has been shown to influence compliance to the extent that it is related to the ability of a patient (or his parent) to understand the treatment.

Radius et al (1978) found that mothers' education (more than 8 years versus less

than 8 years) was positively correlated with compliance to regimens prescribed for their asthmatic children.

Radius and her associates, in the same study, also found a correlation between marital status and compliance. Mothers who were married were more likely to be compliant with their child's regimen. Similar results were found by Becker, Maiman et al (1979) in their study of juvenile obesity. Radius speculates that this positive influence may result from the "various beneficial impacts which other family members can exert in encouraging medication adherence" as discussed in Becker and Green (1975).

Family support is widely held to be important in encouraging and maintaining compliance to positive health regimes such as weight control, dental care, alcoholism treatment and prescribed exercise (Becker & Green, 1975; Becker et al, 1978; Davis, 1967, 1968; Dunbar & Stunkard, 1979; Haynes, 1976; Norbeck, Lindsey, & Carrieri, 1983). The positive influence of family support may be the result of increased supervision of the regime's administration by the supportive family member, including "environmental control" techniques such as restricting the availability of "unsafe" foods; by the family member acting as a "stimulant" or encouragment to the treatment; or simply by helping in day-to-day administration of the regimen.

Wallston, Alagna, DeVellis and DeVellis (1983) consider social support from all sources -- family and clinical -- as important facilitators of adherence. They conceptualize support as quantitative versus qualitative (the amount of support versus the perception of the "goodness" of the support) and instrumental versus expressive (material aid versus emotional support).

Such psychological characteristics of patients as beliefs, attitudes and perceptions have been found to influence compliance and are reviewed in the

section below on the Health Belief Model.

b. Condition Variables

Features of the disease process which have shown themselves to be significant in the prediction of compliance are the duration of the disease, the severity of the disease, the salience of the symptoms and the nature of the consequences of noncompliance.

The most consistent finding is that compliance decreases over time. Within a short-term antibiotic regimen, Charney et al (1967) found that 81% of patients were compliant at the fifth day while 56% were still taking their medication on the ninth day. Sackett and Snow (1979) give 62% as an average compliance rate for short term regimens while they list 54% as average for long term treatment regimens. Blackwell (1973) states that "in chronic illness, forgetfulness, complacency, or boredom can all contribute."

Taylor et al (1978) found with hypertensive steelworkers that after 12 months, the distribution of compliance among their subjects was roughly U-shaped with one third being completely noncompliant, one third being compliant, and the remaining third being distributed over the rest of the continuum. This result has been found in other studies and appears to be a generalizable finding (Cuskey & Litt, 1980; Sackett & Snow, 1979; Taylor, 1979).

In treatment for acute conditions, compliance with the prescribed regimen usually produces symptomatic relief and is therefore reinforced. In long term chronic conditions, or conditions for which treatment is prophylactic in nature, this direct reinforcement is not available. Compliance is not reinforced, but noncompliance (eg. eating a proscribed food) may be immediately reinforcing (Olson et al, 1985). This

is perhaps an even more pronounced problem in the case of conditions like asthma where, even though a patient may be completely compliant, it is not possible to avoid asthmatic attacks (Becker et al, 1978; Deaton, 1985). It is generally difficult to maintain long-term compliance with regimes which have uncertain efficacy, a characteristic common in chronic conditions.

The acceptability of a treatment has been thought to be related to its effectiveness. Witt and Elliott (1985) propose a reciprocal relationship with effective treatments being acceptable, and acceptable treatments being used with integrity, thereby contributing to effective results. Yeaton and Sechrest (1981) suggest that effectiveness is a major factor that a consultant must consider when selecting a treatment and that the strength and ease of administration (as it affects integrity of treatment) are determinants of that effectiveness. The research on this connection between efficacy and acceptability has, however, produced mixed results.

Kazdin (1981, Experiment 1) studied the effect of therapeutic effects on treatment acceptability. Undergraduate psychology students were given brief case histories followed by a statement indicating either strong or weak treatment outcomes. They were then asked to rate the treatments for acceptability. No significant effects were found for treatment efficacy. This study has been criticised (Von Brock & Elliott, 1987; Witt, 1986) for restriction of range of both effectiveness and severity of problem.

Shapiro and Goldberg (1986) studied the effectiveness and acceptability of three group contingency programs for improving spelling in sixth graders. There was no significant difference in effectiveness among the three treatments, but one was clearly more acceptable to the students who had experienced all three programs. The students were judging acceptability on a treatment characteristic other than

efficacy.

VonBrock and Elliott (1987) addressed the relationship between acceptability and effectiveness. They found first that they could differentiate between acceptability and perceived effectiveness using the Behavior Intervention Rating Scale. They provided written case studies to 216 teachers. The case studies described a behavior problem (mild or severe), the treatment used (one of three classroom interventions), and either a general statement as to the usual effectiveness of that particular treatment or no effectiveness information. The results indicated a relationship between effectiveness and acceptability when problem severity is considered, but in unexpected direction. The teachers gave higher acceptability ratings to interventions which were accompanied by effectiveness information when these interventions were linked with mild behavior problems. No significant effects were noted for severe problems, indicating that teachers may be more likely to choose a new treatment for mild problems, but are perhaps less willing to consider alternatives in the case of a severe problem, relying rather on past experience. An implication of this study is that treatment acceptability (and, by extension, outcome) may be influenced by providing effectiveness information, which is best done before the teacher perceives the problem as severe.

VonBrock and Elliott (1987) also found in this study that teachers tend to rate as less effective those interventions that they view as less acceptable for any reason. Witt (1986) suggests that "perceived" effectiveness may be more important in determining acceptability than actual data.

Reimers et al (1987) see the above phenomenon as a concern when using analogue or pretreatment studies to assess acceptability. They state: "If a treatment's acceptability depends primarily on the outcome (effectiveness) of treatment, then

assessing acceptability before the fact may be irrelevant" (p.221). Experience using a treatment will undoubtedly influence eventual acceptability of the treatment in other instances. They suggest that acceptability should be assessed both while treatment is in progress and after treatment as the interim effects of the treatment will likely determine its acceptability, integrity, and further effectiveness.

The severity of a condition influences compliance in that, if the patient (or his parents) or the physician feels that the condition is severe, compliance is more likely (Rapoff & Christopherson, 1982; Cuskey & Litt, 1980; Olson et al, 1985). This was demonstrated by Charney et al (1967) who found that the parent's perception that the condition was severe was associated with high compliance levels. Haynes et al (1979) found that physician's perception of severity does not correlate well with compliance, but Becker and Maiman (1980) state that the patient's perception of severity does predict compliance. Deaton (1985) demonstrated that physicians' estimates of severity predicts compliance with medications but not with behavioral recommendations. This perception by the parent of the severity of the child's condition is an integral feature of the Health Belief Model.

Other authors (Yoos, 1981; Olson et al, 1985) have suggested that severity leads to mixed results in compliance. Olson et al (1985) state that severity only appears to influence compliance when the illness is assumed to be terminal, as in the case of cystic fibrosis.

The severity of a behavior problem has also been shown to influence acceptability of treatment programs designed to modify the behavior of a child in a school setting. When teachers and parents perceive the child's behavior problem as severe, they are more likely to find a proposed treatment acceptable. This has been demonstrated in analogue studies by Frentz and Kelly (1986), Kazdin (1980), Martens,

Witt, Elliott, and Darveaux (1985) and Witt, Moe, Gutkin, and Andrews (1984).

c. Treatment Variables

Features of the treatment regime have been called the most important determinants of compliance (Dunbar & Agras, 1980). Components of the treatment regimen which have been shown to effect compliance are duration of therapy, schedule and complexity of the regime, the type of regime (medication, diet, exercise, etc.), and side effects.

Duration of regime has been linked to poor compliance. The longer the treatment continues, the poorer the level of compliance (Olson et al, 1985). This has been discussed in a previous section dealing with chronic conditions for which long term treatments are prescribed.

Complexity of the treatment is also negatively related to compliance. Blackwell (1973) reports that patients taking three or more medications per day are less likely to adhere than patients taking fewer medicaitons, and that the more frequently the medication is to be taken, the less regularly it will be taken. Two factors could be operating to create this effect:

- The more complex regimen is more difficult for the patient to learn and remember, and
- 2. The more complex regimen is more disruptive to the patient's daily routine. Recommendations to combat this problem are that the regimen should be simplified wherever possible (Blackwell, 1979), and should be tailored to fit the individual (Becker & Maiman, 1980; Dunbar & Stunkard, 1979; Hingson, 1977).

In their review of behavioral treatment acceptability, Witt and Elliott (1985) state: "As a general rule, treatment integrity appears to vary as an inverse function

of treatment complexity" (p. 266). They suggest that teachers, and others responsible for administering treatment, tend to modify treatments in order to make them more acceptable; complex regimens require much teacher time and skill and are less acceptable than simple regimens which require less time and skill (Elliott, Witt, Galvin & Petersen, 1984; Witt & Martens, 1983; Witt, Elliott, & Martens, 1984).

A related finding by Elliott et al (1984) is the interaction between problem severity and treatment complexity, with the most complex treatment (token economy, in this instance) being rated the most acceptable treatment for the most severe problem (destroying property). Also, the least complex treatment (praise) was considered most acceptable for the least severe problem behavior (daydreaming).

Happe (1983) uses an "energy" metaphor to discuss different behavioral treatments. He suggests that interventions which require a high level of time, skill, and resources (high energy treatment plans) are more acceptable for severe behavior problems than for moderate or mild problems. He interprets this to mean either that "the plan requires too much 'energy' in an absolute sense or too much 'energy' in relation to the problem" (p. 34), and suggests that consultants should recommend the least costly -- in terms of time, skill, and resources - intervention plan which will be effective, analogous to tailoring the medical regime to fit the patient's lifestyle.

The type of regimen prescribed for various conditions varies widely. Common regimen types are drugs in various forms (pills, liquids, injections), diets, exercise programs, behavioral modifications, and lifestyle changes. Hingson (1977) makes the comment that "prescriptions" are more easily complied with than "proscriptions". In other words, adding a new behavior is easier than eliminating a previously habitual behavior. Davis (1967) noted that, among three recommendations made to cardiac

patients, change in personal habits such as smoking was the last to be complied with. His cognitive dissonance analysis of compliance leads him to state that "To reduce dissonance, an individual will choose to comply with those regimens which necessitate the least amount of change in his life."

Sackett and Snow (1979) have also noted generally lower levels of compliance with "lifestyle" regimens. The treatment of question in this project is just such a lifestyle regimen: a diet. Becker, Maiman, and Kirscht (1977) report that dietary regimens are notable for poor compliance. Glanz (1979) enumerates several features of diets which are associated with low compliance. Diets tend to be: (a) restrictive of previous habits, (b) of long duration, (c) complex, (d) intrusive into family lifestyle, and (e) unlikely to produce dramatic symptom relief.

Although the child's mother administers diet revision therapy by preparing the child's meals and snacks, the child is still able to obtain and eat 'unsafe' foods from various sources. It is important to survey the characteristics of the child that would influence his compliance with this treatment: the way he normally complies with directions from his parents, the amount of peer pressure he feels to 'cheat' on his diet, and his attitude toward the diet, among other things.

Side effects are often thought to have a negative impact on compliance, but this relationship is not as strong as one would expect (Cuskey & Litt, 1980; Dunbar & Agras, 1980), comprising only 5 to 10 % of the reasons patients cite for noncompliance (Sackett, 1979). Blackwell (1973) on the other hand, believes that side effects, when they are severe, play an important role in influencing noncompliance. Yoos (1984) found side effects were the reason most frequently given by mothers for stopping antibiotics treatments for their children. She suggests, though, that this may be a socially acceptable response. (A more pertinent study

would be to determine what proportion of the people who experience side effects discontinue treatment.)

Side effects have been shown to negatively influence the acceptability of behavioral programs as well. Kazdin (1981, Experiment 2) found that, as the severity of side effects of a treatment increased, the acceptability was reduced. Side effects described included emotional reactions and aggressiveness, such as crying or throwing things when treatment was administered.

Witt and Martens (1983) found that amount of risk to the target child and negative effects of treatment on other children were two factors negatively influencing the acceptability of behavioral interventions in classroom situations.

Side effects of treatment in one setting may appear in another context as found by Forehand, Breiner, McMahon and Davies (1981, cited in Witt & Elliott, 1985). Children who had been in a home-based program to eliminate oppositional behavior were found to have increased levels of inappropriate behavior at school. In the present research, children may be seen to be improving in school, but their behavior ar home may deteriorate, or vice versa.

d. Summary

There are several features inherent in this research project which have been shown in other studies to influence compliance. Among these are: subjects' age, which determines that the treatment must be provided by their parents: the long term and habit changing nature of the regimen: the subtlety and variety of most of the symptoms: and the complexity of the program in its individually prescribed variations.

D. THE HEALTH BELIEF MODEL

The Health Belief Model (HBM) was developed in response to concern in the 1950's and 1960's for explaining certain preventive health behaviors such as having TB tests, Pap smears and immunizations (Rosenstock, 1974), This model is presently an important theory upon which much of the research into compliance with health care recommendations is based (Becker et al, 1979). The Health Belief Model is founded in social psychology and behavioral theory and incorporates decision-making concepts, "wherein behavior is predicted from both the individual's valuation of an outcome and the expectation that a specific action will result in that outcome" (Becker et al, 1977, p. 349).

1. Components of the Health Belief Model

The HBM, as originally formulated, is concerned with predicting the likelihood of an individual taking preventive action to avoid a particular disease threat (Rosenstock, 1974) and as such is comprised of the individual's perceptions of:

- 1. his level of personal susceptibility,
- 2. the severity of the particular disease,
- 3. the benefits to be derived from preventing the disease,
- 4. the barriers to preventing the disease, and
- 5. some stimulus to provoke the individual to take a preventive action.

This model was directed at explaining an individual's desire to avoid an illness. To extend the theory to explain compliance with recommendations to treatment of an already diagnosed condition, Becker and Maiman (1975) revised the HBM to include

- 1. general health motivations,
- 2. the value of illness threat reduction, and
- 3. the probability that compliant behavior will reduce that threat,

as factors indicating an individual's "readiness to undertake recommended compliance

behavior" (Becker and Maiman, 1975, p.20). They identified several modifying and enabling factors:

- 1. demographic variables,
- 2. structural variables of the regime,
- 3. attitudes including satisfaction with the treatment
- 4. interaction with the health professional
- 5. enabling variables such as prior experience and support, etc.

Examining all these factors, they felt it would be possible to predict the likelihood of compliance with prescribed regimens (Becker et al, 1977; Becker et al, 1978; Taylor, 1979).

Thus, the HBM suggests that, in order for patients to undertake a treatment program, it is necessary for them to be concerned about health matters in general and be willing to follow the course of treatment. They must also believe that they are vulnerable or susceptible to the illness or condition in question and that it poses a threat to them. Finally, they must believe that, by following the prescribed treatment, they will reduce the likelihood of being adversely affected by the illness or condition.

At this point, once readiness has been established, modifying and enabling factors are called into play. These are the factors that influence how easy it will be for patients to follow the regimen that has been suggested to them once they have decided to do so.

Age has been shown to be the main bio-demographic variable which influences compliance, with extremes of age and youth predisposing to less compliance (Blackwell, 1973; Haynes, Taylor & Sackett, 1979).

Level of education, as it affects understanding of the regime to be followed (Becker, Drachman & Kirscht, 1972), will influence the ability of the patient to conform to treatment regimens. Reimers et al (1987) regard good understanding as

prerequisite to compliance in their proposed model for acceptability.

The structural variables of the regimen which have an impact on compliance involve the complexity of the regimen and the ease with which the regimen can be accommodated in the patient's daily routine.

2. Criticisms of the Health Belief Model

Controversy exists regarding the theoretical importance and clinical utility of the HBM in predicting compliance. Indeed, Dunbar and Stunkard, in their 1979 article, include an addendum outlining the disagreement between the two authors regarding this theory. Their disagreement rests on Dunbar's feeling that, while correlations between the HBM variables and compliance are significant, they are too low to explain much variance, that variables involving non-belief items such as doctor-patient relationship and prior experience are more significant, and that attitude change following behavior change is more prominent in the research (Taylor et al, 1978; Dracup & Meleis, 1982) than attitudes predicting behavior. Stunkard agrees that much of Dunbar's argument is tenable while maintaining the need for the HBM as a theoretical framework for future research that may be amended in the process.

Stone (1979) comments that the functions which relate the HBM variables are not specified; therefore it is not possible to make absolute quantitative predictions based on the HBM, only relative predictions. That is "If perceived threat is increased (or higher for one group than another), likelihood of action will increase (or be higher for the appropriate group)." (Stone, 1979, p. 73.)

Wallston and Wallston (1984) echo Stone's (1979) concern regarding lack of specification of the relationships between the variables and add their own concerns

regarding lack of consistent operationalization of the variables. They regard the HBM as a catalogue of variables rather than a model.

Cummings, Becker, and Maile (1980) investigated the 109 variables described by 14 models of health behavior and subjected them to Smallest Space Analysis upon evaluation by expert judges. Remarkable agreement on the clustering of variables into six broad groups was noted, which the authors cite as supporting multidimensional scaling of the determinants of health behaviors into a unified framework. "The six factors include (1) accessibility to health care, (2) evaluation of health care, (3) perceptions of symptoms and threat of disease, (4) social network characteristics, (5) knowledge about disease, and (6) demographic characteristics" (Cummings et al, 1980, p. 138).

There is considerable overlap between these factors and the components of the HBM. 'Evaluation of health care' incorporates elements of belief in treatment and benefits of treatment. 'Access to health care' can be considered a constant in this research as all the subjects saw the same doctor and cost was not a factor due to universal medical insurance.

3. Research Using the Health Belief Model

The Health Belief Model has been tested in a variety of contexts to predict compliance with many different types of medical recommendations, among them are studies involving children and long term regimens. These will be discussed in terms of their applicability to the present research.

a. HBM and Antibiotics

Becker, Drachman, and Kirscht (1972) studied health beliefs and compliance in a random sample of 125 otitis media cases at a hospital child care clinic. The children, aged 6 weeks to 10 years, were placed on an antibiotic regimen free of charge, and requested to return for a follow-up visit. Mothers were interviewed immediately after this visit to assess the HBM variables and the mother's knowledge of the regimen prescribed. Urine samples were collected from 59 subjects during unannounced home visits on the fifth day of the treatment. Results of an antibiotic assay indicated a 49.1% compliance rate. Follow-up appointments were kept by 40.7% of the sample. The HBM variables were compared with a dual compliance measure: (a) knowledge of regimen assessed at interview and (b) drug assay results and appointment keeping.

In general, the HBM variables were predictive of compliance. Mothers who complied with the regimen (medication and appointments) were more likely to be concerned about their child's health, to feel that the present illness was a threat to their child, and to believe that the physician was competent and that the treatment would be beneficial, among other things.

As mentioned previously, Charney et al (1967) determined that the parents' perceived severity of the child's illness positively influenced compliance to an antibiotic regimen.

b. HBM and Asthma

Asthma treatment is similar to treatment for food allergy in several respects. Both are long term treatments involving fairly complex lifestyle modifications and are often of uncertain efficacy. The severity of symptoms and episodes ranges from mild

to severe and is variable within individuals and over time. Deaton (1985) suggests that asthma "may serve as a prototype for other chronic illnesses" (p. 3) of childhood. (A possible difference between food allergy treatment and asthma treatment is that on a food allergy diet, children often administer their own treatment!)

Becker et al (1978) investigated mothers' health beliefs and their compliance with regimens prescribed for their asthmatic children. The sample consisted of 111 of the 117 children who were brought to an emergency facility for treatment of an asthmatic attack during a 5 month period. The children ranged in age from 9 months to 17 years (mean = 7.7 years) and had been previously diagnosed as asthmatic. A parent interview was conducted to assess health beliefs and determine self-reported compliance. Blood tests to determine the presence of theophylline (a drug prescribed to prevent asthmatic attacks in these children) were performed on 80% of the children to give objective corroboration to the self-report of compliance. These two compliance measures were correlated r=.913, lending validity to the mothers' reports.

The results of this survey reveal that, even in a situation where compliance does not result in complete remission, the HBM variables are predictive of compliance levels. Significant associations were noted between compliance (objective and subjective) and variables grouped under the topics (a) general health motivations (b) perceived illness threat (c) perceived benefits and (d) perceived barriers. As expected, only two of the demographic and predisposing variables (mother's education and marital status) were associated with compliance.

c. HBM and Diet

The Health Belief Model has been studied in pediatric dietary regimens. Morse, Sims, and Guthrie (1979) investigated the HBM components with regard to mothers' compliance with physicians' recommendations on feeding their infants and found the HBM to be generally supported. The responses of breast feeding and bottle feeding mothers were analyzed differentially. It appears that for bottle feeding mothers, compliance and nutritional knowledge are positively correlated, while breast feeding mothers scores on health concern and importance of nutrition and positively associated with compliance, but nutritional knowledge is not. This finding can be interpreted by inspecting the nature of the physicians' nutritional advice which appears not to have been consonant with current best practices in infant feeding, practices which the breast feeding mothers were more likely to adhere to. This is an instance of the "adaptive noncompliance" discussed by Deaton (1985).

Becker, Maiman and Kirscht (1977) studied dietary compliance and health beliefs in a group of 182 mothers whose children were referred to a clinic dietician for treatment of obesity. The children ranged in age from 19 months to 17 years. The health beliefs of the mothers were determined through a standardized one hour interview. An intervention, in the form of a pamphlet presenting either low or high levels of 'threat' of obesity was given to randomly selected groups of parents following the interview: Control group subjects received no intervention pamphlet.

Measures of weight loss at each of four follow-up visits were used as estimates of compliance to diet, and represent a potential criticism of the study as outcome measures are not reliably related to compliance. A second analogue of compliance was a ratio of long range (12 month) clinic appointment keeping, other than dietician's appointments. A dropout rate of 38% was encountered in the

course of the study but the authors claim that statistical analyses of the information available on the dropouts reveals no differential attrition factor operating.

Indices of general health motivations, perceived susceptibility, perceived severity, perceived benefits, perceived barriers and demographic variables were correlated with the compliance variables and, with the exception of demographics, supported the model, perceived barriers being the least strongly associated of the HBM indices. Of the demographic variables, only age of the child and mother's marital status were positively associated with compliance as measured by success on the diet but not by appointment keeping. The finding that the older children were more successful on the diet was not expected but could be due to the older children responding to the social desirability of losing weight.

The fear arousal intervention appeared to have a positive effect on weight loss, the children of mothers who received the high fear arousing pamphlet losing the most weight. This could be seen as increasing their perceived severity of overweight, although this was not discussed in the study.

4. Summary

Research using the Health Belief Model has generally found the major components of the model to be supported. However, each component has been tailored to fit the individual research context. Thus questions of perceived susceptibility and severity, etc. must be changed for each piece of research, limiting the generalizability of the model across situations.

Use of the Health Belief Model to predict compliance levels in pediatric food allergy therapy was thought likely to be effective based upon the research examples examined. The health beliefs of the parents of the children involved in

this treatment, specifically their perception of the severity of their children's food allergies along with the benefits they believe are to be derived from this treatment, are expected to be associated with compliance to the diet revision therapy. Also expected are relationships between compliance to the diet and the parents' subjective perception of the difficulty they find in integrating this treatment into their family life and the cooperation or resistance they find in their child. The amount of support the parents feel from their contact with the doctor, other personnel in the study, and from their social contacts in regard to this treatment are likely to facilitate compliance as are the general health motivations of the parents.

III. INSTRUMENTATION

In order to fulfill the purposes outlined in Chapter I, it was necessary to construct an instrument which would assess the factors which the literature leads us to believe would influence a family's compliance to diet revision therapy for food allergy. This chapter outlines the steps taken in developing the instrument and establishing reliability and construct validity through administration of the instrument in a pilot study, revision of the instrument, subtest or construct validation and readministration of the instrument to the entire sample prior to final revision.

Ratings were collected from parents, researchers and the physician concerning each subject's compliance. The method of collecting these ratings is described.

First, the research sample is described.

A. SAMPLE

The sample used in this study was drawn from among those 200 parents who responded to a newspaper article describing a proposed research project which would investigate the relationship between food allergies and learning and behavior difficulties. (Appendix I) The first forty-eight subjects who were examined by the physician and found to exhibit symptoms of food allergy and reported to be distractible were invited to participate. Participating parents granted permission for psychological and educational testing of the child.

All subjects lived within a large metropolitan area, within commuting distance from both the doctor's office and the university. There were two exceptions: they lived approximately one and a half to two hours dirve both facilities.

At the start of the study, the children ranged in age from 6 years 4 months to 11 years 9 months. The mean age of the subjects was 9 years 6

months. All but one subject were in attendance at elementary schools. The exception was receiving tutoring at home.

The sample was composed of 33 boys (73%) and 12 girls (27%).

B. RATINGS

In addition to the questionnaire responses, ratings of each child's estimated compliance level were obtained from three sources:

- 1. the child's parent (parental self-report) (SR),
- 2. the graduate student or psychologist researcher who worked with the family (RQ), and,
- 3. the physician who prescribed the diet revision therapy and treated all the subjects (MD).

All ratings were made on a scale with points ranging from 0 to 10. The parents were asked to respond to the item below as the last item on the Diet Revision Therapy Parent Questionnaire (DRTPQ); (Appendix A):

"If 0 represents 'never follows the diet' and 10 represents 'always follows the diet exactly,' how well does your child follow the diet, overall?"

The researchers and the physician were given a rating protocol, presented in Appendix B, with the question:

"How well has this subject complied with all aspects of this study?"

Also provided on the rating protocol are general descriptions of four anchor points along the 0 - 10 scale. Results of this rating procedure are presented in Table 3-1.

Table 3-1

Means, Standard Deviations and Intercorrelations of Compliance Ratings

and DRTPQ Scores

Rater	Mean	S.D.	Parent	Researcher	Physician	DRTPQ Total
Parent	7.4	2.4	100	73	66	68
Researcher	5.8	3.1		100	63	63
Physician	6.2	3.5			100	56

- Note 1. The entire range of rating scale points (0 10) was used by all three categories of raters.
- Note 2. Correlations are presented with decimals omitted and rounded to two places.
- Note 3. Correlations with the DRTPQ Total are based upon the final 38-item version of this test which has a mean of 112.11 and a standard deviation of 13.23.

The ratings are moderately highly correlated with one another and with the total Diet Revision Therapy Parent Questionnaire (DRTPQ). The three ratings were treated as separate variables in subsequent analyses.

C. INITIAL QUESTIONNAIRE CONSTRUCTION

The construction of the test consisted of five steps, each building on the previous step. The five steps were:

- 1. item generation,
- 2. pilot administration and analysis,
- 3. test revision,
- 4. administration,
- 5. analysis and final revision.

1. Item Generation

Items were written to assess different components of the Health Belief Model (Becker & Maiman, 1975), as well as other facotrs logically derived from the literature. The initial item pool consisted of 47 statements drawn up to fit the following general categories:

- 1. Social Support Systems The extent to which the parent has support from family and friends in using this diet. (7 items)
- Relevant Health Beliefs The regular health promoting beliefs and habits of the family. (5 items)
- 3. Lifestyle Congruence The ease with which the family can accommodate the diet revision therapy within their day-to-day life. (7 items)
- 4. Belief in Treatment The extent to which the family believes that the treatment will be effective in helping their child. (8 items)
- 5. Perceived Severity The severity the parent ascribes to the child's allergies. (2 items)
- 6. Optimism, Ease, and Committment The optimism the parents express regarding the outcome of the diet, the ease they feel in keeping their child on the diet, and their opinion as to how successful he or she will be on it. (7 items)
- 7. Positive Child Attitude The attitude of the child toward the diet. (7 items)
- 8. Locus of Control The degree of control the parents assume over the events in their lives. (4 items)
- 9. Estimate of Compliance Items also included in other subtests which ask the parents to estimate the degree of compliance to the diet that they and their child are able to maintain. (3 items)

Items were revised on the basis of critiques received from persons knowledgeable in test construction and/or the project of interest. Guidelines for writing and reviewing Likert or agree-disagree format items from Crocker and Algina (1986, p. 80) were followed.

The 47 statements were arranged in questionnaire format with items from different categories interspersed to prevent the formation of a response set. A series of 4-point Likert-type scales were devised because items could be best answered by a responses describing frequency, quantity, agreement, etc., and the items were grouped under the appropriate scale. Twenty-eight items were positively worded and nineteen were negatively worded. While it is desirable to balance the number of positively and negatively worded items (Crocker & Algina, 1986) this was not possible to do without sacrificing clarity of content. The resulting initial form of the questionnaire is presented in Appendix C.

2. Pilot Administration and Analysis

The parents of twenty-two of the study children attended an evening meeting at the University of British Columbia on February 17, 1987. At that time, the children had been on the diet from one to six weeks. These parents were requested to complete the questionnaire at that time. They were told that the researcher was interested in finding out "what factors make it easier or more difficult for families to follow the diet revision therapy." Comments were invited from the parents with regard to the effect of the diet on their child and any problems they may have been experiencing with the diet revision therapy.

The 22 completed questionnaire protocols were analyzed using LERTAP (Nelson, 1974) to determine the item means and standard deviations, item validity

(point biserial correlations with subtest and total test), subtest reliability (Hoyt's Anova, a measure of internal consistency) and total test reliability (Hoyt's Anova and Cronbach's Alpha for a composite.) The results of this analysis are summarized in Table 3—2.

Table 3-2Analysis of Pilot Data by Subtest

Subtest	No. of Items	Mean	S.D.	Hoyt's Rel.	S.E.M.
1. Social Support	7	19.18	2.08	.09	2.11
2. Relevant Health Beliefs	5	9.41	1.62	.00	1.57
3. Lifestyle Congruence	7	19.14	2.55	.38	1.87
4. Perceived Severity	2	5.91	1.19	.00	.92
5. Optimism, Ease, Commitment	7	19.41	2.72	.27	2.15
6. Belief in Treatment	8	27.09	3.49	.67	1.86
7. Positive Child Attitude	7	19.00	3.94	.68	2.06
8. Locus of Control	4	12.00	1.07	.00	1.00
9. Estimate of Compliance*	3	9.36	2.34	.46	1.40
Total Test	50*	140.40	9.27	.59**	5.89

^{*} This subtest was composed of three items also included in other subtests. The items ask parents to estimate whether or not their child is complying with the diet. The 47 items, therefore, are counted as 50 items in the total test.

The subtest internal consistency figures suggest that the subtest structure originally designed was weak. This may have been due to the small number of items in each subtest, or to the content and wording of the items themselves.

The individual items were inspected with regard to the following criteria:

- 1. at least moderate correlation (> .3) with subtest or total test,
- 2. moderate degree of distribution over the four scale points. (That is,

^{**} The Hoyt's reliability for all 50 items as a single subtest is .59. Cronbach's Alpha for reliability of a composite is .37.

responses spread over at least 2 or 3 points and no more that 80% of the respondents choosing one response point), and

3. apparent contribution to content validity.

Twenty items met these criteria and were selected to remain in the test and form the core items of the revised version. These items are marked with a (*) in Appendix C.

These 20 items were then grouped into three logically derived subtests. The subtests were based on three of the most successful (greatest internal consistency) subtests from the first version and are divided into items which relate to the parents' and families' feelings about the diet (PF), the child's reactions to his treatment (CF), and parents' beliefs that the treatment will benefit their child (BT). The responses to these 20 items were again subjected to LERTAP analysis and the results are summarized in Table 3—3 below. The new organization represents a substantial improvement in reliability over the initial version of the test; it is referred to hereafter as the 'Core Item Test', as it was used to form the core of the subsequent revisions.

Table 3-3

Summary of Core Item Test by Subtest

Subtest	No. of Items	Mean	S.D.	Hoyt's Rel.	S.E.M.
1. Parent and Family (PF)	5	14.77	2.99	.70	1.48
2. Child Factors (CF)	9	23.64	5.08	.75	2.38
3. Belief in Treatment (BT)	6	19.77	3.37	.75	1.53
Total Test	20	58.18	9.16	.84*	3.54

^{*} Hoyt's Reliability = .84; Cronbach's Stratified Alpha = .68;

Table 3-4 presents the correlations between the subtests and indicates that there are moderate associations among them and that the correlation between the subtests and the total test is strong. Each subtest is tapping unique subject matter which contributes to the total test variance.

Table 3—4
Intercorrelation Matrix of Core Item Test

	1. P F	2. C F	3. B T	Total
1. P F	(.70)	.364	.482	.705
2. C F		(.75)	.502	.857
3. B T			(.75)	.803
Total				(.68)*

Figures in italics represent subtest and total test reliabilities.

D. TEST REVISION AND ADMINISTRATION

1. Revision Procedure

a. Subtests

A new subtest structure was designed using a framework of six content areas, and reflects further review of the literature, as well as the retention of valuable items and subtests from the core item version of the instrument.

1. Parent and Family Life Factors (PFL): The attitudes, characteristics, and behaviors of the parents and other family members which will affect their ability to help the target child comply with the diet revision. (11 items)

^{*} Cronbach's Alpha = .68; Hoyt's Reliability = .84.

- 2. Child Positive Factors (CPF): The degree to which the child himself cooperates with the diet, and has support from his environment which assists him in doing so. (11 items)
- 3. Medical and Social Support Factors (MSS): The degree of support the parents feel from the personnel in the study and the other individuals who are involved with their child; their faith in the medical profession. (5 items)
- 4. Belief in Treatment/Benefits (BTB): The belief parents have that the treatment (diet) is good for their children and that the results will be beneficial. (11 items)
- 5. Related Health Beliefs (RHB): The regular health-promoting habits and practices that the family engages in which make following this diet consonant with their beliefs and lifestyle. (5 items)
- 6. Perceived Severity and Susceptibility (PSS): The severity with which the parents view their child's condition and the likelihood they see of a reoccurrence of symptoms. (7 items)

b. Items

The 20 core items were retained as written in the pilot test. Using the new subtest structure as a base, sixteen of the original items were revised and included with changes, and fourteen new items were added after further review of the literature, especially the Health Belief Model tests using pediatric populations (Becker, Maiman & Kirscht, 1977; Becker et al, 1978; Morse, Sims, & Guthrie, 1979;). The second edition of the questionnaire therefore included a pool of 50 items and was designed along similar lines to the first edition. Questions on demographic and family structure variables were asked as an introduction to the questionnaire.

Comments regarding perceived results of the therapy and self-reported compliance estimates were requested after the items were rated.

2. Administration Procedure

The revised Diet Revision Therapy Parent Questionnaire (DRTPQ) was administered to parents of all children who participated in the diet revision therapy. Those parents (n = 15) who attended a parent meeting on April 9, 1987, seven weeks after the first meeting, were requested to complete the questionnaire at that time. They were told that this was part of a continuing project aimed at determining the factors which make it easier or more difficult for families to follow the diet revision therapy. They were also informed that the other parents, not attending the meeting, would also be asked to complete the questionnaire.

Parents who did not attend the meeting but whose children were still involved in the study (n = 19) were asked to complete the questionnaire in the clinic when they brought their child for a post-testing session.

Parents who had withdrawn their children from the food allergy and learning disability study or who had stopped following the diet were contacted by mail. They were sent a letter (see Appendix D) requesting their cooperation and a copy of the Parent Questionnaire. They were asked to peruse the questionnaire in preparation for a telephone call from the researcher who would obtain their responses to the items at that time. It was decided not to survey the parents of two children who were never actually on the diet despite making initial contact with the doctor. One parent was unavailable. Eleven questionnaires were completed in this manner.

Of an original sample of 48 subjects in the overall study, data was collected

E. ANALYSIS AND FINAL REVISION

Responses to the 45 questionnaires were subjected to item analysis using LERTAP. The LERTAP program was set up to include all 50 items in the revised subtest configuration. Item statistics arranged by subtest are presented in Table 3—5.

In order to validate the subtest structure of this instrument, the above description of the subtests was given to a panel of 20 raters along with a copy of the items. The raters were requested to choose the subtest in which they felt each item best fit. The protocol for the raters is included as Appendix E.

Percent agreement, defined as the percentage of raters who agreed with the original placement of the item, was calculated for each item by dividing the sum of correct ratings by the number of ratings received. An item with a percent agreement of 70% or greater was retained in the test. An item with percent agreement between 50% and 70% was considered for retention if it made significant contribution to the content of the test. All 20 core items from the pilot version of the test were retained to provide a means of investigating the stability of the factors being studied.

Items were also evaluated in terms of their relationship to subtest and total test results (item discrimination), and the amount of variance between subjects they contribute (mean and standard deviation). As in the pilot version, items with low correlations (<.3) or with a narrow range of responses were deleted.

This evaluation took place concurrently with the percentage agreement analysis procedure.

Table 3-5

Summary Item Statistics by Subtest: All Items

Subtest	Item No.	Core	Mean	S.D.	r ST*	r _{ТТ} *	P.A.*	Decision
PFL	1	C1	3.178	.834	.394	.527	95	Retain
	2	C 3	3.000	.739	.626	.658	60	Retain:A
	6	C7	2.311	.949	.390	.326	85	Retain
Hoyt's	7		2.667	.798	.680	.544	85	Retain
Rel. =	13		3.422	.500	.296	.411	80	Retain
0.73	15		2.200	.869	.301	.235	80	Retain
	18		2.556	.918	.483	.435	75	Retain
S.E.M.=	27		2.844	.737	.283	.201	85	Delete:B
2.43	33		3.200	.944	.132	.180	80	Delete:B
	40	C40	3.311	.874	.234	.325	85	Retain
	47		2.422	1.138	.450	.297	65	Retain:C
	(Subtest)		(31.11)	(4.92)				
CPF	5	C6	2.844	.903	.668	.782	75	Retain
	8	C8	2.400	.809	.683	.640	100	Retain
	14	C13	2.778	.951	.518	.295	85	Retain
Hoyt's	20	C19	3.022	.690	.744	.573	95	Retain
Rel. =	22	C20	2.800	.991	.604	.691	65	Retain:A
.89	24	C14	2.422	.917	.634	.638	95	Retain
	28		2.489	.895	.695	.521	100	Retain
S.E.M.=	29	C25	2.978	.783	.416	.150	95	Retain
2.09	32	C30	3.044	.825	.653	.433	95	Retain
	34	C27	2.822	.912	.838	.734	100	Retain
	36	C32	2.756	.802	.265	.247	90	Retain:A
	(Subtest)		(30.36)	(6.53)				
MSS	3		3.867	.405	.424	.415	95	Move to BTB
	10		3.578	.543	.473	.384	100	Move to BTB
Hoyt's	11		3.178	.684	.494	.438	50	Move to BTB
Reľ. =	12		3.778	.420	.165	.241	65	Delete:B
0.56	35	C31	3.773	.580	.131	.378	20	Move to PFL
SEM = .96	(Subtest)		(18.13)	(1.62)				_

...continued...

Table 3-5 continued

Subtest	Item No.	Core	Mean	S.D.	r ST*	r TT*	P.A.*	Decision
ВТВ	4	C5	3.222	876	.551	.502	85	Retain
	9	C9	2.978	.965	.660	.457	95	Retain
Hoyt's	17		2.867	1.140	.227	.230	45	Delete:E
Rel.=	37		3.578	.657	.305	.377	10	Move to PSS
.69	38	C38	3.533	.548	.643	.533	35	Move to PSS
	39		3.578	.657	.200	.267	80	Delete:B
SEM=	41		2.867	1.120	.061	.266	65	Delete:B
2.44	42		3.800	.405	.244	.086	35	Delete:B
	43		3.200	.919	.336	.545	85	Retain
	46	C44	3.44	.755	.572	.313	90	Retain
	48		3.178	.960	.280	.350	70	Retain
	(Subtest)		(36.24)	(4.36)				
RHB	16		3.311	.557	266	.177	85	Delete:B
	30		3.689	.514	.120	.261	60	Delete:B
Hoyt's	31		3.689	.701	.040	.339	85	Move to PFL
Rel.=	45		3.422	.812	074	.362	20	Move to PFL
0.0	50		2.333	.953	223	292	70	Delete:D
SEM=	(Subtest)		(16.44)	(1.47)				
1.48					•			
PSS	19		1.467	.548	.138	.200	15	Delete:B
	21		2.711	1.014	.437	.234	65	Retain
Hoyt's	23		1.733	.963	.470	.146	80	Retain
Rel.=	25		2.467	.944	.437	.455	90	Retain
.63	26		3.600	.780	.343	.371	65	Retain
SEM=	44		2.600	1.176	.203	.068	60	Delete:B
2.02	49		1.578	.866	.383	001	70	Retain
	(Subtest)		(16.16)	(3.57)				

Total Test

148.44 14.44

Hoyt Reliability = .85

Cronbach's Alpha = .59

Standard Error of Measurement = 5.48

Decision Comments:

A - Core Item; B - Insufficient Discrimination; C - Good Discrimination;

D - Negative Discrimination; E - Low Percent Agreement.

r_{ST} = Item-subtest correlation r_{TT} = Item-total test correlation P.A. = Percent Agreement

Seven items were deleted and five were transferred to other subtests on the basis of percentage agreement scores. Five further items were deleted due to inadequate (<.3) item discrimination. A further three items were moved because they were left in very small subtests (3 items or less) as a result of deletions. These items were placed in the subtest which seemed the most appropriate on the basis of logical analysis of the item content. Medical and Social Support and Related Health Beliefs lost too many items to be considered viable as separate subtests, and were combined with Belief in Treatment and Benefits and Parent and Family Life respectively.

In all, twelve items were deleted (12, 16, 17, 19, 27, 30, 33, 39, 41, 42, 44, and 50). The resulting test consists of 38 items, combined into 4 subtests. Twenty-seven items are positively worded and eleven are negatively worded.

The final 38 items were subjected to item analysis. Table 3–6 presents the item statistics for the resulting tests, and it summarizes the subtests. Table 3–7 describes the relationship between the subtests in this final version of the questionnaire.

Table 3-6

Summary Item Statistics by Subtest: Final Version

Subtest	Item No.	Core	Mean	S.D.	r ST*	r π*	Comments
PFL	1	C1	3.178	.834	.511	.558	
•••	2	C3	3.000	.739	.646	.693	
	6	C7	2.311	.949	.364	.319	
	7	C/	2.667	.798	.638	.553	
Hoyt's	13		3.422	.500	.357	.443	
Rel.=	15	C15	2.200	.869	.326	.251	
.75	18	CIJ	2.556	.918	.459	.417	
., 3	31		3.689	.701	.350	.347	From RHB
SEM=	35	C31	3.733	.580	.230	.347	From RHB
2.45	40	C40	3.733	.360 .874	.230	.396	HOIH KED
4.7J	40 45	C40	3.422	.874 .812	.296	.360	From RHB
	45 47		3.422	1.138	. 169	.360	пош кпв
	(Subtest)				.30/	.349	
	(Subtest)		(35.91)	(5.13)			
CPF	5	C6	2.844	.903	.668	.798	
	8	C8	2.400	.809	.683	.681	
	14	C13	2.778	.951	.518	.300	
Hoyt's	20	C19	3.022	.690	.744	.587	
Rel.=	22	C20	2.800	.991	.604	.697	•
.89	24	C14	2.422	.917	.634	.672	
	28		2.489	.895	.695	.531	
SEM=	29	C25	2.978	.783	416	.145	
2.09	32	C30	3.044	.825	.653	.437	
	34	C27	2.822	.912	.838	.763	
	36	C32	2.756	.802	.265	.268	
	(Subtest)		(30.36)	(6.53)			
BTB	3		3.867	.405	.207	.419	From MSS
	. 4	C5	3.222	.876	.556	.513	
Hoyt's	9	C9	2.978	.965	.665	.442	
Rel.=	10		3.578	.543	.608	.370	From MSS
.75	11		3.178	.684	.332	.417	From MSS
•••	43		3.200	.919	.390	.566	110111 14155
SEM=	46	C44	3.444	.755	.630	.300	
3L/VI — 1.77	48	C44	3.444	.960	.300	.344	
1.//	(Subtest)		(26.64)	(3.81)	.300	.344	
	(Subtest)		(20.04)	(3.01)			

...continued...

Table 3-6: continued

Subtest	Item No.	Core	Mean	S.D.	r ST*	r TT*	Comments
PSS	21		2.711	1.014	.354	.219	
	23		1.733	.963	.457	.134	
Hoyt's	25		2.467	.944	.436	.420	
Rel.=	26		3.600	.780	.431	.376	
.66	37		3.578	.657	.160	.351	•
	38	C35	3.533	.548	.261	.518	
SEM =	49		1.578	.866	.474	028	
1.82	(Subtest)		(19.20)	(3.37)			
Total			112.11	13.23			
	liablility = .8 s Alpha = .6						
Standard	Error of Meas	urement	= 4.66				

^{*} r_{ST} = Item-subtest correlation

Table 3-7
Intercorrelation Matrix of Final Version

Subtests	1.PFL	2.CPF	3.BTB	4.PSS	Total
 1.PFL	(.75)*	.455	.386	.193	.773
2.CPF		(.89)*	.336	.071	.785
3.BTB			(.75)*	.313	.684
4.PSS				(.66)	.455
Total					(.87)*
					(.61)**

Figures in italics represent subtest and total test reliabilities.

 r_{TT} = Item-total test correlation

^{*} Hoyt's Reliability

^{**} Cronbach's Alpha

F. SUMMARY

The final version of the DRTPQ contains 38 items arranged into four subtests which survey the reactions of parents of children participating in diet revision therapy. The four subtests provide reliable measures of factors which are believed to influence compliance with the diet revision therapy, and combine into an overall instrument which has high reliability (.87) as a total test, and moderately high reliability (.61) as a composite score.

The deletion of twelve items resulted in a slight increase in reliability, rather than a decrease as a result of making the test shorter. This signifies that the revisions -- deletion of items and changing the placement of items -- made definite improvements in the psychometric properties of the test.

The instrument's mean of 112.11 and standard deviation of 13.23, are evidence of the ability of this test to differentiate between subjects on the basis of factors which are believed to influence compliance to diet revision therapy. Total scores range from 82 (2.28 standard deviations below the mean) to 134 (1.65 standard deviations above the mean); although the distribution is slightly skewed, it appears to have normal shape.

The collection of ratings of estimated compliance levels enabled comparisons to be made between subjective perceptions of compliance, the most commonly available compliance estimates in clinical practice, and the subtests of the questionnaire. The use of three different raters provides evidence of the relationships between these different types of information.

The following chapter outlines the use of the DRTPQ to describe how the members of the sample in this study are differentiated with respect to the factors which influence compliance to diet revision therapy.

IV. ANALYSIS AND RESULTS

This chapter outlines the use of the instrument developed in the previous chapter in the analysis of factors which influence compliance to the treatment of food allergy.

To study the factors which influence compliance, members of the sample who exemplify both good and poor compliance based on subjective ratings were compared on the subtests of the instrument. Analyses of the ten subjects who dropped out of the treatment are made. A comparison between the subjective ratings of compliance and the subtest scores was carried out. The group of subjects who participated in the pilot testing of the instrument are compared with respect to their responses to the core items at both administration times.

A. CLUSTER ANALYSIS

Subjective compliance ratings by parent (parental self-report, SR) researcher (RQ), and physician (MD) were analyzed in order to form groups of subjects with similar patterns of ratings. The Statistical Package for the Social Sciences (SPSS, 1986) Cluster routine was used for this analysis.

Clusters were formed on the basis of the average linkage between groups. The program divided the sample first into two groups, then three, etc. until there were as many groups as subjects; that is, until there was no error, or dissimilarity, between group members. The four group solution was chosen as it resulted in the lowest coefficient of error without single member groups.

A description of the groups selected through this procedure is presented in Table 4-1.

Table 4—1.

Summary of the Differences Between Clusters

Cluster	n	Mean SR	Mean RQ	Mean MD	Mean DRTPQ	s.d.	Mean Age
A	24	8.8	7.6	8.8	118.2	9.8	115.3
В	8	<i>7</i> .1	6.1	2.0	110.2	14.0	111.1
С	10	6.4	2.6	5.3	105.3	12.0	111.4
D	3	0.3	0.3	0.0	90.3	1.2	122.3
Total	45	7.4 p<.0001	5.8 p<.0001	6.2 p<.0001	112.1 p<.001	13.2	114.2

The clusters, chosen on the basis of three subjective compliance ratings, are also illustrated in Figure 4–1. The cluster means of parental self-reports of compliance (SR) are fairly tightly grouped with the exception of Cluster D. The other three cluster means have a range of 8.8 to 6.4, approximately one half standard deviation above and below the total group mean. This is typical of self-report measures in which subjects often portray themselves in a favorable light. By contrast, the three members of Cluster D admit to almost total noncompliance.

The researchers' ratings (RQ) are well dispersed among the groups and, with the exception of Cluster C, are similar to the self-reports.

The physician's ratings (MD) also show a wide span among the clusters, with low ratings given to Cluster B as well as to Cluster D.

Cluster A is characterized by high ratings by all three types of raters and Cluster D is characterized by uniformly low ratings.

Cluster C is distinguished by mean self-reports and doctor's estimates only slightly below the total group mean, but researcher reports which fall markedly below these. Researchers made their ratings on the basis of regular telephone

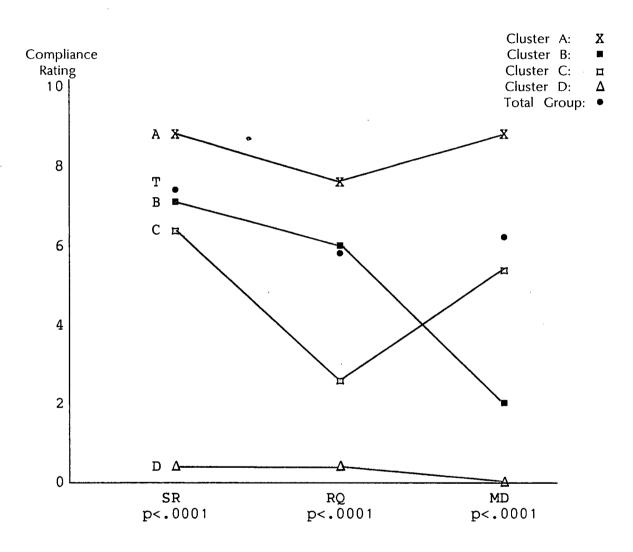


Figure 4-1
Subjective Compliance Ratings by Cluster

contact with the parents and at least two testing sessions with the subject child, and with such frequent contact the parents may have revealed problems that they had concealed from the physician. In some cases, the children told researchers how they acquired and ate unsafe foods.

Cluster B members were estimated by the doctor to have much lower compliance levels than estimated for them by the researchers or by self-report, and were generally those subjects who had not been to the doctor's office for some time.

The total group ratings are fairly similar, with self-report having the highest of the three means, as expected; the researchers' ratings were only slightly lower than the physician's ratings. The self-report ratings are significantly different from both the researchers' and physician's ratings while the latter two did not differ appreciably.

The clusters were analyzed in terms of their member's scores on the four subtests and their total DRTPQ scores. Figure 4–2 presents the mean score on the subtests earned by the members of each cluster and tested for significant differences with an analysis of variance, using the SPSS:X Breakdown routine.

On two of the four subtests, Parent and Family Life (PFL), and Child Positive Factors (CPF), the clusters differ significantly from one another. There was no significant difference between clusters on the Belief in Treatment and Benefits (BTB) subtest or on Perceived Severity and Susceptibility (PSS). The clusters differed significantly on the total score (DRTPQ Total).

The lowest scores were obtained by Cluster D, the members of which also received the lowest compliance ratings, and this cluster was low on all four subtests. Cluster A, with the highest subjective compliance ratings, received the

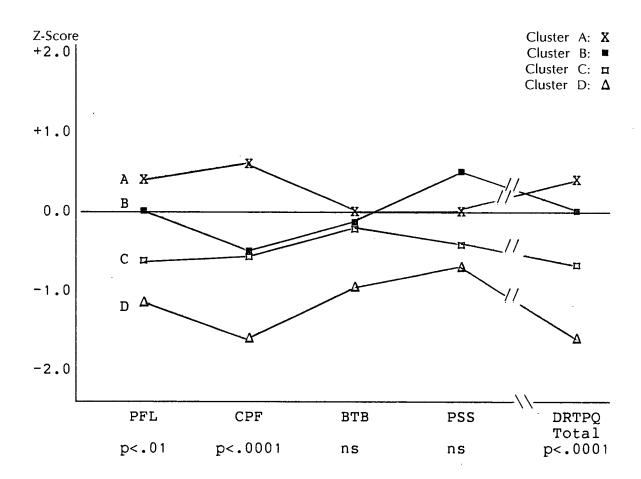


Figure 4-2
Standardized DRTPQ Scores, by Cluster

highest mean subtest scores. Cluster B, characterized by low physician's compliance ratings, appears to have subtest scores near the mean total group score on all but CPF which is low. Cluster C also has low CPF scores as well as moderately low scores on PFL.

The widest range of mean scores earned by the clusters is on the CPF subtest. Low scores on this subtest may indicate that the child resists being on the diet, and sneaks unsafe foods. The other subtest which discriminates significantly between different clusters, PFL, is comprised of items which are concerned with the parents' and families' attitudes toward the diet and the amount of change it represents in their daily lives.

On the total DRTPQ score, the difference between clusters is significant (p<.003). Cluster A, as expected, scored above the mean by approximately one-half standard deviation, and Cluster D scored nearly two standard deviations below the mean. Cluster B scored approximately at the mean while Cluster C is approximately one-half standard deviation below the mean. Thus, the instrument differentiated between clusters formed according to subjects' similarities on the compliance ratings.

B. DROPOUT ANALYSIS

Ten of the forty-five subjects who began the diet revision therapy were classified as dropouts after four months. They were thus classified because they had either declared their intention to stop following the diet revision therapy, or had already done so. Subjects were also deemed to have dropped out if they had quit seeing the doctor regularly (an important part of the therapy) or had not participated in the post testing at the university clinic.

The members of the dropout group did not differ from the total sample in

age or sex, being 70% male and having a mean age of 9 years 6 months.

The parents of these ten subjects were interviewed by the researcher and administered the questionnaire either by mail or by telephone. Reasons given for dropping out varied but common themes of finding the diet too restrictive, too difficult to prepare, or not effective in producing symptom remission or behavioral improvement, and having difficulty keeping the child happy on the diet were noted. Two subjects were following a different treatment for food allergy, and most had modified their child's diet slightly as a result of their diet revision therapy experiences.

The performance of each group on the four subtests and three ratings, expressed in standard scores, are presented in Figure 4-3 below. The dropouts' mean score on the total test was 96.9 (s.d. 11.1), significantly (p<.0001) below the mean of the remaining subjects of 116.7 (s.d. 9.7).

In order to determine if the four subtests of the questionnaire would discriminate between subjects who dropped out of the diet revision therapy completely and those who remained on the diet to some extent, discriminant analysis was performed.

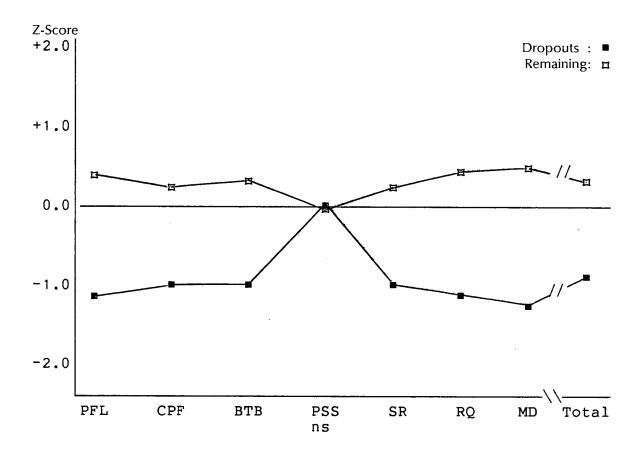


Figure 4-3

<u>Standardized Test Scores and Ratings by Dropout Status</u>

The discriminant analysis based upon the 4 subtests produced a discriminant function which correctly classified 86.7% of the subjects when applied to the sample. The group means of this function applied to subtest z-scores were .58 for the remaining subjects versus -2.03 for the dropouts. Standardized discriminant function coefficients are designed to adjust for the unequal means and standard deviations of the independent variables and combine to form the following discriminant function:

$$Y'_1 = .70 \text{ PFL} + .38 \text{ CPF} + .52 \text{ BTB} - .30 \text{ PSS}.$$

This function is to be applied to individual's subtest scores expressed as z-scores.

Since the PSS subtest produced an unexpected negative discriminant function coefficient, low correlations, and nonsignificant variation between groups, it was decided to perform the discriminant analysis using the first three subtests only. The resulting function proved capable of correctly classifying 88.9% of subjects - a slight improvement over the 4 subtest equation. The revised, 3 subtest discriminant function,

$$Y'_{2}$$
 = .68 PFL + .40 CPF + .44 BTB

yielded group means of .55 for the remaining subjects and -1.95 for the dropouts.

By deleting one variable from the analysis, no loss of predictive accuracy was encountered. Rather, a slight improvement was noted. The increase in efficiency gained by shortening the test is noteworthy.

C. SUBJECTIVE - OBJECTIVE CORRELATIONS

The compliance data collected about the subjects is derived from three subjective ratings and four 'objective' questionnaire subtests. To determine the degree of association between these two sets of variables, a canonical correlation analysis was performed. In addition to providing an estimate of the relationship between the two sets of variables and the significance of that relationship, canonical analysis provides a method of determining the relative importance of the separate variables within each set (Kerlinger, 1979). The canonical analysis was performed using the BMDP6M (Dixon, 1983) program with the three subjective ratings as the first set of variables and the four subtests as the second set.

The relatively high correlations among the three ratings were felt not to compromise this analysis. Squared multiple correlations between each subtest and all other subtests were sufficiently low to indicate the heterogeneity required for the canonical analysis; Although the squared multiple correlations for the ratings were somewhat higher, indicating stronger relationships among ratings, than among questionnaire subtests, they too were low enough to allow the analysis to proceed. The squared multiple correlations are presented in Appendix F.

Three pairs of canonical variates were generated and evaluated for significance. The first canonical correlation was .80 (64% of variance); the second was .32 (10% of variance). Only the first canonical correlation is considered significant (p < .0001) and necessary for interpretation of the relationship between the sets of variable. The other two canonical correlations were not statistically significant ($p_2 = .58$; $p_3 = .86$).

Results of the first canonical correlation are presented in Table 4-2, which includes: correlations between the variables and the canonical coefficients; percent of

variance accounted for within sets; redundancies; and the canonical correlation. In applying a cutoff value of .3 for interpretation of variable coefficients (Tabachnick & Fidell, 1983, p. 170), PSS was the only variable of the 7 included in the analysis which was not useful in explaining the relationship between the sets. This is consistent with that subtest's uncertain performance in the discriminant analysis and lack of differentiation among clusters.

It is evident from this analysis that those subjects who scored high on the PFL, CPF, and BTB subtests would be likely to also receive high ratings on the parental self-report, researchers' and physician's estimates of compliance. Of the three significant subtests, CPF scores contributed most strongly to the equation, having a correlation with the first canonical variable of .96 and a standardized canonical coefficient of .80. PFL and CPF demonstrated significant squared multiple correlations with the set of ratings variables. BTB approached an acceptable significance level (p < .09) while PSS was not significant.

There is marked homogeneity among the correlations of the three subjective ratings; one effect of this is that their standardized canonical coefficients are similarly weighted. Indeed, the three ratings, as raw scores, are quite highly intercorrelated (.624, .662, and .729).

In the first set of variables, the ratings, the canonical variate accounts for a very high within-set variance (78%). This, accompanied by a redundancy figure of 50%, meaning that there is a 50% overlap of subtest variance accounted for by the ratings' canonical variates, indicates a very potent solution for this set.

The more moderately correlated subtest scores produce a set of canonical correlations and standardized canonical coefficients with a larger range. The standardized coefficients for this set of variables range from .80 for CPF to -.11 for

Table 4—2
Summary of Canonical Correlation* Analysis

Variables	Variable/Canonical Correlations	Standardized Coefficients	
Subjective Ratings			
Self-report	.91	.43	
Researcher rating	.85	.27	
Physician's rating	.89	.44	
Percent of variance	78%		
Redundancy	50%		
Subtest Scores			
PFL	.66	.27	
CPF	.96	.80	
ВТВ	.47	.13	
PSS	.04	11	
Percent of variance	40%		
Redundancy	26%		
Canonical Correlation	.80		

^{*}This summary is restricted to the first (and only significant) canonical variate.

PSS. The canonical variates of this set account for 40% of the variation within this set. The redundancy figure of 26% indicates that variation on this set accounts for 26% of the variation in the ratings set.

Percent of variance and redundancy figures indicate that the canonical analysis is more efficient for the the first set of variables. Taken as a pair, the first canonical variates with their canonical correlation of .80 indicates that there is 64% of shared variance between sets of variables.

D. TEST - RETEST CORRELATIONS

Twenty-two subjects participated in the pilot stage of the test construction phase of this research. These subjects also completed the final version of the instrument. As there are 20 core items in common between the two versions of the instrument, it is possible to analyze the responses of these twenty-two parents to these items over time.

The 20 core items of the test are organized into three subtests, the Parent and Family factor (PF), the Child Factor (CF), and Belief in Treatment (BT). This structure was maintained in the test-retest analysis and the test was analyzed by subtest.

The first administration of the core items took place on Feb. 17, 1987, and the earliest administration of the retest took place seven weeks later on April 9, 1987. At that time, 9 of the 22 subjects completed the retest. The balance of the core sample completed the second administration over the subsequent six weeks. Three of these subjects were later classified as dropouts. There was, therefore, no standard test-retest interval. What can be said, though, is that the first administration took place when the children were in the initial stages of diet revision therapy and the second administration took place when the children's diets had been stabilized and they had achieved control of their symptoms to a large extent.

During this interval, change took place within the subjects pertinent to the content of the test, and this will have influenced the responses to the items. It is particularly likely that the PF subtest -- which is designed to measure how well the family is adapting to the diet -- will have changed; for the better in some cases and for the poorer in others. As parents observe the effect of the treatment on their child, their responses to the BT (Belief in Treatment) subtest may change. It is

therefore expected that there will be a moderate relationship between the test and retest scores. Evidence of stability lends support to the use of the instrument as a predictive device, but a very high test-retest coefficient would cast doubt on the sensitivity of the instrument to changes in the subjects.

Table 4-3 presents the subtest results of the two administrations of the core item version of the questionnaire on both occasions.

The group means on the two occasions were very similar. Reliability for the Parent and Family subtest diminished in the retest interval, perhaps due to the variety of different experiences that the families had while on the diet. Overall, however, both types of reliability showed a slight increase, and the range of responses widened.

The obtained test-retest coefficients are as expected (see Table 4-4). The total test reliability over time of .65 is good considering the type of attribute being tested and the fact that true scores were likely changing at different rates during this period. Attitudes are generally less stable than other traits, such as intelligence. The CF subtest test-retest reliability of .82 is high and points to the stability of parents' perceptions of their children's attitudes and behaviors. Lower correlations for the PF and BT subtests were expected, as these are factors that are sensitive to change with experience on the diet.

E. DEMOGRAPHIC VARIABLES

The three demographic variables which emerged in the literature review as having some influence on the compliance of pediatric patients with dietary regimens are mother's marital status, mother's eductional level, and child's age.

Seven of the 45 subjects in this research lived with their single mothers. Of

Table 4 - 3
Core Test Summary Statistics: Time 1 and Time 2

Subtest	Characteristic	Time 1 n = 22	Time 2 $n = 22$	
Parent	Mean	14.77	15.32	
and Family	s.d.	2.99	2.28	
5 items	rel.	.70	.48	
	SEM	1.48	1.46	
	range	6 - 18	8 - 18	
Child	Mean	23.64	25.23	
Factors	s.d.	5.08	5.27	
9 items	rel.	.75	.88	
	SEM	2.38	1.70	
	range	17 - 33	15 - 35	
Belief in	Mean	19.77	20.14	
Treatment	s.d.	3.37	3.48	
6 items	rel.	.75	.88	
	SEM	1.53	1.08	
	range	10 - 24	12 - 24	
Total	Mean	58.18	60.68	
20 items	s.d.	9.16	9.30	
	rel.	.84 (.68)*	.90 (.72)*	
	SEM	3.54	2.83	
	range	40 - 71	42 - 75	

^{*} Hoyt's Reliability (Cronbach's Alpha)

Table 4-4
Test - Retest Correlations of Core Test

Subtest	Correlation	Significance	
Parent and Family (PF)	.4029	.063 (ns)	
Child Factors (CF)	.8247	.000	
Belief in Treatment (BT)	.4091	.059 (ns)	
Total	.6516	.001	

the seven, two (or 28%) were treatment dropouts as compared to 22% of the whole sample. Four (or 57%) were in clusters other than Cluster A as compared to 47% of the whole sample. These are not significant differences in proportion, considering the limited size of the group.

Only two of the mothers in the study reported less than high school graduation as their education level, making analysis by this variable not useful, since the research indicates grade eight as the level at which lack of education becomes significant. Twenty-three of the 45 mothers have at least one year of post secondary education and twenty are high school graduates, making this a relatively well educated sample. This is probably a result of using a newspaper article as a subject recruitment technique.

The mean age of the dropouts was the same as the mean age of the total population (9 years, 6 months). The only significant difference in mean age for the clusters was for Cluster D which was older than the other clusters by less than a year. This is a three member cluster, composed of two 11 year olds and a 7 year old, and does not support generalizations.

Age was correlated negatively with all the subtests and most of the ratings. Although two of the coefficients attain statistical significance at the .05 level with a two-tailed test, the coefficients of correlation, ranging from .0346 (MD rating) to -.2963 (BTB), are so low as to lack any practical significance. (The two significant correlates are the two variables which were least efficient in the other analyses.) The correlations are presented in Table 4–5,

Table 4-5

Correlations of Subtests and Ratings with Age

Subtest	Correlation	Significance	
PFL	0734	.316 (ns)	
CPF	1139	.228 (ns)	
ВТВ	2863	.024	
PSS	2942	.049	
Total	2335	.061 (ns)	
Self-Report	1164	.224 (ns)	
Researcher	0710	.321 (ns)	
Physician	0.0345	.411 (ns)	

F. SUMMARY

In this chapter, the Diet Revision Therapy Parent Questionnaire has been used to investigate the differences between subjects on their ability to comply with diet revision therapy.

Subjects were clustered according to subjective ratings of their compliance levels and compared on their DRTPQ subtest scores. The Parent and Family Life (PFL) and Child Positive Factors (CPF) subtests discriminated significantly between the clusters, as did the total test score. Researcher ratings and physician's ratings, used in the determination of cluster membership, were more heavily weighted in this calculation than parental self-report which tended to have less variance than the other ratings.

Dropouts were compared with remaining subjects on mean questionnaire scores, and a discriminant function of three subtests was derived to predict membership in the dropout group. Parent and Family Life, Child Positive Factor, and Belief in Treatment and Benefits (BTB) were significantly related to dropping out while Perceived Severity and Susceptibility (PSS) yielded an unexpected negative

result and was deleted from the calculation. In this function, PFL was more heavily weighted than CPF and BTB.

A canonical analysis was performed to determine the relationship between the subjective ratings and the questionaire scores. The canonical correlation of .80 between the two sets of variables accounts for 64% of the variance between the ratings and subtests. On this analysis, the CPF subtest was the most powerful component of the equation and the PSS subtest again added little to the relationship.

Appendix G presents profiles for the 45 subjects, including total DRTPQ score, cluster membership, dropout status, canonical variate scores and discriminant function scores.

The overall results point to the strength of three factors in influencing the ability of a family to comply with diet revision therapy. The subtests which represent these factors are: Parent and Family Life, which assesses how well a family adapts to a change in style of eating and methods of meal preparation; Child Positive Factors, which refers to a child's normal level of compliance with daily routine and how he or she feels about the diet; and Belief in Treatment and Benefits, which questions the parents on the results they expect from the therapy as well as their faith that the treatment is beneficial. These three subtests differentiate between subjects who continue treatment and those who drop out, and between subjects judged to be compliant and those judged to be noncompliant.

The core subtests are relatively stable over time and sensitive enough to be useful in detecting change in a subject's condition. Since these items form the basis of the final version of the questionnaire, it is presumed that the final version also has these characteristics.

V. SUMMARY AND CONCLUSIONS

This chapter summarizes the development of an instrument designed to address the factors which influence compliance with diet revision therapy for a school-aged child with food allergies. The instrument was used to analyze compliance differences among treated subjects and their parents.

Suggestions for the use of the instrument in further research are also made, and limitations of this research are identified.

Results of this study are discussed as they relate to clinical practice with families of food allergic children.

A. SUMMARY OF INSTRUMENT DEVELOPMENT RESULTS

The Diet Revision Therapy Parent Questionnaire consists of 38 items organized into 4 subtests. Three subtests, Parent and Family Life, Child Positive Factor, and Belief in Treatment and Benefits have subtest reliabilities of .75 or greater. The fourth subtest, Perceived Severity and Susceptibility (PSS), had a reliability coefficient of .66 which is somewhat lower. The four subtests combined formed a composite with a Cronbach's Alpha reliability of .61. The Hoyt internal consistency of the total score over 38 items is .87.

The subtests have moderately low correlations with one another and moderately high correlations with the total test score, not corrected for overlap. It may be concluded that the subtests measure different traits, but that the different traits combine to reflect an overall attribute. Perceived Severity and Susceptibility performed less well than the other three subtests, having lower correlations with the total test and with the other subtests.

B. SUMMARY OF ANALYSIS

1. Results of Analysis

The Diet Revision Therapy Parent Questionnaire was administered to 45 of the original 48 subjects who began the diet revision therapy, including ten subjects who had dropped out. As the questionnaire was designed to reflect the subjects' experience with the therapy, it was administered after they had been on the diet for a few weeks. Responses of the dropouts were compared with those who remained in treatment. Three subtests formed a discriminant function which effectively differentiated between the two groups, but the PSS subtest did not contribute significantly to the differentiation of dropouts from continuing participants.

Current practice in determining whether a patient is compliant with medical regimes depends heavily upon subjective ratings and clinical judgment. Therefore, cluster analysis of subjects was performed using as a basis subjective ratings by parents, researchers, and physicians. Four distinct clusters were identified, then compared on their questionnaire responses. Cluster A was composed of subjects who were judged by all three raters to be in compliance with the treatment. Members of Clusters B and C were judged to be noncompliant by either the researcher or physician, but not by their parents. Cluster D was composed of three subjects who were judged to be noncompliant by all three raters. The four clusters differed significantly on the Parent and Family Life subtest, the Child Positive Factors subtest, and the Total DRTPQ score. Clusters did not differ significantly on the Belief in Treatment and Benefits and the Perceived Severity and Susceptibility subtests.

A canonical correlation was employed to investigate the relationships between

subjective ratings and questionnaire scores. The results were significant: there was sixty-four percent of shared variance between ratings and questionnaire subscales ([R] = .80).

Moderate test-retest reliability of the instrument was demonstrated through the two administrations of the core items during the test development process. (The core items are the 20 items which remained in the questionnaire throughout the development process.) The sample of subjects was under treatment, so change was expected to occur. The subtest scores were sensitive enough to change in the subjects to indicate moderate but nonsignificant correlations over time for PFL and BTB, while the CPF subtest showed a larger degree of stability. Total test scores correlated .65 over an interval which encompassed initital diet experiences through to the maintenance phase of treatement, a period of 7 to 10 weeks.

Age and mothers' marital status and education were not significantly related to compliance in this sample.

2. Factors Which Influence Compliance

Of four subtests developed, three appear to measure factors which influence compliance.

a. Parent and Family Life

The Parent and Family Life (PFL) subtest is comprised of items such as:

- "This diet is harder to prepare than our previous way of eating",
- "We can usually control the things that happen in our lives", and
- "I have been able to help my child stay on the diet by preparing appealing meals".

Health habits, like taking children to the dentist regularly, and social support from family and other people who deal with the child are included. This subtest had the highest coefficient in the discriminant function for detecting dropouts; it also had a high coefficient in the determination of the canonical variate for the questionnaire.

The PFL subtest items can be related to the Health Belief Model components of barriers to compliance, related health beliefs and the enabling variables such as support and the concordance between the diet and the family's lifestyle.

b. Child Positive Factor

The Child Positive Factor (CPF) subtest consists of items which are aimed at assessing whether or not the subject child is cooperative and compliant. Typical items are:

- "My child is upset that his food is different from his friends' food",
- "My child monitors his own diet and refuses 'unsafe' food", and
- "My child generally does what he is told".

This subtest deals with the day-to-day behavior of the child as it relates to his diet, and appears to have a strong relationship with the ability of the family to succeed in the treatment program. This subtest was the most stable over the test-retest interval; it also had the highest coefficient in the canonical function, and it was important in the discrimination of dropouts. Also, this subtest had highest internal consistency coefficient at .89.

c. Belief in Treatment and Benefits

The Belief in Treatment and Benefits (BTB) subtest taps the faith the parents have in the medical profession and their belief that the treatment will be beneficial:

- "I try to do what my doctors tell me to do no matter what,"
- "This diet will help my child behave and pay attention better," and
- Controlling food allergies will significantly reduce the number of colds my child gets."

This subtest contributed to the discrimination of dropouts, and was weighted significantly in the canonical correlation, but it was not significant in differentiating among the clusters. This subtest was also fairly sensitive to change over the course of treatment. It is logical that parents who saw improvement in their child's condition over the course of treatment would increase their scores on Belief in Treatment, while parents whose child did not improve would cease to believe in the benefits of diet revision therapy.

d. Perceived Severity and Susceptibility

The Perceived Severity and Susceptibility (PSS) subtest was derived from the Health Belief Model. PSS is considered a cornerstone requirement in the motivation of a person to take health action. Sample items from this subtest are:

- "When my child eats something he shouldn't, his symptoms are severe," and
- "My child is more susceptible to illness than other children."

This subtest provided surprising results. People with higher scores on this test, that is, who saw their children as more susceptible and with more severe problems, were more likely to drop out of treatment. Similarly, a negative canonical

coefficient was observed: higher parents' perceptions of severity and susceptibility are linked with lower ratings of compliance. Like BTB, this subtest did not differ significantly among clusters formed on the basis of subjective ratings.

One criticism of the Health Belief Model from which this construct was derived is that the components must be operationally defined anew for each research context and may not generalize due to difficulties in operationalization. This may have prevented the Perceived Severity and Susceptibility subtest from performing better.

Another possible explanation for the PSS subtest's equivocal performance may be that parents who perceive their children's problems as serious may believe that a home-based treatment such as diet revision therapy rather than a technical medical intervention, perhaps including shots and pills, could not be strong enough to be effective. There is some evidence of a similar finding in VonBrock and Elliott's (1987) study of behavioral treatment acceptability: teachers were willing to consider different treatments for mild problems but were not as open to information about new treatments when the problems were severe. This can be thought of as a problem with the face validity of the treatment.

In addition to its ambiguity of interpretation, PSS is also the least reliable of the subtests with a Hoyt's coefficient = .66. When the full questionnaire was analyzed after having deleted PSS, total test reliability was not diminished -- it actually increased from .87 to .88. It is therefore suggested that, in practice, the PSS subtest be administered and interpreted separately from the other subtests.

C. RECOMMENDATIONS FOR FURTHER RESEARCH

The main recommendations for further research arise largely out of two limitations in the present study.

The most limiting element in the design of the present study is the use of the same sample for both instrument development and validation analysis. The instrument should be cross-validated using another sample. The discriminant function for predicting dropouts should be tested on such an independent sample as should the canonical correlation between subtest scores and subjective ratings. With a larger independent sample, the subtest structure might be validated using factor analysis.

A further limitation was the lack of a concrete objective criterion for compliance against which the instrument can be validated. Subjective ratings are commonly used compliance criteria, and arguments against clinical judgment and self-report have been delineated in Chapter Two. The fact remains, however, that in the absence of an objective criterion for compliance with this treatment, a combination of subjective criteria provides a reasonable sustitute. An improvement in this composite subjective criterion might be made by adding another component to the combination, and that might be a self-rating by the subject child.

A separate recommendation for futher research involves extending the concepts derived in this diet therapy research context into other contexts. Adaptations of the DRTPQ for other treatments -- behavioral programs such as parent training, classroom interventions, counselling, etc. and medical programs with children such as diabetic or obesity diets, asthma treatment regimens, etc. -- could be written and validated.

D. SUGGESTIONS FOR USE AND CLINICAL INTERPRETATION

The 38-item 4-subtest version of the Diet Revision Therapy Parent Questionnaire should be administered to parents of children involved in diet revision therapy early in the course of treatment. This administration should be timed to allow for brief experience with the diet, but early enough to provide for intervention before a family becomes discouraged and drops out.

A further administration of the instrument should take place when the child's diet is becoming stabilized and the maintenance phase of the treatment is entered. This point in the treatment is likely be a problem for patients who may find that, since no further dramatic improvements in their condition are experienced, continued compliance is not rewarding. The realization that this diet is a lifelong requirement will be encountered at this point and resistance may be provoked in some subjects. Thus, the success of the treatment, in reducing symptoms, may actually dispose the patient toward noncompliance.

Families with problems in different areas, evidenced by low scores on different subtests, require individually tailored intervention programs.

An intervention program to help a family demonstrating deficiency on the Parent and Family Life subtest would focus on tailoring the regime to fit the family's lifestyle, providing a training program in administering the diet (possibly including meal plans), and providing support and encouragement to the parent in less structured ways.

The nature of the patient, the allergic child in this instance, clearly plays an important part in determining the success of the treatment. Implications for intervention are strong. If the child is resisting the diet, resulting in a low Child Positive Factor score, the parents may need assistance in winning the cooperation of

the child. Parenting classes, family counselling, or assistance with simple management techniques are indicated by relatively low scores on this subtest.

An educational program designed to increase the parents' awareness of the consequences of untreated food allergies and of the wide ranging improvements they can expect from compliance to the treatment is an indicated intervention for families with low BTB scores.

It is possible that this subtest failed to discriminate even though the 'educational function' had already been accomplished for these subjects. Some parents' belief in treatment was insufficiently strong motivation to overcome the barriers they encountered in family lifestyle or in gaining their child's cooperation.

The PSS subtest is best dealt with in an individual manner, since both high and low scores have been linked to noncompliance. This topic should be discussed between the physician and patient.

A guide for administering and scoring the Diet Revision Therapy

Questionnaire is presented in Appendix H.

E. CONCLUSION

This study has shown that there are several factors which influence compliance to diet revision therapy for food allergic children. Among them are the parents' perceptions of the intrusiveness of the treatment into their family life, the attitudes and behavior of the child, and the parents' belief in the benefits to be derived from the treatment.

By measuring these variables with the Diet Revision Therapy Parent

Questionnaire developed in this study, it is possible to predict which patients are

likely to experience difficulty following the diet therapy and to provide appropriate

intervention and support for them.

The DRTPQ has been shown to possess sufficient reliability and validity for use both early in treatment and in the maintenance phase of diet revision therapy to enable such identification of potential problems.

This instrument will enable a physician employing diet revision therapy for food allergies to serve his patients better by anticipating their compliance difficulties and providing focussed intervention.

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APPENDIX A: DIET REVISION THERAPY PARENT QUESTIONNAIRE

APPENDIX A

DIET REVISION THERAPY PARENT QUESTIONNAIRE

Child's Name		Birthdate		
Name of persor	completing questionnaire			
Relationship to	child			
Diet started				
Please list the p	people living in your home.			
Name	Age		Relationship	to child
Mother's occupa	ation			
Mother's occupi				
Education:	Less than high school grad High school graduate Years of post secondary educ Degrees	eation yrs		
What hours	are worked?			
Father's occupat	ion			
Education:	Less than high school grad _ High school graduate _ Years of post secondary educ Degrees	cation yrs		
What hours	are worked?			
Where does yo	ur child eat lunch?			
•				
Where is the c	hild cared for after school?		····	
Who supervises	him/her there?			

Who	does the famil	y food shopping?		
Who	prepares the fa	amily meals?		
	Breakfast?			
	Lunch?		•	
	Dinner?			
	Snacks?			<u></u>
To the	sponds to your he following se	e following questions. Belo answer. eries of questions, please		
this t	true for you?"			
	Not at all 0	Just a Little 1	Pretty Much 2	Very Much 3
1.	Our whole fan	nily is supportive of this d	iet. 2	3
2.	I have been meals.	able to help my child sta 1	y on the diet by pr 2	reparing appealing
3.	The people in	volved in the study have b 1	peen pleasant and frie 2	ndly.
4.	My child has 0	been better since we starte 1	ed this treatment.	3
5.	I believe that we have notic	my child will stick with a	this diet to maintain	the improvement
	0	1	2	3
6.	This diet is ha	arder to prepare than our 1	previous way of eating 2	g. 3
7.	Our family is 0	having difficulty adapting to 1	o this new way of ea . 2	ating.
8.	My child obje	cts to being on this diet. 1	2	3

	ot at all 0	Just a Little 1	Pretty Much 2	Very Much 3
This	diet will help 0	my child behave ar 1	nd pay attention better. 2	3
The	people we've 0	dealt with in this st	tudy have been efficien 2	t and competent.
l tr	y to do what 0	my doctors tell me 1	to do, no matter what	3
The	reasoning beh 0	nind the diet revision 1	therapy has been mad	le clear to me.
Ond	ce I've made i 0	up my mind to do s 1	something, I usually do 2	it. 3
Му	child's friends 0	encourage him to g	o off his diet. 2	3
l ca	an find "safe" 0	foods on restaurant	menus. 2	3
i m	ake sure my o 0	children go to bed e 1	early enough to get a 2	complete rest. 3
		started this diet, I su I his behaviour and s 1	symptoms.	between the food
Oth	er members o 0	f our family are follo 1	owing the diet.	3
	child's food a eed to do. 0	llergies and allergic r 1	eactions keep me from	doing the thing
Му	child understa	nds the benefit of th	nis new way of eating. 2	3
l w	orry about my 0	child's health.	2	3
Му	child has prol	bably been off the c	ore diet this week.	3

	Not a all 0	t	Just a Little 1	Pretty Much 2	Very Much 3
23.	My chil	d is more	susceptible to illnes 1	s than other children. 2	3
24.	My chil	d is upset	that his food is di	fferent from his friend [,] 2	s food.
25.	When r	ny child ea	ts something he sh 1	ouldn't, his symptoms 2	are severe.
26.	Food al	lergy can b	oe a serious health 1	problem. 2	• 3
	he follov family?"	ving statem	ents, please answer	the question "How o	often is this true in
	Never Seldon 0		Sometimes Little 1	Often or Usually 2	Always or Nearly Always 3
27.	We like 0	to reward	ourselves with foo	d treats.	. 3
28.	My chil 0	d monitors	his own diet and	refuses "unsafe" food.	3
29.	My chil 0	d generally	does what he is t	cold.	3
30.	l am c	onscious of	the nutritional valu	ue of different foods.	3
31.	l am u year. 0	sed to taki	ng my children to	the dentist for regular	r check-ups twice a
32.	_	d probably	sneaks "unsafe" fo		3
33.	We like	e to eat in	restaurants at least	once a week.	3
34.	My chil	d resists st	aying on the diet. 1	2	3

То	the following sta	tements, please answe	r the question "How many?	**
	None 0	Few 1	Some 2	Many 3
35.	I have informe 0	d others who deal wi	ith my child about this diet 2	. 3
36.	My child has 0	found some treats with 1	hin his diet. 2	3
	the following sta disagree with the		er the question "How much	do you agree
	Definitely Disagree 0	Slightly Disagree 1	Slightly Agree 2	Definitely Agree 3
37.	Food allergies	are a lifelong problem	n. 2	3
38.	Food allergy difficulties. 0	may be at the roo	ot of my child's learning	and behaviour
39.	Diet revision o	an help but not cure 1	food allergies.	3
40.	We can usuall	y control the things tl 1	hat happen in our lives. 2	3
41.	My child's hea 0	ılth will probably impro 1	ove even if his allergies are 2	not controlled.
42.	When I first recognized my		ptom pattern attributed to	food allergy, 3
43.	This is a healt	hy diet and my child 1	is getting everything he ne	eeds. 3
44.	My child's foo athletic activitie 0	· ·	gic reactions interfere with	his social and
45.	If you wait lo	ng enough, children w 1	vill get over most any illnes 2	s. 3

	Definitely Disagree 0	Slightly Disagree 1	Slightly Agree 2	Definitely Agree 3
46.	This diet will im	prove my child's acade 1	emic performance.	3
47.	If we cheat onc	e, it is difficult to ge [.] 1	t back on the diet.	3
48.	Controlling food child gets.	allergies will signific	antly reduce the num	nber of colds my
49.	My child genera 0	lly enjoys good health. 1	2	3
50.	I usually take m 0	y child to the doctor 1	at the first sign of ar	ny illness. 3

COMMENTS

We're interested in hearing how you and your child are doing now that he/she has been on the diet for some time.

- 1. What changes have you noticed in your child since you began diet revision therapy?
- 2. Have his/her teachers made any comments? What about neighbours and relatives? What have they noticed?
- 3. How was his/her recent report card compared to previous resports?
- 4. Have there been any other changes in the way your child has been treated, at home or at school? For example, have you used different parenting strategies, special help at school, tutoring, etc. Please explain.

5.	Sometimes parents can't bring their child back to the clinic or doctor's office for the next appointment. What are some of the things that might make you miss an appointment?
6.	Have you ever gone on a diet for some health or fitness reason?
	How successful do you feel you were?
7.	Do you know any other people outside this study who have food allergies?
	Have you discussed your experiences on this diet with them?
	If so, how helpful do you feel this was?
8.	Do you ever have trouble keeping your child on the diet?
	What do you do to deal with this?
9.	How much of the time does your child follow the diet?
	Less than Half Half Most All
10.	If 0 represents "never follows the diet" and 10 represents "always follows the diet exactly," how well does your child follow the diet, overall?
0	1 2 3 4 5 6 7 8 9 10
Thank	you for your cooperation.
If you	u have any further comments, please feel free to use the rest of this page.

APPENDIX B: RESEARCHER QUESTIONNAIRE

APPENDIX B

RESEARCHER QUESTIONNAIRE II

POST TEST RATING SCALE

Please rate the subjects named below on the following 0 to 10 point rating scale.

"How well has this subject complied with all aspects of this study?"

- Very poor compliance: never follows the diet, dropped out early, didn't really try.
- Fairly poor compliance: frequently off diet, stuck to it for a while, not really involved any more.
- Fairly good compliance: only occasional or minor deviations from the diet, will probably continue to some extent.
- 10 Very good compliance: always follows the diet exactly, under good control, still very involved, has incorporated this way of eating into their lifestyle.

All statements on each rating point need not be true. Your general impression is what is required.

Please make your rating immediately after your post testing session with each family and deposit the rating slip in my folder in the clinic.

Thank you very much for your help.

Liz

POST TEST RATING SCALE CHILD'S NAME — RESEARCHER — Very poor Compliance Very good Compliance Compliance Compliance Researcher Researcher Post Researcher Very good Compliance Researcher Post Researcher Post

APPENDIX C:

INITIAL VERSION: DIET REVISION THERAPY PARENT QUESTIONNAIRE

APPENDIX C

INITIAL VERSION: DIET REVISION THERAPY PARENT QUESTIONNAIRE

		Name			
		Child			
Plea mar	ise answer all questions. Beside each ite k.	em indicate	your res	sponse witl	n a check
	To the following group of questions, please answer the question, "How much sis this true for you?"	(0) Not at All	(1) Just a Little	(2) Pretty Much	(3) Very Much
1.*	Our whole family is supportive of this diet.				
2.	This diet is a major change of lifestyle for us.				
3.*	I have been able to help my child stay on the diet by preparing appealing meals.				
4.	The people involved in the study have been pleasant and friendly.				
5.*	My child has been better since we started the treatment.				
6.*	I believe that my child will stick with this diet long enough for improvement to be apparent.				
7.*	This diet is harder to prepare than our previous way of eating.	·	:		
8.*	My child objects to being on this diet.				
9.*	This diet will help my child behave and pay attention better.				
10.	I understand the reasoning behind the diet revision therapy.				

		<u> </u>		
	(0) Not at All	(1) Just a Little	(2) Pretty Much	(3) Very Much
11. Once I've made up my mind to do something, I usually do it.				
12. I, or someone close to me, has had a successful experience with a diet.				
13.* My child's friends encourage him to go off his diet.				
14.* My child is upset that his food is different from his friend's food.				
15. I can find "safe" foods on restaurant menus.				
16. Exercising is a regular routine in our family.				
 I have suspected a connection between food and my child's behaviour and symptoms. 				
18. I'm paying more for food since my child started on this diet.				
19.* My child understands the benefit of this new way of eating.				
20.* My child has probably been off the core diet this week.				
21. When your child eats something he shouldn't, his symptoms are severe.				
22. Food allergy is a serious health problem.				

To the following statements, please answer the question, "How often is this true in your family?"	(0) Never or Seldom	(1) Sometimes	(2) Often or Usually	(3) Always or Nearly Always
23. We like to reward ourselves with food treats.				
24. We like to eat out at least once a week.				
25.* My child generally does what he is told.				
26. I am conscious of the nutritional value of different foods.				
27.* My child resists staying on the diet.				
28. I am used to giving vitamins and/or flouride to my children daily.				
29. I find it difficult to keep appointments.				
30.* My child probably sneaks "unsafe" foods.				
To the following group of statements, please answer the question, "How many?"	(0) None	(1) Few	(2) Some	(3) Many
31.* I have informed others who deal with my child about this diet.				
32.* My child has found some treats within the core diet.				
33. I know other people on allergy diets.				

To the following group of statements please answer the question, "How much do you agree or disagree with these statements?"	Definitely	(1) Slightly Disagree	(2) Slightly Agree	(3) Definitely Agree
34. Kids usually outgrow food allergies.				
35.* Food allergy may be at the root of my child's learning and behaviour difficulties.			·	
36. It is possible to live on this diet lot term.	ng			
37. My friends think I'm wasting my time to try this.	9			
38. Just a little bit of an "unsafe" food won't hurt.				
39. Eating (snacking) is socially important for kids.				
40.*We can usually control the things th happen in our lives.	at			
41.*When I first heard about the symptomattern attributed to food allergy, I recognized my child.	m			
42. This is a healthy diet and my child getting everything he needs.	is			
43. Changing habits is very difficult.				
44.* This diet will improve my child's academic performance.				
45. If we cheat once, we might as well go all out.				
46. My child's food allergies keep him from doing as well as he could.				
47. It is possible for a person to modify his behaviour and learning style.	,			
	-			

	Name
	Child
What changes hav	/e you noticed?
Have his or he relatives? What ha	er teachers made any comments? What about neighbours and ave they noticed?
How long did it	take before you noticed any changes?
Are you having a	ny problems? Are there any questions we can help you with?

APPENDIX D: DROPOUT'S PARENT LETTER

APPENDIX E: SUBTEST STRUCTURE RATING PROTOCOL

APPENDIX E

SUBTEST STRUCTURE RATING PROTOCOL

Dear Colleague,

I would like to request a few minutes of your time to help me with the test validation project I am doing as part of my thesis.

The attached questionnaire is part of an instrument being developed to assess the degree to which parents are compliant with a medically prescribed diet revision therapy for suspected food allergy in their children. The parent is required to respond to each statment by circling a number from 0 to 3 which corresponds most closely to the scale points given that is true for them. In the parent version, the 0 to 3 rating numbers are placed in the space below each statement. In this version of the questionnaire, they have been replaced with letters which stand for the subtests which formed the basis of the instrument's design.

The following definitions describe the concepts behind the subtests embedded within the attached questionnaire. Please read the descriptions of each subtest and then decide to which subtest each item belongs. Some items are negatively worded, but most are positive.

Please mark your choice by circling the appropriate letter in the space below each item

Thank you for your assistance,

Liz Harris

PFL Parent and Family Life Factors

The attitudes, characteristics, and behaviours of the parents and other family members which will affect their ability to help the target child comply with diet revision.

CFP Child Positive Factors

The degree to which the child himself cooperates with the diet, and has support from his environment which assists him in doing so.

MSS Medical and Social Support Factors

The degree of support the parent feels from the personnel in the study and the other individuals who are involved with their child; their faith in the medical profession.

BTB Belief in Treatment/Benefits

The belief the parent has that the treatment (diet) is good for their child and that the results will be beneficial.

Related Health Beliefs

The regular health-promoting habits and practices that the family engages in which make followig this diet consonant with their beliefs and lifestyle.

PSS Perceived Severity and Susceptibility
The severity with which the parent views their child's condition and the liklihood they see of a reoccurence of syptoms.

APPENDIX F: SQUARED MULTIPLE CORRELATIONS

APPENDIX F

SQUARED MULTIPLE CORRELATIONS

A. Squared Multiple Correlations of Each Variable in the First Set With All Other Variables in the First Set

Variable	R-Squared
Self-Report	.60
Researcher	.57
Physician	.48

B. Squared Multiple Correlations of Each Variable in the Second Set With All Other Variables in the Second Set

Variable	R-Squared
PFL	.28
CPF	.24
BTB	.24
PSS	.11

APPENDIX G:

SUBJECT PROFILES: DRTPQ SCORES, DROPOUT STATUS,
CLUSTER, CANONICAL VARIATES AND DISCRIMINANT FUNCTIONS

APPENDIX G

Subject Profiles: DRTPQ Scores, Dropout Status,

Cluster, Canonical Variates and Discriminant Functions

DRTPQ Z-Score	Subject	Status	Cluster	Canonical Ratings Variate Score	Canonical Subjects Variate Score	Dropout Discriminant Score
1.65	5	+	Α	0.608	1.415	2.895
1.45	14	+	Α	1.009	1.808	1.762
1.35	4	+	Α	1.175	1.386	1.381
1.25	8	• +	Α	0.834	1.319	1.977
1.25	21	+	Α	1.1 <i>7</i> 5	1.395	1.689
1.25	36	+	В	-0.851	0.844	1.427
1.15	28	+	C	0.618	0.967	1.497
1.05	34	+	Α	0.834	1.004	0.957
0.95	1	+	Α	0.834	1.134	1.429
0.95	3	+	Α	1.200	1.429	1.244
0.95	19	+	Α	0.774	0.880	0.887
0.95	39	+	Α	0.793	1.018	1.077
0.95	43	+	Α	0.530	0.551	1.518
0.65	23*	- '	В	-1.217	-0.396	0.323
0.55	42	+	Α	0.458	0.513	0.582
0.44	17	+	В	-0.075	-0.063	1.073
0.34	12	+	Α	1.009	0.140	0.466
0.34	33	+	Α .	0.443	0.136	-0.030
0.24	10	+	В	-0.112	0.075	0.377
0.14	2	+	Α	0.305	-0.800	-0.328
0.14	13	+	Α	0.834	0.597	0.012
0.14	20	+	C	-0.184	- 0.079	0.363
0.14	35	+	Α	0.433	-0.375	0.844
0.04	11	+	Α	1.200	0.653	-0.208
0.04	18	+	Α	0.618	0.724	0.578
0.04	31	+	В	0.079	0.228	0.391
-0.06	44	+	C	-0.628	-0.280	-0.009
-0.16	30	+	С	-0.375	0.052	0.151
-0.16	32	+	С	-0.046	-0.215	-0.511
-0.36	37	+	Α	0.721	0.495	0.852
-0.36	40	+	Α	0.289	-0.699	-0.484
-0.56	29*	+	Α	0.608	-0.121	-1.069
-0.66	41*	+	Α	0.417	-0.799	-1.012
-0.76	7	-	В	-0.836	-0.723	-1.300
-0.86	6	+	С	-1.019	-1.378	-0.427
-0.86	27*	+	В	-0.528	-1.636	-0.782

Appendix G continued

DRTPQ Z-Score	Subject	Status	Cluster	Canonical Ratings Variate Score	Canonical Subjects Variate Score	Dropout Discriminant Score
-0.86	38	•	С	-0.585	-0.829	-0.956
-0.97	15	-	С	-1.054	-0.964	-1.924
-0.97	16	-	С	-1.142	-0.964	-1.924
-1.07	25*	+	Α	0.305	-0.507	-1.104
-1.57	9	-	D	-2.625	-2.029	-2.104
-1.57	45	-	D	-2.625	-1.183	-2.027
-1.77	24	-	D	-2.347	-1.753	-2.610
-2.07	26	-	В	-0.485	-1.427	-3.147
-2.28	22	-	C	-1.367	-1.541	-3.795

^{*} Subjects misclassified by discriminant function.

Note 1: Status: + = remaining subjects - = dropout

Note 2: Five subjects were misclassified on the basis of the dropout discriminant function. One subject, Number 23, was a false positive. That is, she was classified on the basis of subtest scores as a remaining subject but in actual fact had dropped out. This family had not been to see the study physician for some months and the mother, while commenting that they were following the DRT, told the researcher in interview about many "unsafe" foods and eating practices that they used.

The four false negatives (25, 27, 29, & 41) represent subjects who, while still classified as remaining subjects, are experiencing compliance difficulties. Their questionnaire scores suggest that intervention to aid compliance would be appropriate. Two are significantly low on the CPF subtest and three are low on BTB.

APPENDIX H:

GUIDE TO ADMINISTRATION AND SCORING OF THE DIET REVISION THERAPY PARENT QUESTIONNAIRE

APPENDIX H

GUIDE TO ADMINISTRATION AND SCORING OF THE

DIET REVISION THERAPY PARENT QUESTIONNAIRE

The parents are asked to read each item and circle the number which best reflects their current experience with the treatment.

The scores for the subtests are obtained by referring to the Scoring Table below. The subject's score on the subtest is the total of his item scores for that subtest.

The subtest scores were compared with the sample's mean score and standard deviation. In the discriminant function analysis, a score one standard deviation below the mean was typical of the dropout group.

The Perceived Severity and Susceptibility subtest is best interpreted in clinical interview format rather than as a standardized score.

PFL SCORING TABLE

			,							
	Item #	0 Item Responses 2								
						Scores				
	1		1		2		3		4	
	2		1		2		3		4	
	6		4		3		2		1	
	7		4		3		2		1	
	13		1		2		3		. 4	
	15		1		2		3		4	
	18		1		2		3		4	
	31		1		2		3		4	
	35		1		2		3		4	
	40		1		2		3		4	
	45		1		2		3		4	
	47		4		3		2		1	
Subtest Total =		=		+		+		+		

Mean = 35.91

Standard Deviation = 5.13

CPF SCORING TABLE

	Item #	0	Iten	Item Responses		
	nem #	U	1	2	3	
					•	
				Scores		
	5	1	2	3	4	
	8	4	. 3	2	1	
	14	4	3	2	1	
	20	1	2	3	4	
	22	4	3	2	1	
	24	4	3	2	1	
	28	1	2	3	4	
	29	1	2	3	4	
	32	4	3	2	1	
	34	4	3	2	1	
	36	1	2	3	4	
Subtest Total =		=	+	+	+	
Subject Total -			,	,	1	

Mean = 30.36 Standard Deviation = 6.53

BTB SCORING TABLE

			Item Responses								
	Item #		0		1		2		3		
						Scores					
	3		1		2		3		4		
	4		1		2		3		4		
	9		1		2		3		4		
	10		1		2		3		4		
	11		1		2		3		4		
	43		1		2		3		4		
	46		1		2		3		4		
	48		1		2		3		4		
Subtest Total =		=		+		+		+			

Mean = 26.64 Standard Deviation = 3.81

PSS SCORING TABLE

	ltem #	0		Item 1	Respor	nses 2		3
	Scores							
	21	1		2		3		1
	23	1		2		3		1
	25 26	1		2 2		3 3		1
	37	1		2		3		1 1
	38	1		2		3		1
	49	4		3		2		4
Subtest Total =	=	: <u> </u>	+		+		+	
Mean = 19.20	Standard Dev	iation = 3	3.37					
Total Test =	PFL +	- CPF	+	втв	+	PSS		
	+	- <u></u>	+		+			
Mean = 112.11	Standard De	viation =	13.23					

APPENDIX I: SUBJECT RECRUITMENT ARTICLE

APPENDIX I

Subject Recruitment Article

The following article appeared in the Vancouver Sun, Page B6, November 22, 1986.

Learning problems could begin with diet

By Anne Mullens Sun Medical Reporter

Two Vancouver doctors are undertaking a study to determine whether food allergies are a cause of children's learning disabilities.

Dr. Stephen Gislason, who specializes in allergies and nutrition, and Dr. Julianne Conry, of the University of BC.'s education clinic, have proposed a study of children who are performing below expectations at school or have behavioral problems coupled with any number of recurring physical symptoms such as constant colds, headache or skin irritations.

"It is my belief that these children's problems are rooted in food allergy, and that through diet revision, they will see a dramatic improvement," said Gislason.

Although many have speculated in the past that hyperactive children can be better controlled through diet, Gislason said studies have not conclusively linked learning disabilities to food allergies.

He hopes to do just that.

"In talking with teachers, there is a consensus that too many children are dysfunctional for no apparent reason and that existing remedial methods are not that effective...These illness patterns are prevalent and I suspect that everyone has food allergy in one degree or another."

Gislason and Conry propose to first screen about 50 children who are having trouble in school to see if there is an improvement following diet revision. Gislason hopes to follow the initial study with a controlled study, in which some children receive diet revision and others do not, in an effort to determine whether diet revisions can become a primary treatment for learning disabilities.

Instead of traditional "elimination" diets in which various items are slowly removed from the diet to determine the allergy, Gislason says he revises the diet, eliminating all food additives and usually the two staple food groups, dairy products and cereal grains.

"The diet revisions will be tailored to the child," he said. "Dairy products and grains have the highest incidence of idiosyncratic reaction."

Gislason is looking for children five to 12 years of age to take part in the study with the following symptoms:

- Difficulty or failure in school as a result of behavioral problems or underachievement.
- Chronic and recurring physical symptoms such as frequent colds or flu-like illness, skin rashes, hearing loss, headache, abdominal or limb pain, diarrhea, bed-wetting, moodiness, sleep disturbances.
- Normal or above average IQ.
- No defined neurological handicaps or diagnosed psychiatric illness.
- No current use of behavior-modifying drugs or parent willingness to discontinue use.
- Parental willingness to revise child's diet.

 Parents interested in their children taking part in the study are asked to call

(Mullens, 1986)