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Intact Families with a Multiple Sclerotic Parent: Social and Emotional Adjustment of Parents and School-Age Children

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INTACT FAMILIES WITH A MULTIPLE SCLEROTIC PARENT SOCIAL AND EMOTIONAL ADJUSTMENT OF PARENTS AND SCHOOL-AGE CHILDREN

A Dissertation

Presented in Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

by

Jean A. McCutchan

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ABSTRACT

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SOCIAL AND EMOTIONAL ADJUSTMENT OF PARENTS
AND SCHOOL-AGE CHILDREN

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ABSTRACT OF GRADUATE STUDENT RESEARCH

Dissertation

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School of Education

Title: INTACT FAMILIES WITH A MULTIPLE SCLEROTIC PARENT: SOCIAL AND EMOTIONAL ADJUSTMENT OF PARENTS AND SCHOOL-AGE CHILDREN

Name of researcher: Jean A. McCutchan

Name and degree of faculty chair: Donna J. Habenicht, Ed.D.

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Problem Statement

Research on children with a multiple sclerotic parent has been minimal and until recently focused only on negative aspects. This study investigated how families successfully cope with multiple sclerosis (MS) and how their school-age children are affected, positively or negatively.

Methodology

This research used the case study approach with intact Caucasian families, 10 where the mother was the patient and 3 families where the father was the patient. The 20 children were ages 5 through 19. Following a clinical interview, the family members responded to the Family

Adaptability and Cohesion Evaluation Scales-II, the Family Hardiness Index and the Family Crisis Oriented Personal Scales. The children responded to age-appropriate instruments including an empathy scale, the Survey of Interpersonal Value, the Piers-Harris Children's Self-Concept Scale, the Human Figure Drawing, the Kinetic Family Drawing, and the Roberts Apperception Test. The schools completed the Vineland Adaptive Behavior Scales for the elementary children, and reported an IQ for the secondary children.

Results

The families generally appeared balanced, and functioning and coping successfully. The children seemed to be adapting adequately and had basically well-adjusted personalities. They had very positive self-concepts, particularly regarding their physical self, behavior and happiness. They had good interpersonal relationships, and generally average and above empathy. The adolescents placed very high value on altruism, high value on being supported, and little value on independence. Anxiety and aggression were above average in the adolescents, and below average and normal, respectively, for the younger children. Across the age range, they seemed to have high depressive tendencies. Two families were found to have children with serious adjustment problems.

Conclusions

Although MS creates definite stresses for a family, those who generally coped successfully before the onset of the illness continued to adapt to the new stressors. The 13 intact families in the study were coping well. The children accepted the additional responsibilities and loss of independence without apparent resentment. The children appeared to be positively and negatively affected by the parental illness. However, they appeared to be developing relatively normally, and should not be considered a problem population, but one in need of support.

DEDICATION

My father, Rev. H. Robert Gemmer, was a minister and ecumenical leader in Christian social action and service. When I was young, every family trip was enhanced by a visit to a center of social service. I was encouraged not only into caring for our community, but for the world community. I learned very young from my dad's dedication and energy, that goals were important and one just does not give up, no matter how hopeless the situation may seem at the moment.

I decided to seek a doctorate because I really liked counseling families and children to better understand illness and handicaps, seeking creative ways of helping families to help themselves and their children to fuller lives. I knew I needed to further my knowledge and expertise.

Dad encouraged me with his imperishable love and enthusiasm. When my MS struck, I eventually had to give up the job of Director of Special Education, which I loved, and the income which paid for my education. Dad said with confidence, "Don't worry, the MS won't get the better of you. We'll help." And help in many forms came from both of my parents. So I forged ahead despite several debilitating episodes of MS. Every telephone call or visit from my dad brought gentle nagging to keep working. The doctorate

became his, too, at that time.

Then in 1992 we noticed his perpetual motion of community activity was slowing down. Even the physicians were not aware, since his changes were so gradual. On December 21, 1992, dad drowned in his pool at their home in Florida. I lost not only my father, but my dearest friend.

Dr. and Mrs. Wilfred Futcher knew it now fell on their shoulders to keep me going. I would never have given up though, because I felt dad's presence with the Lord providing the "wind beneath my wings."

I have finally reached the fruition of my labors. Dad will be at my graduation, proud and loving. My wheelchair and crutches may be present, but my spirit soars into victory.

For these many reasons, I gratefully dedicate this dissertation to my father.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ACKNOWLEDGEMENTS

Although I take great satisfaction in having completed my doctoral program after so many years, my completion is not the result of only my dedication and tenacity. Wilfred G. A. Futcher, Ph.D., you have been a major source of support as my research assistant, driving me to the families for interviews, offering comments and ideas, serving as my secretary when I could not write my thoughts, and encouraging me. You simply expected things of me I did not know I could accomplish until they were done. I cannot thank you enough. Mrs. Futcher, you patiently let me borrow Dr. Futcher for so many hours and were so wonderful, repeatedly word processing the dissertation into the wee hours of exhaustion. I appreciate your help more than I can express. Without the two of you I could not have finished. You have become my extended family.

My family has been so patient and loving through the many years I have worked on my doctorate. As I worked on the program, I delivered two marvelous boys, Eric and Andrew, whom I can credit with being the source of my questioning which led to this dissertation. Through my struggle with my MS and my own family's need to adjust and flex with changing requirements of the disease and family

development, my husband, Larry, has suffered, struggled, and eventually succeeded with me. Larry, I thank you for being a source of strength. You may still have to be more of a "Mr. Mom" than most dads, but it will only be because of the MS. My mother, Myrna Gemmer, continued my father's financial help for the doctorate with her enthusiasm and humor. Thank you, Mother, for helping keep my family healthy and loved, by visiting regularly and serving as a mother once again. I love you all deeply and realize with appreciation that you have all had to give up so much because of me, my MS, and my doctorate.

I also wish to thank my chairperson, Donna Habenicht, Ed.D., and the other members of my dissertation committee, Robert Fadeley, M.Ed., Wilfred Futcher, Ph.D., and Elsie Jackson, Ph.D., for all their help and support. Dr. Habenicht has been a wonderful source of strength and drive, with superb expertise and dedication, always available to me. Dr. Jackson has offered a different, refreshing perspective for me when things began to drag. Mr. Fadeley has made me feel confident and proud, and has inspired me with his personal strength as he also deals with a chronic illness. Thank you all for your patience, prayers, and personal encouragement.

I want to express my gratitude to Thomas Vidic, M.D., and Robert Aber, Ph.D., who helped me locate my sample and shared both skepticism and enthusiasm, which incited me to

work harder on my study. I appreciate my 13 families' courage and willingness to give up their time and privacy to open themselves up to a stranger. I did not feel like a stranger with any of these families, and I believe we parted friends, comrades in a mutual disease and desire to find answers by not giving up.

However, my greatest source of love, support, and encouragement comes from God who has helped me through hours of frustration, pain, and exhaustion. He has helped me find my inner reserves when I thought all were lost, and redirected my attention to priorities (which contributed to the length of time it has taken to complete my doctorate). He has helped me realize my support system is simply an extension of His everlasting, enduring love.

CHAPTER 1

INTRODUCTION

Multiple sclerosis (MS) is a chronic disease of the central nervous system for which a cause has not been identified; no cure exists, and there is no known prevention. It affects individuals of both sexes, although two to three times more women have been diagnosed with it than men. Most races are affected by multiple sclerosis, but at varied incidence rates. Caucasians have the highest rate, whereas Blacks have about half of that incidence. Orientals and American and Eastern Indians are less commonly affected by multiple sclerosis. Eskimos, the Gypsies, the Yakuts in Siberia, and the Bantu in Africa have no reported cases of multiple sclerosis (Rosner & Ross, 1987, p. 10). Incidence is higher in northern moderate climates. The disease is rare in Asia and Africa and very rare in tropical and sub-tropical climates. Multiple sclerosis does not discriminate between social backgrounds, although there is a higher incidence in countries with high standards of sanitation.

The disease initially appears most often in young adulthood, the period of life when the individual would

ordinarily be most productive. Multiple sclerosis manifests itself differently in every affected individual. Common symptoms include extreme fatigue and problems with strength, stamina, balance, coordination, vision, speech, sensation, and bladder control. The severity and type of problems an individual experiences with the disease vary from year to year, day to day, and sometimes even hour to hour. Lechtenberg (1988, p. 7) estimates that 1 in 1,000 people in the United States have been diagnosed with multiple sclerosis. Therefore, about 250,000 people are trying to deal with multiple sclerosis in the United States alone. That also means that about 250,000 families in the United States are trying to deal with a loved one who has multiple sclerosis.

Statement of Problem

Although psychological research has been done with the multiple sclerotic individual, the spouse and care-giver have received less attention, and minimal research has been conducted with the children of a multiple sclerotic parent. Psychological research has focused on how the chronically ill adult deals with the disease and how the spouse and care-giver deal with the ill individual. Psychological and medical research have historically focused on pathology. The underlying assumption of the pathology model is that, if

there is something bad or wrong in the environment, there must be a negative psychological effect on the individual. Only in the last decade have researchers begun investigating the positive effects of undesirable situations.

Studies of families with a chronically ill parent demonstrate the importance of recognizing the differences in family systems that result from this situation. However, children have not been investigated extensively. With their unique vulnerability and potential for the future, studies are needed on how children develop and deal with life under these circumstances.

Purpose of Study

The purpose of this study was to investigate the personality of school-age, 5-19-year-old children who have a parent diagnosed with multiple sclerosis. This includes aspects of cognitive development.

In addition, the social and emotional development of these children was studied. The specific elements studied were the self-concept, empathy and altruism/prosocial behavior.

Research Questions

This study attempted to answer the following research questions:

1. How do children with multiple sclerotic parents perceive their families?

2. How do these children perceive themselves, their physical image, and their place within the family?

3. As the families have adjusted their structure, roles and expectations, support systems, and financial situation as a response to the disease affecting one of the productive adults, how have the children related to these adjustments?

4. Is the emotional and social development of these children following a normal developmental pattern, specifically with respect to the development of empathy and altruism/prosocial behavior?

5. If the children are developmentally delayed or accelerated, is it the apparent result of the multiple sclerosis in the family?

Theoretical Framework

The study of a family is best undertaken in relation to a family systems model. There are several models from which to choose. For the purposes of this study, the Circumplex Model of Family Systems (Olson, 1989) was selected due to its relationship to families in crisis. This is a three-dimensional model, utilizing as the three dimensions cohesion, adaptability, and communication--dimensions encompassing variables independently focused on over the past decade by a number of theorists. The Circumplex Model is illustrated in figure 1. Here, the two dimensions shown are Cohesion and Adaptability, each of which has four levels (pp. 8, 9).

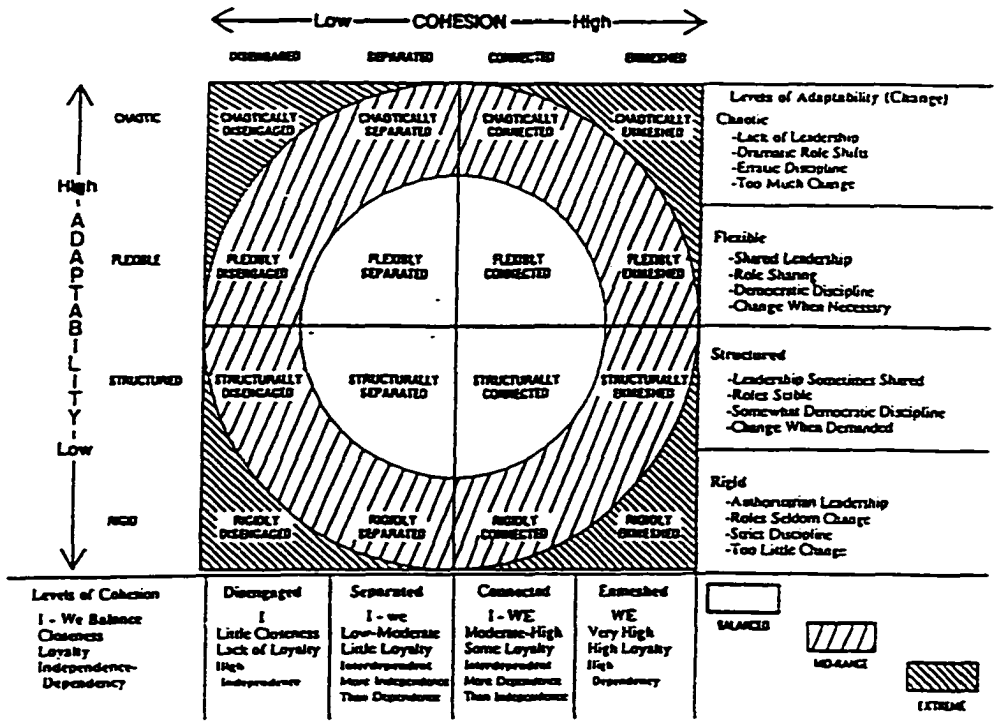


Figure 1. The circumplex model of marital and family systems.

The horizontal dimension--Cohesion, or Togetherness--encompasses such specific variables as emotional bonding, boundaries, coalitions, time, space, friends, decision-making, and interests and recreation. On this dimension, the two central levels, separated and connected, are considered most conducive for optimal family functioning. The extremes, disengaged (low extreme) and enmeshed (high extreme), are seen as problematic for relationships. Relationships at the two middle levels are better able to balance being alone versus being together (Olson, 1989, pp. 9, 11).

The vertical dimension--Adaptability, or Change--is defined as "the ability of a marital or family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress" (p. 12). Family power encompasses such variables as assertiveness, control, and discipline. Again, the two central levels--structured and flexible--are considered to be the most functional, in contrast to the extremes of rigid (extreme low) and chaotic (extreme high) (p. 12).

The third dimension, Communication, is critical in facilitating families with their movement in the other two dimensions. As a facilitating dimension, it is therefore not included in figure 1 (p. 12).

From figure 1, it is obvious that the central, balanced

portion displays the most functional family relationships.

Definition of Terms

Altruism: "Behavior which occurs when the individual offers assistance without regard to the rewards s(he) might gain as a result of doing" (Tabor, 1980, p. 2).

Prosocial Behavior: Used synonymously with altruism, primarily in relation to younger children.

Empathy (for this study, emotional empathy only): "Understanding of the feelings, sufferings or situation of another person, without these feelings being communicated by words" (Wolman, 1973, p. 119).

Delimitation

The sample was delimited to 12 to 15 families in northern Indiana and northeastern Illinois.

Limitations

Due to the limited size of the population and range of sampling, random sampling was not possible. Thus generalizability is limited. This study was an exploratory study which may later lead to more controlled studies.

Importance of the Study

Medical, educational, religious, and mental health practitioners are beginning to realize the importance of the family in helping the individual deal with a chronic illness. Without knowledge of the milieu in which all

family members are functioning, the practitioners would be ineffective in assisting the patient and family members in learning how to cope with the far-reaching effects of the chronic illness.

Practitioners are also beginning to recognize the value of preventive education and treatment. With studies which identify what can be expected of children in a family with a multiple sclerotic parent, the professionals will be more capable of helping other children who are faced with the same situation.

Outline of Dissertation

Chapter 1 has dealt with the background and statement of the problem, the purpose and rationale for the study, questions to be answered, definitions of terms, and delimitations and limitations.

Chapter 2 is a review of related literature.

Chapter 3 outlines the methodology of the research, including a description of sampling procedures, instrumentation, pilot study, and general procedures.

Chapter 4 reports the interview and assessment findings, family by family, treating each as an independent case study.

Chapter 5 analyzes the findings from the separate case studies, in order to seek trends in this specific sample.

Chapter 6 summarizes the material of the previous chapters, and contains conclusions and recommendations.

CHAPTER 2

RELATED LITERATURE

Research already available covers some aspects of families dealing with chronic physical illness in one of the adults and families dealing with multiple sclerosis. The latter is reviewed only as it deals with families who have school-age children. Normal development of empathy and altruism in school-age children is also reviewed.

Using the computer search facilities at the James White Library, Andrews University, research with the children of a multiple sclerotic parent was located. The following programs were utilized: (1) MEDLINE (U.S. National Library of Medicine) back to 1966; (2) CINAHL (Nursing and Allied Health) back to 1983; (3) ERIC (Educational Resources Information Center) back to 1966; (4) Dissertation Abstracts back to 1860; (5) PsychLIT (of the American Psychiatric Association) back to 1974; and (6) SPORT Discus (of sports health-related topics) back to 1975. The majority of literature is in dissertation form and has not been formally published.

Research on Families with Multiple Sclerosis

Realistically, one might expect that, when a parent develops a chronic, potentially disabling, illness, certain changes in the family system could occur. There might be a dramatic cut in the family's income, necessitating job change by the spouse, and a draining of financial resources due to medical expenses. There might also be family role changes regarding household responsibilities, and new dependent-caregiver relationships among spouse, patient, and children.

Moore (1959) studied the experiences, attitudes, and responses of the patient and the spouse to the disease. He found that stress was the prominent impact of MS. Rintell (1985) found significantly more role change in families with ill fathers than in those with ill mothers.

Stuifbergen (1988/1989), surveying previous research in this area, found that chronically ill individuals perceive their experience with the illness as stressful and impacting family relationships. She specifically lists marital and parent-child relationships, self-care and dependency, family roles, home management, employment and income, sexual aspects of marriage, emotions, social interaction and recreation-leisure activities (Braham, Houser, Cline & Posser, 1975; Hanson, 1982; Luft, 1975; McSweeney, Grant, Heaton, Adams & Timms, 1982; Parsons, 1977; Power, 1979; Schmitt & Neubeck, 1985; Sjogren & Fugl-Meyer, 1982).

Stuifbergen's own research revealed that there is a negative relationship between the severity of the chronic illness of a parent and the functioning of the family system. The effects of the severity can be moderated by parental agreement as to the impact of the illness, and by clear and open communication about the illness, within and outside the family. Carter and McGoldrick (1980) found that a family's adaptation to chronic illness is determined by the stage of family development. The older the family, the greater the ability to maintain previous family functioning. Further, the family's life-stage and cultural beliefs affect their approach and adaptation to chronic illness (Wishner & O'Brien, 1978).

Bruhn (1977) concluded that chronic illness may prevent a parent from carrying out a previously nurturant role. The ill parent may suffer depression, anxiety, or irritability, and be preoccupied. Spouses may suffer frustration, fear and disappointment, trying to accommodate to the necessary role changes. He believed that relationships with the extended family become more dependent after the onset of the illness.

Power (1975, 1977, 1985) studied mothers and fathers in families with MS and Huntington's disease. He concluded that the family is a major determinant in how the patient will adjust to his or her illness. He found that fathers more frequently reacted to their illness with depression

than did mothers. Fathers tended to enter a "dependent state," relinquishing their family responsibilities to the healthy spouse. In contrast, the mothers tended to remain active by maintaining their customary family roles. This activity helped manage their depression. Power's (1979) study of 74 men with MS found a clear differentiation between men who adjusted and those who failed to do so. Factors contributing to their adjustment include pre-illness family relationships, previous success in coping with stress, "role complementarity" (a willingness of all family members to adopt role fluidity), and their beliefs about the illness. The family's healthiness or pathology was increased by chronic illness. These men paid more attention to their residual abilities than to their limitations.

Monroe (1988/1989) studied mothers with MS. She found good overall adaptation to their illness on the part of her 13 subjects. They felt very positive about their parenting experiences, but had issues of frustration, guilt, limit setting, and discipline. The couples had become stronger and more interdependent by pulling together to cope with the illness. The mothers adjusted by remaining as independent as they could, while accepting the need to ask for help when necessary.

Sullivan (1974/1975), in studying 50 healthy families and 50 families where one parent had MS, found that disabled parents had to have their needs met by their adolescent

children and/or spouses. They were, therefore, unable to meet their adolescent's needs. Few of the MS families in her study engaged in outside activities which included all family members.

Research on Children in MS Families

The first piece of literature recognized on this subject dates back to 1959. Although concepts of the family and knowledge of MS have significantly changed since that time, Arnaud's (1959) research with 60 children is still considered a definitive contribution. She described three patterns of these children: false maturity, dependent longings, and social alienation. The false maturity refers to a tendency, more frequently found in girls, to inhibit one's own emotions in the interest of determining what is appropriate or expected (compliance). Dependent longings, which were higher in those children who had developed false maturity, are the strong dependency needs the child is forced to deny due to the situation. Social alienation, in her view, was an outgrowth of family conflict and a lack of predictability of parental behavior. She also found these children had higher than normal levels of body concern, dysphoric feelings, and hostility, with the boys higher than the girls. She found higher than normal levels of anxiety in the children between the ages of 7 and 12. Based on her research findings, Arnaud believed that, despite the continuing stress provoked by the chronic illness, normal

ego development and integration may occur. From the broad group trends in her sample, she concluded that young children seem to react to the situation with considerable generalized apprehensiveness and unhappiness. As the children grow older, and their ego system matures, they gradually develop varied defensive measures which allow them to restrict and control their anxieties, and thrust their conflicts, dysphoric feelings and anxieties out of consciousness. However, dependent longings, body concerns, and hostile resentment do not change appreciably with age.

Yuditsky and Kenyon (1979) interviewed 10 adolescents who had a parent with MS. The subjects reported less time for themselves because of additional household responsibilities. There was fear about inheriting the disease, and for their parent's condition. They described guilt over leaving their ill parent, yet also resentment toward that parent.

Olgas's (1974) research is impressive in that she studied 124 children of parents visibly disabled by MS, and 60 control children of healthy parents. She found that body image distortion was significantly greater in girls with MS mothers than in girls with MS fathers or boys with MS mothers. Her results reflected a trend toward greater body image distortion in children with MS parents than in the control group. Same-sex identification with the parent may play a minimal role.

Carpio (1981) worked with 18 mother-daughter dyads, where the mother had MS, and compared them with healthy dyads. Daughters of MS mothers placed less importance than the control group upon learning about their bodies. She also found no difference in the daughters' interpersonal relationships.

Sullivan's (1974/1975) research further found that adolescents with MS fathers reported a significantly higher incidence of personal symptoms compared to adolescents with MS mothers and adolescents with healthy parents.

Solomon (1981) studied 27 adolescent children of MS parents and a matched control group. She found that adolescents with an MS mother were significantly better adjusted than those whose father had MS. She found no significant differences between the MS group and the control group in individual adjustment, family adjustment, or health and physical development.

Results supporting positive adjustment were also reported by Rintell (1985), when he studied 12 families with 30 children. Although there was some distribution of self-concept scores, most were close to the mean, suggesting that the children of the MS patients, as a group, were not a "deviant" population. In contrast to Olgas and Solomon, however, Rintell stated that

> psychological adjustment of the children in the study . . . was not found to be statistically significantly related to the sex of the ill parent, the degree to which the ill parent is

> disabled, age of the child, birth order of the children or status as the oldest child in the family (p. 99).

Statistical conclusions from such a small sample should be cautiously considered.

Rintell found that adolescents who were older at the onset of their parents' symptoms had a better body image than those who were younger. Better body image was also associated with fewer years since the onset of symptoms. He also found that families with ill fathers had significantly more role changes than those with ill mothers, and those changes in roles involved decision making. The older the children, the greater was their participation in family responsibility. He speculated that better adjustment in older children was associated with participation in family responsibility and decision making. Finally, adolescents who received help from the local MS clinic had better overall adjustment than those who received help only from the parent's physician.

Power (1984) studied 69 adolescents with a parent with either Huntington's disease or MS. He found that most of these adolescents were adjusting well, using "positive denial," which is a denial of the severity of the illness or a denial of the effects the illness has on the family. He found this to be only a temporary coping mechanism; but it was a foundation for an adaptive life pattern and a way to reduce anxiety. Determinants of how well the adolescent

dealt with the impact of the parental illness were family understanding of the illness, family expectations for both the parents and the children, and positive family adjustment to the disability. He found that religious involvement facilitated this adjustment.

Peters and Esses (1985) studied 33 secondary-age children with a non-hospitalized MS parent and a matched control group in regard to their perception of the family environment. The MS group felt more conflict, less cohesion, less intellectual-cultural orientation, less moral-religious emphasis and less organization than the control group. No significant differences were found with respect to expression, independence, achievement orientation, active-recreational orientation, and control.

Blackford (1992) studied children with ill mothers, 17 of whom had MS, and compared them to a control group. She found that the children of ill mothers demonstrated a significantly higher potential for mature friendship relations. These children had a high degree of sensitivity to others, usually associated with empathic skills.

Summary of MS Family Research

The research reviewed indicated that a chronic illness causes stress in the family, and affects family relationships, roles and communication. The impact of the illness could be moderated by the stage of family development, the parent's desire and ability to remain

active, family willingness to change roles, effective communication, and joint effort to cope.

Children in MS families were basically well-adjusted. Although young children seemed to have more apprehensiveness and depressive tendencies, adolescents seemed to develop defense mechanisms which helped them cope. The research delineated differences related to which parent had MS, the age of the child at the onset of the MS, the child's responsibility in the family, and perceptions of the family.

Research on Development of Empathy and Altruism

Utilizing the same research facilities in the James White Library, a review was made of the literature relating to the development and measurement of empathy and prosocial and altruistic behavior. Very little relevant literature was identified. Measurement is discussed in the Instrumentation section of chapter 3.

According to Kohlberg (1969), cognitive-developmental theory claims that, as children mature, their capacity for abstract thinking also develops. This involves the understanding of another person's cognitive, affective, or perceptual perspective. It is believed that this growth in cognitive capacity brings about qualitative changes in children's moral reasoning.

Eisenberg (1979, 1982) found that young children are egocentric, and base their moral decisions on needs orientation, which she presumed to be early empathic

reasoning, but lacking in prosocial reasoning. Elementary-age children's moral decisions reflected a desire for approval and to behave in a socially acceptable manner. Secondary-age children's moral decisions reflected abstract principles, including internalizing emotional reactions that relate to one's principles and self-reflective empathic reasoning. Developmental stages were delineated through Eisenberg's later research (1983, 1987, 1991). "The link between empathy and altruism is strengthened as children become more able to understand another's life circumstances beyond the immediate situation" (Eisenberg et al., 1987, p. 718).

Based upon cognitive-developmental theory, Eisenberg et al. (1983) suggested that children whose parents encourage them to understand the views of others and to participate in decision making should be able to make moral judgments more effectively than children who have authoritarian parents. Based on social-learning theory, the same authors suggested that nurturant, supportive, non-punitive parenting facilitates prosocial development in the early years, when children are more likely to be dependent on, have respect for, and to model such parents.

Feshbach (1978) stated that experiencing the expression and restraint of feeling as part of the socialization process was highly relevant to the development of empathy. She also found that the ability to empathize improved

with age.

From the research discussed, it is evident that empathy and altruism (prosocial behavior) are related, and both become stronger with age. However, altruism does not appear to begin to develop as early as empathy.

CHAPTER 3

METHODOLOGY

Type of Research

This research was an exploratory study which it is hoped will become the springboard for further studies. The study, therefore, is largely of a qualitative nature. Comparative studies were also utilized as appropriate.

Population and Sampling Procedures

The population of interest consisted of families with school-age children (ages 5 through 19), where one of the parents has multiple sclerosis, and the second parent (or step-parent) is present.

I, myself, am limited in my ability to travel over a wide geographic area to meet with subjects due to my own multiple sclerosis. Therefore, the population was delimited to families residing in northern Indiana and northeastern Illinois.

Initially, the support of the National Multiple Sclerosis Society was sought. They expressed interest in the proposed study, but indicated that the subjects would need to be identified through the local chapters. As it turned out, however, it was not necessary to approach the

local chapters, due to the enthusiastic support of two neurologists and a psychologist. My personal neurologist offered to have his office secretary send the demographic questionnaire (described below) and his cover letter to each of his multiple sclerosis patients and their families in June of 1992. Those families which included school-age children and were willing to participate in the study returned to me the completed questionnaire and a consent form signed by each family member. Thus, no other patients were identified by name to me. Five qualified families were thus identified for the study.

A major multiple sclerosis clinic in the Midwest was then contacted for a wider population. The director of the clinic and one of his psychologists willingly agreed to submit a revised research protocol to their human subjects research committee. After the committee's approval had been received, the psychologist wrote a cover letter which he sent in February of 1993 with the demographic questionnaire to the clinic's patients in the identified geographical area. It was hoped that completed questionnaires and consent forms would be received from an adequate number of potential subject families, to enable selection to be made in such a way as to remove the effect of some of the independent/moderator variables listed later in this chapter.

Description of the Sample

The first mailing from the major clinic resulted in 4 qualified families agreeing to participate. A second mailing from this clinic brought 4 more usable families. Thus a total of 13 families were identified for the study. As it turned out, one of these families found it very difficult to schedule the initial interview appointment, due to the number of persons living in the home and the heavy extra-curricular program of some family members. This family, though initially very interested in the research, eventually was not able to participate. A 13th family was anxious to join the study after hearing it discussed in an MS support group by another participant in the study.

The sample thus consisted of 13 families. A general demographic description of the families is as follows: In 10 families the mother, and in 3 families the father, had MS. Four families lived within the large city, and one in its suburbs. Two families lived in small cities (large towns). Four families lived in small towns, and two in rural areas. All were Caucasian.

Together, the families included 4 elementary-age sons, 6 elementary-age daughters, 4 secondary-age sons and 6 secondary-age daughters.

Non-Qualified Interested Respondents

Before responses began to trickle in from families meeting the criteria for inclusion in the study, several

were returned from families who were interested in participating but failed to meet the criteria. By the conclusion of data collection, 27 responses had arrived by mail, and 4 by telephone, from such families. Each of these 31 interested respondents wrote or shared messages of support for the research. The reasons for their failure to meet the criteria were varied. Seven female respondents and four men had no children. Two fathers and one mother had families who agreed to participate, but were too busy to be able to set appointments. Three mothers had no spouse, and two of these said their divorces were due to the MS. The children of eight mothers and one father were adults. Two mothers and two fathers had someone in the family unwilling to participate. One mother reported that her child was living with her ex-husband. One father informed me that he no longer lived in the area, and one wife reported that her husband had recently died.

Variables

Dependent Variables

The dependent variables of interest in this study are: (1) self-concept; (2) family relationships; (3) basic personality; (4) cognitive development; and (5) social relationships, in particular empathy and altruism/pro-social behavior. These variables are delineated more specifically and operationally in the Instrumentation section which follows.

Independent/Moderator Variables

The independent/moderator variables are: (1) the gender of parent with multiple sclerosis; (2) the age of parent and age of children at the time of diagnosis; (3) whether or not the child knew the parent before diagnosis, in relation to the previous variable; (4) the length of time since the diagnosis; and (5) the degree of disability of the parent.

It was hoped that the participating sample might be selected in such a way as to control one or more of these variables. As only 13 qualified families within a reasonably accessible area offered to participate, however, all were used. Thus none of these independent or moderator variables could be controlled.

Instrumentation

Several instruments were utilized for this study, in order to obtain evidence from more than one source. Interpretations were then a combination of the results from these multiple tests and the interviews. These are here discussed in the approximate order of their use.

Population Identification Questionnaire

As was discussed under Population and Sampling Procedures, a package was prepared by me and sent by the neurologist or psychologist to each of their multiple sclerosis patients, together with a covering letter of their

own. This package consisted of an introductory letter from me, a demographic information questionnaire, and a consent form (see copies in appendix A).

The letter introduced me, and mentioned the need for research to be undertaken on families and school-age children where a parent has multiple sclerosis. Interested parents and their children were invited to complete the questionnaire and consent form and mail them back to me in the stamped, addressed envelope provided. They were advised of the necessity of more than a single interview. Care was taken in the letter to stress the provisions to ensure confidentiality, the right to withdraw, and my personal responsibility to avoid discomfort to the family or any member. My home telephone number was provided.

The questionnaire requested the following information: names and ages of the parents; name, age, and school grade of each son and daughter; name, age, and relationship to family of any others living in the home, and of any other family member not living at home; designation of which parent had multiple sclerosis; when, and by whom, the illnesss was diagnosed; daily-occurring symptoms; willingness to participate--in own home or perhaps elsewhere, and on more than one occasion; address, home phone number, and work phone number for both husband and wife, and best time to contact each. The consent form contained a declaration by me regarding the protection of

the rights of the family members. Each member of the family, and an independent witness, was asked to sign the consent form, which was to be returned to the researcher together with the completed questionnaire. A yellow tear-off copy of the consent form was provided for the family to keep.

On receiving the forms, I sent the family a letter of appreciation, with a promise of further contact (copy in appendix A).

Interview Schedule (Pilot-Study Form)

I developed a schedule (see appendix B) to guide through the interview so that all essential points would be covered at each interview. The top sheet, to be destroyed after all research had been completed for that family, requested name, birthdate, educational level, and details concerning the occupation of each parent; date of marriage; name, gender, birthdate, school, grade, and name of teacher of each child; and name, relationship, age, and length of time in home of others living in the home. The other five pages contained questions with a largely unstructured response format. It was hoped that analysis of the responses from the pilot-study sample would enable some structuring of the response format for the major study to simplify recording of responses. This did not turn out to be the case.

Each question/section of the schedule is related in

Table 1 to one of the six research questions stated in chapter 1 and/or to one of the potential independent/moderator variables listed in the present chapter.

The Family Adaptability and Cohesion Evaluation Scales--II (FACES-II)

The FACES-II is one of several scales developed by the Family Inventories Project in the Department of Family Social Science, University of Minnesota. The Director of the Project is David H. Olson.

Although a fourth version of FACES was under construction, the authors recommended the continued use, for the present, of FACES-II, which has considerably higher reliability than FACES-III (copy of statement in appendix B).

The Family Adaptability and Cohesion Evaluation Scale was designed to enable placement of families into the Circumplex Model developed by Olson and Associates. The scale enables family members to describe how they perceive their family.

> Family Cohesion is defined as the emotional bonding that family members have toward one another. There are four levels of cohesion ranging from disengaged to separated, to connected, to enmeshed. The developers of this framework hypothesized that the central levels of cohesion (separated and connected) are the most viable for family functioning. The extremes (disengaged or enmeshed) are generally seen as problematic.
>
> Family adaptability is defined as the

TABLE 1

RELATIONSHIP OF INTERVIEW SCHEDULE TO RESEARCH QUESTIONS

Question/Section	Research Question # (pp. 3, 4)	Independent Variable # (p.25)
Church affiliation/ organization	3	
Volunteer work/other activities	3	
Diagnosis of MS (6 questions)	3 Supportiveness of doctor	2, 3, 4
Sharing of diagnosis	3 Support system	
How diagnosis was dealt with	1, 3, 4, 5, 6	
Supportiveness of each group	1, 3, 4, 5, 6	
Symptoms, problems, treatments and medications	3	5
Assistance, insurance counseling; family changes; children in school	1, 2, 3, 4, 6	

> ability of a marital or family system to change its power structure, role relationships, and relationship rules in response to situational and developmental stress. The four levels of adaptability range from rigid, to structured, to flexible, to chaotic. As with cohesion, it is hypothesized that central levels of adaptability (structured and flexible) are more conducive to marital and family functioning, while the extremes (rigid and chaotic) are the most problematic for families as they move through the family life cycle. (McCubbin & Thompson, 1991, p. 66)

FACES-II was developed in 1981 by Olson, Portner, and Bell to provide a shorter instrument than FACES-I, that could be used by children. An initial scale of 90 items was reduced to 50 items on the basis of item analysis and factor analysis. Each of the statements was initially responded to on a 5-point response scale (Strongly Disagree to Strongly Agree). Further analysis, after administration to 2,412 individuals, reduced the scale to 30 items. These include 2 items for each of eight concepts relating to the cohesion dimension--emotional bonding, family boundaries, coalitions, time, space, friends, decision making, and interest and recreation--for a total of 16 items for cohesion; and 2 or 3 items for each of the six concepts relating to adaptability--assertiveness, leadership, discipline, negotiation, roles, and rules--for a total of 14 items for the adaptability dimension.

A recent update of the instrument (Olson, McCubbin, & Associates, 1992, pp. 12-18) modified the response format so that the five response categories are: almost never, once

in a while, sometimes, frequently, and almost always. They supply directions for a scoring procedure, leading to a score which may be interpreted in a linear manner from the Circumplex Model (see Figure 2).

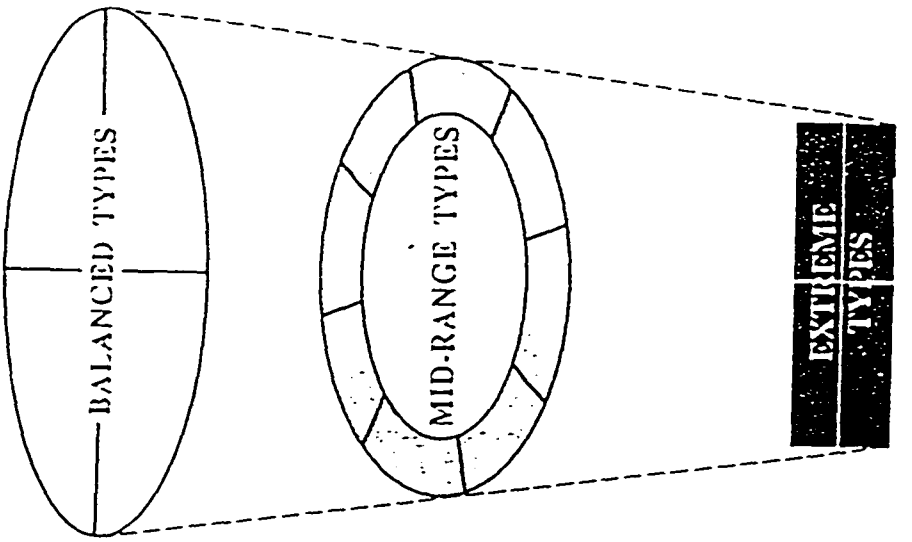
Reliability and Validity

Reliability coefficients obtained were: alpha values of .87 for Cohesion, and .78 for Adaptability, and .90 for the full scale, based on the 30-item scale; and test-retest-coefficients over 4 to 5 weeks of .83 for Cohesion, .80 for Adaptability and .90 for the full scale, based on the 50-item scale. A concurrent validity study compared scores on FACES-II with scores on the Dallas Self-Report Family Inventory, using the global measure of family health. Validity coefficients were reported as .93 for Cohesion and .79 for Adaptability.

Family Crisis Oriented Personal Scales--F-COPES

The F-COPES is another scale of the Family Inventory Project, and was developed in 1981 by Hamilton L. McCubbin, David H. Olson, and Andrea S. Larsen of the University of Wisconsin, Madison, Family Health Program. It was developed to record effective problem-solving attitudes and behavior which families develop to respond to problems or difficulties.

The set of 30 items is introduced by the general statement: "When we face problems or difficulties in our



Cohesion			Adaptability			Family Type	
8	80	Very Connected	8	70	Very Flexible	8	Balanced
	74			65			
7	73		7	64		7	
	71			55			
6	70	Connected	6	54	Flexible	6	Moderately Balanced
	65			50			
5	64		5	49		5	
	60			46			
4	59	Separated	4	45	Structured	4	Mid-Range
	55			43			
3	54		3	42		3	
	51			40			
2	50	Disengaged	2	39	Rigid	2	Extreme
	35			30			
1	34		1	29		1	
	15			15			

(___ Cohesion + ___ Adaptability) ÷ 2 = Type

Figure 2. FACES-II: Linear scoring and interpretation.

family, we respond by . . . ." This introduction is followed by the 30 statements, each with a 5-point response format from Strongly Disagree to Strongly Agree.

An initial set of 49 items was reduced by factor analysis to 30 items, each loading from .39 to .85 on one of eight factors in two dimensions--internal and external family coping patterns. The three Family Resources (internal patterns) are: (1a) Confidence in Family Problem Solving; (1b) Reframing Family Problems; and (1c) Family Passivity, each of four items. The five Social and Community Resources (external problems) are: (2a) Church/Religious Resources (4 items); (2b) Extended Family (4 items); (2c) Friends (4 items); (2d) Neighbors (3 items); and (2e) Community Resources (3 items) (Olson, et al., 1992, pp. 121-122).

Factor analysis of scores from a large sample of 2,740 subjects provided a factor structure similar to the original, but with slight modifications. Some of the original eight factors merged to form more global factors. One item was deleted from the scale. The resulting five factors are:

Coping 1: Acquiring Social Support. Nine items measure a family's ability to actively engage in acquiring support from relatives, friends, neighbors, and extended family (factors 2b, 2c, 2d).

Coping 2: Reframing. Eight behavior items which

assess the family's capability to redefine stressful events in order to make them more manageable (factors 1a and 1b).

Coping 3: Seeking Spiritual Support. Four behavior items which focus upon the family's ability to acquire spiritual support (factor 2a).

Coping 4: Mobilizing Family to Acquire and Accept Help. Four behavior items which focus upon the family's ability to seek out community resources and accept help from others (factor 2e plus one additional item).

Coping 5: Passive Appraisal. Four behavior items which assess the family's ability to accept problematic issues minimizing reactivity (factor 1c) (Olson et al., 1992, pp. 123-125).

Reliability and Norms

In Table 2, the item numbers for each of the coping subscales are given, together with two reliability estimates for each: coefficient alpha (internal consistence) from a sample of 2582, and test-retest-reliability from a sample of 116.

Percentile norms are provided for adult males and females and for adolescent males and females, and for all combined, for the complete 30-item instrument and for each of the five subscales. Means, standard deviation, and modes are also provided, together with indices of kurtosis and skewness.

TABLE 2

F-COPES SUBSCALES AND RELIABILITIES

Subscale	Item numbers	Coefficient alpha (N=1582)	Test-retest reliability (N=116)
Acquiring social support	1,2,4,5,10, 16,20,25,29	.83	.78
Reframing	3,7,11,13,15, 19,22,24	.82	.61
Seeking spiritual support	14,32,27,30	.80	.95
Mobilizing family to acquire and accept help	6,8,9,21	.71	.78
Passive appraisal	12,17,26,28*	.63	.75
Total scale		**.86**	**.81**

Note. From Family Inventories (p. 125) by David H. Olson, Hamilton I. McCubbin, and Associates, 1992, St. Paul, MN: Family Social Science, University of Minnesota (p. 125).
*These four items must be reversed when scoring.

Family Hardiness Index (FHI)

The Family Hardiness Index was developed by McCubbin, McCubbin, and Thompson (1986) as part of the research at the Family Stress, Coping and Health Project at the University of Wisconsin-Madison. This is a 20-item instrument in which the respondent is to assess the degree to which each statement describes the current family situation. Each item has a 4-point response scale: False, Mostly False, Mostly True, True, and an additional option--Not Applicable.

The instrument contains four subscales, measuring the four interrelated components of family hardiness, and confirmed by factor analysis. These four subscales/components are given below, with items listed in order of size of factor loading:

1. Cooriented Commitment: Items 5, 7, 18, 13, 11, 9, 4, 6. Each item loaded above .51 on this factor, This factor measures the family's sense of internal strengths, dependability, and ability to work together.

2. Confidence: Items 8, 10, 3, 2. Each loaded above .58 on this factor. The factor measures the family's sense of being able to plan ahead, being appreciated for efforts, and members' ability to endure hardships and experience life with interest and meaningfulness.

3. Challenge: Items 17, 15, 16, 14, 12. Each item loaded above .52 on this factor. The factor measures the family's efforts to be innovative, active, to experience new

things, and to learn.

4. Control External: Items 19, 20, 1. Each item loaded above .77 on this factor. The factor, in its positive aspect, measures the family's sense of being in control of family life rather than being shaped by outside events and circumstances (McCubbin & Thompson, 1991, pp. 127, 129, 130).

Positive items are scored from false = 0 to true = 3. Negative items are scored from 3 to 0. These negative items are numbers 1, 2, 3, 8, 10, 14, 16, 19, 20. For all items, Not Applicable = 0.

Reliability, Validity and Norms

For reliability as internal consistence, a coefficient alpha of .82 was obtained for the complete FHI. No reliability information is at present available for the subscales.

In addition to the construct validity evidenced by the factor analysis, some concurrent validity information is provided. The FHI was correlated with the Family Flexibility subscale of FACES-II (r = .22); with the Family Time and Routines Index (McCubbin et al., 1986) (r = .23); and with the five subscales of the Quality of Life Instrument (Olson & Barnes, 1982): Family Satisfaction (r = .20), Marital Satisfaction (r = .11), and Community Satisfaction (r = .15).

Although all these correlations are significant at the

.05 level, they are not very strong.

No normative data on the subscales are available. However, the authors do provide a table of percentile ranks corresponding to raw total scores on the FHI from a sample of 304 families. They also provide the Mean, Median, Standard Deviation, and Range.

Vineland Adaptive Behavior Scales

The Vineland Adaptive Behavior Scales, developed by Sparrow, Balla and Cicchetti, is a 1984 revision of the Vineland Social Maturity Scale, developed by Doll (1935, 1965). The authors define adaptive behavior as "the performance of the daily activities required for personal and social sufficiency" (Sparrow, Balla, & Cicchetti, 1984, p. 6). It is "age-related, is defined by the expectations or standards of other people, . . . and is defined by typical performance, not ability" (p. 6).

There are three forms. The Survey Form, of 297 items, is administered by a trained interviewer to a parent, caregiver or an individual from birth to 18 years, 11 months old.

Each item is a statement of the performance of a daily activity (e.g., "Apologizes for mistakes or errors in judgment"). A score of 2 is assigned for a rating "Yes, usually"; 1 for a rating "sometimes, or partially"; and 0 for a rating "no, never." For each domain, scoring commences with the item designated for the individual's age.

The Expanded Form contains an additional 280 items and is administered in the same way as the Survey Form.

The Classroom Edition contains 244 items from both the other forms, and is independently completed by a teacher of a student from 3 years of age to 12 years 11 months. The present research used the Classroom Edition for only the elementary school students in the sample. The authors determined, from literature review and their own clinical and research experiences, that the daily activities of most individuals could accurately be categorized into four behavioral domains: Communication, Daily Living Skills, Socialization, and Motor Skills. An original set of about 3,000 items was reduced by careful analysis to 800 items and, after pilot tests, to 529 items. These were used in a national tryout using 361 females and 362 males from the major regions of the United States and "from all socioeconomic categories, as measured by parental education, and from white and minority races or ethnic groups" (Sparrow et al., 1984, p. 10). About half of the 529 items were then used as a standardization edition for the Survey Form. The standardization sample consisted of 3,000 individuals at 35 sites in 24 States, ranging in age from birth to 18 years, 11 months.

Table 3 gives a content definition for each of the four domains and their sub-domains, and the number of items for each in the Classroom Edition.

TABLE 3

CONTENT OF VINELAND CLASSROOM EDITION

Domain and Sub-domain	Content definition	# of items
Communication		
Receptive	What the individual understands	10
Expressive	What the individual says	29
Written	What the individual reads and writes	24
Total scale		63
Daily living skills		
Personal	How the individual eats, dresses, and practices personal hygiene	36
Domestic	What household tasks the individual performs	21
Community	How the individual uses time, money, the telephone and job skills	42
Total scale		99
Socialization		
Interpersonal relationships	How the individual interacts with others	17
Play and leisure time	How the individual plays and uses leisure time	18
Coping skills	How the individual demonstrates responsibility and sensitivity to others	18
Total scale		33
Motor skills		
Gross	How the individual uses arms and legs for movement and coordination	16
Fine	How the individual uses hands and fingers to manipulate objects	13
Total scale		29
Adaptive behavior composite		244

Reliability, Validity and Norms

The authors report several reliability estimates for the Survey Forms: (1) corrected split-half coefficients for the domains, measured within each of 15 age groups, ranging from .70 to .95, and for the composite score within each of the age groups, from .89 to .98; (2) test-retest (2-4 week interval) coefficients ranging from .76 to .93 for standard scores and from .77 to .98 for raw scores; (3) interrater reliability coefficients ranging from .62 to .75 for the domains and .74 for the composite for standard scores, and from .96 to .99 for domain raw scores.

The authors give a great amount of validation data--construct and criterion-related--both supporting the validity of the instrument. Content validity was ensured by the careful item selection and analysis.

For each age group, in 3-month increments, tables are provided enabling a raw score of each domain to be converted to a deviation IQ-type standard score. For each sub-domain, at each age level, a table is provided to transfer raw scores to adaptive level descriptors.

Human Figure Drawing (HFD)

The HFD is a technique where a child is given a blank piece of paper and a pencil and is asked to draw a whole person. The method is attributable to Koppitz (1968), who claimed that it can be used as a projective technique to

seek signs of unconscious needs, conflicts, and personality traits.

Koppitz claimed that 30 developmental items and 30 emotional indicators could be identified from a child's HFD. These items were not significantly related to the child's drawing ability or training. She warned that evaluation should not be made on the basis of a single HFD indicator. The combination of all indicators should be evaluated, with other test data, taking into account the child's age, maturation, social and cultural background, and emotional state. Only the emotional indicators were used in this study.

The Kinetic Family Drawing (KFD)

Burns and Kaufman (1970) added the concept of "doing" to the drawings. It was hoped that the addition of movement would draw forth the child's feelings into the area of interpersonal relations in addition to those related to self-concept. The procedure is simply described in Burns and Kaufman (1972).

> The drawings are obtained from children individually. The child is asked to seat himself on a small chair at a table of appropriate height. A sheet of plain white, 8.5" x 11" paper is placed on the table directly in front of him. A No. 2 pencil is placed in the centre of the table and he is asked to "Draw a picture of everyone in your family, including you, DOING something - some kind of action." (p. 5)

I first clinically evaluated each picture as a whole.

Then I scored the following research variables: activity level, activity type, communication level, cooperation level, figure nurturing, figure body, relative size of figures, orientation between figures, and barriers (Burns & Kaufman, 1972). These variables were selected as they relate to the family concepts I was studying.

Several studies have investigated the inter-rater reliability of the KFD. McPhee and Wegner (1976) obtained coefficients ranging from .655 to 1.0, with a median of .87. Mostkoff and Lazarus (1983) reported inter-judge agreement ranging from 86% to 100%, with a mean of 97%. Layton (1984) reported high inter-rater reliability for 133 of the 157 signs investigated in her research. As a further check of the objectivity of my scoring, the drawings of 6 subjects were independently evaluated by another child psychologist experienced in the use of projective drawings. Their scoring was in very close agreement with mine.

Empathy Scales

A computer search was undertaken to seek to identify a normed empathy scale, reliable and valid for the present study. The search was made, using the PSYCHLIT data base (from 1974), and the Dissertation Abstracts data base (from 1861). Two instruments were identified as being of greatest usefulness, one for secondary-age children and adults, and one for elementary-age children. These were selected for use in this study.

The Emotional Empathic Tendency Scale (EETS)

The Emotional Empathic Tendency Scale was developed by Albert Mehrabian and Norman Epstein (1972). The authors aimed to develop a measure of emotional empathy, a vicarious emotional response to the perceived emotional experiences of others. A large pool of items was reduced to an instrument of 33 items, each being a statement of empathic response to some situation, person, or object, with a 9-point response scale running from very strong agreement (+4) to very strong disagreement (-4) for positive items, with scoring reversed for negative items. These final items were selected using three criteria: insignificant correlations with the Crowne and Marlowe (1960) social desirability scale; significant correlations ($p = .01$) with scale total score; and content validity "inferred in part from factor analyses of a larger pool of items" (Mehrabian & Epstein, 1972, p. 527). These seven factors were named as Susceptibility to Emotional Contagion, Appreciation of the Feelings of Unfamiliar and Distant Others, Extreme Emotional Responsiveness, Tendency to Be Moved by Others' Negative Emotional Experiences, Sympathetic Tendency, and Willingness to Be in Contact with Others Who Have Problems. The subscale intercorrelations all exceed .30 (p. 527).

The scoring instructions provided by Mehrabian stress that the above factors were described only for the purpose of identifying the content composition of the scale--not to

be employed as separate subscales. Appendix B contains the personal letter from Dr. Mehrabian authorizing reproduction of the scale for the present study, but refusing permission for any items of the scale to be listed in a dissertation or any such medium for distribution to others. Hence no copy of the scale is included in the dissertation. Mehrabian obtained a split-half reliability of .84 for the complete measure.

In their 1972 paper, Mehrabian and Epstein describe two experiments to test two hypotheses proposed by Feshbach (1964). These were: (1) that the more empathic person is discouraged from using aggressive instrumental behavior to achieve non-aggressive goals, and (2) the immediacy and intensity of the pain reaction of the victim are important factors in inhibiting aggression. Using the EETS to measure emotional empathy, they obtained partial confirmation of these hypotheses. In both experiments an interaction effect between empathic tendency and immediacy indicated that only highly empathic subjects showed less aggression in the more immediate condition.

In one of the experiments, the less empathic males were found to be generally more aggressive (Mehrabian & Epstein, 1972, p. 541). A further experiment, using the EETS, obtained results which were "interpreted as evidence that empathic tendency is the major personality determinant of helping behavior" (p. 542).

In a later paper, Mehrabian, Young, and Sato (1988) provided further evidence relating to the validity of the EETS.

Of the reports on research involving empathy among adults and adolescents which were identified by the computer search, the Mehrabian and Epstein EETS was used more frequently than any other empathy scale (Eysenck & Eysenck, 1980; Randhawa, DeLacey, & Saklofske, 1986; Strayer & Roberts, 1989).

Index of Empathy for Children and Adolescents

Bryant (1982) sought to extend the Mehrabian and Epstein EETS downward to accommodate a wide range of children and adolescents. She selected the EETS for three reasons: (1) the Mehrabian and Epstein definition of empathy as a vicarious emotional response to the perceived emotional experiences of others met Bryant's primary interest in the development of her scale; (2) ease of administration, in contrast to the slide projector and viewing facilities required by the other major available instrument (Feshbach & Roe, 1968); and (3) the need for comparable forms of an empathy index for use with children, adolescents, and adults.

To develop her instrument, Bryant reworded 17 items selected from EETS, so as to be more suitable for use with children. Five of these items each yielded a second item

when reworded, four by making parallel boy/girl items, and the fifth by the writing of both a positively worded and a negatively worded item. Thus, Bryant arrived at a scale of 22 items, parallel to EETS and valid for children.

Norms, Reliability and Validity

Bryant's norming sample included boys and girls in grades 1, 4, and 7. For the seventh graders, she used the 9-point response scale of EETS. For the other two grades, she used a 0 (No), 1 (Yes) response scale. She provides mean and standard deviation for each of these 3 age groups.

Bryant gives internal consistency reliability values (Cronbach's alpha) of .54 for first graders, .68 for fourth graders, and .79 for seventh graders. Test-retest (2-week interval) reliability coefficients were obtained as follows: .74 for 53 first graders; .81 for 108 fourth graders; .83 for 80 seventh graders; and .85 for these same seventh graders using the adult EETS.

Bryant offers considerable evidence for discriminant, convergent, and general construct validity.

In a personal telephone conversation with my measurement/statistical adviser, Dr. Bryant authorized duplication of her instrument for the purpose of the present study. She recommended use of the Mehrabian and Epstein instrument for grade 8 and above--perhaps even grade 7. As the Bryant instrument is already in the public domain, it is reproduced in appendix B.

Survey of Interpersonal Values

The same computer search that was made for instruments measuring empathy was also made to seek a normed instrument to measure altruism or prosocial behavior. A number of instruments (not normed) were identified, mostly measuring prosocial behavior in pre-school children through observation of contrived play-acting situations.

Eventually an instrument was identified, which purports to measure six constructs: support, conformity, recognition, independence, benevolence, and leadership. This is the Survey of Interpersonal Values, developed by Leonard V. Gordon. The construct Benevolence, measured by the fifth scale, is defined as "doing things for other people, sharing with others, helping the unfortunate, being generous." This definition is in accord with my operational definition of altruism/prosocial behavior. The information on development, reliability and validity has been taken from the Second Edition of the Manual (Gordon, 1975).

As the instrument is composed of only 30 items, and requires only about 15 minutes to administer, I decided to administer the complete instrument. The other five scales were then also scored and used. These are:

1. Support: Being treated with understanding, receiving encouragement from other people, being treated with kindness and consideration.

2. Conformity: Doing what is socially correct,

following regulations closely, doing what is accepted and proper, being a conformist.

3. Recognition: Being looked up to and admired, being considered important, attracting favorable notice, achieving recognition.

4. Independence: Having the right to do whatever one wants to do, being free to make one's own decisions, being able to do things in one's own way.

5. Leadership: Being in charge of other people, having authority over others, being in a position of leadership or power (Gordon, 1975, p. 1).

The instrument uses forced-choice format. Each of the 30 items is a triad. The respondent is asked to select one statement as representing what is most important, and one statement as representing what is least important to himself or herself. The remaining statement is left unmarked. A high score on a scale indicates that what is represented by the item content of that subscale is valued by the respondent (Gordon,1975, p. 1).

From a review of the literature, 10 construct hypotheses were developed, which were considered to be reasonably independent of each other. Initially 210 single items were prepared, with approximately equal representation of these 10 constructs. Other criteria used in the development of the items were that they were intended to measure values defining relationships between "normal"

people and that a reasonable response variance should be expected. The forced-choice format was selected because all the values under consideration were considered to be socially acceptable, and hence the relative importance of these values to the individual would be the subject of measurement.

Following administration to a college-student sample, a factor analysis of the items led to 7 of the 10 constructs emerging as orthogonal factors. At this point, the items were arranged in triads, in such a way that each triad represented 3 of the constructs. It proved difficult to match items of the factor Aggression in this way and, in a trial run, the aggression item was almost always selected as the least important choice. Hence this dimension was removed, and a new form was prepared including only the six factors defined above (Gordon,1975, p. 2).

Scoring of the six scales is easily accomplished by means of a hand-overlay stencil which is placed in a different position over the response sheet to score each separate scale.

Reliability

The manual gives reliability estimates for 10 samples. For high school students, the sample of interest for this study, the internal consistence coefficients were .82, .86, .75, .86, .81, and .84 for the six scales respectively. For college students, short-term (10 day) test-retest

reliability coefficients ranged from .78 to .89. For various other samples, longer range (12 weeks to 1 year) test-retest coefficients ranged from .55 to .82 (p. 3).

Norms

Means and standard deviations are supplied for the six scales, derived from the 144 high school students in the sample. Percentile norms are supplied, based on a sample of 2,026 male and 1,629 female high school students. These were 11th- and 12th-grade students only. However, norms are given also for ninth-grade vocational students from urban schools. The sample of 11th- and 12th-grade students included 26 sampling units from suburban and rural schools, representing approximately equally eastern and western regions of the country, and urban schools in these regions and also the central region. Blacks and Spanish surnames together comprised 17.2% of the urban sample, and an undetermined but small percentage in the other samples (p. 6). For this study the more appropriate of these two sets of percentile norms, depending on grade level, was used.

Validity

The major validity evidence relevant to the present study is that provided by the factor analysis. The manual includes 44 pages (pp. 10 to 53) of further validity information from studies using a wide variety of samples. Just three of these studies involved high school students.

1. The construct, bureaucratic orientation, is measured in the School Environment Preference Schedule (SEPS). Significant positive correlations were obtained between this construct and the Conformity scale of the SIV for 42 twelfth-graders (r = .32), 65 eleventh-graders (r =.37) and 61 tenth-graders (r = .35). Significant negative correlations were obtained between SEPS and the Independence scale of SIV (-.54 for grade 12 and -.24 for grade 10). For the grade 10 sample, in addition, a correlation of +.32 was obtained between SEPS and the Recognition scale of SIV; and a correlation of -.21 between SEPS and the Benevolence scale of SIV (p. 11).

2. Another study compared scores on the SIV by high school counselees with scores obtained from 74 counselors who responded to the SIV as they thought their counselees would. Counselors were most accurate in perceiving the values of their counselees who scored high on Conformity and/or Benevolence (values highly esteemed in traditional schools) and low on Support and/or Indepencence (p. 16).

3. For a group of 169 students in highly structured, traditional school environments, correlations were obtained between a measure of attitude toward school and the SIV scales. Significant correlations were obtained for Independence (-.35), Conformity (+.24) and Recognition (+.16) (p. 24).

A copy of the Survey of Interpersonal Values

appears in appendix B.

Piers-Harris Children's Self-Concept Scale

The Piers-Harris Children's Self-Concept Scale was developed over a period from 1952 to 1973. The definition of self-concept guiding the development of the instrument was based on a number of theoretical assumptions about the nature of children's self-concept.

1. Self-concept is viewed as phenomenological in nature. That is, it is not directly observable, but must be inferred from behaviors or self-report.

2. It includes global components (feelings about self as a whole person) and specific components, such as physical self, moral self, academic self, etc.

3. It is relatively stable.

4. It is self-evaluative as well as self-descriptive.

5. It is experienced and expressed differently by children at various stages of development.

6. It serves an important organizing function and plays a key role in motivation (Piers, 1984, pp. 43-44).

An initial pool of 164 items reflected 11 aspects of children's self-concept. These were physical characteristics and appearance; clothing and grooming; health and physical well-being; home and family; enjoyment of recreation; ability in sports and play; academic performance and attitudes toward school; intellectual abilities; special talents; "just me-myself"; and

personality, characteristics, inner resources, and emotional tendencies. Each item is a simple declarative statement on The Way I Feel About Myself, responded to by Yes or No. Approximately half of the items indicate positive self-concept if the answer is "Yes." The others require a "No" answer to indicate positive self-concept.

After administration to a sample of 90 children from grades 3, 4, and 5, the initial pool was reduced to 140 items. Items were dropped, in the main, because they were answered in one direction by less than 10% or more than 90% of the children. After administration to a sixth-grade sample of 127 students, items which did not significantly p = .05) discriminate between the 30 highest and 30 lowest scores were dropped. Also, items not answered in the expected direction by at least half the highest scorers were dropped.

The factor structure of the instrument was investigated in six separate samples. Six interpretable factors resulted. Only those items which replicated across studies were retained. The resulting scale consisted of 80 items. The six factors are: Behavior (16 items), Intellectual and School Status (17 items), Physical Appearance and Attributes (13 items), (freedom from) Anxiety (14 items), Popularity (12 items), and Happiness and Satisfaction (10 items). Fifteen of the 80 items load on no factor, but are included in the total scale score--global self-concept, which is the

most commonly used and most well-researched score. It is the sum of all items responded to in the direction of positive self-concept. Forty items each load on one scale, 13 load on two scales, and 2 load on three scales (Piers, 1984, pp. 44-47).

The instrument was written at third-grade reading level, and was prepared for children and adolescents ages 8 to 18 years. A copy of the instrument is contained in appendix B.

Reliability and Norms

Internal consistence reliability coefficients for total scores in six studies with various subgroups range from .88 to .93. Coefficients for the subscales, corresponding to the six factors, range from .73 to .81 (Piers, 1984, p. 56). Norms, in the form of percentile ranks and stanines, are given for the global score and the six subscales.

As the Piers-Harris scale has been standardized for use only above the third-grade level, it was used only above third grade in this study. This instrument has been used in at least three previous studies of the psychological effects of chronic illness (Anderson, Miller, Auslander, & Santiago, 1981; Rintell, 1985; Tavormina, Kastner, Slater, & Watt, 1976).

Roberts Apperception Test for Children (RATC)

The RATC differs from the other commonly used

apperception tests in five major respects:

1. It was designed for a wider age range--ages 6-15--and all 16 stimulus cards depict children.

2. It deals with daily interpersonal events of life today, including (on four cards) situations requiring an aggressive response (of varying degrees).

3. The 16 stimuli are consistent, drawn in a uniform manner by the same artist.

4. The scoring is easy and objective, with high interrater consistence.

5. Clinical interpretation of test results is possible in relation to provided norms obtained on a sample of 200 well-adjusted children, ages 6-15.

Of the 16 situations depicted, 11 have two cards each, one each showing a boy or girl. The appropriate stimulus card is used in these 11 situations.

From the child's responses, scores may be obtained on 16 measures. Of these, 8 are adaptive scales, namely Reliance on Others, Support-Other, Support-Child, Limit Setting, Problem Identification, Resolution 1, Resolution 2, and Resolution 3. There are 5 clinical scales, namely Anxiety, Aggression, Depression, Rejection, and Unresolved. Three dimensions, rarely occurring in well-adjusted children, are considered critical indicators. These are Atypical Response, Maladaptive Outcome, and Refusal. Additionally, the child's responses may be summarized on the

Interpersonal Matrix, which indicates the relationships between the scales and indicators and the figures identified by the child. Three other measures potentially useful for specific clinical applications are Ego Functioning Index, Aggression Index, and Levels of Projection Scale (McArthur & Roberts, 1982, pp. 1-5).

Based on previous research findings, the authors determined that ideal stimuli should use human rather than animal characters; realistically display clinically relevant situations; and involve ambiguity, though clearly suggesting a particular theme. The cards were developed between 1968 and 1969 by administration to various samples of children, mainly middle- to low-socioeconomic status Caucasian children (McArthur & Roberts, 1982, pp. 71-72).

The normative sample of 200 children was comprised of 20 males and 20 females in the 6-7 years age group; 20 males and 20 females in the 8-9 years age group; 30 males and 30 females in the 10-12 years age group; and 30 males and 30 females in the 13-15 years age group. The age groups were decided upon because these groups best displayed significant age effects upon scores (pp. 73-74). Means and standard deviations, cumulative frequency of raw scores, and T-scores are provided for each of the four age groups on each of the 16 measures.

Reliability

Two types of reliability were assessed, namely

inter-rater agreement and split-half reliability. Inter-rater agreement was determined as follows. For 17 doctoral-level clinicians, average agreement ranged from 85.8% for the high-difficulty protocol to 92.8% for the low-difficulty protocol. For 8 master's-level clinicians, agreement ranged from 80.0% for the high-level difficulty to 89.8% for the low-difficulty protocols. Split-half reliability, with the Spearman-Brown correction, ranged from .48 to .86 for the adaptive and clinical scales (McArthur & Roberts, 1982, pp. 76-77).

Validity

Validity studies of several types were undertaken. Relationships among the 16 measures were studied in the correlation matrix by convergent and discriminant validity procedures, and also by principal component factor analysis. Both procedures provided evidence of the construct validity of the measures.

Further studies compared samples of well-adjusted and clinic children (200 in each sample). Of the 15 scales studied (all except Refusal), significant differences between the groups were found on 12 scales.

Finally, concurrent validity was studied by comparing the RATC with two other projective tests, the Children's Apperception Test and the Thematic Apperception Test, and with three scores from the Behavior Problem Checklist (McArthur & Roberts, 1982, pp. 77-91).

Research Procedures

The initial approach to potential subject families has been described in the sections on Population and Sampling Procedures and under Instrumentation. In summary, I prepared a demographic questionnaire, an introductory letter, and an informed-consent form. A sufficient number of these packages were delivered to the office of my personal neurologist, who added an introductory letter of his own before his secretary mailed them to their multiple sclerosis patients. Those patients with school-age children, with a spouse living in the home, and who were willing to participate in the study, returned to me the completed questionnaire and consent form in the stamped and addressed envelope, retaining a copy of the consent form for themselves.

The neurologist and psychologist in the Midwest clinic agreed to use their office resources in a similar way. In January of 1993, I delivered 250 demographic packets to the psychologist. He offered to compose a personal cover letter and to place a copy in each package. The packets were mailed in mid-February to the center's multiple sclerotic patients in the designated area. All of these patients, who have school-age children and were willing to participate, mailed the completed questionnaire and consent form to me.

Pilot Study

I had the services of an assistant, who drove me to the

homes of the subjects and served as research assistant. The pilot study sample was composed of two of the families identified by the first mailing. One had an elementary child and the other had two secondary children. These families were contacted by telephone to arrange the appointment for the first interview.

At the first appointment, the whole family was present. I conducted the interview following the interview schedule. Following the interview, family members were asked to respond to the FACES-II, the FHI, and the F-COPES instruments. My assistant or I read the questions of FACES II to those children unable as yet to read. Only the parents and adolescent children responded to F-COPES and FHI. The parents were then asked to sign the form authorizing the teacher of each child in elementary school to complete the Vineland Scale with respect to that child and to release the IQ. This permission form, with the scale, was mailed to the teacher. For secondary school students, a request for IQ, signed by the parents, was mailed to the principal.

At the close of the initial interview, arrangements were made for a second appointment to meet with the children in the home. At this session I administered the three projective tests, and my assistant administered the appropriate objective tests. These were administered in such an order as to vary the type of test situation for each

child as was appropriate.

I considered it important that the interviews with all the children be conducted within the same time frame to avoid possible contamination of one child's response by hearing discussion of the interview/testing sessions by other children.

Ideally, it would have been appropriate to undertake a clinical interview with each individual child on a later day, after the data from the child interviews and assessments had been evaluated. However, due to the geographical area being covered, this was not possible. Therefore, the clinical interview was undertaken by me during the individual testing time, particularly when discussing the drawings with the child.

A further brief interview was then arranged to elicit the reactions of the family members to the previous 2 sessions, wich could lead to possible modification of the procedures for the major study. The questions asked whether the process had been intrusive, if they had thought of any new information, and if the family members had any questions or suggestions.

Major Study

It was expected that the information received from the families in the closing interviews during the pilot study, together with my personal observations, might lead to modifications in the procedures for the major study. As

chapter 4 discloses, this was not, in fact, the case. All the remaining family and child interviews were conducted in the same way as the pilot study. The third interview was included for all families, and proved useful in yielding further important information.

Methods of Analysis

The information yielded by the three sessions with each family was evaluated, as a separate case study for each family; this is reported in chapter 4.

These analyses were undertaken in relation to the Circumplex Model of Olson and Associates.

The qualitative analysis was enhanced by the reporting of standardized scores on the various instruments.

In chapter 5, these 13 case studies are further evaluated in an effort to obtain general trends and concepts related to children in families where one parent has MS.

CHAPTER 4

FINDINGS

The findings from the interviews and assessment instruments are presented in this chapter as 13 independent case studies. Except for occasional passing comments, no attempt is made to compare the families or to make general conclusions.

Pilot Study

Two families comprised the pilot sample. In one family, the patient was the mother, and there was one elementary-age child. In the other family, the patient was the father, and there were two adolescent children.

Family 101

This family was among the earliest in responding to the initial mailings. When contacted almost a year later to arrange for the initial interview, their response was still enthusiastic. Appointments were made with no delays, and my assistant and I felt welcomed into their home, and even more so on the second and third visits. Each session was 2 to 2-1/2 hours long. The family lived in a pleasant,

middle-class apartment complex in a small town.

Demographics

Family 101 consisted of the mother (the patient), age 33; the father, age 32; and the daughter, age 6. Mother was expecting a second child in June 1993. All family members were available during all sessions. Both parents were high school graduates and Father intended to begin college in the fall. They were married in June of 1984. Daughter was in the first grade in a local public elementary school. Mother had worked in a restaurant for 10 years, and in a department store office for 2 years until approximately 1 year before the interview. She stopped working due to a worsening of her multiple sclerosis (MS). Father had been a local factory worker for the previous year since moving from Michigan, where he had had similar occupations. His work schedule was a regular 40-hour week.

Diagnosis and Acceptance

Father and Daughter were reported as enjoying normal health. Mother's MS was diagnosed in 1987, following referral by the family physician to a neurologist, who confirmed the physician's suspicions. Diagnosis was described as quick and easy, requiring only an examination and a magnetic resonance imagery (MRI) scan. Instead of giving Mother the diagnosis, the neurologist began discussing MS, "almost as if he was uncomfortable giving me

the diagnosis." She had to ask him if she had MS. She cried in the office for a few minutes and described her grief cycle as shock, anger, frustration, and finally "I'll just go and beat it." Father believed he did not have as much shock, because he had begun to prepare himself when the family physician first suspected MS. Mother's condition was stable until 1991, when the MS began rapid deterioration. In the follow-up interview, Father shared that it took them about 5 years to get to the point of acceptance. He admitted to feeling considerable anger as Mother's health deteriorated, but had recently realized he wanted to begin training in a helping profession. I believe this is a result of his increased awareness and compassion. Daughter was less than a year old at the time of the diagnosis, and did not relate personal feelings about Mother and her MS until working individually with me. The parents related that Daughter seemed proud of Mother and was not ashamed. She was a great help to her Mother.

The parents shared the diagnosis with all members of both families and co-workers and friends. Mother's parents were in total denial until about the time of the interview. They kept trying to find other more easily treatable reasons for her health problems. Her siblings had no problem accepting the diagnosis, except when influenced by their parents. Father's parents' reactions were "pretty good," with his mother experiencing some shock; but within a few

days both were accepting and supportive. "My parents love her so much, they would kill me if I left her, which I've never been tempted to do anyway."

They received no problems from either place of work. Employers were tolerant and flexible. Permission was readily granted when it was necessary for Father to leave work to help Mother. It was Mother's decision to resign her position; she had received no pressure from her employers. The couple's friends had been very supportive. As the nuclear family, Mother and Father related that their relationship had improved as a result of the MS. They believed the family was growing stronger every day. Father and Daughter were more attentive to Mother, and admitted they worry somewhat about her. Father stated he had learned to pay more attention to details. The parents felt Daughter had not been adversely affected.

Symptoms and Treatment

Mother began experiencing symptoms 3 months after Daughter was born. The initial symptoms included some symptoms which she was still experiencing--a flaccid bladder allowing poor control over its functions; difficulty walking due to "rubber legs," vascillating with severe spasticity in the legs; and extreme fatigue. Initial symptoms which she was not experiencing at this time included hearing loss and loss and visual malfunctions of double vision and blind spots in the visual field.

As her condition deteriorated, she briefly experienced bowel spasms, and began to suffer difficulties with speech, swallowing, and fine motor control.

During the current pregnancy, Mother's neurologist had an "extremely expensive" Lioresal pump surgically implanted to deliver anti-spasmodic medication directly to the spine. Mother and Father agreed that the pump had been of great benefit in reducing the severe spasticity. She had periodically received physical therapy for her gross motor problems and occupational therapy for her fine motor problems.

All medications had helped. These and all of the other patients' medications are listed in appendix F.

Assistance

At the time of the interview, Mother used a wheelchair because her balance and strength were affected by the pregnancy. She intended to return to using a walker after the baby was born. Most of the help Mother needed was provided by Father. This included housekeeping and personal assistance. Mother assumed most of the responsibility for Daughter, who helped by running errands for Mother. Father's sister had offered to help with the new baby.

Mother received monthly Social Security disability payments. She also received medical insurance coverage through Father's employment. They felt it was a significant help with the medical costs.

The family had not sought professional counseling. Father had sought advice from co-workers, including a part-time minister and had exchanged ideas with a co-worker who also had an ill wife.

Emotional Issues

When asked if they ever became angry, Father's response was "Yes, at the FDA" for not quickly approving new medications. He also admitted to sometimes losing patience with Mother, and then feeling guilty. He realized he was mad at the disease--not Mother. He believed Daughter was angry at times, but was unsure about how to deal with it.

Mother added that she sometimes got mad when she saw couples walking together. She realized there was a trace of jealousy.

Description of Daughter by Parents

Daughter was described by her parents as an excellent student. She "sasses" her mother some. Father was afraid Daughter might grow up to resent Mother because she needed to help around the house so much. Most of the time she seemed to enjoy doing things to help.

Socially, she seemed to have few friends. Mother was glad she was then starting to bring friends home.

The Family Tests

The first two tests were responded to only by the

parents, as described in chapter 3. Table 4 gives the scores of each family member on each of the three Family tests.

Family Hardiness Index (FHI)

Father's FHI was slightly higher than Mother's, with both above the mean of the norming sample. Mother viewed the challenges of life in a somewhat more positive manner than did Father. Both felt little control over external factors which are beyond their control. (On this subscale, a lower score denotes greater reliance on external factors.) Both scored close to maximum points on the Cooriented Commitment scale, which measures their joint internal strength; and on the Confidence scale, which measures their sense of cooperation and mutual adequacy. This suggests that there is joint family hardiness, helping them to deal with the extra stressors caused by Mother's MS.

Family Crisis Oriented
Personal Scales
(F-COPES)

The problem-solving attitudes of the two parents showed greater differences as measured by the F-COPES instrument. Father indicated much greater ability to face difficulties effectively. Most significant is this family's lack of seeking spiritual support. Father even seemed defensive about this, but wanted to discuss it with me. As was revealed in the interview, Father acquired social support

TABLE 4

FAMILY 101--FAMILY TESTS

Scale	Subscale	Maximum Score	Patient (Mother)	Spouse (Father)	Daughter Gd. 1.9
FHI					
	Cooriented-Commitment	24	19	23	Too
	Confidence	12	10	12	
	Challenge	15	13	9	Young
	Control-External	9	8	7	
	Total	60	50 (63)[a]	51 (73)	
F-COPES					
	Acquiring-Social Supp.	45	25 (32)[b]	31 (76)	Too
	Reframing	40	29 (38)	35 (88)	
	Seeking-Spirit. Sup.	20	10 (<5)	14 (26)	Young
	Mobilizing	20	12 (44)	16 (94)	
	Passive-Appraisal	20	16 (99)	18 (99)	
	Total	145	92 (37)	114 (95)	
FACES-II					
	Cohesion	80	67 (6)[c]	77 (8)	55 (4)
			z=0.25	z=1.44	z=0.14
	Adaptability	70	48 (5)	45 (4)	48 (5)
			z=0.29	z=0.74	z=0.33
	Family Type	-	(5.5)	(6)	(4.5)

[a] Numbers in parentheses are percentile ranks from the appropriate norms: One overall norm for total score only. [b] Numbers in parentheses are percentile ranks from the appropriate norms: norms are for adults or adolescents, male or female. [c] Numbers in parentheses are from Linear Scoring Model (figure 2).

more successfully than Mother could, apparently because she did not work out of the home. Father seemed to view mobilizing the family to acquire and accept help as the most effective coping strategy, as did Mother to a lesser degree. Father seemed more able to reframe (redefine stressful events in order to make them more manageable) than did Mother. Both Father and Mother scored very high on the Passive Appraisal scale, suggesting that they do not resort to giving up or ignoring problems. The items on F-COPES on which Father's and Mother's responses were most at variance include those that involve family or friends as resources, possibly reflecting Mother's frustration with the lack of support from her parents.

Family Adaptability and Cohesion Evaluation Scales (FACES-II)

All three members of the family responded to FACES-II. Mother and Father reflected moderately balanced family types. Mother believed they were connected on the Cohesion dimension and flexible on the Adaptability dimension. Father believed they were very connected but structured. Daughter reflected a centered family type. She believed that the family was separated and flexible.

It is of interest to note the items on which responses of family members were at least 2 response positions apart from each other. In most of these cases (7 of 11) Daughter responded differently than the parents. Table 5 displays

TABLE 5

FAMILY 101--SELECTED FACES RESPONSES[a]

	Almost Never	Once in Awhile	Some-times	Freq-uently	Almost Always
6. Children have a say in their discipline.	P,Sp				D
12. It is hard to know what the rules are in our family.	All				
13. Family members consult other family members on personal decisions.		D		P	Sp
15. We have difficulty thinking of things to do as a family.	P,Sp			D	
17. Family members feel very close to each other.		D		P	Sp
18. Discipline is fair in our family.				All	
23. Family members like to spend their free time with each other.		D			P,Sp
26. When problems arise, we compromise.	D		P	Sp	
29. Family members pair up rather than do things as a total family.	P,Sp				D
30. Family members share interests and hobbies with each other.					All

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

the 10 most interesting response patterns.

This response pattern seems to indicate that Daughter felt left out of the family unit, possibly as a result of Father giving so much support to Mother that neither was able to give much attention to Daughter. The responses to items 10 and 14 may indicate that Father felt he was most responsible for the family, and therefore could not voice his opinions for fear of hurting Mother. Mother's different responses to items 9 and 21 are understandable, as she watches the others go off separately to work and school, or together shopping.

Individual Testing of Daughter

Various assessments techniques, as outlined in chapter 3, were used with Daughter. Most were administered to her in the second session. The Vineland, however, was mailed to her classroom teacher, together with a letter of request from the parents, after the first interview.

Vineland Adaptive Behavior Scales

The teacher returned the fully completed Vineland scales within two weeks. She rated Daughter within the average range in all areas (Communication, 109 on a deviation IQ scale; Daily Living Skills, 106; Socialization, 98; and 104 on the Adaptive Behavior Composite).

Looking within the individual scales, the teacher indicated some concern about Daughter's personal care

relating to her own health issues. Within the domestic sub-domain, the teacher was not aware of how much Daughter was described by parents as helping in the home. Within the interpersonal relationships sub-domain, the teacher suggested a little concern about Daughter's skills in developing friends.

In the summary observations, the teacher added numerous strengths: Daughter was friendly with both adults and peers; she learned quickly and did average to above average work; she was "very responsible"; and she was very positive and loving.

A few concerns were related: Daughter seemed to need lots of attention, and sometimes she was "too social."

When my assistant and I returned to the home for the second session, Daughter was standing at the window, and answered the door with "Where have you been?" Mother related how excited Daughter was about our impending visit.

Table 6 gives the results of the objective testing of Daughter. Due to her age, she was able to respond to only one instrument.

Empathy scale

The Bryant Index of Empathy test was read to Daughter by the assistant. With a z of 1.45, Daughter's level of empathy was well above average.

TABLE 6

FAMILY 101--CHILD TESTS

Scale	Subscale	Maximum Score	Daughter Gd. 1.9
EMPATHY			B1[a] 18 z=1.45
PIERS-HARRIS	Behavior	16	
	Intellect	17	Too
	Physical	13	
	Anxiety	14	Young
	Popularity	12	
	Happiness	10	
	Total Scale	80	
SIV			
	Support	45	
	Conformity	45	Too
	Recognition	39	
	Independence	48	Young
	Benevolence	45	
	Leadership	48	

[a]B1 = male or female norms for Grade 1 on Y/N Bryant Scale with score range = 0-22.

Projective tests

Daughter was very cooperative and verbal for the projective tests. The Human Figure Drawing (HFD) was most interesting, because Daughter set up an environment before drawing the person. This is usually done by children who are avoiding a problem and hiding feelings. The completeness of her drawn environment--including house, car, plants, and sunny weather--also reflects her strong cognitive ability.

Daughter chose to make the Kinetic Family Drawing (KFD) representative of the family 3 years before the interview. She had them shopping together in a discount store. She identified the correct ages of each family member for that period. As she drew Mother, she verbalized "Mommy used to use a cane," and she drew it. Daughter reflected a happy, well-adjusted family for that time. Since she had to think back a few years in order to draw her family, this may indicate that she felt some loss of that security. Anxiety was reflected in both the KFD and DAP.

The Roberts Apperception Test for Children (RATC) revealed Daughter's above average ability to express herself verbally. Within the Adaptive area, she demonstrated a strong ability to cope with aversive situations. She had extremely strong problem-solving skills, strengthened by her desire to please and by her self-sufficiency. The only concern in this area was a

weakness in supporting others. This seems to correspond with how the teacher viewed Daughter, but not how the parents did.

The Clinical area of the RATC reflected the anxiety already suggested. Of most concern were the very high scores on Depression and Rejection. Rejection was alluded to in the discussion of FACES-II, but seemed to be much more of a problem for Daughter than first appeared. She also related personal feelings about this during the administration of the RATC. The depression was unexpected, but not abnormal when one considers the high level of her feelings of rejection. Childhood depression is known to manifest itself differently from adult depression. Her "sassing" of Mother, as Father related, as well as her strong adaptive and coping skills, appears to be camouflaging depressive symptoms. The profile of Daughter's RATC scores is included in appendix E.

Exit Interview

The entire family was present and still highly cooperative throughout the third interview. Daughter initially monopolized the conversation so she could demonstrate her reading skills and to give me a homemade card expressing her love.

Once the interview could commence as planned, I inquired as to their general feelings about their participation in the research. Daughter had no hesitation

in responding "It was fun; I'd like to do more." Father said he was not comfortable with simply "Yes" or "No" response options, explaining that was why he added further remarks. I asked if Father believed that, when giving the tests to the the families, I should tell them that they are welcome to write in additional thoughts. He agreed that was a good idea, but pointed out that he had not needed permission. The decision was later made that such instructions should not be added so that this family could be considered part of the main sample. It was hoped that the family members would ask me any questions they might have while responding to the family survey instruments, just as this family felt comfortable doing.

I then asked specific questions regarding length of time, difficulty of instruments, intrusion into their privacy on the part of any question, and whether they believed that anything should be deleted from or added to the content of the interview. The 2-hour time frames were comfortable and acceptable to all of the family members. Difficulty was not a problem. Mother thanked the assistant for writing her responses on the instruments, as she considered her writing illegible. This option was made available to all the families. None of the family felt any embarrassment with regard to the highly personal aspects of the study. Father did share, however, a sense of embarrassment regarding the lack of organized religion in

their lives. A lengthy discussion followed concerning his feeling of rejection by God at the time of Mother's rapid deterioration. As a result of studying Why Bad Things Happen to Good People, by Harold Kushner, which a co-worker had given him, he realized he had been mistaken in blaming God for Mother's illness. He added that the family believed in God and chose to pray among themselves, rather than attending church.

In response to the final question, no one felt there should be any deletions from, or additions to, the interview. Daughter used this opportunity to ask, "Why does my Mother have MS?" I explained that nobody knows why; and, having sensed that the real question was related more to "does MS kill?" added "Do you know what MS is?" Daughter answered "Not really." I went on to explain MS to Daughter in a fashion she could understand, emphasizing that it is not fatal. Immense relief was immediately evident in Daughter's face and demeanor. The parents admitted that they had not realized the importance of discussing this with Daughter.

The parents asked if they could be told any of the results of Daughter's evaluation. I had prepared for this question because of the parents' obvious interest in their daughter. Apologetically, I explained that no results could be shared until all of the families' data had been collected and analyzed. They asked if they could

have a copy of the results, and a promise was made to provide a summary of the whole project, including specific information regarding their daughter. Each succeeding family was given the same promise.

Family Summary

Family 101 consisted of the pregnant mother patient, the father, and a six-year-old daughter, who was less than a year old at the time of diagnosis. Although very disabled by rapid deterioration, Mother was a very positive, hopeful person; Father was supportive, and Daughter was outgoing.

The family inventories revealed a joint family hardiness, favorable family types, and effective coping skills, with Father being stronger than Mother. However, Daughter felt somewhat left out of the family unit; Father felt great responsibility which may be overwhelming at times, and Mother felt separated by her disabling condition.

The individual testing indicated that Daughter had average cognitive ability and a very strong self-concept. She was very responsible, highly social, in need of attention, and possessed a well above average level of empathy. Although well-adjusted, with extremely strong problem-solving skills, she was experiencing anxiety, depression and feelings of rejection, which seemed to have evolved over the previous few years as Mother deteriorated and Father had to focus more on Mother.

Family 102

The father of family 102 was contacted 10 months after receipt of their completed questionnaire. He was still very receptive, but concerned because his adolescent daughters were heavily involved in extra-curricular activities. It required repeated contacts over a period of 1 month to schedule the first interview.

The family lived in a small town in a rural community. They had a large, comfortable home in a new development.

Demographics

Family 102 consisted of the father (the patient), age 41; the mother, age 41; and two adolescent daughters. The parents were married in August of 1974. Daughter 1 was 15 years old and in the 10th grade at the local high school. Daughter 2 was 13 years old and was in the seventh grade at the local middle school. Father had a master's degree in education, and taught Social Studies to the seventh grade at the middle school attended by Daughter 2. He had worked full time in that job for 20 years. Mother had a bachelor's degree in education, and directed children's ministry and Christian education for the local United Methodist Church, of which the whole family were members. She had worked 30 hours a week for the church for the previous 11 years.

Diagnosis and Acceptance

Mother and Daughters were reported as being generally

healthy. Father's MS was diagnosed in 1981, 3 years after he had nearly died from a neurological illness the doctors were unable to diagnose with certainty. They suspected it was brainstem encephalitis or meningitis. Father and Mother both said Father had "never been well" since that time.

In 1981, neurological symptoms returned and a leading neurologist in the Midwest diagnosed these symptoms as "probable MS." The diagnosis was based on two spinal taps, neurological examinations, and past history. Father continued his care with a local neurologist, who agreed with the diagnosis. When asked whether the doctors were supportive, he replied that they were "nice," but the true support came from the nurses. He was surprised by the diagnosis, but did not relate any sense of grief. He shared that he dealt with the diagnosis by doing his own research about MS. Mother said the diagnosis of the MS added nothing new to their knowledge of Father's illness. She expressed a feeling of having been overwhelmed since he had first been ill. As she spoke, it was obvious that she was not denying the presence of an illness; however, she did not appear to be accepting all of the effect the MS could have on her and the family.

Daughter 1 was only 1 year of age when Father first became sick, and 4 when the MS was diagnosed. Daughter 2 was then 1 year old. They laughed as they responded that they had no memory of the diagnosis. However, Daughter 1

claimed to remember staying with family friends while Father was in the hospital during his first illness. She could not relate any feelings with that memory, so Mother downplayed the memory by suggesting Daughter's memory was based on pictures from that time period. Daughter was hesitant to give up the memory.

When the parents were asked with whom they shared the diagnosis, Mother responded, "There was nothing new to spread." Father added that they shared it with family, their church, colleagues, and the football players he was coaching at that time. He pointed out that since they lived in a small community, news travelled quickly. When asked to elaborate about the family's reaction, he said his parents were not alive. At that point, he shared that he never knew his father, and was only 3 when his mother died. He was raised by his maternal grandmother, who lived in Ohio. He indicated she knew about his MS, "but she really doesn't."

Mother's parents lived in a nearby city and had been extremely supportive. They cared about and treated Father like a son, according to Mother. Her brother, who lived in the same city as their parents, was agreeable, but "oblivious to the MS." She pointed out that he was very self-concerned.

Mother indicated there had not been a "clear time" to tell the daughters their father had MS. "This is the way it's always been" for them. Daughter 1 added that she had

asked Father once, when she was in his class in the seventh grade. She believed that was the first time she became curious, and it was because some boys rudely asked, "What's wrong with your father?" Daughter 2 became curious when she went to the hospital for a tonsillectomy. She added that her friends cared about Father and thought of him as their father. They seemed to be empathetic toward her as well as Father, suggesting, "This makes you more sensitive." Daughter 1 then added that her friends felt the same way about Father.

As a teacher, Father used the MS to help his students learn. They were interested in his difficulties and, by being open, they developed understanding and patience, he believed. All the staff at the school cared, and he had grown very close to the few who had known him since before he was ill.

Mother said that the MS had never interfered with her work. The church family was always asking how Father was doing. He appeared to accept this as caring, and appreciated it; however, Mother appeared to be irritated by the constant questioning. Their friends came from their work and church, so they did not add further comments about friends' responses.

When asked how the MS had changed their lives, the daughters were first to respond. Daughter 1 replied that they played more outside with Father when they were "young."

"Now he tries as hard as he can." She realized he became tired easily and could not run, but she was "used to it." In fact, Father "falls asleep every night in his chair." She did not feel she had had to change. Daughter 2 responded, "Things have been better for me; I've grown up with it." She felt that she was closer to her father than her friends were to theirs. She enjoyed helping him with yard work. Daughter 1 was not embarrassed to admit she did not help much around the house because she was so busy with her personal activities (which are expanded upon below). They jokingly agreed that they did not often go to the mall with Father. Mother later added that the family avoided going places where one had to walk.

Father shared the differences in his life throughout the interview. The MS had caused major frustrations for him, with which he had successfully dealt. These included having to give up coaching, difficulty eliciting self-enthusiasm, and increasing difficulty coping. He seemed very well adjusted to his limitations. He added, with modesty, that his former principal had commented on an evaluation that Father was an inspiration.

During this part of the interview, Mother had sat quietly, wringing her hands. It took urging on my part to gain a response regarding how Father's MS had changed Mother's life. She began slowly and hesitantly, watching Father's face, stating, "Over the years I've had to do

more." Daughter 1, apparently seeing Mother's distress, interjected, "She always likes to clean." This seemed to bother Mother, as she replied defensively that children normally dc chores around the house; but the daughters were so busy they could not help much. It appeared as though she had always taken more responsibility upon herself than she needed to, then experienced the consequent feelings of being overwhelmed, and became angry. Her anger did not seem to be directed either at herself for accepting misplaced responsibility, or at the family for not taking more responsibility. It appeared as if her anger was directed towards the MS, which she had not accepted. Therefore, I believe, Mother may also be overwhelmed with ambivalent feelings toward Father.

She began crying as she shared thoughts she had never before shared with the family--"What he can do is different than the average husband." Daughter 2 jumped up and gave Mother a box of Kleenex, hesitantly returning to her chair. Daughter 2 was also observed throughout the sessions to pat Father with loving care as she passed him.

Mother felt she tried to do too much to pick up the "slack"--all the traditional women's duties, plus a job, and then some of the men's duties, "carrying a burden-and-a-half." She tried to find others to help her do things, and her father helped out a lot. Father assumed a defensive pose, but said nothing. Mother continued by agreeing with

Daughter 2, "he really tries," but she believed there were times when he should not. Father believed she was overprotective of him. Mother responded that she wanted to help if she could.

Symptoms and Treatment

Father's first symptoms involved poor coordination of his hands and legs, leg weakness, and balance problems. As an afterthought, he added fatigue, emphasizing that he was always tired. During the first illness, he suffered optic nerve damage, so he seemed to have ignored any visual problems. He mentioned a short bout of double vision, which I assured him can be a symptom of MS. Presently, his symptoms included urinary dysfunction (causing urinary tract infections), twitching of his legs and spasticity when asleep, poor penmanship, and a slower reaction time. Father walked without any aids, but his gait was cautious and deliberate. He initially had physical therapy, because he had to learn to walk again. He had had to have a cystostomy for his urinary problems. When first diagnosed, he had taken ACTH intramuscularly to help alleviate the relapse.

Assistance

The family did not receive any financial assistance, as Father still worked. Mother made it eminently clear that she received little help with the household chores. Father did not need any personal

assistance. Medical insurance for the family was provided through Father's job. The family had not sought professional counseling.

Description of Daughters by Parents

Daughter 1 had been a B to C student, recently improving her grades. Behaviorally, she was "no trouble," but they both agreed she talked too much. If she had a social problem, it was that she was too social.

Daughter 2's lowest grade had been a B+. She was consistently on the high honor roll. She was a "good girl." Socially, she got along well with her peers.

Self-Description by Daughters

Daughter 1 had some difficulty remembering all the activities in which she was involved. She began with golf (which seemed to be her favorite activity), basketball, track, "show choir," the church's youth group, Campfire Girls, Students Against Drunk Driving, the yearbook staff, student council, and the concert choir. She also had a part-time job selling clothes.

Daughter 2 had no hesitancy in sharing her activities. These included track (for which she had many ribbons displayed on the refrigerator), volleyball, basketball, the church's youth group, cheerleading, gymnastics, and the Card and Computer Club.

Daughter 1 volunteered in the church nursery. Daughter

2 did volunteer babysitting and extra work with the youth group, such as helping to repair a house.

The only two sports in which both participated were basketball and track, which were the sports Father had coached before the MS interfered with his ability to do so.

The Family Tests

All family members responded to all the tests. They isolated themselves from one another to ensure completely personal responses. Table 7 gives the results of each family member on each of the three tests.

Family Hardiness Index (FHI)

Father's and Mother's scores on the Family Hardiness Index were both close to the mean of the norming sample. Examining the individual factors, Father viewed the challenges of life in a somewhat more positive manner than did Mother. Mother felt subject to external forces over which she had very little control. Father sensed that external forces exerted control over his life to an extent more typical of the norming group. Both scored the maximum points possible on confidence in themselves as a family. Both scored very high on belief that they are mutually strong.

A comparison of Father's and Mother's responses to individual items is revealing. The questions concerning seeking and enjoying new experiences versus enduring boredom

TABLE 7

FAMILY 102--FAMILY TESTS

Scale	Subscale	Maximum Score	Patient (Father)	Spouse (Mother)	Daughter 1 Gd. 11.9	Daughter 2 Gd. 7.9
FHI						
	Cooriented-Commitment	24	19	23	17	18
	Confidence	12	12	12	6	12
	Challenge	15	12	9	7	12
	Control-External	9	6	3	3	6
	Total	60	49 (59)[a]	47 (48)	33 (02)	48 (54)
F-COPES						
	Acquiring-Social Supp.	45	29 (66)[b]	30 (65)	33 (88)	29 (63)
	Reframing	40	30 (46)	38 (96)	32 (82)	28 (42)
	Seeking-Spirit. Sup.	20	18 (79)	19 (86)	14 (37)	20 (99)
	Mobilizing	20	6 (07)	11 (31)	8 (32)	11 (62)
	Passive-Appraisal	20	11 (84)	14 (97)	14 (95)	14 (95)
	Total	145	94 (54)	112 (91)	101 (82)	102 (84)
FACES-II						
	Cohesion	80	61 (5)[c] z=-0.46	63 (5) z=-0.23	62 (5) z=0.62	59 (4) z=0.29
	Adaptability	70	41 (3) z=-1.35	43 (4) z=-1.05	54 (6) z=1.09	49 (5) z=0.46
	Family Type	-	(4)	(4.5)	(5.5)	(4.5)

[a]Numbers in parentheses are percentile ranks from the appropriate norms: one overall norm for total score only. [b]Numbers in parentheses are percentile ranks from the appropriate norms: norms are for adults or adolescents, male or female. [c]Numbers in parentheses are from Linear Scoring Model (figure 2).

were answered in a positive light by Father, but in a negative light by Mother. Although one could imagine Father would be the one who would suffer from boredom due to his restricted mobility, it was Mother who seemed to feel this frustration, possibly as a result of feeling overwhelmed by the "burden-and-a-half" at home. As already discussed, Mother felt controlled by external forces, whereas Father did not. For example, on item 19, "Most of the unhappy things that happen are due to bad luck," Mother responded mostly true, but Father responded false. In contrast, on item 1, "Trouble results from mistakes we make," Mother answered "Mostly false," whereas Father answered "True."

The daughters' FHI's were very different from each other except for Coordinated Commitment, where they both indicated the family was mutually strong, in agreement with the parents. Daughter 1 scored surprisingly low in comparison with the rest of the family on the overall FHI. Daughter 1, like mother, felt very controlled by external forces, whereas Daughter 2, like Father, viewed this control in a more typical fashion. Daughter 2 viewed the challenges of life in a more positive manner than did Daughter 1. Daughter 2 indicated the maximum degree of confidence possible in her family's ability to cooperate and function successfully, whereas Daughter 1 was much less sure of this.

An examination of the response patterns revealed that Daughter 1 felt very much like Mother, and Daughter 2

reflected much of Father's optimism. When there was a considerable difference between the parents' and the daughters' responses, Daughter 1 stood alone. For example, on item 5, "We have a sense of being strong even when we face big problems," Daughter 1 answered "False," whereas the rest of the family answered "Mostly true," or "True." On item 8, "We do not feel we can survive if another problem hits us," Daughter 1 responded "True," whereas the rest of the family responded "False." The one question to which all four gave the identical response of "Mostly true" was item 13, "We listen to each other's problems, hurts and fears." The results of this test suggested that the family ties tended to be more in dyads, rather than the family connecting as a whole in their efforts to deal with the extra stressors that may be a result of Father's MS. The family's ability to empathetically listen is dependent on their comfort in talking. Mother and Daughter 2 appeared to be less likely to openly discuss their concerns to avoid causing personal or family discomfort.

Family Crisis Oriented
Personal Scales
(F-COPES)

As was the case with the FHI, responses to the Family Crisis Oriented Personal Scales further demonstrate the differences in the parents' problem-solving abilities, Mother's responses indicating a much greater ability to face difficulties effectively. Father's overall score does not

indicate a poor ability, but rather is comparable to the average population.

Both parents accepted the problematic issues they faced, minimizing reactivity. The only item in this section on which they disagreed is number 26, "Feeling that no matter what we do to prepare, we will have difficulty handling problems." Mother moderately agreed, whereas Father strongly disagreed. On the other items, though they both responded in the effective direction, Mother's response was stronger. Both parents utilized their connections with the church for spiritual support. Perhaps Mother's job in the church afforded her greater opportunity. Both parents successfully acquired social support. Although Father's responses indicated average ability to redefine stressful events in order to make them more manageable, Mother's responses indicated much greater effectiveness in doing so. Father tended to respond in the neutral fashion of neither agreeing nor disagreeing with the statements in this subscale, whereas Mother gave the more strongly positive response to each item. The subscale on which they responded well below the average involves mobilizing the family to acquire and accept help. They viewed this as their least effective coping strategy.

Both daughters indicated strong problem-solving attitudes. However, by examining the individual subscales, differences appeared in their utilization of the various

support strategies. Just as with the parents, both daughters accepted the problematic issues they faced minimizing reactivity. Daughter 2 clearly utilized this resource more effectively. Both daughters successfully acquired social support. Daughter 1 clearly utilized this resource to a greater extent, supporting the parents' belief that she had "too many friends." This should not be viewed negatively, as it appeared to be an effective support mechanism for her. Although the responses of Daughter 2, like Father's, indicated average ability to redefine stressful events to make them more manageable, Daughter 1's responses, like Mother's, indicated greater effectiveness doing so. Daughter 1, like her parents, responded below the average with mobilizing the family to acquire and accept help. Daughter 2 indicated a greater ability in this area. The subscale where the daughters demonstrated greatest disagreement was in seeking spiritual support. Whereas both attended church services and had a strong belief in God, Daughter 2, who helped Mother with her church responsibilities, was in a position to have more opportunity to participate in church activities and to consult with the minister.

Family Adaptability and Cohesion Evaluation Scales--II

On FACES-II, the parents reflected very similar family types, with connected on the Cohesion dimension, and

structured on the Adaptability dimension. Father's overall view of the family was the family type in the mid-range, and Mother's was right on the border between mid-range and moderately balanced. The responses of the parents were very different on the two items. To item 15, "We have difficulty thinking of things to do as a family," Father responded "Sometimes," and Mother "Almost never." To item 26, "When problems arise, we compromise," Father responded "Once in a while," whereas Mother responded "Frequently."

The daughters reflected different feelings from each other in the Cohesion dimension. Daughter 1, like the parents, believed they were connected, whereas Daughter 2 believed they were separated. On the Adaptability dimension, both daughters disagreed with their parents in indicating that the family was flexible. The overall view of the family type on the part of Daughter 2 corresponded to Mother's, right in the center, between mid-range and moderately balanced. Daughter 1's overall view was that the family type was moderately balanced, the most favorable.

On the items where family communication is discussed, Father remained consistent in his belief that family members were open only sometimes, whereas daughters and Mother together were inconsistent in their beliefs as to the openness of the family. On two items, Daughter 1 stood clearly alone from the other family members. To item 8, "Family members discuss problems and feel good about the

solutions," she responded "Almost always," but the rest of the family responded "Sometimes." On item 12, "It is hard to know what the rules are in our family," she responded "Sometimes," and they responded "Almost never." It is of interest to point out the items where the entire family responded identically, and on each occasion at an extreme. To items 1 and 17, the entire family responded "Almost always," indicating their confidence in the mutual support of family members at difficult times, and their closeness to one another.

At the end of the first session, when I was seeking to schedule a date for the second session, the daughters immediately checked their very full calendars, and came up with a mutually convenient evening. Once the girls had left the room, Mother quietly asked if the appointment could be moved to the evening after the one suggested by the girls. She explained that she was having some outpatient surgery on that first day, but had not as yet informed the daughters. Father checked the girls' calendars, and the appointment was rescheduled.

Individual Testing of Daughters

When my assistant and I returned for the second session, Daughter 1 answered the door, while Daughter 2 was completing some homework. Both my assistant and I confused Daughter 1 with Daughter 2. Both girls assertively pointed

out that they were very different. Father was available during the testing, so I asked him how Mother was doing, not knowing if the daughters knew anything about her surgery. He said she was doing well. Neither daughter mentioned Mother's surgery. I brought it up with each girl during their testing. Neither was comfortable discussing it; but Daughter 2, when asked directly, said that they had not been informed until the day before the surgery because Mother "did not want to worry anyone."

Various assessments, as outlined in chapter 3, were used with these adolescent daughters. All were administered to them during the second session. After the first interview, a letter was sent to the principal of each girl's school, requesting the latest IQ standard score. Both scores were the Cognitive Skills Index (CSI) from the Indiana Statewide Testing for Educational Progress (ISTEP). Daughter 1 was reported as having a CSI of 99, while Daughter 2's was 120. This placed Daughter 1 within the average range of intelligence, and Daughter 2 within the superior range. Daughter 1's score may be somewhat depressed, possibly because her attention is focused on adolescent socialization and participation rather than academics.

Table 8 gives the results of the daughters' objective tests.

TABLE 8

FAMILY 102--CHILD TESTS

Scale	Subscale	Maximum Score	Daughter 1 Gd. 11.9	Daughter 2 Gd. 7.9
EMPATHY			M[a] 36 z=-0.38	M 71 z=1.29
PIERS-HARRIS	Behavior	16	11 (32)[b]	15 (81)
	Intellect	17	11 (38)	17 (98)
	Physical	13	12 (91)	12 (91)
	Anxiety	14	7 (26)	13 (90)
	Popularity	12	9 (52)	11 (86)
	Happiness	10	9 (72)	10 (90)
	Total Scale	80	57 (60)	74 (97)
SIV			*[c] 25 (93)[d]	**25 (99)
	Support	45		
	Conformity	45	5 (04)	4 (04)
	Recognition	39	25 (99)	20 (97)
	Independence	48	14 (50)	10 (34)
	Benevolence	45	10 (08)	19 (61)
	Leadership	48	11 (52)	12 (67)

[a]M = Mehrabian overall norms with score range = -132 to +132. [b]Figures in parentheses are percentile ranks for the complete norming population. [c]** = Grade 9 vocational norms, male or female; * = Grade 11 and 12 norms, male or female. [d]Figures in parentheses are percentile ranks for the appropriate norms.

Empathy scale

On the Emotional Empathetic Tendency Scales the two girls continued to score very differently. Daughter 1 reflected a less than average ability to empathize, and Daughter 2 reflected an ability well above average.

Survey of Interpersonal Values (SIV)

The SIV was selected because it includes the Benevolence construct, the definition of which corresponds to my concept of altruism. On this subscale, Daughter 1 scored at the eighth percentile on grades 11 and 12 female norms (she was completing grade 10). Daughter 2 scored at the 61st percentile of vocational grade 9 female norms (she was completing grade 7). These results parallel those of the EETs, with Daughter 1 scoring well below average, and Daughter 2 above average on the importance of altruism.

On the rest of the Survey, the daughters' scores were more comparable. Both scored extremely high on valuing Feeling Supported and Receiving Recognition. Daughter 1 placed average value, and Daughter 2 above average value on Leadership. On the subscale measuring the value of Independence, Daughter 1 scored average, Daughter 2 below average. Finally, both daughters scored extremely low on the measure of the value of Conformity.

Piers-Harris Children's
Self-Concept Scale

Both girls had a positive self-concept. The profiles of their scores on the Piers-Harris Children's Self-Concept Scale are included in appendix D. Daughter 1 was average on three subscales--Behavior, Intellectual and School Status, and freedom from Anxiety--and above average on the other three subscales--Popularity, Happiness and Satisfaction, and particularly Physical Appearance and Attributes. Daughter 2 was well above average on all six subscales.

Projective tests

The daughters were very cooperative and verbal, adding much extra information to the projective testing than is normally expected.

Daughter 1's Human Figure Drawing (HFD) was a simple drawing for her age, but suggested several emotional indicators. Sexual adjustment appears normal for an adolescent. The picture suggested repression of aggressive tendencies. It also revealed a moralistic personality, which may be controlling the aggressive tendencies and presenting them as assertiveness.

Daughter 2 displayed excellent artistic ability, which Daughter 1 had already mentioned. Her HFD reflected positive interpersonal relationships, high intellectual aspirations, and normal adolescent sexual adjustment. The other emotional indicators suggested a concern over body

image and the normal adolescent development of autonomy.

Daughter 1's Kinetic Family Drawing (KFD), again, was simplistic, but very revealing. She had the family eating dinner together at home. She began by drawing herself, and then added the others in relation to herself, suggesting an egocentric approach. The KFD reflected the conflict between Mother and herself, which she and Daughter 2 both discussed freely during the individual testing. (Both daughters independently, stated that, if there is a fight in the family, it is between Mother and Daughter 1.) Father was drawn as very receptive to all the family members, which both daughters had also shared during the testing. Mother was drawn in a reclusive pose, but attending to Father. Daughter 2 was drawn in a fashion that reflected her mediator role in the family. Daughter 1 was drawn to reflect her desire to be more social, as a result of her beginning independence from the family.

Daughter 2's KFD had her family nicely dressed and attending church, affirming the family's mutual connection to their church. She began by drawing Mother as a powerful figure, to whom everyone else in the family must relate. Her drawing indicated her closeness to Father, and the distance of Daughter 1 from Mother. Mother and Father were seen as the core of the family. Ineffective family interaction was indicated.

Throughout the Roberts Apperception Test for Children

(RATC), Daughter 1's stories seemed to grow longer and more complicated. The Adaptive scale showed a strong ability to cope with aversive situations. She demonstrated above average problem-solving skills for her age. Her only area of concern was her very weak Support to Others score. The Clinical scale revealed a very high level of anxiety and strong feelings of rejection. The RATC profiles are included in appendix E.

When Daughter 2 was telling her stories for the RATC, she made them all very personal and creative. Daughter 1 had already informed me that Daughter 2 was very good at developing stories. Daughter 2's Adaptive scale reflected an exceptionally strong ability to cope with aversive situations, a strong sense of self-sufficiency and problem-solving ability, and an average ability to support others. Both daughters' stories suggested above average limit-setting ability. Daughter 2's Clinical scale revealed very low anxiety and aggression, yet above average depressive tendencies and feelings of rejection. Her stories demonstrated her desire to keep situations peaceful by serving as the mediator.

The conversations the daughters had with me were very open and revealing. Daughter 1 was seen by both girls as the family member who has kept things unbalanced by her strong will and independent spirit since she was very young. Daughter 2 was seen by both girls as the "good little girl"

who does not understand Daughter 1's behavior. Both daughters seemed to accept with pride these roles in their family. Daughter 1 hoped that Daughter 2, for her sake, would grow in independence. However, Daughter 2 had a clear belief that she was responsible for her family's coalescence. Daughter 2 hoped, for her part, that Daughter 1 would grow in her understanding that Mother was so hard on her because she wished to see her grow in maturity. However, Daughter 1 believed that Mother was simply trying to limit her independence. Both daughters said they were most like Father. Daughter 1 felt she had Father's sense of humor, and Daughter 2 was more like Mother, who was controlled by oversensitivity and a serious outlook on life. Daughter 2 felt she was like Father in patience and anger control, and that Daughter 1 was explosive like Mother, although it took more to get Mother angry. Both daughters had deep respect for Father and his success in overcoming so many problems. They both expressed love for Mother, with some consternation on the part of Daughter 1 and concern on the part of Daughter 2. Daughter 1 said it best, "Mother could worry for all the mothers [in town], but she couldn't deal with it."

Exit Interview

When the exit interview was scheduled at the close of the second session, all family members planned to attend. However, the parents mentioned that Daughter 1 had, at the

close of the school year, begun another job, and that they would contact me if the job would interfere with the interview. Therefore, when I returned for the exit interview and discovered that Daughter 1 was missing, I was disappointed. Mother explained that Daughter 1's schedule was so full that it would be extremely difficult to arrange for the whole family to be present. At the conclusion of the interview, I asked the parents to share the exit questions with Daughter 1, and have her call me if she wished to contribute.

No one present had any questions, problems, or recommendations regarding the family interview or the time spent with the daughters. Daughter 2 boldly told me, "You did a nice job." Mother asked if they would receive a copy of the results--in fact Father had been under the impression that this was the purpose of the third visit, although the true purpose had been explained when scheduling this interview at the close of the second session. I promised to send a summary of the research, after the completion of all the analyses, together with specific information relating to their family.

As my assistant and I prepared to leave, both parents stressed their appreciation of my assistant and me and of the research being undertaken.

Family Summary

Family 102 consisted of the father patient, the mother,

and two daughters ages 15 and 13. At the time of the diagnosis, they were 1 and 4 years old. Although Father was not significantly disabled, the daughters had been very aware of his deterioration. However, they still considered that they had a better father than most of their friends. Father accepted, Mother regretted, and Daughters resented that Mother was the self-appointed family leader. Daughter 2 was very protective of both parents' feelings.

The family tests revealed confidence in themselves as a family. The family believed they were mutually strong. Father and Daughter 2 were more optimistic than were Mother and Daughter 1. Although Father believed he could cope effectively, Mother believed she had the greater coping ability. The Daughters' strong coping abilities used very different support strategies than did their parents'. They all believed they were a favorable family type.

Individual testing indicated that Daughter 1 was of average cognitive ability and Daughter 2 was superior. Daughter 1 showed less than average level of empathy and altruism, whereas Daughter 2 was well above average in both. The Daughters had positive self-concepts and well-developed value systems. Daughter 1 was experiencing normal ambivalent feelings and frustrations relative to her growing sense of autonomy. She had a high level of anxiety and strong feelings of rejection, but above average problem solving skills. Daughter 2 had high motivation and

an exceptionally strong ability to cope with aversive situations. She seemed to have developed a sense of responsibility to serve as a mediator in family and peer situations. She was experiencing depression and feelings of rejection.

Major Study

As has been indicated in the reports of the closing interview held with families 101 and 102, neither family called for any change in the research procedures or content. Thus, it was considered that these two families, initially included as a "Pilot Study," could now appropriately be included as part of the main study. This necessitated the addition of the closing interview with each remaining family included in the sample. The originally planned numbering system is, however, adhered to. These "pilot study" families are numbered 101 and 102. The remaining families are numbered consecutively from 201.

Family 201

Family 201 was among the earliest in responding to the initial mailings. When contacted nearly a year later, the father remembered the family's commitment to participate in the study. Appointments were difficult to make, because the mother worked days and the father worked nights, making it necessary to hold the family interviews on weekends. To complicate matters, the eldest child was in a group home for

the handicapped, and visited the family on alternate weekends, and I did not want to interfere with those visits. Once the appointments had been made, my assistant and I were welcomed into their modest home in a small city.

Demographics

Family 201 consisted of the mother (the patient), age 44; the father, age 36; the daughter, age 7; and the son, age 5. An older daughter, age 9, who was born moderately mentally and physically handicapped, did not participate in the research. Both parents had completed their freshman year in college. They were married in July 1980. Daughter was in the second grade, in a local public elementary school, having started school early. Son had just completed his first year in a local church-related preschool. Mother had worked in the local branch of a large bank for 22 years. She continued to hold a full-time job, although her responsibilities had recently changed, so that she would not have to travel a long distance to the new location of the main office to retain her former position. Father had worked in a local manufacturing company for 17 years. He usually worked from 48 to 56 hours per week at his full-time job.

Diagnosis and Acceptance

Father and the two children at home were reported as enjoying normal health. Mother's MS was diagnosed around

the time of their marriage, but they could not agree as to whether it was before or after they were married. Mother was very sure it was before, and Father equally sure it was after. A local neurologist diagnosed Mother by placing her in the hospital for numerous tests, including a spinal tap and a myelogram, to rule out other diagnoses. According to Mother, from those results, and a study of her medical history, she was told she definitely had MS. Father remembered the doctor saying, "You won't qualify for life insurance any more. It is my opinion you probably have MS." The doctor seemed competent to both parents. He gave them a few instructions and some literature.

Mother's problem had begun in 1978 with a tingling sensation all over her body, sudden loss of eyesight in one eye, poor coordination, and weakness. She was put into the hospital at that time, and subsequently recovered. She said that MS was suggested at that time; but, as she recovered, she ignored the fact that she had suffered those problems. When the problems exacerbated in 1980 or 1981, the diagnosis was hard for Mother to accept. "I wanted to get pregnant, but didn't know anything about [MS]." She added that she cried a lot and had to learn how to deal with the problems, admitting it took 4 to 5 years to adjust. Father commented that he just wanted to know what was wrong. He shared that he had been born with hip dysplasia, and often was in the hospital throughout childhood. He felt he coped better

with Mother's diagnosis because of his personal history.

Mother's parents took the diagnosis hard, although Mother's mother had helped her during her problems in 1978. Her mother had suffered a serious stroke in 1979. Mother's father always had difficulty dealing with illness, and this was apparently too much for him to handle effectively. Father indicated that there were no close relationships among any of his family members. Therefore, their responses ranged from "Gee, that's too bad" to no interest at all. Mother had one brother, who lived out of state. He knew she had MS, but acted "rather oblivious." Father described Mother as having adopted an attitude of not giving up and "that's been the best adjustment for us."

Mother's employers had been supportive and cooperative. Although her condition worsens when she becomes sick, this has never interfered with Father's work. They believed their friends felt sorry for them, but had been very understanding and supportive. Some of the friends had since had family members develop MS, so Mother felt she had been a resource to them.

When asked how the children were informed about Mother's MS, the parents admitted they probably had not discussed it with the children. Their first child, from birth, had been the focus of the family. Later, Son commented to me, "She's handicapped," referring to his oldest sister.

The family became involved in a local church when the children were born. Mother continued weekly to take the children, but had to return home, herself, in order to rest. Father slept due to his night work schedule. I did not sense that church plays a highly supportive role in their lives.

Symptoms

Of the original symptoms already mentioned, Mother still had balance and coordination problems. Additionally, she related that she had cognitive problems, involving a shorter attention span, a poor short-term memory, and weaker comprehension. A loss in her sense of depth perception had forced her to limit her driving. She added that she suffered with bladder problems and constipation, faulty pain perception, and stiffness. She reported the same leg twitching when in bed as had been described of Father in Family 102 by his wife. Mother stated that she could not fight fevers, and gets sick more easily than she did before she had MS. The doctor considered her MS to be mild and presently in remission.

Assistance

Mother used no aids to walk, but exhibited a stiff, rolling-from-the-hip gait. She had medical insurance coverage through her work. The family received no financial assistance. Child care was needed with the eldest daughter,

but the parents felt that would have been necessary for any normal family. Father took care of the house, and watched the two younger children when they were not in school. He had them help with little jobs. When Mother returned home from work, she took over the care of the children, and Father went to bed. However, Daughter said Mother falls asleep every night in the chair, as was reported of Father in Family 102.

The family had never received any counseling. When asked if counseling might not have been necessary after the birth of their first child, Father proudly shared their leadership role in a parents' support group that was a part of the hospital's high-risk nursery. It appeared that they considered themselves to be in the role of counselors rather than counselees in this support group.

Description of Children by Parents

Daughter was described as a good student who liked arts and crafts; Daughter added "but not worksheets." Father proudly discussed how Daughter did very well, even though she was sick during the week of comprehensive group testing. Daughter was described as an angel by both parents, the "perfect little girl." She loved being among her peers and, in fact, "runs the neighborhood."

Son had been an excellent student in preschool, but did not like singing. Behaviorally, he was a "little more of a

stressor," according to Father. Mother agreed, and added that rules and discipline were shared by both parents. Son was a little shy when first meeting people, although I found that he talked easily while the rest of the family was responding to the family tests.

The Family Tests

Table 9 gives the results of the family members on these tests. The first two tests were responded to only by the parents.

Family Hardiness Index

Father's FHI was quite a bit higher than Mother's, with Mother at about the average of the norming sample and Father very high. The two total scores, however, are separated by only 9 points.

The greatest difference was in the amount of control they felt was exerted by external factors beyond their control. Father felt no such control, scoring maximum on this scale, whereas Mother's score reflected her uncertainty about what role luck, specifically, played in her life. Father viewed the challenges of life in a somewhat more positive manner than did Mother. Father scored maximum points, and Mother close to maximum, on the Coordinated Commitment scale, indicating their joint internal strength, and on the Confidence scale, indicating their sense of cooperation and mutual adequacy.

TABLE 9

FAMILY 201--FAMILY TESTS

Scale	Subscale	Maximum Score	Patient (Mother)	Spouse (Father)	Daughter Gd. 2.9
FHI					
	Cooriented-Commitment	24	23	24	Too
	Confidence	12	10	12	
	Challenge	15	9	11	Young
	Control-External	9	5	9	
	Total	60	47 (48)[a]	56 (95)	
F-COPES					
	Acquiring-Social Supp.	45	21 (17)[b]	24 (35)	
	Reframing	40	36 (91)	39 (99)	Too
	Seeking-Spirit. Sup.	20	14 (19)	14 (26)	Young
	Mobilizing	20	14 (71)	11 (43)	
	Passive-Appraisal	20	16 (99)	20 (99)	
	Total	145	101 (69)	108 (88)	
FACES-II					
	Cohesion	80	64 (5)[c] z=-0.11	64 (5) z=-0.11	58 (4) z=0.18
	Adaptability	70	55 (7) z=0.77	58 (7) z=1.23	50 (6) z=0.58
	Family Type	-	(6)	(6)	(5)

[a] Numbers in parentheses are percentile ranks from the appropriate norms: One overall norm for total score only. [b]Numbers in parentheses are percentile ranks from the appropriate norms: norms are for adults or adolescents, male or female. [c]Numbers in parentheses are from Linear Scoring Model (figure 2).

The family hardiness evidenced by the parents' answers to the FHI presumably developed in response to both Mother's MS and the eldest daughter's handicapping condition.

Family Crisis Oriented Personal Scales (F-COPES)

Differences in the problem-solving attitudes of the two parents showed on the F-COPES instrument, the greatest being how they viewed mobilizing the family to acquire and accept help. Mother viewed this as a fairly effective coping strategy, whereas Father was closer to the average of the norming sample. Both Mother and Father scored very high on the Passive Appraisal scale, suggesting that they did not resort to giving up or ignoring problems. Both seemed very capable of reframing, redefining stressful events in order to make them more manageable. Neither parent felt very successful in acquiring social support. Although both felt relatives could not be depended upon, Father is more willing than Mother to ask friends and neighbors for help. This family showed a lack of seeking spiritual support, although they had shared earlier that they felt it was important for the children to attend church and had, in fact, attended with them when they were younger.

Family Adaptability and Cohesion Evaluation Scale-II

The entire family attempted to respond to the FACES-II.

However, Son did not seem to understand many of the questions, even though they were read to him. He began to act silly, so I asked him if he would feel more comfortable not helping with this test. I then discussed the rest of the procedures with him, and assured him that, if he did not want to participate, that would be agreeable. His total cooperation was needed. He proceeded to discuss totally unrelated topics, thoroughly ignoring his mother and her MS, and emphasizing that it was his older sister who was handicapped. He apparently made this connection himself, as there had been no mention of the word handicap in relation to the MS. I told him that when I returned for the second interview, he could tell me whether or not he wanted to cooperate.

The rest of the family reflected moderately balanced family types. Mother and Father felt they were connected and very flexible. It is of interest to point out the items on which their responses differ to a greater extent. These are shown in Table 10.

Although Daughter also reflected a moderately balanced family type, it was achieved through different positions on the Cohesion and Adaptability dimensions. Using the adolescent norms, she felt the family was separated and flexible, respectively.

In regard to the previously mentioned items where the parents' responses differed considerably, Daughter's

TABLE 10

FAMILY 201--SELECTED FACES RESPONSES[a]

	Almost Never	Once in Awhile	Some-times	Freq-uently	Almost Always
1. Family members are supportive of each other during difficult times.		Sp	D		P
3. It is easier to discuss problems with people outside the family than with other family members.		P,D			Sp
7. Our family does things together.			All		
9. In our family,everyone goes his/her own way.	Sp	D	P		
11. Family members know each other's close friends.					All
17. Family members feel very close to each other.					All
19. Family members feel closer to people outside the family than to other family members.	Sp		D	P	
24. It is difficult to get a rule changed in our family.	Sp,D		P		
29. Family members pair up rather than do things as a total family.	P	D	Sp		

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

responses were divided equally in agreement with one or the other parent. There were two items on which her response was "Sometimes" whereas the parents' responses were "Almost never." These were item 12, "It is hard to know what the rules are in our family"; and item 25, "Family members avoid each other at home." This suggests that Daughter may be feeling ignored at times.

The family agreed completely on three items. These are also in Table 10.

Individual Testing of Daughter

Vineland Adaptive Behavior Scales

The teacher returned the Vineland Adaptive Behavior scales with many handwritten notes; one sub-domain was not completed. I took her comments and extrapolated a score from the manual to obtain the results for the Daily Living Skills domain. The teacher rated Daughter within the average range in Daily Living Skills (estimated 106) and in Socialization (98). Her Communication domain was above average (115), and the Adaptive Behavior Composite was average at 107.

Within the sub-domains, the teacher indicated some concern about Daughter's personal care relating to health issues of herself. The domestic sub-domain, which relates to helping around the home, was left blank. Within the interpersonal relationships sub-domain, the teacher expressed a little concern that Daughter did not seem to

have a best friend. Within the coping skills sub-domain, the teacher did not believe Daughter had developed strong self-control with respect to her judgment. In the summary observations, the teacher added that Daughter was well groomed and demonstrated good manners. She was a good leader and highly motivated. She sometimes had difficulties with other children if they teased her. The teacher summarized her feelings with, "I've enjoyed having her in my class. She's smart and an asset to the class."

When my assistant and I returned for the second session, Daughter answered the door, and led us to the kitchen table to do the testing. She seemed happy and was very cooperative throughout the testing. She had commented that Son was outside playing. When she brought her brother in, he told Mother he did not want to participate, even though Daughter had told him it was a lot of fun. The results on the objective tests are shown in Table 11.

Empathy scale

On the Bryant Index of Empathy, Daughter's level of empathy was much below average. As she read this test herself and scored so low, I wonder whether the meaning of each item was clear to her.

Piers-Harris Children's Self-Concept Scale

Daughter's very high total score on the Piers-Harris Children's Self-Concept Scale indicated a high degree of

TABLE 11

FAMILY 201--CHILD TESTS

Scale	Subscale	Maximum Score	Daughter Gd. 2.9
EMPATHY			81[a] 6 z=-2.75
PIERS-HARRIS	Behavior	16	15 (81)[b]
	Intellect	17	17 (98)
	Physical	13	11 (84)
	Anxiety	14	13 (90)
	Popularity	12	10 (69)
	Happiness	10	9 (72)
	Total Scale	80	75 (98)
SIV			
	Support	45	
	Conformity	45	Too
	Recognition	39	
	Independence	48	Young
	Benevolence	45	
	Leadership	48	

[a]81 = male or female norms for Grade 1 on T/N Bryant Scale with score range = 0-22. [b]Figures in parentheses are percentile ranks for the complete norming population.

self-esteem. The profile of her scores is included in appendix D. All six subscales' scores were much above average. Consistent with her teacher's assessment in the Vineland, Daughter appeared less comfortable with her popularity than in the other subareas.

Projective tests

Daughter's HFD suggested that she considered herself an assertive girl, who had high aspirations and parental support, but felt constrained by external factors.

The KFD added to what was represented by the DAP. Daughter, like the daughter in family 101, had her family shopping together. The handicapped sister was placed between the parents and the other children. Although Daughter apparently felt separated from her parents and unable to do anything about it, she did seem to identify with her father. The importance of the placement of the handicapped sister was emphasized when Daughter commented that her sister was usually not with the family when they shop. The KFD showed a high level of aggression which concerned me as none had been detected in the family.

Daughter gave short, but fairly complete, stories throughout the RATC. The profile of her scores is included in appendix E. The Adaptive scale indicated a strong ability to cope with aversive situations. She may overly rely on others for approval, but did appear

to have very strong self-sufficiency, assertiveness, and ability to support others. She demonstrated an extremely well-developed ability to identify problems and to resolve them effectively. Within the Clinical scale, Daughter's score suggested a high level of depression and an above-average level of aggression. Even though the KFD suggested that the sister interfered with Daughter's feelings of closeness to her parents, the RATC does not indicate an abnormal feeling of rejection.

During the objective testing, Daughter did not often talk spontaneously. However, she did share the family's plan to visit an amusement park during the summer vacation. She was excited about this prospect, but also demonstrated ambivalent feelings, as she did not know if her sister was going with them.

Exit Interview

My assistant and I were warmly welcomed back into this family's home. The four members who were present for the initial interview again participated. Father spoke for the whole family when he said there had been no problems as a result of the previous visits. Mother commented that the initial interview seemed like an intake interview for counseling, but she saw why it was needed. I was puzzled by this comment, because it made it appear as if she had, in fact, received counseling, though she had stated in the

initial interview that this was not the case. After the children had spoken, Mother shared that she had remembered that, at the recommendation of her neurologist, she had had a "few" sessions of counseling after her initial problems.

Daughter emphatically stated she had had fun. Son continued to be resistant, and talked about basketball. Father interrupted him and pointed out that "he's not a serious guy."

Mother added that she also was suffering from psoriasis, which was diagnosed at the same time as the MS. Her general practitioner told her it was due to the MS. I was not aware of any such connection. Mother continued with, "This is an aggravating disease. You gotta keep fighting this. I'm not going to let it conquer me." Father added, "It's simply mind over matter," a comment with which Mother clearly did not agree.

As my assistant and I were leaving, the parents expressed their appreciation and their interest in the eventual results, particularly relating to adolescents, so they might be better prepared for that stage.

Family Summary

Family 201 consisted of the mother patient, the father, a daughter age 7, and a son age 5. A 9-year-old daughter, who was born very handicapped and did not live in the home, but visited periodically, was not included in the study. All children were born after the diagnosis. Only the

7-year-old daughter participated in the study. Although the son was invited to take part, he did so flippantly, and soon chose to play instead.

The family inventories revealed solid family hardiness, constructive problem solving attitudes, and moderately balanced family types. The individual testing indicated that Daughter had average cognitive ability, very strong self-esteem, high aspirations, and much below average empathy. She appeared to be struggling with her feelings about her sister, who, although not living at home, seemed to be demanding more attention than Daughter received. Although there were above average depressive and aggressive tendencies, there were indications that Daughter had strong coping ability and a desire to be able to support others.

Family 202

Family 202 was the first to respond to the initial mailings. When contacted almost a year later, the father was excited to know the research was beginning, but the mother needed to make the appointments due to her extremely busy schedule. My assistant and I were warmly welcomed into their modest home in a small town.

Demographics

Family 202 consisted of the mother (the patient), age 40; the father, age 44; and the son, age 12. All were available during all the sessions, but Son demonstrated his

apparent discomfort with the situation by frequently removing himself, and only returning when requested. Mother was a graduate of law school, holding a doctorate of jurisprudence. She was an elected City Court judge, had a part-time private law practice, and was a certified mediator. She worked a 40-hour week between all these responsibilities, having reduced her weekly hours since her health demanded it. She had been a lawyer for 15 years, and a judge for 9. Father had a bachelor's of science in mechanical engineering, and had been a mechanical engineer in companies within a 30-mile radius for 18 years. He had always had a 40-hour work week. The two were married in June of 1974. Son was completing the seventh grade in a local public middle school, after having attended a local parochial elementary school.

Diagnosis and Acceptance

Father was reported as enjoying good health. Son was healthy, but took Ritalin for an attention deficit disorder with hyperactivity, which was diagnosed at age 6. When asked, the parents reassured me that he was on the medication at the time of the interview.

Mother was diagnosed in 1990, by a local neurologist, with a "demyelination syndrome." From 1985 to 1990, Mother had been experiencing symptoms, and the neurologist repeatedly told her that there was nothing wrong, she was just under too much stress "as a woman." Mother felt the

neurologist believed it was psychological, thereby "putting her through too much." Finally in 1990, a senior internist colleague of the neurologist with whom he consulted, insisted that she be hospitalized for tests. These included X-rays, a CAT scan, an MRI, a spinal tap, and an EEG with nasopharyngeal leads. Mother said "it was so wonderful to know what it was." She then went to the library to do her own research on the disease. She was most concerned to learn about the cognitive aspects of MS. Mother did not believe she had been receiving any support from the neurologist, but admitted she had "let him get by with that" until this past year. Mother had always enjoyed free-lance writing, and was given the opportunity to write a chapter in a book of autobiographies of people with MS. She found this very therapeutic, and even gave the neurologist a copy of the published book. She believed he appreciated the book, because he confided in her since receiving it that he had felt threatened by her intelligence and determination. She admitted to being a strong personality. My assistant and I agree, but see this as a very positive trait.

Father reported he "almost felt relief," finally knowing what the problem was. He continued with, "I have much confidence in [Mother] that she could overcome anything." He felt his responsibility was just to be around to help. The importance of this attitude was evident in the reporting of the exit interview.

Son was 9 years old when Mother was diagnosed. According to the parents, he had seen Mother fall a lot, but had never questioned why. When Mother was finally hospitalized, Son became "mean," his grades dropped, and he developed a discipline problem. They had believed it was wisest to have Son visit her in the hospital. However, for this particular child, they felt it had been a mistake, as his behavior then worsened. When Mother returned home, and life readjusted to near normal, Son's behavior improved.

Mother's parents lived out of state. She commented that they "are very controlled people, acting as though everything will be fine, yet exaggerating to others how bad it is." Father's parents "live within their own world"; however, his mother was a worrier.

Mother was not close to any of her siblings, and they did not talk much to each other. Father was an only child.

Mother added that, at the time she was hospitalized for diagnosis, the children in Son's class made her get-well cards. These were the best support she felt she had received. She did not believe the family was working as a unit to deal with the problems brought on by the MS. In Mother's opinion, Father denied its presence. Father believed he could not do much to help because she did not talk about it. Her problems were internal, and he was "just waiting for her to talk," implying that he could not see the problems.

At first, Mother had hoped her work would remain the same; but, through a long, difficult process, she learned to prioritize and to adjust her schedule day to day. Father's work was affected only when he had to take Mother to specialists, which she was reluctant to ask him to do.

The Catholic church of which they are members had been a big support for the family, because it "is like a big family," according to Mother. The church's Christian Education department organized a meeting to discuss MS. It was of interest to me that it was at this meeting that one of my long-term clients had learned about MS, and then related the learning experience to me.

Family friends had been "pretty supportive," the parents agreed. However, when Mother was in remission, feeling well and doing more, some of the friends were angered as if she had obtained their support under false pretences. As her condition obviously worsened, these same "friends" questioned her need for her motorized cart. She believed these friends were in denial. Father believed they were merely responding to Mother's strong will.

Symptoms and Treatment

In 1985, Mother began experiencing fainting symptoms, which were eventually diagnosed as hypoglycemia. She was put on a diet to control this. She then was diagnosed with very low blood pressure. Migraines then became the primary symptom, with dizziness, fatigue, and "shocks in the body."

The shocks had lessened, but the fatigue and dizziness continued. Mother had been born with cataracts, and very early surgery left her blind in the right eye. Therefore, she often overlooked visual symptoms of blurriness. Cognitive deficits with memory had been most frustrating to Mother. She added that she had difficulty with urination, due to bladder spasms, along with hand tremors and a weak back. A short time before the interview, Mother had had one seizure, losing two hours in her day. She had never experienced this before, and was very confused, and, I believe, frightened. An EEG taken soon after showed left-side seizure activity. She had taken numerous medications for the various diagnoses and was very sensitive as to how much each helped.

Assistance

Mother used a cane at times, and a cart to get around in the courthouse. She said her arms were not strong enough for a wheelchair. In her home, her walk was very stiff and jerky.

Mother's medical insurance was through her judgeship. The family received no financial assistance. Father and a housekeeper cared for household duties. When questioned as to whether anyone had to receive counseling, as a result of the MS, Mother evasively said that she had seen a neuropsychologist for testing, due to her cognitive deficits. The counseling that resulted from the testing was

to help her deal better with the legitimate cognitive deficits, yet she would not accept it as therapy. Father openly shared that he had received counseling for depression, which had worsened after the MS. "It was just too much for me." He took Prozac.

Description of Son by Parents

After reiterating that Son was suffering from ADHD, the parents also stressed that he had been diagnosed as gifted at Wright State University. Son had been an A and B student at the parochial elementary school, and he had been on the honor roll at the public middle school. Son stated, "The middle school is easier." The parents shared that he was very social, "has sorry souls around all the time," unconditionally accepted all children, and abhorred competition, such as in sports. Son was described as a personable young man, who received "glowing" behavioral reports from school that year. In elementary school, he was so outgoing he would not be quiet.

The Family Tests

All three family members responded to all three Family tests. As with family 102, they isolated themselves from one another. The results are shown in Table 12.

Family Hardiness Index

Both parents' FHI scores were well above the average of the norming sample. Looking at the individual factors, both

TABLE 12

FAMILY 202--FAMILY TESTS

Scale	Subscale	Maximum Score	Patient (Mother)	Spouse (Father)	Son Gd.7.9
FHI					
	Cooriented-Commitment	24	24	20	24
	Confidence	12	12	12	11
	Challenge	15	12	12	14
	Control-External	9	8	7	6
	Total	60	56 (95)[a]	51 (73)	55 (91)
F-COPES					
	Acquiring-Social Supp.	45	23 (23)[b]	25 (40)	34 (90)
	Reframing	40	36 (91)	30 (46)	37 (95)
	Seeking-Spirit. Sup.	20	16 (40)	16 (48)	14 (41)
	Mobilizing	20	9 (16)	12 (57)	12 (68)
	Passive-Appraisal	20	18 (99)	15 (98)	9 (45)
	Total	145	102 (71)	98 (67)	106 (87)
FACES-II					
	Cohesion	80	68 (6)[c] z=0.37	61 (5) z=-0.46	62 (5) z=0.62
	Adaptability	70	51 (6) z=0.17	49 (5) z=-0.14	51 (6) z=0.71
	Family Type	-	(6)	(5)	(5.5)

[a] Numbers in parentheses are percentile ranks from the appropriate *norms: One overall norm for total score only.* [b]Numbers in parentheses are percentile ranks from the appropriate norms: norms are for adults or adolescents, male or female. [c]Numbers in parentheses are from Linear Scoring Model (figure 2).

viewed the challenges of life in a very positive manner, and had very strong confidence in themselves as a family. Neither felt subject to the external forces over which they had no control. Father felt strongly, and Mother even more so, that the family was strengthened by their commitment to one another. Only 2 of the 20 items revealed an important difference in their beliefs. With item 1, "Trouble results from mistakes we make," Mother disagreed, but Father agreed. On item 16, "It is better to stay at home than go out and do things with others," Father disagreed, but Mother agreed.

Son's FHI was also well above the average. He was even more positive than his parents in viewing the challenges of life, and was also confident in his family. Son felt somewhat more controlled by external forces than did his parents. He was as sure as Mother that the family was strengthened by their commitment to one another. On the two items on which the parents differed, Son agreed with Father, but even more strongly. On all the other items, he was in alignment with his parents. On 12 of the 20 items, all three family members gave identical responses.

Family Crisis Oriented
Personal Scales
(F-COPES)

Overall, the parents' scores on the Family Crisis Oriented Personal Scales indicated an above average ability to cope effectively with difficulties. The one subscale on which they both scored very high, Passive Appraisal,

suggested that they accept the problematic issues they faced, and minimized reactivity. The only item in this section on which they disagreed was number 28, "Believing if we wait long enough, the problem will go away"; Mother strongly disagreed, whereas Father neither agreed nor disagreed. On the other items, although they both responded in the effective direction, Mother's response was stronger. Whereas Father's responses indicated average ability to reframe stressful events in order to make them more manageable, Mother's responses indicated much greater effectiveness in doing so. On most of the items in this section Mother tended to respond with strong agreement, whereas Father moderately agreed. Both parents were on the low side of average in seeking spiritual support. Although they both found value in attending church, participating in church activities, and having faith in God, Mother was strongly against seeking advice from her minister, whereas Father was willing to do so.

In the other two subareas, Father remained in the average range, whereas Mother dropped significantly. She did not feel she successfully acquired social support, nor did her responses indicate an interest in doing so. She also did not see herself as capable of mobilizing the family to acquire and accept help. This, in fact, was her least effective coping strategy. Within the subarea Acquiring Social Support, the two items on which the parents greatly

differed were items 1 and 16. Mother was willing to share concerns with close friends, but not with relatives, whereas Father expressed the opposite view. Within the Mobilizing the Family subarea, these opposing beliefs continued to be in evidence.

Son's F-COPES results were rather different from his parents'. His Passive Appraisal score fell within the average range, suggesting that he is less able than his parents to minimize reactivity to problematic situations. On two items, his responses were at the opposite extreme to those of his parents, choosing the less effective way of coping. He resorted to watching television, and believeed that no matter what they did to prepare, they would have difficulty handling problems. Son's ability to reframe stressful events in order to make them more manageable was extremely strong, and more comparable to Mother than to Father. Son's score on Seeking Spiritual Support, at the average level for his age, was very comparable to his parents' scores. Son was much more willing than his parents to acquire and utilize social support as a coping mechanism. The one item on which the entire family agreed was in this subarea. For item 2, "Seeking encouragement and support from friends," their response was "Strongly agree." On the other items, he disagreed with one or both parents, expressing the more effective method of coping. Considering Son's age, his attitude toward mobilizing the family was

more positive than his parents'.

Family Adaptability and
Cohesion Evaluation
Scales-II

On FACES-II, the parents reflected a similar belief that their family was of a moderately balanced type. Both felt they were connected on the Cohesion dimension and flexible on the Adaptability dimension. On two items, although Father answered "Sometimes," Mother answered at an extreme. On item 11, "Family members know each other's close friends," Mother said "Almost always." On item 15, "We have difficulty thinking of things to do as a family," she said "Almost never."

Son's responses reflected a moderately balanced family type, with connected and flexible, just as his parents'. Although his actual scores on the dimension were very similar to his parents', his responses to individual items were different. There are two items on which he differed most significantly from both parents. Item 5, "Our family gathers together in the same room," drew a response of "Once in a while" from Son, and "Frequently" from the parents. On item 23, "Family members like to spend their free time with each other," Son answered "Once in a while," and the parents answered "Frequently." There are five items on which the entire family completely agreed. These are shown on Table 13.

When scheduling a date for the second session, Father

TABLE 13

FAMILY 202--SELECTED FACES RESPONSES[a]

	Almost Never	Once in Awhile	Some-times	Freq-uently	Almost Always
8. Family members discuss problems and feel good about the solutions.				All	
12. It is hard to know what the rules are in our family.	All				
18. Discipline is fair in our family.					All
25. Family members avoid each other at home.	All				
27. We approve of each other's friends.			All		

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

asked if the parents needed to be home. Interpreting this as "Will we be tested?" I responded "No." Father's immediate response was "Good, we'll go out to dinner." I found it curious that two strangers would so readily be entrusted with their son.

Individual Testing of Son

When my assistant and I returned for the second session, Son greeted us at a door level with the driveway, thus avoiding the necessity of climbing the steps to the front door as we had on the first occasion. Father was anxiously awaiting Mother's return home, so they could leave for dinner. Son took me to the kitchen for the first part of the testing, and initially seemed very cooperative. As the clinical testing proceeded, however, he became resistant and visibly angry about being required to reveal information that was highly personal. His passive aggressiveness may have affected his responses to the objective tests, as well as to the clinical.

The principal of Son's middle school supplied his IQ score after the second session. He reported a CSI from the ISTEP of 94, within the average range. This was considerably lower than I had expected from the parents' reports of previous individual testing. This apparently depressed score might also be a reflection of his passive aggression. Son's ADD also may suppress group testing scores.

Table 14 gives the results of the objective tests.

Empathy scale

When administering the Y-N form of the Bryant Index of Empathy, my assistant was under the impression that Son was giving too little thought to his responses. I agreed with his suggestion that Son should be asked to respond to the 9-point form of the instrument at the time of the closing interview. The hope was that this would encourage Son to respond more thoughtfully. This hope did not materialize. Son responded just as carelessly, and his results on the two forms were similar. Neither should be accepted with great confidence. The result on the initial Y-N form is reported in Table 14. This result suggested a very low level of empathy in relation to his peers.

Piers-Harris Children's
Self-Concept Scale

Son had a positive self-concept, scoring about average on all subscales. The profile of his scores is included in appendix D. Son was most confident in Happiness and Satisfaction, Intellectual and School Status, and Freedom from Anxiety. Not as strong, but still above average, were confidence in Behavior, and Physical Appearance and Attributes. His sense of Popularity was the weakest, and only just above the average range when compared to peers.

TABLE 14

FAMILY 202--CHILD TESTS

Scale	Subscale	Maximum Score	Son Gd. 7.9
EMPATHY			B7[a] 8 z=-1.65
PIERS-HARRIS	Behavior	16	14 (65)[b]
	Intellect	17	15 (81)
	Physical	13	10 (73)
	Anxiety	14	12 (81)
	Popularity	12	9 (52)
	Happiness	10	10 (90)
	Total Scale	80	68 (89)
SIV			
	Support	45	
	Conformity	45	Too
	Recognition	39	
	Independence	48	Young
	Benevolence	45	
	Leadership	48	

[a]B7=male or female norms for Grade 7 on Y/% Bryant Scale, range=0-22. [b]Figures in parentheses are percentile ranks for the complete norming population.

Projective tests

Son's resistance was even evident in the drawing tests. His HFD appeared to be a horned, spiked spined, clawed animal standing upright. When I reiterated the instruction that he draw a human, he insisted that the figure "is human!" He then reproduced a comic book character that was part human and part robot. Obviously, Son was being evasive and overly self-protective; but he also indicated a non-trusting attitude and hostility. By depersonalizing his drawings, he revealed an apparent disrespect for himself. Although careless drawings can come from an attention deficit disorder, these were not drawn impulsively.

Son's KFD continued to demonstrate his aggression. He drew himself standing with Mother, far away from Father, who was pouring gasoline on their barbecue, which was exploding. None of the figures had any facial features. The emotional indicators further suggested superficial interpersonal relationships, evasiveness, and lack of cooperation.

Son's responses throughout the RATC were short, but revealing. He required a lot of urging to develop his short answers. The profile of Son's RATC scores is included in appendix E. The Adaptive scale suggested a very weak capacity to ask for and to use outside help to overcome a problem. He also does not appear to have the ability to support others. Self-sufficiency was low average for his

age. He received a low score on Limit-Setting, suggesting either a lack of parental involvement or a lack of ability or desire to conform to social expectations. Son's ability to identify problem situations was in the low average range--he tended to seek easy resolutions to the problems, or was unable to resolve them at all. The Clinical scale revealed strong feelings of rejection, but average levels of depression and anxiety. Aggressive tendencies appeared to be low, due to an obvious attempt to keep aggression out of his stories. Even the cards which are expected to elicit aggression drew forth stories of fear and rejection. One of Son's stories seemed to encapsulate his own problems. "The kid is sensing fear. He doesn't want to face it. He just keeps fearing."

Exit Interview

Upon our return, my assistant and I noticed that Son appeared unhappy. As during the initial interview, he quickly absented himself from the room. At one point, as he walked through the room to go outside with a large water gun, he stopped and aimed it at me and Mother. When I looked at him, he showed no signs of embarrassment, but smiled and left.

Mother and Father were more welcoming. Mother commented that the questions had made a lot of sense, and Father said they were not too intrusive. I commented that Son would probably not agree. They said they had not had an

opportunity to discuss the research with Son. This led to a discussion about him. In the book to which Mother had contributed a chapter, there are several chapters which discuss parents who cannot do things with their children because of the MS. Mother shared that she cried while reading these chapters. She believed that she could generally do things with Son when time allowed. Father added that Son's teacher of the previous year had asked Father to read several entries in Son's "private" school journal. Son had described Mother as being more handicapped than she was, near death, and unable to function. Mother interjected that he had always been insecure when she could not "take care of things. I'm ordinarily so much in control."

Father added that "she believes she is invincible." She admitted that she wanted to be able to do things "at the same level as before." Mother shared that Son at times seemed embarrassed about her, and would ask her to not use her cane or cart. Father wondered if that was part of Son's perfectionistic attitude, and continued to point out that Son did not do well on ISTEP group testing, because he considered this a waste of time. The private testing had revealed an IQ of 128. I agreed that Son did not perform up to his potential on the ISTEP, and added that there were more problems than were obvious to them. Father said that Son was 5 when his problems started. I believe the problems

at 5 are related to his ADD. Mother failed to realize that the present problems which were being discussed were related to her MS. She commented that Son had always believed that if Mother was "doing it, it will happen." When she was unable to bring about a change at his private school, he became very angry. The fact that the change had not occurred was unrelated to her MS. One of Mother's final statements would seem to better explain the reason for Son's problems. "I am somebody who is not like anyone else."

I left with a growing concern over Son's mental health. As a researcher, my responsibility to this family would seem to have ended. However, Son's results were so abnormal that I spoke of my concerns with several fellow professionals and professors at the university, maintaining confidentiality. I then determined I should contact the parents and let them know of my concerns, once the research truly indicates that these results suggest the necessity of an intervention. This intervention should clearly be on the part of another professional.

Family Summary

Family 202 consisted of the mother patient, the father, and a 12-year-old son, who was 9 at the time of diagnosis. The parents' self-reports suggested they might be suffering depression. Although Mother was not severely disabled, because she was a high-level professional, the family members all felt significant adjustment had been necessary.

The family tests revealed confidence in themselves as a family strengthened by their commitment to one another. Father seemed to have the greatest ability, and Son the least, to cope. Father was the mobilizer of the family, Mother was more effective in reframing stressful events, whereas Son utilized social support. They all saw the family as being of a moderately balanced type.

Individual testing indicated that Son was of at least above average intelligence, with a positive self-concept, and low empathy. It is regrettable that, due to his age, I had not elected to administer the SIV, since I later successfully used this instrument with children near his age.

Son was suffering a great amount of ambivalence about himself and toward his parents. Nurturing was not as he desired, or from whom he wished it could be. Although he wanted to be close to Mother, he was angry with her and yet also worried about her. Father was admittedly more of a parent, but Son did not feel close to him and was angry with him also. Son seemed to be trying very hard to control his aggressive impulses and, with his above average intelligence and self-concept, appeared at that time to be for the most part successful. However, further stress, such as impending adolescence, could easily upset this fragile balance. It was not surprising that Son had very low empathy and desire to help others. He was utilizing all of his psychological

energy on keeping his angry self controlled in this controlled family.

Family 203

The mother of family 203 contacted me after hearing of the study while attending an MS support group in the metropolis. After discussing the study over the phone, she requested the packet of information to share with the family. They quickly returned the package, and were contacted soon after to set up appointments. The father was very friendly and an initial appointment was quickly arranged. Due to travel difficulties for me, their appointment had to be changed. This was not viewed as a problem when speaking with the father. This was the first spouse who inquired as to whether I could climb the steps to their house, offering his help if needed, and a back door alternative. My assistant and I arrived 30 minutes early, and were welcomed into their modest home that lies within a large metropolis.

Demographics

Family 203 consisted of the mother (the patient), age 37; the father, age 36; the daughter, age 8; and the son, age 5. Mother completed a bachelor of science in commerce, and Father completed a master of science in finance. They were married in May 1981. Daughter had just completed the first grade in a neighborhood parochial school. Son had

just completed preschool in the same school. Mother had worked in a large bank in a full-time position until 1985, when she reduced to part time to care for the children. She emphasized this was not due to the MS. In 1991, after 14 years of service, her job was dissolved. She felt the timing was appropriate for her personal needs, as her MS had been worsening since 1990. Father had been an accountant for 16 years, holding his present position for 3 years. His full-time job ranged from 45 to 48 hours per week.

Diagnosis and Acceptance

Father and Daughter were reported as healthy. Son was diagnosed with asthma in 1991, after a serious attack requiring hospitalization. The asthma was now under control. Mother seemed proud to be able to relate that her MS had not exacerbated during this crisis. When I asked if it had, once the crisis was over and the stress was reduced, she was unable to remember.

Mother's first symptoms appeared near the end of 1977. She experienced numb legs and trouble with her vision. During her spring break of the next year, "right before (she) graduated from college," her MS was diagnosed. She had been referred to a large university hospital by her opthalmologist. The diagnosis was made through vision tests and a positive spinal tap. The physician who informed her of the diagnosis apparently was too blunt for Mother. He informed her that the results of the tests indicated she had

MS. He continued by saying she could recover as much as 90% of what she had lost. He told her to get lots of rest and to call the MS society. Mother felt he offered her no support, and was unfriendly. So she changed to another neurologist whom she still sees. She openly shared that she did not accept the diagnosis, and her remit/relapse condition helped reinforce her denial. She believed she gradually developed acceptance over the ensuing years, because, as the disease had worsened over the past 3 years, she looked at it as "merely a bother."

Father had known Mother before the diagnosis. They were dating when she shared this with him. He remembered thinking that it was "no big deal."

The diagnosis was also shared with a few friends, who were very supportive, and with both sets of parents. Mother and Father felt fortunate that the two sets of parents got along well together, despite very different lifestyles. Mother's father was convinced that her problems were simply because "she was burning the candle at both ends." As the disease progressed, he had not said much, but expressed faith that Father would take care of Mother. Mother added that there was always some crisis going on with one of her siblings, and their mother was always there to help. Because he was an only child, Father believed his parents were more able than Mother's parents to give support to her. Because Mother's siblings "have their own problems, . . .

they don't deal with [my MS]." She did not feel close to any of them.

Both Mother and Father believed that their employers had been understanding and cooperative. When Father had to take Mother to doctors' appointments in the city, he was allowed to "juggle" his time at work.

Neither parent thought the church had offered any support. They even seemed surprised that this should be expected.

When asked if the family had changed as a result of Mother's MS, Father responded, "It has to. MS impedes doing things." He felt that the fatigue factor was most interfering. Mother agreed that a lot had changed. "He looks at me differently. Before, I was a wife and a partner. Now he has to take care of more." She felt his role had changed from husband to caregiver. Father's body language indicated agreement.

Symptoms and Treatment

Mother's initial symptoms did stop, and she did return to near normal. Fatigue became a part of her daily life from the first acute episode. As the remit/relapse course progressed, her legs and vision continued to be affected, with less recovery with each remission. Mother had experienced numbness in her arms, spasticity in her legs, expecially when tired, and fine-motor clumsiness.

Mother's physician had hospitalized her for ACTH

treatment several times over the years. The last time it was tried, it offered no help. Other medications had been tried and she had positive feelings about their usefulness.

Assistance

At home Mother walked without any aids, in the same stiff, rolling fashion as the mother in family 201. On the day the children were tested, she shared privately with me her growing belief that she should begin to use a cane. She discussed her fear of how her use of a cane might affect the children and Father. I urged Mother to give priority to her personal needs, and merely to inform the other family members of the necessity for the use of a cane. The truth of Mother's response--"this would not be easy"--did not become fully apparent until the time of the final interview.

Mother was keeping up the house regularly, and had a cleaning lady help once a month. When Mother had to go into the hospital, her mother had taken care of the children, saving vacation days for this purpose.

Mother was receiving Social Security Disability and Medicare, and had supplemental health insurance through Father's employment.

At the time of the interview, Mother had been receiving counseling for 18 months. It had originally been marriage counseling; but, after about 3 months, the counseling changed its focus to Mother, much to Father's apparent relief. When asked if the MS was given priority in the

counseling, Mother replied that it did seem to be the underlying subject.

Mother seemed pleased to report that Father had recently joined a national network of partners of people with MS. When Father was asked about this, he seemed comfortable but had no comments, as he had just joined.

Emotional Issues

Although Father had been very friendly over the phone, once in their house my assistant and I both felt he was very uncomfortable with the situation. He so intently watched all the writing, with what appeared to be nervousness, that my assistant felt it necessary to cease note-taking. Father responded to any questions directed toward him, but did not appear comfortable answering those which delved into the emotional areas. He did seem to become more open as the interview progressed. When my assistant and I left the initial interview, we both admitted having felt uncomfortable. However, in the final interview, it became evident that Father's behavior had been a result of a reserved personality, rather than a suspicious one, combined with some initial nervousness. In contrast, Mother was open and exuberant about participating in the study.

Mother delineated Father's support as "he will take care of problems; but the emotional support is not there." Father countered with "men and women take care of problems differently. Men want to fix it, and women analyze it."

Mother was very forthcoming in sharing her understanding that some of her pain stemmed from their very different personalities.

Description of Children by Parents

During the initial interview, the children played in a separate room, and had to be coaxed by the parents to participate to the small extent required of them. Daughter was described as an honor roll student. The parents felt she behaved well most of the time. Problems occurred when she talked and did not listen, and when she was resistant to new things and change. She had many friends, and seemed to get along better with children than with adults.

Son had done very well in preschool, and the parents believed he was excited about entering kindergarten. He tended to cling to Mother and to make friends with girls. He followed rules well.

The parents ended the discussion of their children by agreeing that both were extremely sensitive and cried easily. Daughter "smoulders," and would let things build up and bother her. Son would get over things quickly.

The Family Tests

Table 15 gives the results of the family members' responses to the Family tests. The children responded only to FACES-II.

TABLE 15

FAMILY 203--FAMILY TESTS

Scale	Subscale	Maximum Score	Patient (Mother)	Spouse (Father)	Daughter Gd. 1.9	Son Presch.
FHI						
	Cooriented-Commitment	24	13	18	Too	Too
	Confidence	12	6	10		
	Challenge	15	4	9	Young	Young
	Control-External	9	7	5		
	Total	60	30 (02)[a]	42 (20)		
F-COPES						
	Acquiring-Social Supp.	45	20 (14)[b]	29 (66)		
	Reframing	40	23 (07)	36 (92)	Too	Too
	Seeking-Spirit. Sup.	20	10 (<5)	16 (48)	Young	Young
	Mobilizing	20	9 (16)	13 (69)		
	Passive-Appraisal	20	15 (99)	15 (98)		
	Total	145	77 (08)	109 (90)		
FACES-II						
	Cohesion	80	41 (2)[c] z=-2.85	62 (5) z=-0.35	51 (3) z=-0.58	61 (5) z=0.51
	Adaptability	70	42 (3) z=-1.20	47 (5) z=-0.44	39 (2) z=-0.81	45 (4) z=-0.45
	Family Type	-	(2.5)	(5)	(2.5)	(4.5)

[a]Numbers in parentheses are percentile ranks from the appropriate norms: one overall norm for total score only. [b]Numbers in parentheses are percentile ranks from the appropriate norms: norms are for adults or adolescents, male or female. [c]Numbers in parentheses are from Linear Scoring Model (figure 2).

Family Hardiness Index

Even though Father's FHI score was somewhat higher than Mother's, both are well below the average of the norming sample. They were in closest agreement about the amount of control they felt was exerted by external factors out of their control. Both responded in a fashion which suggested they felt personally responsible for the development of problems.

Father viewed the challenges of life in a much more positive manner than Mother. Whereas her responses indicated that she found family life boring and unsupportive, he completely disagreed. Although Father believed there was a sense of cooperation and mutual adequacy, Mother was not as confident about this. Neither felt appreciated. The parents' Cooriented Commitment scores were the second best for each. Mother, however, did not have as much faith in their joint internal strength as Father.

In Table 16 there are 5 items of interest. Two of the 6 items to which the parents responded identically, indicated an agreement which items 11, 13 and 17 appear to contradict. Mother seemed to feel that Father could be counted on, but apparently not for emotional support.

Family Crisis Oriented
Personal Scales

The significant differences in how the parents handle

TABLE 16

FAMILY 203--SELECTED FHI RESPONSES[a]

	False	Mostly False	Mostly True	True	Not Applic
7. While we don't always agree, we can count on each other to stand by us in times of need.			P,Sp		
11. We strive together and help each other no matter what.		P	Sp		
13. We listen to each other's problems, hurts and fears.	P		Sp		
17. Being active and learning new things are encouraged.		P		Sp	
18. We work together to solve problems.			P,Sp		

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son.

stress showed also on the Family Crisis Oriented Personal Scales. Their most positive problem-solving attitude was on the Passive Appraisal scale, where they both scored very high. Neither would resort to giving up or ignoring problems. Mother's low scores on the other four subscales suggested an ineffective ability to cope. She did not seem to find strength through mobilizing the family, acquiring social support, reframing, or seeking spiritual support. This last is consistent with the parents' comment in the first session indicating surprise that the church should even be expected to offer support. In contrast, Father's scores were average or above on these four subscales.

As shown in Table 17, Father and Mother differed significantly on several of the 16 items. Father seemed to want to solve the problems within the family and by seeking advice from others, but not through professional help. Mother, in contrast, seemed to have little faith that the problems could be solved within the family, and saw the need for professional help, rather than simply seeking advice. There are three items to which they responded identically. In comparing responses to items 1 and 25, Father was at least willing to share difficulties with relatives, but neither wants the relatives to respond.

Family Adaptability and Cohesion Evaluation Scale-II

The entire family responded to the Family Adaptability

TABLE 17

FAMILY 203--SELECTED F-COPES RESPONSES[a]

	Strongly Disagree	Moderate Disagree	Neither	Moderate Agree	Strongly Agree
1. Sharing our difficulties with relatives.	P				Sp
7. Knowing we have the strength within our own family to solve our problems.		P		Sp	
9. Seeking information and advice from the family doctor.	P				Sp
14. Attending church services.		P		Sp	
19. Accepting that difficulties occur unexpectedly.					P,Sp
21. Seeking professional counseling and help for family difficulties.		Sp			P
24. Defining the family problem in a more positive way so that we do not become too discouraged.		P		Sp	
25. Asking relatives how they feel about problems we face.	P,Sp				
30. Having faith in God.					P,Sp

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son.

and Cohesion Evaluation Scale. It was read to the children. Even though Son was very young (5), he wanted to participate in this test, and seemed to understand the questions very well.

The family's scores indicated that Mother and Daughter believed that their family type was on the border between mid-range and extreme, whereas Father believed they were moderately balanced, and Son believed they were on the border between moderately balanced and mid-range. Even though Mother's and Daughter's family type was the same, they reached this point through very different responses on the two dimensions. Mother had them disengaged on the Cohesion dimension and structured on Adaptability. Daughter had them separated and rigid. Father and Son both had the family connected on the Cohesion dimension; but Father believed they were flexible in Adaptability whereas Son, like Mother, believed they were structured.

It is not surprising that there are many responses of interest among various subgroups. Table 18 shows these.

Father's answers on item 27 and 28 seem to be in opposition to one another; but he, apparently, was differentiating an opinion from a feeling which was "on their minds." There were no items on which the whole family completely agreed. The children do not feel that they are allowed to contribute with the family for problem solving, and this may be resented by Daughter.

TABLE 18

FAMILY 203--SELECTED FACES RESPONSES[a]

	Almost Never	Once in Awhile	Some-times	Freq-uently	Almost Always
2. In our family, it is easy for everyone to express his/her opinion.	D			P,Sp,S	
3. It is easier to discuss problems with people outside the family than with other family members.		D,S	Sp		P
4. Each family member has input regarding major family decisions.	D,S		Sp	P	
6. Children have a say in their discipline.	P,S		Sp		D
9. In our family, everyone goes his/her own way.		Sp,D	S	P	
16. In solving problems, the children's suggestions are followed.			P,Sp,D	S	
17. Family members feel very close to each other.	P	S		Sp,D	
18. Discipline is fair in our family.				P,D,S	Sp
19. Family members feel closer to people outside the family than to other family members.	S	Sp,D			P
20. Our family tries new ways of dealing with problems.		P,Sp	S		D
23. Family members like to spend their free time with each other.	P		D	Sp,S	
25. Family members avoid each other at home.	S	Sp		P,D	
26. When problems arise, we compromise.	D		P,Sp,S		
28. Family members are afraid to say what is on their minds.	S	Sp		P,D	
30. Family members share interests and hobbies with each other.	P		D	Sp,S	

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son.

Individual Testing of Children

Vineland Adaptive Behavior Scales

Daughter's teacher from the previous school year quickly returned the Vineland Adaptive Behavior Scales. She rated Daughter within the average range in Communication (102), in Daily Living Skills (106), and in Socialization (97). The Adaptive Behavior composite was average at 101. The only sub-domain where problems were noted was in Interpersonal Relationships. The teacher had not observed Daughter with a fairly regular group of friends or with a best friend. In the written comments, the teacher added that Daughter appeared to be very competitive and sometimes forgets to remember the feelings of others. She appears very bright and "has a tremendous memory."

Son's Vineland was not returned by the teacher to whom it was initially sent, having apparently been mislaid. Upon contacting the school, I was asked to send a new form to Son's current teacher, who returned it promptly. She rated Son slightly below average in Communication (89), and average in Daily Living Skills (94), Socialization (109), and Motor Skills (96). The Adaptive Behavior composite was average at 96. The sub-domains where problems were noted were Expressive and Written Communication, and Domestic Living Skills. The teacher did not feel Son was given much self-responsibility in his home. This corresponded to my reaction to my own observations in the home. The teacher

felt that Son's strengths were his social skills and listening ability.

When my assistant and I returned for the second session, Daughter was in day camp. Son was to have been there also; but, after his first few days, he had refused to continue, preferring to stay home with Mother. She was very concerned because Son had become more clingy since the first session. Son was excited about the testing, but requested that Mother be allowed to stay in the room. This was agreed to on the condition that Mother remain quiet. Son had no problems when Mother left 15 minutes later to pick up Daughter. Son told me that Daughter had tried to convince him that I was a "murderer," but he had not believed her. When Daughter arrived home, she avoided me. Son told her how much fun he had been having, but she did not care. Mother eventually persuaded Daughter to cooperate by bribing her with a snack; but she remained very oppositional. The children's scores on the objective tests are shown in Table 19.

Empathy scale

The Bryant Index of Empathy was read to the children by the assistant, who observed that Daughter was apathetic toward the testing. Daughter's score was very low, indicating a very poor ability to empathize, as had been suggested by her teacher. Son's score was approximately at the mean for grade 1 children. As he was at that time a

TABLE 19

FAMILY 203--CHILD TESTS

Scale	Subscale	Maximum Score	Daughter Gd. 1	Son Presch.
EMPATHY			B1[a] 8 z=-2.05	B1 12 z=-0.09
PIERS-HARRIS	Behavior	16	9 (18)[b]	
	Intellect	17	11 (38)	Too
	Physical	13	4 (11)	
	Anxiety	14	13 (90)	Young
	Popularity	12	9 (52)	
	Happiness	10	7 (39)	
	Total Scale	80	53 (49)	
SIV				
	Support	45		
	Conformity	45	Too	Too
	Recognition	39		
	Independence	48	Young	Young
	Benevolence	45		
	Leadership	48		

[a]B1 = male or female norms for Grade 1 on Y/N Bryant Scale with score range = 0-22. [b]Figures in parentheses are percentile ranks for the complete norming population.

preschooler, this would suggest a better than expected empathy level for him.

Piers-Harris Children's Self-Concept Scale

Due to their ages, the Piers-Harris Children's Self-Concept Scale was administered only to Daughter. The profile of her scores is included in appendix D. Her total score was within the average range. Her degree of comfort with her physical appearance and attributes was below average. Her sense that she is free from anxiety was well above average. Although the other subscale scores were within the average range, her confidence in her behavior is barely within that range. Remembering her teacher's note referring to a lack of friends, it is of interest that she saw herself slightly above average in popularity.

Projective tests

Daughter's HFD showed a sneering girl with no hands and distorted legs. The picture suggested rigid, inhibited, stubborn, and impulsive tendencies. There were also indications of depression, dependency, and poor adjustment. Son's human figure drawings were all of better than expected quality for his age, although his lines were wavy and he drew no faces. His HFD suggested that he was a friendly, but timid, boy.

Daughter's KFD placed the children in front of, and

between, the parents. The children were aligned, Daughter closer to Father and Son to Mother.

No one had hands, and neither parent had legs. Everyone but Father was happy, and Father appeared to be trying to control hostile feelings. Everyone seemed to be ineffective in dealing with life, and Daughter was very confused as to whether the parents or the children were the caretakers. Son's KFD had the parents between the children, with Son next to Father and Daughter next to Mother. Son seemed to identify with Father's feelings of inadequacy and Mother's feelings of weakness. None of the family had hands; but, at his age, this is not significant.

Daughter was very resistant to telling stories in relation to the pictures of the RATC, but she did give short responses that were scorable. A break was taken halfway through the test, because I felt the need of a respite from Daughter's continual accusations that I was a murderer, and Daughter's refusal to discuss why she thought this. The RATC's Adaptive scale showed that Daughter had an average ability to rely on others for support and to identify problems. Her ability to resolve problems, to support others, and her self-sufficiency, were all below average. The Clinical scale showed average levels of anxiety and aggression, below average dependency needs, and above average feelings of rejection and unresolved feelings.

It was somewhat difficult to elicit responses from Son

on the first three cards of the RATC. As he told stories, his eyes grew red, but he did not cry. The first three stories focused on children not dealing well with MS. When it became obvious that he felt children could also develop MS, the testing was stopped, so that I could discuss MS with Son. Mother was still in the room at this point, and said they had discussed it with him. I explained that he apparently needed more information, and Mother agreed. I assured Son that MS is not contagious, that children do not contract it genetically (except in very rare cases), and that MS, of itself, is not a fatal disease. The boy released a great deal of tension, and continued his stories with a smile. He continued to include MS in his stories periodically, but more realistically.

The RATC's Adaptive scale suggested weak ability to ask for outside help and to find the strength within himself. He had an above average ability to identify problems, and an average ability to resolve them. There appeared to be average ability to support others and to recognize and set limitations. The Clinical scale showed a high level of anxiety and an above average level of depression. Unresolved feelings were in the high average range. Feelings of rejection and aggressive tendencies were average for his age. The profiles of children's RATC scores are included in appendix E.

Mother's Emotional Issues

While Daughter was completing her tests with the assistant, and Son was eating a snack in the same room, Mother and I were in a different room. Mother took the opportunity to discuss with me some of her concerns about the children. She shared that Son was more open than Daughter, who kept everything to herself, "like I was. That's why I go to therapy." Mother believed both were afraid she would die, even though she had assured them that she would not die because of the MS. Son's clinging worried her. I told her that he seemed much relieved since my discussion with him; but both children did seem very concerned about Mother. Several suggestions were given to Mother for both children. This appeared to go beyond my responsibility in the situation. However, Mother had openly asked for help, already aware that the children had problems. The brief time taken seemed to give Mother a new sense of assurance, and she appeared immeasurably grateful. She decided that Daughter needed to see a therapist, and I encouraged her in this.

Exit Interview

When my assistant and I arrived for the final session, Father had not yet returned from work. While awaiting his return, we sat with Mother and Son. He eagerly showed and discussed some of his possessions, while Daughter remained alone in her room. When Father arrived home, it was

apparent he was pleased to see us. He ordered Daughter to join the group, after she had bluntly refused to comply with initial requests. She entered the room carrying a water gun, and pointed it directly at me. This was a startling parallel to the exit interview with the previous family. Father instructed Daughter to sit down and leave the gun alone. She brought a chair from another room, placed it on the opposite side of the room from me, and sat on it with her back to the whole group.

With some discomfort, I asked for feedback on the process. Father said it had not been intrusive. Mother had appreciated it. Son said he had enjoyed it. Daughter said "it was boring." According to Mother, Daughter would not share with anyone why she thought I was a murderer. The parents surmised that a younger neighbor friend, who had a vivid imagination, might have planted the idea in her mind, because Daughter had recently said that this girl had told her of a neighbor boy murdering the art teacher with a butcher knife. I pointed out that I was apparently threatening to Daughter because I was focusing on material which Daughter did not want to address. The parents said Daughter had never shown any reaction to the MS until recently. When she became angry or unhappy, she withdrew. Father commented that she was strong-willed, worked hard at everything she did, and had a low frustration tolerance. He added that a kind approach to Daughter's misbehavior only

served to evoke even worse behavior. He agreed professional help was warranted. Although it was a relief to both me and my assistant to leave the hostility of Daughter, there was also a sense of satisfaction because the parents now appeared comfortable discussing their children and the MS.

Family Summary

Family 203 consisted of the mother patient, the father, an 8-year-old daughter, and a 5-year-old son. Both children were born after the diagnosis. Mother was very concerned about the mental health of the children. Father originally appeared suspicious, but this evolved into open concern about the children. Daughter's suspiciousness and anger were magnified during the time spent with the family. Son excitedly cooperated.

The family inventories revealed a low level of hardiness, with a feeling of personal responsibility for the development of problems. Mother believed she was ineffective in her ability to cope, but would not give up or ignore problems. Father was average in his coping ability. Father and Son believed the family was of a favorable type, but Mother and Daughter had a more extreme view of the family.

The individual testing indicated that Daughter was of average cognitive ability, had problems with interpersonal relationships, a very low ability to empathize, and a weak self-concept. Although she could rely on others for

support, and was able to identify problems, she was unable to resolve them. Feelings of rigidity, depression and rejection were all of concern.

Son's individual testing indicated average intelligence, strong socialization, a weak sense of responsibility and dependency, and an average ability to empathize. Son appeared much more emotionally healthy than his sister, but still projected a sense of weakness. He openly shared his fear of the MS, and was relieved after I discussed his concerns. He seemed able to identify and resolve problems. Anxiety and depressive tendencies were above average.

Family 204

Family 204 responded quickly to the third mailing. When contacted to arrange for the initial interview, both parents were very receptive, friendly, and cooperative. They showed great flexibility in arranging appointments. My assistant and I were readily welcomed into their home, on a legal holiday, by the father who had just arrived home from work. The family lives in a modest home within a large metropolis.

Demographics

Family 204 consisted of the mother (the patient), age 42; the father, age 42; and three daughters, ages 15, 14, and 10. Mother was a high school graduate, with a half-year

of college. She said she realized that her career aspirations did not require a college education. Father attended 1 year of college, and basically came to the same realization. They were married in May of 1975. Daughter 1 had just completed grade 10 in a community parochial high school. Daughter 2 had just "graduated" from the eighth grade in a community parochial elementary school. Daughter 3 had just completed the fourth grade in the same elementary school. Mother had worked in her family's restaurant from the age of 12 until 1981, when she decided she needed to stay home with her young daughters. When she left the restaurant she had been managing it full time. Father had been a policeman in the metropolis for 17 years, usually working a 40-hour week.

Diagnosis and Acceptance

Father and daughters were reported as enjoying normal health. Mother's MS was diagnosed in 1974 by a neurologist associated with a large hospital in the city. This was after her family doctor had provisionally diagnosed her and referred her to the hospital. Mother and Father were engaged at the time, and the family doctor chose only to reveal the diagnosis to Father, who passed it on to Mother's parents, who were very angry with him. The diagnosis was not known to Mother until a year later when a neurologist confirmed it. The tests that were run while she was in the hospital were a visual evoked potential, a brain scan, and a

spinal tap. She was told she had a mild case, and "we'll take care of it as it comes along." This family seemed to appreciate the neurologist's initial downplaying of the situation. Mother continues to see this neurologist, who is described by both parents as "wonderful." Mother admitted that at first he seemed cold, but she has found him to be very compassionate. Father would recommend him to anybody.

When asked how they had dealt with the diagnosis, Mother responded that she had begun to think that she was a hypochondriac, and was very defensive once told of her diagnosis. At the time of this interview, she was obviously still perturbed that the diagnosis had been kept from her for that year. Her description of her behavior after diagnosis included irritability, anger, denial, and grief. The anger seemed more directed at the people who had kept the diagnosis from her rather than at the disease; but she did not seem consciously aware of that. She commented "it was hard, but [Father] is strong." Father described the situation with relative ambivalence. The two had known each other 5 years, and the diagnosis had not altered their marriage plans. He admitted he had not expected her to have a chronic illness, but said he was merely surprised, not angry. He admitted "it wasn't hard for me; I didn't have it." At no point did I pick up the anger that comes from being forced into a caretaker role, as MS can require. Mother shared that Father had been a great support. "He

makes me laugh," and she proudly added that he had become very insistent about accessibility in the city.

As already mentioned, Mother's parents were very angry at Father when he told them the diagnosis. They even attempted to break the engagement, but finally accepted the situation. Father's parents never discouraged the marriage. They "went with [him] with the punches." Both Father and Mother claimed a closeness with his parents, in contrast to hers. Mother's and Father's siblings were all emotionally close and accepting. The diagnosis was also eventually shared with their church, his co-workers, and their friends. Mother felt a tremendous support coming from the church. "If I ever need anything, . . . they're really good about providing." Father said there had been no problems with his work, even when called away suddenly to help Mother. Mother painfully discussed how her two best friends had dropped her. They felt she was a burden, and claimed her personality had changed. Her family disagreed with both. "The only people who really give a hoot are family." This comment included their extended families.

As all the daughters were born after the MS diagnosis, their acceptance is best summed up by Daughter 1's comment: "no big deal." They all shared that their friends knew and liked their mother, and did not perceive any problems.

Symptoms and Treatment

Mother's initial symptoms were a total loss of vision

in both eyes, and a loss of feeling in her hands. Her vision and hands improved, but remain damaged. She briefly had "palsy" (probably nystagmus) in her eyes. At the time of the interview, her legs felt heavy and had spasms and twitches, seriously interfering with walking, and necessitating the use of a walker. She described bladder dysfunctions, extreme fatigue, a general slowness, and balance problems. Although medications had been used, Mother was rather ambivalent over their value. She was being considered by her physician to participate in research groups with two experimental drugs.

Assistance

Most of the help that Mother needed was being provided by the daughters and Father. All agreed with Mother's statement that the daughters started helping while very young. None of the girls seemed bothered by this responsibility. Mother's and Father's mothers had also given periodic help.

Mother was receiving no financial assistance, but was included under Father's medical insurance coverage at his work. Mother was using adult protective undergarments. She had gone from a cane, to a four-pronged cane, to the walker. Her gait was rather stumbling and tenuous, appearing as if she could not lift her feet. When out of the house, she was using an electric cart, which had been bought for her by the city, through Father's work. She also had hand controls on

her car. She proudly said she "rides a stationary bike for 30 minutes every other day." The whole family displayed pride in her efforts when she mentioned this.

The family had not sought professional counseling. Mother felt the greatest help came from talking to friends with MS.

Emotional Issues

When asked how the family had changed as a result of the MS, Father answered immediately, "You learn right away that life isn't fair. You do what you gotta do." Mother believed that it had required all of them to make a lot of adjustments. Daughter 1 did not believe that any of these adjustments had been major. Daughter 2 agreed, adding that "there are things that have to be done first," implying caring for Mother before their own needs.

Description of Daughters by Parents

Daughter 1 had been on the Honor Roll during the previous academic year. She had no behavior problems, and had many friends. Father said "she has her own phone book of friends' numbers." Although she had been a cheerleader, she was not involved in any activities around the time of the interview.

Daughter 2 had been on the High Honor Roll "for ever." She also had had no behavior problems. She was described as a homebody and a hard worker. She participated in

volleyball and bowling.

Daughter 3 had been on the Honor Roll also. Her only behavior problem was that she liked to talk too much. Mother said "everybody loves her, and she gets along with everybody." She was involved in basketball and gymnastics.

After the second session, Mother shared some valuable information. Daughter 1 was very peer-oriented and projected an image to her mother that "her turn was up" regarding helping in the house. She was described as the leader of the three girls, even though the younger two would not admit that they followed her lead. Daughter 2 was described as the most responsible, having had babysitting jobs for 2 years. She had been using this money to buy her own clothes, and Mother was very proud of this. However, Mother saw her as an aggravation to her sisters. Father had mentioned privately to me, after the conclusion of the first interview, that Mother and Daughter 2 "are too much alike, and this causes problems." Mother also shared that Daughter 3 did not like school. Mother had overheard the daughters discussing Mother's moodiness and how it was affected by her medicine, making it necessary for them to regulate their behavior so as not to get in trouble.

The Family Tests

The parents and Daughters 1 and 2 responded to all the tests, whereas Daughter 3, due to her age, responded only to FACES-II. Because the house was small, several remained at

the kitchen table to respond to the tests. At times they commented to one another about the tests, without any discussion which could have affected their responses. Table 20 gives the results for each family member.

Family Hardiness Index

Mother and Father differed considerably on their overall FHI percentile rank. Whereas she was well below the average of the norming sample, he was well above. On Coordinated Commitment, the subscale which deals with working jointly and cooperatively, they both scored very well. On each item of this subscale they gave a similar response, with Mother being slightly more positive on a few items. Examining the other subscales, Father viewed the challenges of life more positively than did Mother. Father scored the maximum points possible with his confidence in the family as a unit, whereas Mother did not feel the same level of confidence. Mother felt subject to external forces over which she had very little control, whereas Father had no such feeling (maximum score). Items of interest are delineated in Table 21. Although Mother had seemed to be a very positive person, it did appear as if the family was helping to keep her spirits up. She also felt that she was not doing as much around the home as she believed she should and, therefore, might feel as if she does not deserve appreciation.

Daughters' FHI scores were well above the average, with

TABLE 20

FAMILY 204--FAMILY TESTS

Scale	Subscale	Maximum Score	Patient (Mother)	Spouse (Father)	Daughter 1 Gd. 10.9	Daughter 2 Gd. 8.9	Daughter 3 Gd. 4.9
FHI							
	Coorienting-Commitment	24	22	20	24	23	
	Confidence	12	6	12	11	12	Too
	Challenge	15	6	10	14	11	
	Control-External	9	6	9	7	5	Young
	Total	60	40 (13)[a]	51 (73)	56 (95)	51 (73)	
F-COPES							
	Acquiring-Social Supp.	45	36 (93)[b]	30 (71)	40 (99)	36 (94)	
	Reframing	40	33 (77)	36 (92)	39 (99)	38 (99)	Too
	Seeking-Spirit. Sup.	20	11 (05)	16 (48)	14 (37)	11 (12)	Young
	Mobilizing	20	7 (09)	11 (43)	14 (92)	6 (14)	
	Passive-Appraisal	20	17 (99)	18 (99)	15 (99)	17 (99)	
	Total	145	104 (77)	111 (92)	122 (99)	108 (92)	
FACES-II							
	Cohesion	80	54 (3)[c] z=-1.30	73 (7) z=0.96	65 (6) z=0.96	72 (7) z=1.71	57 (4) z=0.08
	Adaptability	70	55 (7) z=0.77	54 (6) z=0.62	50 (6) z=0.58	55 (7) z=1.22	37 (2) z=-1.06
	Family Type	-	(5)	(6.5)	(6)	(7)	(3)

[a]Numbers in parentheses are percentile ranks from the appropriate norms: One overall norm for total score only. [b]Numbers in parentheses are percentile ranks from the appropriate norms: norms are for adults or adolescents, male or female. [c]Numbers in parentheses are from Linear Scoring Model (figure 2).

TABLE 21

FAMILY 204--SELECTED FHI RESPONSES[a]

	False	Mostly False	Mostly True	True	Not Applic
1. Trouble results from mistakes we make.	Sp		D1	P,D2	
3. Our work and efforts are not appreciated no matter how hard we try and work.	Sp,D1,D2		P		
6. Many times I feel I can trust that even in difficult times things will work out.				All	
7. While we don't always agree, we can count on each other to stand by us in times of need.				All	
8. We do not feel we can survive if another problem hits us.	Sp,D2	D1	P		
12. When our family plans activities we try new and exciting things.		P	Sp,D1, D2		
14. We tend to do the same things over and over...it's boring.	Sp,D1	D2		P	
16. It is better to stay at home than go out and do things with others.	D1		Sp,D2	P	
20. We realize our lives are controlled by accidents and luck.	All				

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

Daughter 2's overall score identical to Father's, and Daughter 1's even higher. Just as the parents, they believed the family worked jointly and cooperatively, with Daughter 1 scoring maximum and Daughter 2 dropping only 1 point. Daughter 2 indicated a maximum degree of confidence in the family as a unit, whereas Daughter 1 dropped 1 point. Daughter 1 viewed the challenges of life in a more positive manner than did Daughter 2, but both were more positive than the parents. Daughter 2, like Mother, felt more controlled by external forces than did Daughter 1, who was more like Father. Daughter 1's responses seem to reflect her adolescent independence.

Family Crisis Oriented
Personal Scales

On the Family Crisis Oriented Personal Scales, Father continued to demonstrate a stronger coping ability than Mother's, although both are well above average in the overall score. Table 22 shows the items with responses of interest. Both parents scored extremely high in their ability to face problematic issues while minimizing reactivity. Both parents successfully acquired social support, with Mother doing so to an even greater extent than Father. Father appeared to be willing to share with relatives, but not close friends; and was willing to seek advice, but not pity, from relatives. Although Mother's responses indicated an above average ability to redefine

TABLE 22

FAMILY 204--SELECTED F-COPES RESPONSES[a]

	Strongly Disagree	Moderate Disagree	Neither	Moderate Agree	Strongly Agree
1. Sharing our difficulties with relatives.					All
5. Seeking advice from relatives.					All
7. Knowing we have the strength within our own family to solve our problems.					All
8. Recieving gifts and favors from neighbors.	P,Sp	D2		D1	
9. Seeking information and advice from the family doctor.		D2		P,Sp,D1	
10. Asking neighbors for favors and assistance.		P,Sp		D1,D2	
11. Facing the problem "head-on" and trying to get solution right away.					All
15. Accepting stressful events as a fact of life.	P			D1	Sp,D2
16. Sharing concerns with close friends.		Sp		P,D2	D1
17. Knowing luck plays a big part in how well we are able to solve family problems.	P,Sp	D2	D1		
21. Seeking professional counseling and help for family difficulties.	P,D2		Sp	D1	
22. Believing we can handle our own problems.				P,Sp,D2	D1
24. Defining the family problem in a more positive way so that we do not become too discouraged.				P,Sp,D2	D1
25. Asking relatives how they feel about problems we face.		Sp		P	D1,D2
26. Feeling that no matter what we do to prepare we will have difficulty handling problems.	Sp,D1,D2			P	
28. Believing if we wait long enough the problem will go away.	P,Sp,D2	D1			
29. Sharing problems with neighbors.	P,Sp,D2		D1		
30. Having faith in God.					All

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

stressful events in order to make them more manageable, Father's responses indicated an even greater ability. On the other two subscales, Father scored near average, but Mother very low. These are "Seeking Spiritual Support" and "Mobilizing Family to Acquire and Accept Help." Although they both strongly agreed that their faith in God was important to their coping ability, to the other three items relating to spiritual support Father responded neutrally, whereas Mother was very negative. This same difference occurred on two of the items of the mobilizing subscale. They both would not be comfortable receiving gifts and favors from neighbors but were willing to seek information and advice from the family doctor.

Daughters 1 and 2 were both extremely high in their total score when compared to other female adolescents, with Daughter 1 slightly higher. Just like their parents, they both scored extremely high in their ability to face problematic issues while minimizing reactivity. All the responses on this subscale were close. Like their parents again, both daughters successfully acquired social support, with Daughter 1 doing so to a slightly greater extent than Daughter 2. There were no significant differences between the daughters' responses to any of the items on this subscale.

There were two items to which they completely agreed with both parents. These were numbers 1 and 5. On a

further two items, the daughters completely agreed with each other, but disagreed with one or both parents.

Both daughters had an extremely strong ability to reframe stress to make it more manageable. On item 15, their responses were close to Father's, which was in opposition to Mother's. The entire family strongly agreed with items 7 and 11. Daughter 1 seemed to believe that the family had an exceptional ability to mobilize to acquire and accept help. Daughter 2, in contrast, showed little confidence in this ability. With three of the four items on this subscale, Daughter 1 moderately agreed, whereas Daughter 2 moderately or strongly disagreed. On item 8, Daughter 2 responded similarly to the parents, whereas on item 9 it was Daughter 1 who was similar. With "Seeking Spiritual Support," both daughters were below average, with Daughter 2 being more so. Daughter 1 tended to be neutral, whereas Daughter 2 tended to be negative, except that both, like their parents, indicated a strong faith in God.

Family Adaptability and Cohesion Evaluation Scales-II

The entire family responded to the Family Adaptability and Cohesion Evaluation Scales. Although the parents and the two older daughters believed that their family type was moderately balanced to balanced, Daughter 3 believed they were in the mid-range. She reached this point through responses that placed her family's Cohesion as separated and

its Adaptability as rigid. Mother agreed that the family was separated on the Cohesion dimension; but she saw their Adaptability as very flexible. Daughter 2 also had them very flexible on the Adaptability dimension, whereas Daughter 1 and Father believed they were flexible. On the Cohesion dimension, Father and Daughter 2 saw the family as very connected, whereas Daughter 1 saw them as connected.

Table 23 delineates items worthy of note. The responses to items 10 and 20 are an example of Daughter 3's position in the family, where Daughter 1's "turn was up" and Daughter 2 was becoming the primary source of Mother's help. It is important to point out that Daughter 3's responses to items 3 and 19 were in contrast, whereas the responses of other family members are consistent. It appears that, although Daughter 3 felt close to other people, she would discuss problems only with her family members.

All five family members gave identical responses to two items, items 1 and 28. Daughter 3's conflicting responses to items 14 and 28 seem to suggest that she was not afraid to say what is on her mind, but rarely actually did so.

Mother stood in contrast to the other four family members on three items of interest, numbers 17, 25 and 30. These seem to indicate that Mother felt a sense of isolation, even within the home.

TABLE 23

FAMILY 204--SELECTED FACES RESPONSES[a]

	Almost Never	Once in Awhile	Some-times	Freq-uently	Almost Always
1. Family members are supportive of each other during difficult times.					All
3. It is easier to discuss problems with people outside the family than with other family members.	D2,D3	D1	P,Sp		
10. We shift household responsibilities from person to person.		D3			P,Sp, D1,D2
14. Family members say what they want.	D3			D1	P,Sp, D2
17. Family members feel very close to each other.			P		Sp,D1, D2,D3
19. Family members feel closer to people outside the family than to other family members.	Sp,D2	P,D1			D3
22. In our family, everyone shares responsibilities.	D3				P,Sp, D1,D2
25. Family members avoid each other at home.	Sp,D1, D2,D3				P
28. Family members are afraid to say what is on their minds.	All				
30. Family members share interests and hobbies with each other.	P			D1,D3	Sp,D2

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

Individual Testing of Daughters

When my assistant and I returned for the second session, Daughter 2 answered the door with a warm greeting. Mother was available during the testing, but isolated herself in the bedroom so as not to disturb the testing. I was shown to the kitchen, while the assistant worked in the living room. All the daughters and Mother were suffering from summer colds, but were very agreeable and cooperative.

The school principal reported an IQ of 116 (Cognitive Skills Index of the California Achievement Test) for Daughter 1.

Vineland Adaptive Behavior Scale

Daughter 2's Vineland was returned from the elementary school from which she had just graduated at the time of the interview. Although her age was 1 year beyond the norms, some interesting information was gleaned from the results. Her teachers felt that her socialization (117) and daily living skills (116) were above her chronological age, using age equivalent norms. Communicative skills (106) demonstrated a weakness in the receptive area, whereas the expressive and written were above age level. In the comments section, the teachers described her strengths as responsibility, consideration, perseverance, and carefulness. Her weaknesses were identified as being easily annoyed and subject to losing her temper. They believed she

has the special characteristic of setting high work standards.

Daughter 3's Vineland was not returned within the expected time period. Since Daughter 2's had been returned quickly, and was from the same school, a call was made to the school to ensure that the school had not lost Daughter 3's Vineland. This was the only time some difficulty was experienced with an elementary school, as the teacher feigned ignorance. When I discovered that the present principal had been the teacher who had filled out Daughter 2's Vineland, I spoke with her and was assured that, if I sent a new Vineland, it would be returned promptly. Unfortunately, it was not returned until after I had contacted Mother to enlist her aid. Daughter 3's teacher felt that her socialization skills were adequate for her age (103), her daily living skills were superior (128), but her communication skills were below average (85). Overall adaptive behavior was seen as adequate (105). Within the Socialization domain, her play and leisure time sub-domain was her strength. Within the Daily Living Skills domain, personal and community sub-domains were moderately high, and her domestic was even higher. Within the Communication domain, expressive was seen as adequate, but written was moderately low and receptive was even lower. In the teacher's comments, she shared that Daughter 3 was friendly, but seemed to have low self-esteem. The teacher was

concerned that she constantly questioned and seemed unsure of what to do in class. This information suggests that Daughter 3 might benefit from testing for a language learning disability.

Table 24 gives the results of the daughters' objective testing.

Empathy scales

The two older girls were administered the Emotional Empathetic Tendency Scale and the youngest, the Index of Empathy. On the appropriate norms, Daughters 1 and 3 reflected a well above average ability to empathize, whereas Daughter 2 a less than average ability.

Survey of Interpersonal Values

On the Benevolence subscale of the SIV, all three daughters scored well above average, suggesting highly developed senses of altruism. Daughter 2 scored the highest, in contrast to her below average sense of empathy.

On the rest of the survey, the daughters' scores reflected considerable differences. On the subscale which measures the value of Feeling Supported, Daughter 2 scored above average, whereas Daughters 1 and 3 were below average. On the measure of the value of Conformity, Daughters 1 and 3 were above average, whereas Daughter 2 was low average. On the measure of the value of Receiving Recognition, Daughter 1 was low average, Daughter 3 below

TABLE 24

FAMILY 204--CHILD TESTS

Scale	Subscale	Maximum Score	Daughter 1 Gd. 10.9	Daughter 2 Gd. 8.9	Daughter 3 Gd. 4.9
EMPATHY			M[a] 72 z=1.33	M 37 z=-0.33	B4 17 z=1.00
PIERS-HARRIS	Behavior	16	16 (95)[b]	16 (95)	13 (51)
	Intellect	17	13 (60)	15 (81)	13 (60)
	Physical	13	12 (91)	13 (97)	10 (73)
	Anxiety	14	7 (26)	12 (81)	12 (81)
	Popularity	12	8 (38)	10 (69)	11 (86)
	Happiness	10	10 (90)	10 (90)	10 (90)
	Total Scale	80	62 (74)	69 (91)	67 (87)
SIV					
	Support	45	**[c] 14 (26)[d]	* 21 (73)	** 14 (39)
	Conformity	45	21 (76)	15 (42)	16 (63)
	Recognition	39	12 (45)	6 (07)	9 (35)
	Independence	48	8 (14)	8 (14)	12 (47)
	Benevolence	45	25 (83)	29 (97)	23 (82)
	Leadership	48	10 (45)	11 (52)	16 (89)

[a]M = Mehrabian overall norms with score range = -132 to +132. B4 = male or female norms for Grade 4 on Y/N Bryant Scale, range = 0-22. [b]Figures in parentheses are percentile ranks for the complete norming population. [c]** = Grade 9 vocational norms, male or female; * = Grade 11 and 12 norms, male or female. [d]Figures in parentheses are percentile ranks for the appropriate norms.

average, and Daughter 2 well below average. The two older girls appear to value Independence less than would be expected for adolescents, possibly as a reflection of their sense of responsibility to the family. The youngest scored average on this subscale. Daughter 3 valued Leadership much more than her siblings, with her score being much above average and theirs average.

Piers-Harris Children's Self-Concept Scale

All three girls had a positive self-concept. The profiles of their scores from the Piers-Harris Children's Self-Concept Scale are included in appendix D. Daughter 1 was average on two subscales, Freedom from Anxiety, and Popularity; and above average on Behavior, Physical Appearance and Attributes, Happiness and Satisfaction, and Intellectual and School Status. Daughter 2 was well above average on all six subscales. Daughter 3 was just above average in Behavior, and Intellectual and School Status, with the other subscales well above average. This appears to be in opposition to the teacher's observation of low self-esteem. The teacher may be picking up Daughter 3's discomfort in the classroom, particularly if she does have an undiagnosed learning disability.

Projective tests

The daughters were very friendly and cooperative, but not very verbal. Daughter 1's HFD demonstrated some

artistic ability, although she claimed to have little such ability. The emotional indicators suggested rigid inner control, concern about her personal strength, and discomfort about impending sexuality. Daughter 2's HFD reflected difficulty reaching out to others, a desire to inhibit impulsive behavior, and discomfort similar to her sister's over impending sexuality. Daughter 3's HFD was very small, but detailed. She seemed out of balance, insecure, and impulsive.

Daughter 1's KFD had the family watching television together. She asked to be allowed to draw them standing, as she claimed she could not draw chairs. They were lined up stiffly, not relating to each other. Only Daughter 3 was actually watching the television, and Mother seemed to be turning away from the rest of the family. Daughter 1 seemed to believe that she and her siblings were closest to their father. This seems to support Mother's feeling of isolation as reflected by the family tests.

Daughter 2 also drew the family watching television, but organized the family in a more effective stance for relating. However, Daughters 1 and 2 were sitting on the couch on either side of Father in a close threesome. The couch gave them an insulated, separated look from the rest of the family. Mother was to their right in her chair, looking away from them and the television, just as Daughter 1 depicted her. Daughter 3 was lying on the floor "like she

usually does," in a position preventing her from watching television.

It is not surprising that Daughter 3's KFD has the family watching television together, on one couch. It is interesting to note that she was the only one to draw something on the television for them to watch. Whereas her sisters had drawn the family members in positions where it was difficult to relate to one another, she had them reaching out for each other. A concern about body weakness was evident. She gave herself the remote control, suggesting a need or desire for her to control the family.

Daughter 1's responses, throughout the RATC, were short, but generally complete. The Adaptive scale showed at least an average ability to cope with aversive situations. She demonstrated an average ability for her age to identify problems and to resolve them. She seemed to over-rely on others, yet she indicated an average sense of self-sufficiency. She had an above-average ability to support others. The Clinical scale indicated a very high level of anxiety and a level of depression slightly above average. Daughter 2 experienced difficulty developing stories, yet she demonstrated an average ability to identify and resolve problems. An extremely high limit-setting score suggests that she may be overly concerned about pleasing authority figures or conforming to social expectations. Her tendency to support others was average, whereas her self-sufficiency

was above average. The Clinical scale revealed above average aggressive tendencies. Daughter 3's RATC stories seemed to ramble, and she experienced difficulty identifying and resolving problems and, in fact, gave two unexpected maladaptive responses. The Adaptive scale suggested above average limit setting, and average reliance on others, supporting others, and self-sufficiency. The only subscale of the Clinical scale which was in the average range is Aggression. Her anxiety, depression, and feelings of rejection were abnormally high. The profiles of daughters' RATC scores are included in appendix E.

When the testing was completed, all present sat in the kitchen and talked, joking about family foibles, as they told little stories about one another. No one seemed offended or defensive.

Exit Interview

When my assistant and I returned for the final interview, we were welcomed back into the home as though we were old friends. The family was slow assembling, because Daughter 3 was receiving tutoring from a cousin. Father began the conversation with his belief that this research was a "good thing." Mother commented that no problems had occurred due to the focusing on her MS. The family had, however, discussed various relationships seemingly as a result of their involvement in the research. Mother shared that they had decided that Daughter 1 was emotionally

closest to Father, and Daughter 3 was closest to Mother. Daughter 2 did not seem to have a direct identification but was described as the quietest and the strongest of the three. Mother added that all of her girls were very caring. She felt it was important for me to know that Father, with 18 years' service in the police department, had remained a patrolman rather than accepting promotion, so that he would be available for Mother and the girls. Father modestly agreed, saying his family was most important to him. One of his final comments was very important: "You can't do anything about the physical, but you can the mental." This certainly exemplified his "cheerleading" role in the family.

As it became time to leave, everyone seemed to experience difficulty saying goodbye. The family hoped that my assistant and I would keep in touch. Father and Daughter 2 walked us to our van, and continued to talk, mostly about an experimental medication which Mother hoped to take.

Family Summary

Family 204 consisted of the mother patient, the father, and three daughters, age 15, 14, and 10. All the children were born after the diagnosis. This was a warm, open family, each member being willing to share his or her problems. It was obvious that Mother and Daughter 1 were very close, and Father and Daughter 2 were very close. However, there was friction between Mother and Daughter 2. Daughter 3 did not seem connected with any family member,

but was clearly loved by all.

The family tests suggested that, although the parents believed they worked jointly and cooperatively, Father was more positive than Mother about the family hardiness. Daughters 1 and 2 had confidence in their family. All four possessed a strong coping ability, primarily in facing problematic issues while minimizing reactivity. All five considered their family to be of a favorable type.

Individual testing indicated that Daughters 1 and 2 were of above average cognitive ability, whereas Daughter 3 appeared average. All three had a positive self-concept. Daughter 1 reflected a well-developed ability to empathize, and a highly developed sense of the value of altruism. Possibly due to her sense of responsibility to the family, her value system did not seem to be developing consistently. She demonstrated an average ability to identify and resolve problems, and to cope with aversive situations. She appeared very anxious, with mild depressive tendencies. She seemed to view her family as rigid in their relationships to one another. Daughter 2 reflected a less than average ability to empathize, but a highly developed sense of the value of altruism. Her value system did not seem to be developing consistently either, possibly for the same reason as in the case of her older sister. She demonstrated an average ability to identify and resolve problems, with very strong self-control. Considering there were indications of

aggressive tendencies, her motivation to inhibit her behavior was very positive. She viewed her family as relating in a positive manner. Both Daughters 1 and 2 reflected normal discomfort over their impending adolescent sexuality. Daughter 3 reflected a well-developed ability to empathize, and a highly developed sense of the value of altruism. Her value system seemed to be developing in the healthiest manner. She seemed to have trouble identifying and resolving problems, resulting in high levels of anxiety, depression, and feelings of rejection. She appeared to be insecure and to believe the family members needed more support from each other.

Family 205

Family 205 responded to the first mailing from the metropolitan clinic. The mother had to be contacted at her place of work, because the father, who had the MS, had experienced severe speech problems. Appointments were somewhat difficult to set up because of the mother's long hours and the two adolescent sons' responsibilities outside the home. The family lived in a fairly new split-level home, which they were in the process of selling in order to move into a single-level home. Both homes were in a pleasant suburb of the large metropolis.

Demographics

Family 205 consisted of the father (the patient), age

44; the mother, age 39; and two sons, ages 15 and 16. Father had 3 years of college study in business management and had always been self-employed in real estate and sales. After the diagnosis, Father gradually reduced his hours of work, eventually ceasing work completely about 3 years prior to the interview, due to the rapid degeneration. Mother had studied business in college for 2 years. She was the manager of the local branch of an in-home health-care service, working 55 hours per week. The couple was married in October 1971. Son 1 had just finished the 11th grade in the local public high school. Son 2 had just completed the ninth grade in the same high school.

Diagnosis and Acceptance

Mother and sons were reported as enjoying good health. Father's MS was diagnosed in 1985, when he was referred to a neurologist due to the vision problems he was experiencing. The neurologist had been a friend of one of Father's friends. An MRI and "brain mapping" were completed, because "I was not thinking straight." Father was "put off" by the neurologist to another doctor to be informed of his diagnosis. Father's mother had had MS for 30 years, and died in 1989 from complications. This seemed to be the reason the neurologist had been unable to tell Father that he had also developed MS. There was no support from either of the physicians. Father felt he had not suffered by being given the diagnosis. Later in the interview, however, he

made it clear that he had immediately stopped going to church, although he had been religious prior to the diagnosis. Mother said the diagnosis had not bothered her at first, because "he was fine, except he couldn't see well." She admitted that she was not doing as well at the time of the interview. Father's deterioration is discussed under symptoms.

Although the sons were 9 and 7 years old at the time of the diagnosis, they claimed that neither could remember Father before. Mother told Son 1 of the diagnosis; but Son 2 came to know of it only by overhearing.

The only other persons with whom the diagnosis was initially shared were Mother's parents. Father's father had been dead since 1970, and it was never shared with his mother. They even hid Father's symptoms from her when visiting her in the nursing home, in order to avoid causing her to "suffer guilt."

Father said that Mother's parents showed "no emotion whatsoever" when they were told of his diagnosis. Mother was very defensive, and asked Father, "How do you know that's true?" Father retreated from his position a little by responding that it had been close to it. Her parents apparently had not discussed it at that time. Mother and Father did agree that her parents had eventually become supportive.

Siblings were told only as Father's condition

deteriorated. Father's siblings, on the whole, had been resentful of their mother's MS. The brother had been fully responsible for her care, and one sister never dealt with it because she lived some distance away. The younger sister is a physician, and allowed her studying to distract her from emotionally dealing with their mother's MS; but she did help the brother with her care. Father believed that they were all "burned out" in some fashion by their mother, and therefore did not recognize and accept his MS. He felt close to his brother, who had been a good support for everything except the MS.

Mother was the oldest in her sibling group, having felt emotionally distanced from her brother and sister. However, her sister seemed to deal well with Father's MS, and had been very helpful to the family. As an afterthought, Mother added that one of Father's aunts (his mother's sister-in-law), had noticed Father's speech and walking problems, and worried about alcohol. Mother had assured her it was MS, not alcohol. The aunt had become very upset.

Because Father was self-employed, he was able to adjust his schedule as necessary for his condition. Mother had "never used it [Father's MS] as a sympathy vote. I view it as a negative for my job." So she had never even mentioned it at work. They had not shared the diagnosis with their church by the time they stopped attending.

When questioned about whether friends had been told,

Father became very emotional, as he had during the discussion of his mother. Mother commented "this [the MS] draws a fine line between friends and acquaintances," who apparently stopped being available to the family. She continued that "most have just not gotten used to it." They had one very caring neighbor, whom they discussed, and one friend. Father shared that "people talk to [Mother] about me when I'm there," obviously feeling hurt by these occurrences.

Emotional Issues

It is important to point out body language that was observed during this interview, which further indicated how the family members felt about, and responded to, one another. Father was seated in an easy chair, separate from the L-shaped couch. The sons were both seated on the couch when my assistant and I sat down near them. Mother joined the group and sat next to Son 2. Fairly early in the interview, Son 1 got up to throw away Father's tissues, which had been used to wipe his drool. He then placed himself on stairs between Father and Mother. Through the rest of the interview, he seemed to be watching Father, so he could help him when needed. Apparently, Son 1 was also watching Mother, because he caught a spider that had been bothering her. When Father had to use the bathroom, both sons came to his aid, as he was incapable of walking.

Symptoms and Treatment

As already discussed, Father's initial symptoms were mild visual problems and some cognitive difficulties. For the next 5 years, Father apparently was stabilized. Over the 3 years prior to the interview, he deteriorated rapidly, and was diagnosed as in the progressive deterioration condition. He had started by dragging his left leg, and had reached the point of no leg control. Speech was very slurred and dysarthric, but still mostly intelligible. He was suffering from swallowing problems and poor bladder and bowel control. Everyone agreed the cognitive deterioration had been slower.

When asked about the various medications which had been tried, Father commented, with apparent satisfaction, "My doctor will try anything." He then listed various medications which had been tried, expressing frustration at their uselessness. He also was hospitalized once a year for a "tune-up," when his physician "blasts me with drugs."

Assistance

As Father's condition deteriorated, assistance became necessary. For a while, Son 1 had to come home at lunch to get Father's meal and to check on him. Son 2 would come home right after school to give Father a shower. Both boys believed they "had to stay around a lot" for Father's sake. Within the year prior to the interview, Mother had managed to "convince" the Department of Rehabilitation to pay for a

certified nurse's assistant to come into the home for 4-1/2 hours per day, Monday through Friday. This man took care of Father's lunch, shower, dressing, and moving out of the bedroom. All of the family members demonstrated appreciation, not only of the help, but of the young man personally. Father received Social Security disability payments and had Medicare because of his early disability. Father had used a succession of mobility aids, starting with a cane, then a walker, and finally a manual wheelchair which he eventually could not push himself. He was unable to transfer (such as from bed to chair) by himself, and was often carried, such as to the bathroom. When the sons did this during the interview, his dead weight caused his feet to drag across the floor.

There had been no drug or alcohol misuse in the family. No counseling had been sought outside of the family. Mother believed that "we counsel each other." Yet, later in this interview, Mother said Father "is not one to talk," and had a tendency to get depressed.

It was obvious to my assistant and me that Father's emotional control had been affected by the MS. Although, generally, his laughing and crying were at appropriate times, the intensity seemed exaggerated. Mother added that they scream and slam doors all over. It appeared from the son's body language that she was discussing herself only.

Family Changes

Mother was very quick to respond to the question of how the family had changed as a result of Father's illness. Their tempers had all become very short, and they easily became annoyed by Father and his many requests. Mother thought that, since the onset of his MS, Father's priorities had changed, and everything had become a big problem. She bluntly reported that Father calls her at work "about real stupid things," and "likes to cause trouble." When I asked if Father's changes might be due to his confinement to the home, Mother reluctantly agreed. Mother also focused on Son 1, whom she felt was very irritable, with a short fuse.

Description of Sons by Parents

Son 1 had a GPA of 4.2 on a 5.0 scale. He had the best sense of humor in the family, according to Mother, and was "a joy to have in the classroom." Son 2 added "all he does is goof off." Son 1 said, "Mom picks on me." Mother believed Son 1 was very popular and had lots of friends, yet he did not bring them home. Son 1 added, in a teasing manner, "Women are a liability."

Son 2's GPA was 4.9. Mother described him as nice, polite, and a gentleman who never got into trouble. Her statement that he was particularly popular with girls caused him to blush. He apparently tried to invite friends over, but "they tried not to stay." Father added that both boys

were extremely helpful and "good kids."

The Family Tests

All the family members responded to all the tests. Because of Father's spasticity, my assistant read the questions to Father and recorded his answers. Table 25 gives the results of each family member on each of the three tests.

Family Hardiness Index

Father's and Mother's FHI scores were both well above the average of the norming sample. Reviewing the individual factors, Father had more confidence in the family than did Mother. Mother scored slightly higher than Father on approaching the challenges of life in a positive manner and on not feeling subject to external forces over which they have little control. Both scored extremely high in their beliefs that they are mutually strong.

A comparison of their responses to individual items is interesting. Table 26 shows the items of interest. Mother's answers refuted the influence of luck, whereas Father accepted it. Similarly, Mother believed that trouble results from mistakes we make, whereas Father did not. Even with Father's homebound, dependent life, he seems to see more meaning in life than Mother. There were nine items on which the parents totally agreed with each other. Most of these related to the family working things out together.

TABLE 25

FAMILY 205--FAMILY TESTS

Scale	Subscale	Maximum Score	Patient (Father)	Spouse (Mother)	Son 1 Gd. 11.9	Son 2 Gd. 9.9
FHI						
	Coorlented-Commitment	24	23	24	20	21
	Confidence	12	12	6	12	12
	Challenge	15	11	14	12	13
	Control-External	9	5	7	9	6
	Total	60	51 (73)[a]	51 (73)	53 (84)	52 (80)
F-COPES						
	Acquiring-Social Supp.	45	15 (<10)[b]	30 (65)	19 (12)	37 (96)
	Reframing	40	36 (92)	33 (77)	30 (62)	39 (99)
	Seeking-Spirit. Sup.	20	6 (<7)	6 (<5)	4 (<9)	7 (<9)
	Mobilizing	20	7 (11)	8 (13)	6 (11)	9 (37)
	Passive-Appraisal	20	14 (97)	16 (99)	15 (99)	15 (99)
	Total	145	78 (11)	93 (40)	74 (09)	107 (88)
FACES-II						
	Cohesion	80	60 (5)[c] z=-0.58	71 (7) z=0.73	50 (2) z=-0.68	56 (4) z=-0.03
	Adaptability	70	45 (4) z=-0.74	58 (7) z=1.23	50 (6) z=0.58	55 (7) z=1.22
	Family Type	-	(4.5)	(7)	(4)	(5.5)

[a]Numbers in parentheses are percentile ranks from the appropriate norms: one overall norm for total score only. [b]Numbers in parentheses are percentile ranks from the appropriate norms: norms are for adults or adolescents, male or female. [c]Numbers in parentheses are from Linear Scoring Model (figure 2).

TABLE 26

FAMILY 205--SELECTED FHI RESPONSES[a]

	False	Mostly False	Mostly True	True	Not Applic
2. It is not wise to plan ahead and hope because things do not turn out anyway.	P,S1, S2	Sp			
3. Our work and efforts are not appreciated no matter how hard we try and work.	P,S1,S2	Sp			
4. In the long run,the bad things that happen to us are balanced by the good things that happen.				All	
5. We have a sense of being strong even when we face big problems.				All	
6. Many times I feel I can trust that even in difficult times things will work out.			S1	P,Sp, S2	
7. While we don't always agree, we can count on each other to stand by us in times of need.				All	
8. We do not feel we can survive if another problem hits us.	P,S1,S2	Sp			
10. Life seems dull and meaningless.	P,S1,S2			Sp	
11. We strive together and help each other no matter what.				All	
12. When our family plans activities we try new and exciting things.		S1	P,Sp, S2		
13. We listen to each other's problems, hurts and fears.		S1	S2	P,Sp	
14. We tend to do the same things over and over...it's boring.	All				
17. Being active and learning new things are encouraged.			P	Sp,S1, S2	
18. We work together to solve problems.			S1,S2	P,Sp	
20. We realize our lives are controlled by accidents and luck.	Sp,S1, S2		P		

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All= All family members.

Both sons scored even higher than the parents on the total scale. The only factor on which they disagreed was the control by external forces, where Son 2 feels some of this control, but Son 1 felt none. They both scored very high on the other three factors. Examination of the response pattern reveals five items on which all family members agreed, four on which the two sons agreed with Father, and two on which they agreed with Mother. When the sons disagreed with each other, Son 1 varied more from the family. Two of the items on which the family were in complete agreement are items 4 and 7.

Family Crisis Oriented Personal Scales

Father's overall score on the Family Crisis Oriented Personal Sales indicated low problem-solving abilities. Although Mother's responses indicated a higher ability, it was still low average. Both parents effectively accepted the problematic issues which faced them, minimizing reactivity. Whereas both parents' responses indicated strong ability to redefine stressful events in order to make them more manageable, Father's responses suggested greater effectiveness in doing so. The item on this factor to which their responses were most different was number 19, "Accepting that difficulties occur unexpectedly." Father answered "Strongly agree," whereas Mother strongly disagreed. Neither parent believed that their strength or

support came from their spiritual beliefs. Mother did not even feel she had faith in God, whereas Father was not sure. Mother utilized social support as a coping skill, whereas Father, understandably, saw little value in this. In relation to this factor, neither parent was inclined to share difficulties with relatives or to seek advice from them; however, Mother was very willing to ask for their opinion. Table 27 delineates the responses to the items of interest. They both responded well below average on the subscale which involved mobilizing the family to acquire and accept help. This seemed to reflect their confidence in the family's own ability to effectively cope as a unit, as shown on the FHI.

Son 2 indicated very strong problem-solving attitudes. Son 1, however, was more comparable to Father. Just as their parents, their most effective coping mechanism was accepting problematic issues, minimizing reactivity. Two of the items in this subscale are of particular interest, items 17 and 26. Whereas the responses of Son 1, like Mother's, indicated an above average ability to redefine stressful events to make them more manageable, Son 2's responses, like Father's, indicated an even greater effectiveness to do so.

Like their parents, the two sons did not see seeking spiritual support as an effective coping mechanism. Son 1, like Mother, did not feel he has faith in God, but Son 2 was moderately sure. Although, like their parents, they both

TABLE 27

FAMILY 205--SELECTED F-COPES RESPONSES[a]

	Strongly Disagree	Moderate Disagree	Neither	Moderate Agree	Strongly Agree
2. Seeking encouragement and support from friends.		Sp		P,S1	S2
3. Knowing we have the power to solve major problems.					All
13. Showing that we are strong.		S1		Sp	P,S2
14. Attending church services.	All				
16. Sharing concerns with close friends.	P			S1,S2	Sp
17. Knowing luck plays a big part in how well we are able to solve family problems.	S1	Sp	P	S2	
21. Seeking professional counseling and help for family difficulties.	All				
23. Participating in church services.	All				
25. Asking relatives how they feel about problems we face.	P,S1			S2	Sp
26. Feeling that no matter what we do to prepare we will have difficulty handling problems.	S1,S2		Sp	P	
27. Seeking advice from a minister.	All				
29. Sharing problems with neighbors.	P,S1			S2	Sp

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

scored below the average on mobilizing the family to acquire and accept help, Son 2 was considerably closer to the average than the others. The subscale where the sons demonstrated greatest disagreement was in acquiring social support. Son 2 clearly saw this as a beneficial coping mechanism, whereas Son 1, like Father, saw little value in it. Son 2 seemed more comfortable than any other family member in turning to relatives for support.

Of the 30 items, the family was in total agreement on only 5, as indicated in Table 27.

Family Adaptability and Cohesion Evaluation Scales-II

The family's scores on the Family Adaptability and Cohesion Evaluation Scales-II indicated that Father saw their family type as on the boundary between mid-range and moderately balanced; Mother believed it was balanced; Son 1 believed it was mid-range; and Son 2 rated it as moderately balanced. Even though these four types are very similar, the family members reached these points through very different responses to the two dimensions. Father had them connected on the Cohesion dimension, and structured on Adaptability. Mother had them very connected and very flexible. The sons varied from their parents markedly on the Cohesion dimension, with Son 1 believing they were disengaged and Son 2 believing they were separated. They were closer to Mother on the Adaptability dimension, with

Son 1 rating them as flexible, and Son 2, as very flexible.

By examining the individual responses, one is able to see individual and family patterns of interest. Table 28 shows the items of interest. Father stands alone on item 6. Mother stands alone on item 20. Son 1 stands alone on item 8. On item 24, Father and Son 1 agree with each other, whereas Mother and Son 2 agree with one another. There were three items on which the family members completely agreed with one another, as shown in Table 28.

This test seems to indicate that Son 1 was beginning to separate from his family in appropriate adolescent manner. This separation had been evident throughout the first session, as he physically separated himself on the steps during the interview, and then even farther while completing the family inventories. He went to the kitchen, on a separate level, and stood at a counter, while everyone else remained seated on the lower level. Although Son 2 was also an adolescent, he apparently felt more responsibility in the home, and continued to accept that tie to the family. Father's surprisingly positive responses to the family tests as a whole seem in contradiction to his apparent submission to the MS. He may be experiencing MS-induced mania, which can occur in deteriorative forms of the disease.

Individual Testing of Sons

The high school which the boys attended returned the letters requesting the latest IQ standard score with the

TABLE 28

FAMILY 205--SELECTED FACES RESPONSES[a]

	Almost Never	Once in Awhile	Some-times	Freq-uently	Almost Always
6. Children have a say in their discipline.	P			Sp,S1, S2	
8. Family members discuss problems and feel good about the solutions.		S1		P,Sp, S2	
12. It is hard to know what the rules are in our family.	All				
13. Family members consult other family members on personal decisions.		P,S1	S2	Sp	
17. Family members feel very close to each other.		S1		P,S2	Sp
20. Our family tries new ways of dealing with problems.	P,S1 S2			Sp	
24. It is difficult to get a rule changed in our family.	Sp,S2		P,S1		
28. Family members are afraid to say what is on their minds.	All				
29. Family members pair up rather than do things as a total family.	All				

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

comment "Is not available." I have no doubt that, since both were in advanced classes and had consistently received high grades, both were of at least above average intelligence. They both also may have over-achieving tendencies.

When my assistant and I returned for the second session, the sons were at home with Father, who remained in his bedroom until his nursing assistant arrived. At that time, he was moved to the patio, but did not interrupt the testing. Table 29 gives the results of the sons' objective tests.

Empathy scale

Both boys were administered the Mehrabian Emotional Empathetic Tendency Scale. Although both scored near the middle of the possible range of scores, this was well below the mean of the male norming population.

Survey of Interpersonal Values

On the Benevolence subscale of the Survey of Interpersonal Values, both sons scored well above average, with Son 1 higher. This demonstrated highly developed senses of altruism. On the rest of the survey, the sons' scores reflected some considerable differences. Neither valued Leadership or Independence, which is surprising for adolescents. On the value of Conformity, Son 1 was above average, whereas Son 2 was well below average. On the value

TABLE 29

FAMILY 205--CHILD TESTS

Scale	Subscale	Maximum Score	Son 1 Gd. 11.9	Son 2 Gd. 9.9
EMPATHY			M[a] 3 z=-0.91	M -1 z=-1.09
PIERS-HARRIS	Behavior	16	16 (95)[b]	16 (95)
	Intellect	17	17 (98)	16 (90)
	Physical	13	11 (84)	13 (97)
	Anxiety	14	12 (81)	14 (97)
	Popularity	12	10 (69)	11 (86)
	Happiness	10	9 (72)	10 (90)
	Total Scale	80	69 (91)	74 (97)
SIV				
	Support	45	**[c] 16 (55)[d]	* 25 (96)
	Conformity	45	19 (70)	9 (17)
	Recognition	39	11 (37)	19 (88)
	Independence	48	9 (11)	7 (06)
	Benevolence	45	25 (94)	18 (69)
	Leadership	48	10 (26)	12 (38)

[a] M = Mehrabian overall norms with score range = -132 to +132. [b] Figures in parentheses are percentile ranks for the complete norming population. [c] ** = Grade 9 vocational norms, male or female; * = Grade 11 and 12 norms, male or female. [d] Figures in parentheses are percentile ranks for the appropriate norms.

of Receiving Recognition, Son 1 was below average, whereas Son 2 was well above average. On the value of Feeling Supported, Son 1 was average, whereas Son 2 was well above average.

Piers-Harris Childrens' Self-Concept Scale

The boys had very positive self-concepts. The profiles of their scores on the Piers-Harris Childrens' Self-Concept Scale are included in appendix D. They were above average on all subscales. The lowest score for each was in Popularity. Son 2 was slightly higher in Happiness and Satisfaction, Freedom from Anxiety, and Physical Appearance and Attributes. Son 1 was slightly higher in Intellectual and School Status. Their scores were identical on Behavior.

Projective tests

Sons were pleasant and cooperative and fairly open in their discussions. The HFD of each son indicated feelings of being out of balance, and mild aggressive tendencies. Son 1 seemed to be searching for internal strength. Son 2 was apparently anxious about impending independence.

Son 1 drew his family "going to the mall," in his KFD. They were merely lined up at the bottom of the page as Father, Mother, self, and brother. Father, however, was drawn last, and in a wheel chair. Mother was heavily overlapping Father, and Son 1 was overlapping with Mother,

whereas Son 2 was separated. His manner of drawing suggested that the family is introverted and unenthusiastic about environmental contact, consistent with the family inventories. The entire family reflected a sense of resistance and body weakness. When asked if he was embarassed about lifting Father, or by any aspect of Father, Son 1 answered "No; it don't bother me much that he can't help himself; he is helpless." He continued by emphasizing that Father was his and his brother's responsibility.

Son 2 drew his family eating out, with Father and Mother across from each other, and self across from brother, between the parents. He drew himself last, and in a manner that represented anxiety. Father was drawn, in a regular chair, supported by the table. Son 2 began to discuss Father spontaneously. In a very matter-of-fact fashion, he said, "The most important thing to him is his lottery ticket." When I suggested that might be one way in which Father remained in contact with the outside world, Son 2 nodded and added "He does watch CNN most of the day." With apparent hurt, he shared that Father had not wanted to see him play tennis the previous year, because he was not very good, and "you have to be number one for him." With a combination of mild anger and guilt, he added that it hurt his back to carry Father.

Son 1's responses throughout the RATC were relatively short. The Adaptive scale showed an unusual profile, which

suggested he may encounter some difficulty coping with aversive situations. His above average limit-setting score may reflect strong authority-pleasing behavior. He demonstrated an average ability to identify problems, but sought to resolve them in an easy fashion, not utilizing insights or constructive resolutions. He would appear to tend to rely on himself rather than others to overcome problems, and demonstrated a below average tendency to give assistance or emotional support to others. This seemed to be in opposition to his high altruism score on the SIV, but corresponds to his low empathy score on the Mehrabian. His Clinical scale indicated an above average level of depression. Feelings of anxiety, aggression, and rejection were in the average range.

Son 2's responses to the RATC were also short. His Adaptive scale indicated an extremely high level of self-sufficiency, with average levels of reliance on others, and ability to support others. He had appropriate limit-setting and problem-solving ability, and adequate and constructive solutions for dealing with problems. He would seem to have at least average ability to cope with aversive situations. The Clinical scale indicated an above average level of depression, and slightly above average aggressive tendencies. Feelings of anxiety and rejection were within the normal range. The profiles of the sons' RATC scores are included in appendix E.

It is important to point out that, although neither boy overheard the other's stories, there were unusual commonalities. Both frequently had one parent "yelling" at the other, or at their children. They also had the parents apologizing often to the children. Neither son discussed how this might be reflecting on their own home and, in fact, tried to avoid questions relating to these specific problems.

Exit Interview

When my assistant and I returned for the final interview, we were welcomed into the family's new home. Father talked more openly than he had in the initial interview. He made several insulting remarks about Son 1, which seemed related to Son 1's desire to pull away from the home. When the family finally sat down for the interview, Son 2 was sitting next to Father and near Mother, whereas Son 1 was next to Mother and distant from Father.

Mother began the conversation by sharing that she believed Son 1 to be more angry than Son 2. Although Son 1 remained silent, Son 2, as if in defense of himself, pointed out that "as soon as I arrive home from school, [Father] asks for something, and it is irritating." While saying this, he was patting Father's back, and he leaned over and whispered, "I'm sorry." At that point, Mother began to cry. Son 2 added that Father's nursing assistant had been a great help to the family. All of the family assented and agreed

that he was also likeable. Mother said that she had constant concern for Father, and would like to check on him frequently; but telephone calls bother him. Son 2, almost in an effort to relieve the apparent tension Mother was experiencing, jokingly said, "He'd sleep all day, if you didn't call." Mother tearfully concluded "This is not [Father], the man I married."

Father stated that Son 1 did not do anything anymore; Son 2 was doing it all. At that point, Son 1 finally spoke up: "I'm tired of the way he talks to me." Mother responded to this by reminding him that "this" was not his father either. It was obvious that Father had changed so significantly and so rapidly for this family that no one had emotionally adjusted, even though physical modifications had been made and responsibilities had changed.

Father concluded the interview by complaining about tingling in his hands, which the doctor had tried to relieve without success. Father had had the problem for 6 months, and he flatly stated, "If it doesn't work in 6 months, it's not going to work." The rest of the family silently shook their heads.

When it was time to leave, I hugged Father (as I had all the other patients), he began to cry, and held on very tightly, unwilling to yield the comfort it apparently gave him. Mother and the sons accompanied my assistant and me to the door, and thanked us warmly for giving them the

opportunity to participate.

Family Summary

Family 205 consisted of the father patient, the mother, and two sons, ages 16 amd 15, who were 9 and 7 at the time of the diagnosis. Father had rapidly deteriorated within the 3 years prior to the interview, and had become extremely dependent on his sons. This had also necessitated Mother's taking over Father's responsibility for financial support of the family. The recent introduction of a nurse's assistant in the home seemed to provide necessary relief for all three.

The family inventories revealed all four had confidence in their family and believed they are mutually strong. Son 2 appeared to be the only one of the four who had strong problem-solving abilities. The other three were low average or below. All four viewed the family as being of a favorable family type.

Although the latest standard scores were not supplied by their high school, both sons seemed to be of at least above average intelligence. Both boys displayed below average levels of empathy, but were above average in their sense of the value of altruism. I suspect that their lower level of empathy may be a result of having had to give so much to Father. Both had very positive self-concepts. Son 1 placed more value on conformity and feeling supported than on leadership, independence, and receiving recognition. He

may encounter difficulty coping with aversive situations because, although he could identify problems, he sought to resolve them easily rather than effectively. He displayed depressive tendencies, possibly as a result of his inability to express within the family his frustration about his heavy responsibilities toward his father. Son 2 placed more value on receiving recognition and feeling supported than on conformity, leadership and independence. He seemed to have a well-developed ability to cope with aversive situations. He displayed depressive tendencies with mild aggressive tendencies. The fact that, in their stories, both boys independently of one another had "yelling" parents, who apologized often to the children, suggests an intense level of anxiety and guilt in this family.

Family 206

Family 206 responded to the second mailing from the metropolitan clinic. Although the family had recently moved from the inner city to a suburb, that had not lessened their willingness to participate in the study. The mother's concern stemmed from the fact that they had not discussed her MS much in the family, and she did not want the son to become unduly stressed by focusing on it. I assured her that the study had not been considered by previous participants as being overly invasive, and the children involved had seemed to benefit from participating. The mother seemed comfortable, and an initial interview was

arranged. My assistant and I arrived at their modest home a half hour early, interrupting the family's dinner. Although the family expressed willingness to begin the interview immediately, we urged them to complete their meal first. The son finished first, and joined my assistant and me, asking questions and sharing information about himself.

Demographics

Family 206 consisted of the mother (the patient), age 44; the father, age 47; and the son, age 9. Mother completed a 3-year nursing program and became an RN. She had been a nurse in hospitals for 23 years. She had "retired" 1 1/2 years before the interview, due to her MS. Father was a high school graduate, who had done automobile body work for 25 years. He had recently returned to work, having been unemployed for 9 months because his previous place of employment went out of business. The positive aspect of this period of unemployment was that it had facilitated their move. Both parents had worked 40 hours per week. I had not realized until the parents stated their date of marriage that Father was in fact a stepfather. The couple had been married in October 1991. Son had just completed the third grade in the parochial school of his former neighborhood. He was intending to enter the fourth grade in the parochial schoool in the new neighborhood.

Diagnosis and Acceptance

Stepfather (Father) and Son reported good health. As a nurse, Mother began suspecting MS a year before she went to a physician for diagnosis. She admitted that the suspected diagnosis scared her, because her work had brought her in contact with several severe cases of MS. From 1982 to 1986, she sought a diagnosis. Although a Visual Evoked Potential demonstrated optic nerve damage in 1982, it was not until a positive MRI and spinal tap in 1986 was received that MS was diagnosed by the physician.

Mother explained that she had a B_{12} deficiency, which may have confused the diagnosis; but, even with treatment for the deficiency, she felt that her doctors considered her a hypochondriac. "They embarrassed themselves. I wanted to slap them." When the MS was finally diagnosed, one doctor actually apologized to her. She continued with this neurologist, because he was nice and seemed compassionate. However, when Mother's MS began to seriously interfere with her work, and numerous people were advising her to apply for Social Security Disability, this doctor would not support her application. She changed neurologists after she had talked to a few others. Her new doctor was "tough on people. He wants you to do the best with what you've got"; but he recognized when filing for disability was appropriate. She started receiving disability in 1991.

When Mother was diagnosed, she felt "pretty open" in

sharing the information, except with her co-workers. She admitted to a strong denial system, so it was questionable as to how much she had actually shared with people. When she complained that her co-workers gave her no leeway for her health problems, I thought she had scarcely made it possible for them to give support. She admitted that she did not accept the diagnosis until 1989, when the symptoms worsened and "got in the way." She added that she did not feel angry until 2 years later, thereby casting doubt on her "acceptance." She continued by earnestly saying, "I pray a lot."

Mother's parents had never been considerate of her needs. The diagnosis caused them to feel frustrated, because they did not understand, until her condition deteriorated. Now they "are a little over-protective." Mother's siblings "are into their own things." One brother cried and began to accept it little by little. One sister asked, "Can I catch it?"

Son was born in the midst of her seeking a diagnosis. Mother was never married to Son's father, whom she described as "very creative, alcoholic, and self-involved." Son began asking Mother questions when he was 4 and had noticed the difference in her walk. She believed "he took a while getting used to it," but he still did not seem to comprehend his mother's disease process.

Mother had not been much involved with the church.

Friends were her greatest source of support. She admitted to initially looking for sympathy, and they had given it to her. As her needs for support had changed, so her close friends had changed to meet the needs.

Mother met Father in 1989 and informed him of her MS on their third date. He commented, "I knew something was wrong--she had a cane; but it was up to her to tell me." He had an aunt with MS, and borrowed a book to read from a co-worker. Basically, his response was "So what?" He shared that he had fallen in love with her the first time they met. Mother believed he was comfortable with it. She appreciated that he did not baby her, but was helpful when needed. His parents were rather oblivious to Mother's MS, because they were helping care for relatives who had suffered strokes.

Symptoms and Treatment

Mother began experiencing symptoms in 1978. These included numbness in her left arm and hand, which later remitted. Mother shared that, in 1981, she was under quite a bit of stress, and symptoms returned. Additional symptoms included problems with her gait, fine-motor control, vision, balance (including dizziness), and bladder control. The fine-motor and vision problems went into remission, and the rest of the symptoms stabilized. Additional symptoms which she was dealing with at the time of the interview included spasticity in her legs, jerking in her arms, numbness in her hands, and severe fatigue.

Mother does not have much faith in the value of her medications for the alleviation of her symptomology.

Assistance

While Mother was still working, she had paid someone to clean her house. Once she had "retired," she found herself unable to keep up with all the responsibilities in the home. She shared, "I compulsively clean, if I get started." Son did the vacuuming and cared for the family dog. He stated, "I help you, even if you don't ask," and Mother agreed. Father had taken care of family finances, the yard work, laundry and the shopping while he was between jobs. When he returned to work, Mother took over the laundry, and shopping became a family affair. Her responsibilities included the cooking, dusting, and general cleaning.

Mother never sought help in caring for Son. She was covered under Father's union's medical insurance. She had used a cane since 1990, and reluctantly agreed to use a wheelchair in places requiring much walking. Because of her balance problems, she was very curious about my Canadian crutches. Mother's gait included a swinging of the legs from the hips, with more insecurity and dragging than had been observed in previous patients.

Emotional Issues

During the initial interview, when asked if the family had sought counseling for any problems, Mother reluctantly

mentioned, in a very soft voice, that both she and Father were recovering alcoholics. She seemed angry that this had been discussed in front of Son, yet, in the later sessions, she discussed this more openly. As with the overall discussion of her MS, her initial intrepidations were apparently alleviated. I had encouraged the parents to be more open with Son, to help the family better deal with their various problems. The parents were receptive, and Mother later expressed appreciation for my helpfulness.

Mother continued that she had periodically sought counseling on her own since the age of 25 for "life stuff." When Son was 3 years of age, they had begun to seek counseling for some behavior problems. The counseling did not help until Mother also took parenting classes when he was 5.

The parents pointed out that they were still settling down as a family. They did not believe that the MS was a serious interference with this process. Son did not openly disagree, but his body language indicated disagreement.

Description of Son by Parents

Son basically received B's and C's, but was an A student in Social Studies and a D student in Spelling. He pointed out that he liked to read the National Geographic. Even with the recent move, Son had developed new friends. Mother felt he played well with other children. The greater part of the discussion of Son dealt with his behavior.

Apparently, the earlier behavior problems had been a result of unresolved anger. Son believed he was doing much better. Father had helped develop a more effective discipline plan that "didn't include hitting." Although Son had some trouble completing homework, at the time of the interview Mother said, "He's like a saint now."

The Family Tests

Table 30 gives the results of the family members on the Family tests. Son responded only to FACES-II.

Family Hardiness Index

Mother's FHI was well below the average of the norming sample, whereas Father's was average. This difference seems to be mainly due to two factors. Father views the challenges of life in a much more positive manner than does Mother. Although Father believed there was very good joint internal strength, Mother was not quite as confident about this. However, Mother did feel that there was less control exerted by external factors. The parents' Confidence scores indicated that both felt fairly confident in their family.

A few items which showed the greatest difference are of interest, and are delineated in Table 31. Of the seven items to which they responded identically, the four to which their answers were "True" are of most importance, namely, items 4, 5, 7 and 9.

TABLE 30

FAMILY 206--FAMILY TESTS

Scale	Subscale	Maximum Score	Patient (Mother)	Spouse (Father)	Son Gd. 3.9
FHI					
	Coorlented-Commitment	24	20	24	Too
	Confidence	12	10	9	
	Challenge	15	8	14	Young
	Control-External	9	6	1	
	Total	60	44 (29)[a]	48 (54)	
F-COPES					
	Acquiring-Social Supp.	45	32 (71)[b]	33 (86)	
	Reframing	40	27 (29)	31 (58)	Too
	Seeking-Spirit. Sup.	20	18 (73)	18 (79)	Young
	Mobilizing	20	14 (71)	16 (94)	
	Passive-Appraisal	20	14 (97)	15 (98)	
	Total	145	105 (80)	113 (94)	
FACES-II					
	Cohesion	80	66 (6)[c] z=0.13	72 (7) z=0.85	65 (6) z=0.95
	Adaptability	70	46 (5) z=-0.59	47 (5) z=-0.44	42 (3) z=-0.43
	Family Type	-	(5.5)	(6)	(4.5)

[a] Numbers in parentheses are percentile ranks from the appropriate norms: One overall norm for total score only. [b] Numbers in parentheses are percentile ranks from the appropriate norms: norms are for adults or adolescents, male or female. [c] Numbers in parentheses are from Linear Scoring Model (figure 2).

TABLE 31

FAMILY 206--SELECTED FHI RESPONSES[a]

	False	Mostly False	Mostly True	True	Not Applic
4. In the long run, the bad things that happen to us are balanced by the good things that happen.				P,Sp	
5. We have a sense of being strong even when we face big problems.				P,Sp	
7. While we don't always agree, we can count on each other to stand by us in times of need.				P,Sp	
8. We do not feel we can survive if another problem hits us.		P		Sp	
9. We believe that things will work out for the better if we work together as a family.				P,Sp	
19. Most of the unhappy things that happen are due to bad luck.		P		Sp	
20. We realize our lives are controlled by accidents and luck.	P			Sp	

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son.

Family Crisis Oriented
Personal Scales

Both parents scored well above the average for the norming sample on the Family Crisis Oriented Personal Scales. Their most positive problem-solving attitude was on the Passive Appraisal scale, where they both scored very high. The subscale with the biggest difference was Reframing, indicating that Mother experienced more difficulty redefining stressful events to make them more manageable. The other three subscales' scores were above average for both parents.

It is of interest to note a few of the seven items on which they differed markedly and several to which their responses were identical. These are found in Table 32. This couple readily agree that relatives are important to them, and are willing to share with and ask for help from them. They also are willing to share with a counselor, a minister, and close friends, but strongly oppose sharing with neighbors.

Family Adaptability and
Cohesion Evaluation
Scale-II

The entire family responded to the Family Adaptability and Cohesion Evaluation Scale-II. The family scores indicated that Mother and Father believed that their family type was moderately balanced, and Son believed they were on the border between mid-range and moderately balanced.

TABLE 32

FAMILY 206--SELECTED F-COPES RESPONSES[a]

	Strongly Disagree	Moderate Disagree	Neither	Moderate Agree	Strongly Agree
1. Sharing our difficulties with relatives.				P,Sp	
3. Knowing we have the power to solve major problems.				P,Sp	
5. Seeking advice from relatives.				P,Sp	
9. Seeking information and advice from the family doctor.		P		Sp	
10. Asking neighbors for favors and assistance.		P		Sp	
11. Facing the problem "head-on" and trying to get solution right away.		Sp		P	
14. Attending church services.					P,Sp
19. Accepting that difficulties occur unexpectedly.				P,Sp	
21. Seeking professional counseling and help for family difficulties.					P,Sp
30. Having faith in God.					P,Sp

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son.

Mother and Son had the family connected on the Cohesion dimension, whereas Father had them very connected. Mother and Father saw the family as flexible on the Adaptatability dimension, whereas Son saw them as structured. This reflects Mother's previous comments that Father had introduced structure with Son in regard to his behavior, which she had been unable to accomplish.

Items of interest are delineated in Table 33. There are many on which Son disagreed greatly with one or both of his parents. Items 5, 8, 14 and 26 reflect that, whereas Mother and Father were working together, probably as a function of their developing marital relationship, Son did not feel a part of this togetherness. There were three items on which the responses of all three agreed. These are item 1, 10, and 25.

Individual Testing of Son

Vineland Adaptive Behavior Scales

Son's teacher for the new school year returned the Vineland Adaptive Behavior scales after 6 weeks of school. He apologized for being brief, but he did not feel he knew Son very well yet. He rated Son within the average range in Communication (90) and in Socialization (95). Daily Living Skills were ranked slightly below average (85), because the teacher felt Son was not adequately able to deal with expectations in the community. The Adaptive Behavior

TABLE 33

FAMILY 206--SELECTED FACES RESPONSES[a]

	Almost Never	Once in Awhile	Some-times	Freq-uently	Almost Always
1. Family members are supportive of each other during difficult times.					All
3. It is easier to discuss problems with people outside the family than with other family members.	Sp,S		P		
5. Our family gathers together in the same room.		S			P,Sp
8. Family members discuss problems and feel good about the solutions.		S		P	Sp
10. We shift household responsibilities from person to person.	Sp		P,S		
11. Family members know each other's close friends.					All
14. Family members say what they want.		S		P,Sp	
19. Family members feel closer to people outside the family than to other family members.	All				
25. Family members avoid each other at home.	All				
26. When problems arise, we compromise.		S	P	Sp	

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

composite was slightly below average at 88. All of the sub-domains other than Community were rated adequate. In the written comments, the teacher added that Son's strengths were in oral communication, socializing, and listening skills. His only weakness was listed as writing skills. The teacher added to the form an IQ score of 130, without identifying the instrument from which it was obtained.

When my assistant and I returned for the second session, only Mother was home with Son. She asked to speak privately with me, and expressed concern that "all the talking about the MS" was bothering Son. I discussed this briefly with Mother, and asked if the discussion could continue after the testing of Son was completed. Son's scores on the objective tests are shown in Table 34.

Empathy scale

Son's score on the Bryant Index of Empathy Scale was well above average, indicating a well-developed ability to empathize.

Piers-Harris Children's Self-Concept Scale

The profile of Son's scores on the Piers-Harris Children's Self-Concept Scale is included in appendix D. His total score was above the average range. His sense of happiness and satisfaction with himself was strongest, with his degree of comfort with his behavior, intellectual and school status, and physical appearance and attributes almost

TABLE 34

FAMILY 206--CHILD TESTS

Scale	Subscale	Maximum Score	Son Gd. 3.9
EMPATHY			B4[a] 15 z=1.02
PIERS-HARRIS	Behavior	16	15 (81)[b]
	Intellect	17	15 (81)
	Physical	13	11 (84)
	Anxiety	14	8 (37)
	Popularity	12	9 (52)
	Happiness	10	10 (90)
	Total Scale	80	64 (79)
SIV			
	Support	45	
	Conformity	45	Too
	Recognition	39	
	Independence	48	Young
	Benevolence	45	
	Leadership	48	

[a]B4 = male or female norms for Grade 4 on Y/N Bryant Scale, range = 0-22. [b]Figures in parentheses are percentile ranks for the complete norming population.

as strong. His sense that he was free from anxiety was high average, and he had slightly above average belief in his popularity.

Projective Tests

Son's HFD actually was a scene rather than simply a drawing of a person. A somewhat defiant, strong-looking boy was standing on a slight hill, near a windswept tree, with a happy sun, angry clouds, and carefree birds. This demonstrated not only Son's artistic ability, but possibly that he might have been trying to control a problem. There were also indications of an impulsive, aggressive, reaching out to his environment, which is counterbalanced by an assertive potential.

Son's KFD had his family at an amusement park. He began by drawing himself, then Mother with her cane, and Father last, separated from Mother and Son. He then drew a ferris wheel, midway games, a railroad, go-carts, and a water ride. Although they seemed to be enjoying themselves, the emotional indicators suggested that the family was sensitive to criticism. Mother was represented as a concerned, loving, but controlling parent, whereas Father appeared hostile.

Although Son seemed to have especially enjoyed the drawing tasks, he also heavily invested himself in telling the stories for the RATC. He gave thorough, complicated stories, with morals and well-developed resolutions.

Several of the stories were excellent examples of how he seemed to be working out his feelings about Mother's health and a new father. Son's ability to develop constructive answers to problems was much higher than expected for his age. The profile of Son's RATC scores is included in appendix E. His Adaptive scale indicated a strong capacity to use outside help, and an extremely strong sense of self-sufficiency, with very well-developed problem-solving and limit-setting skills. He also demonstrated an above average tendency to support others. His Clinical scale showed average levels of aggression, depression, and rejection, and below average anxiety.

Mother's Emotional Issues

While Son was completing his tests with the assistant, Mother and I stayed in a different room to talk. Mother shared that Son's birth father had died a year ago that week. He had been a "terrible alcoholic," but was always close to Son. When Son was 4, Mother became worried about the drinking, and did not want Son to visit his father. Son became very mad, so Mother took him to visit his father, who was moderately drunk. She believed that was when Son realized that his father was not perfect, and even became slightly scared of him. Son's half-brother, through his father, was "just like his dad," but Son idolized him. When his father died, Son remained in shock until the funeral, when he cried very hard.

She and Son had known Father for 5 years, and it had been a slow adjustment for them all. Soon after the marriage, Father adopted Son with the birth father's blessing. Although Mother was grateful for Father's help with the discipline, and she realized that Son thought his discipline was harsh, he never used physical coercion. Son's birth father had hurt him twice when disciplining, but Son did not seem to remember that.

Mother added that Father took medicine for high blood pressure, and she also had asthma; but they did not want to worry Son. It was at this point that I felt comfortable assuring Mother that Son appeared to be dealing well with her MS.

Exit Interview

When my assistant and I arrived for the final session, Son warmly welcomed us and made sure there was a place for us to sit. As Father arrived home a little late, the actual closing interview was delayed until his arrival. Son spent the time talking about his vacation and showing things that he had done.

When Father joined the group, Mother began by thanking me for time we had spent together during the previous session. She said she felt quite a bit more comfortable after the talk. Father tacitly agreed. Son enthusiastically interjected that he had enjoyed himself, particularly with the drawing. Mother continued with her

concern about how the family would need to change again, since Father was back to full-time work. "I want to make sure I don't give myself an excuse to not do things." Father added, "I don't want you doing too much either." Mother seemed honestly concerned that if she had not already "given up" to the MS, she would soon do so. I was happy to assure her that nothing she had said or done in our time together had given the impression that this was likely. She seemed much too positive, sensitive, and determined for this to be possible. Mother's face lit up, while Father nodded agreement and Son patted Mother on the arm. Mother closed the session by stating how much she appreciated the fact that the research was being done, and that they could be a source of help for other people.

Family Summary

Family 206 consisted of the mother patient, the father, and the son, age 9, who had been born in the midst of her seeking a diagnosis. Mother was very concerned about the mental health of her son, and admitted to having discussed the MS very little with him. He was friendly, open, and very willing to cooperate. Father had been a part of the family since Son was 4, and their somewhat strained relationship added another dimension to family functioning.

The family tests revealed that the parents were fairly confident in their family, but Mother was not as firm in her belief in their mutual strength. Both had effective

problem-solving skills. All three see the family as a favorable family type.

The individual testing indicated that Son was of superior coqnitive ability, but with slightly below average adaptive behavior. He had a well-developed sense of empathy, and a very positive self-concept. He demonstrated very strong problem solving abilities, with highly developed resolution skills. He seemed to be developing a solid value system, with constructive coping abilities. He had an apparent history of aggressive tendencies, for which Mother had sought counseling for herself and Son. He seemed to have learned self-control and self-sufficiency. Although there was apparent resentment toward Father, Son appeared to be trying to live amicably with him.

Family 207

Family 207 responded to the first mailing from the metropolitan clinic. When they were contacted by phone, their pleasure at being included in the study was evident, and an initial interview was readily arranged. They lived in a small town west of the metropolis in a very well-kept, modest ranch home. When my assistant and I drove up, Mother came out to warmly greet us.

Demographics

Family 207 consisted of the father (the patient), age 32; the mother, age 31; a daughter, age 7; and a son, age 5.

Both parents were high school graduates. Father was pursuing an associate degree. He had been a machinist for 10 years, and worked 40 hours a week. Mother had technical training to become a certified nursing assistant, and had been working in a nursing home for 4 years. She worked 25 to 30 hours per week. Mother cared for the children during the day, then went to work shortly after Father's return home. Then he cared for the children. The parents married in November 1983. Daughter was entering the second grade in the neighborhood public elementary school. Son was entering kindergarten in the same school.

Diagnosis and Acceptance

Mother had been recently diagnosed with Benign Positional Paroxsymal Vertigo, which had been caused by a head injury from an auto accident. Originally she had been diagnosed with Menieres Syndrome, due to severe dizziness and tinnitus. With the eventual BPPV diagnosis, she learned that there was no effective treatment, except a serious surgery which would destroy her hearing. Her condition was considered severe enough by her doctors that they encouraged her to take sign language lessons, which she was doing, in preparation for eventual surgery. The children were reportedly in excellent health.

Father's MS was eventually diagnosed in 1991 by an ophthalmologist who specialized in the nervous system. Father's father had Myasthenia Gravis, which led to his

neurologist initially misdiagnosing Father. Following the advice of the opthalmologist, he sought a second opinion from another neurologist. An MRI confirmed the correct diagnosis. Father had found the new neurologist encouraging and supportive.

Father was in shock at first. He shared, rather philosophically, that he became mad at times. "After all, I'm losing something I used to be able to do. I try to take things in stride," taking into account what he was still capable of doing. Apparently, he was always aware of what the MS can potentially do, so he seemed grateful that he was relatively healthy.

Mother was scared by Father's diagnosis because she had worked in the nursing home with a young man with severe MS. It was a very stressful time for the parents, because of the suddenness of the symptoms; however, because the symptoms were not severe, the parents were able to adjust more quickly than they had expected. The children were 6 and 4 at the time, and they learned quickly "don't bother Daddy." The parents had openly discussed Father's MS with the children, and they had responded differently. Daughter was angry and became rebellious towards Father. This anger had apparently disseminated by the time of the interview. Son was rather young, but Mother believed he understood and accepted it. The parents pointed out that Daughter was more serious about everything, and Son was more "laid back." The

parents believed that the MS had helped draw the nuclear family together, through their coping and playing.

Father's mother, a nurse, became very upset when informed of the MS. Her anger grew to the extent that she became distraught, and Father worried about her. His father did not believe there was a problem until they were together, and Father experienced serious symptoms. Mother's father was deceased. Her mother "cuts out every article that could help, especially stories about success." Father's siblings were very passive, and tended to avoid him. He claimed that this did not bother him. Mother's brothers had not changed in their treatment of Father, and would help whenever needed.

The family belonged to the Catholic church in a nearby town. They felt that the large size of the congregation hampered their seeking support from that community. The presence of a number of religious items in their home, and several statements throughout the sessions, demonstrated their faith in the supporting presence of God. Father's friends had basically ignored him. "They've chosen not to deal with it. We don't have a choice." He believed he had only one friend left, who had been a friend from school, and was like family. Father had not informed his supervisors at work about the MS until just before the interview. Because his job was highly physical, he was afraid his condition would jeopardize his job. Mother believed that Father's

boss was trying to build a case to fire him. Father agreed. Mother's employer had been very supportive by releasing her when needed.

Symptoms

As previously mentioned, Father's initial symptoms were with his eyes. One eye had begun to wander. His acuity was best described as "greasy." There apparently also was some nystagmus, as he described jerky movements of his eyes. These symptoms improved, although his left eye was still observed to wander slightly, and he shared, "My eyes are not as good as before." Father began to experience fatigue fairly early in his disease process, and one of his legs was periodically numb. He mentioned that he suffered "bladder sensations," which interfered with his ability to void.

A particularly troublesome symptom, in light of his job, was the occasional sudden loss of sensation and control of his dominant arm. The most significant symptom that he had experienced was severe vertigo, caused by laying flat and by sudden changes of position. At the time of the interview, Father was having to sleep in a recliner chair in order to get a good night's sleep. The vertigo was so severe that he would become violently ill, and his physician had been unable to find any medication to help.

Father had received ACTH while in the hospital, and it had helped to bring about a remission. He admitted he did not take his medications regularly, but also complained they

did not help his symptoms. Father was anxiously waiting to hear whether he was going to be included among the relatively small group to first receive Betaseron, the newest drug approved for use with MS, reportedly successful in reducing the severity of the MS process itself, rather than just symptoms. As a newly diagnosed, mildly affected patient, Father was similar to the sample used by the drug company to gain FDA approval. Therefore, he was very optimistic about the possibility of being helped by this treatment.

Assistance

Although Mother said she took responsibility for the house and yard year round, she commented, "I don't want him to feel he can't do anything." In fact, when I returned for the final interview, Father was mowing the grass with a push mower. He added that he fixes and builds things. At that time, he was building a shed in the back yard. Mother admitted to being worried about his roofing it; but he did not seem concerned, even though he had already fallen off the roof once. He laughed as he said, "It's not very far from the ground."

Father used no aids to walk and, only after sitting for a period of time did he appear stiff. He did exhibit a tilt to his walk, common with balance problems. He had medical insurance coverage through his work. The family received no financial assistance. Child care had been necessary when

Father "had an episode" of severe vertigo. Grandparents provided the care.

Emotional Issues

The parents had attended group counseling at the neurological clinic which Father visited for medical care. They wanted to continue with it; but, being in the heart of the metropolis, it was too far to go for weekly sessions. When asked if there were any alcohol or drug problems, there was an emphatic "No." In fact, if Father drank just one beer, it intensified his vertigo. He shared that a brother and a brother-in-law were alcoholics, and Mother shared that her father had been one also.

The family believed that the MS had drawn them closer, as they had to rely on each other. The parents gave their faith much credit, stating that it had become even stronger since Father's diagnosis. They believed they had "a great attitude," and my assistant and I agreed. The couple believed that their success was also a result of Mother's unlimited energy, and the fact that Father would stick to things until they were done. Additionally, I felt that this family accepted anger and crying. The parents were afraid that the children were having to grow up too fast, because they had to learn ways to help at a younger age.

Description of Children by Parents

Before the initial interview began, the children

collected coloring books and crayons, and placed themselves in the middle of the living room. They were active participants in the discussion, with nods and occasional comments. If either left the room, it was only to go to the bathroom or to find something to show me.

Daughter was a high-achieving student, having received awards for academics. She was also artistic. She was described as "a good girl, who is polite and listens." She apparently was vocal at home, where she felt comfortable verbalizing disagreements. She got along well with other children, and was highly imaginative. Son was described as a quick learner, who was looking forward to entering school. He was a good boy, cooperative, did not talk back to his parents, and had lots of friends.

The Family Tests

Table 35 gives the scores on the Family tests. The first two tests were responded to only by the parents. Daughter responded to the third test.

Family Hardiness Index

Father's FHI was higher than Mother's, with Mother being above average, and Father even higher, though only 2 raw score points separated them.

Although both Mother's and Father's scores were quite high on three subscales, Father's was slightly higher on his Confidence subscale; these scores indicated their sense of

TABLE 35

FAMILY 207--FAMILY TESTS

Scale	Subscale	Maximum Score	Patient (Father)	Spouse (Mother)	Daughter Gd. 1.9
FHI					
	Cooriented-Commitment	24	21	23	Too
	Confidence	12	12	10	
	Challenge	15	14	12	Young
	Control-External	9	5	5	
	Total	60	52 (80)[a]	50 (63)	
F-COPES					
	Acquiring-Social Supp.	45	39 (99)[b]	38 (97)	
	Reframing	40	39 (99)	33 (77)	
	Seeking-Spirit. Sup.	20	18 (79)	19 (86)	
	Mobilizing	20	18 (98)	17 (94)	
	Passive-Appraisal	20	17 (99)	13 (95)	
	Total	145	131 (99)	120 (99)	
FACES-II					
	Cohesion	80	74 (8)[c] z=1.08	69 (6) z=0.49	62 (5) z=0.62
	Adaptability	70	62 (7) z=1.83	52 (6) z=0.32	49 (5) z=0.84
	Family Type	-	(7.5)	(6)	(5)

[a] Numbers in parentheses are percentile ranks from the appropriate norms: One overall norm for total score only. [b]Numbers in parentheses are percentile ranks from the appropriate norms: norms are for adults or adolescents, male or female. [c]Numbers in parentheses are from Linear Scoring Model (figure 2).

cooperation and mutual adequacy. Father's score was also slightly higher on the Challenge subscale, indicating that he viewed the challenges of life in a slightly more positive manner than did Mother. Mother's score was slightly higher on the Coordinated Commitment subscale; their scores indicate their joint internal strength. The one subscale on which they scored surprisingly low was the Control External, suggesting they felt somewhat controlled by external factors out of their control.

There are only two items to which their responses were markedly different. To item 2, "It is not wise to plan ahead and hope, because things do not turn out anyway," Father responded "False" and Mother, "Mostly true." To item 5, "We have a sense of being strong, even when we face big problems," Father answered "False," whereas Mother answered "True." On 13 of the 20 items, their responses were identical. In most of these cases, the responses were at the extremes, indicating a strongly positive mutual outlook on life.

Family Crisis Oriented Personal Scales

Relative to their separate male and female adult norms, both Father and Mother scored well above average on the Family Crisis Oriented Personal Scales. Mother scored slightly below Father in Passive Appraisal, though both still demonstrated that they did not resort to giving up or

ignoring problems. Mother's weakest coping skill, although relatively strong, seemed to be Reframing, redefining stressful events in order to make them more manageable. They both felt their problem-solving abilities were strongest in mobilizing the family to acquire and accept help, acquiring social support, and seeking spiritual support.

Of the 30 items on this scale, there is only 1 on which their answers varied greatly. This was item 26, "Feeling that no matter what we do to prepare, we will have difficulty handling problems," with which Father strongly disagreed, whereas Mother moderately agreed. Half of the items drew identical responses from the parents. They mutually believed that their support system encompassed their relatives, friends, neighbors, minister (and God), and professionals.

Family Adaptability and
Cohesion Evaluation
Scale-II

The parents and Daughter were very close in their concept of their family. On the Cohesion dimension, Mother and Daughter rated the family as connected, whereas Father believed they were very connected. On the Adaptability dimension, Mother and Daughter felt they were flexible, whereas Father believed they were very flexible. Not surprisingly, Mother and Daughter reflected moderately balanced family types, whereas Father's was balanced.

Although Daughter's response was very different from one or both of her parents on 15 of the 30 items, only 2 need to be discussed. To item 1, "Family members are supportive of each other during difficult times," Father and Mother responded "Almost always," whereas Daughter responded, "Once in a while." To item 9, "In our family, everyone goes his/her own way," Father responded "Almost never," Mother responded "Sometimes," and Daughter responded "Almost always." It would appear from the family's response patterns that Mother and Father utilized their strong relationship to help them adapt and cope, but they had not yet enlisted their young children into the family support system, and Daughter was aware of this. The 7 items to which their answers were identical all reflect a strong sense of cooperation and sharing within the family.

Individual Testing of Children

Vineland Adaptive Behavior Scales

The children's teachers were very slow in returning the scales. When it was recognized that they had not been returned, the school was closed due to extreme weather. I contacted Mother, who was very willing to follow up with the school. Daughter's teacher called me to apologize for the delay, explaining that her father had died suddenly in the fall. She was very interested in the research, and asked if the brief report of the findings could be sent to her. I

was pleased to agree to the request.

The teacher included information related to Daughter's IQ. On the Otis-Lennon, her full-scale was 90; Verbal, 89; and Non-Verbal, 93, which are low average. The teacher rated Daughter's Daily Living Skills and Socialization as adequate (90 and 92 respectively); but Communication was low (76). Overall, this resulted in a moderately low Adaptive Behavior Composite (82). Within the Daily Living Skills domain, she rated Daughter's domestic sub-domain as adequate, personal as moderately high, but community as moderately low. Within the Socialization domain, all sub-domains were adequate. Within the Communication domain, the receptive sub-domain was adequate; but expressive and written were moderately low. The teacher made some astute comments, recognizing that Daughter was physically strong and well coordinated, but not very verbal, or academically strong. She saw her as a sweet, reserved child, who seemed to be within the normal range, but was performing lower than most of her classmates. She was concerned that Daughter might not be experiencing the same exposure to life as other children her age, and might be over-protected. Certainly, with parents who work opposite shifts, and who were both chronically ill, her life experience would be expected to be different.

Son's teacher rated him within the average range in Communication (96) and Socialization (96). He was rated

above average in Daily Living Skills (116), and superior in Motor Skills (128). The Adaptive Behavior composite was above average at 110. The sub-domains which were rated as moderately high were Personal and Domestic Living Skills, and Fine Motor Skills. His highest sub-domain was Gross Motor Skills, where he was rated high. There were no sub-domains where problems were noted. In the written comments, the teacher shared that Son was very cooperative and a good listener. He seemed to be a quiet child, who needed to be prompted to get him to talk.

When my assistant and I returned for the second session, Mother warmly greeted us, and prepared the kitchen table for use in the testing. Part way through the testing, Father arrived home from work and Mother left for her job. This was obviously a common occurrence, because it did not disrupt either child. Table 36 gives the scores on the one objective test taken.

Empathy scale

Although Son had wanted to take the Bryant Index of Empathy test along with his sister, and the assistant read it to him, it was felt to be invalid. He did not seem to understand the statements. Daughter's level of empathy seemed to be below average according to this instrument.

Projective tests

According to the Projective tests, daughter's HFD

TABLE 36

FAMILY 207--CHILD TESTS

Scale	Subscale	Maximum Score	Daughter Gd. 1.9
EMPATHY			B1[a] 12 z=-0.65
PIERS-HARRIS	Behavior	16	
	Intellect	17	Too
	Physical	13	
	Anxiety	14	Young
	Popularity	12	
	Happiness	10	
	Total Scale	80	
SIV			
	Support	45	
	Conformity	45	Too
	Recognition	39	
	Independence	48	Young
	Benevolence	45	
	Leadership	48	

[a]B1 = male or female norms for Grade 1 on Y/N Bryant Scale with score range = 0-22.

suggested that she had a normal level of dependence, but felt out of balance in her life. Son's HFD should not be evaluated for emotional indicators due to his young age. However, his reproduction of a person appeared immature for his age, and may indicate some anxiety or sense of inadequacy on his part.

Daughter's KFD had the family playing table games. She commented that they often played games together. She said that Father and Mother were already playing the game Monopoly, whereas she and her brother were just joining the game. Her picture showed her and her brother together on one side of the table with Father and Mother on the other side, suggesting a natural pairing within the family. Again, a lack of balance was suggested in her drawing. She may also have felt a sense of insecurity in a limited environment, where she had to inhibit impulsive behavior, and was expected to always be on her best behavior. This correlates with the parents' discussion of how they expected certain behavior from the children when Father was not feeling well. This expectation must, then, be increased when Mother is not feeling well, and may be overwhelming to these children.

Son wanted to use his crayons for his KFD, but readily agreed to use a pencil, as I requested. He drew Mother first, then Daughter, then Father, and finally himself. He lined them up with Father and Mother together in the middle,

himself next to Father, and Daughter next to Mother. Although he had not overheard his sister, he also had his family playing a game, but his was "hide-and-go-seek," rather than a board game.

Daughter's stories were rather short, but fairly complete, throughout the RATC. The Adaptive scale suggested a good ability to cope with average situations. She may have over-relied on others; but she should not have needed to, as she had a very strong sense of self-sufficiency. She had an above average ability to identify problems and had solid resolution skills. Her above average sense of limit-setting may be a reflection of her need to please authority. She demonstrated a very low-level ability to support others, consistent with the Bryant. The Clinical scale indicated an extremely high level of depression, and an above average level of aggression. Feelings of anxiety were below normal, and the sense of rejection was within the normal range. In her stories Daughter had recurring themes of illness and disappointment. With both parents having chronic illnesses, these themes are not surprising.

Son's RATC stories were very short and often unresolved, but had enough of a story line for good analysis. Within the Adaptive scale, he seemed to have an average need to rely on others, and the ability to support others. He had average levels of self-sufficiency and limit-setting behavior. He was able to identify problems

well, but unable to resolve them. The Clinical scale suggested higher than normal levels of feelings of rejection, but normal levels of aggression and depression. Just as his sister, he had below average levels of anxiety. The profiles of the children's RATC scores are included in appendix E.

Exit Interview

Between the second and final sessions, Father, Daughter, and Son were in a serious car accident. Son was the most seriously injured, and was in a coma for 12 hours. They were all home, but still on the mend, when my assistant and I arrived just 1 week after the accident. Their welcome was just as warm as though no problem had occurred. After the initial shock of the accident, this family had seemed to cope more easily with the traumatic situation than one would normally expect.

Father initiated the discussion by saying he believed all the right questions had been asked. Mother commented in a matter-of-fact fashion that it was simply a question of changing your lifestyle to incorporate a problem. Father pointed out that, right after the accident, relatives immediately offered assistance and helped them handle the emergency. Mother emphasized the importance of family. Daughter and Son did not say much, but thanked me for the fun they had had.

In a brief discussion following the formal interview,

Father shared his frustration with people who do not understand that there are many illnesses which do not necessarily make one look ill. Mother laughed because, when Father was ill with his severe dizziness, there was no question that "he looks sick." Father wanted to add that he believed his MS had started after he had suffered a bout of shingles. Daughter proudly gave my assistant and me a collage she had completed for us. We found it difficult to leave the friendly atmosphere of this family.

Family Summary

Family 207 consisted of the father patient, the mother, a daughter age 7, and a son age 5, who were 5 and 3, respectively, at the time of diagnosis. Mother was also suffering from a recently diagnosed chronic illness. Both parents were positive and enthusiastic about life and their children, who were excited to be involved.

The family inventories revealed a strong sense of family hardiness and a joint positive outlook on life. Both parents also demonstrated strong problem solving ability. They and Daughter all viewed their family as of a favorable family type.

The individual testing indicated that Daughter had average cognitive ability, but below average adaptive behavior skills. This may have resulted from over-protection by the parents. Her level of empathy seemed below average. She may have tended to over-rely on others,

but had a strong sense of self-sufficiency. She had an above average ability to identify and resolve problems. Depressive tendencies were of particular concern. Although aggressive tendencies were high, she appeared to be capable of controlling them. Son had average to above average cognitive and adaptive behavior abilities. He seemed to have an average ability to support others, although he was too young for an empathy scale. Although intelligent, self-sufficient and able to identify problems, he was unable to resolve problems. His sense of rejection was higher than normal.

Family 208

Family 208 responded to the first mailing of the metropolitan clinic. The father was contacted at his place of business, because the mother was often away from home. The father was very friendly, yet stressed that the family was very busy. He emphasized that the family did want to help, if they could. An appointment was scheduled after speaking several times with both the father and the mother.

The family lived in a large, attractive, tri-level home in a rural area near several large cities. Once my assistant and I arrived, there was no question as to the warmth of the welcome.

Demographics

Family 208 consisted of the mother (the patient), age

45; the father, age 46; a daughter, age 22; a son, age 21; and a daughter, age 14. The parents were married in April of 1969. All of the children were still living at home. The eldest daughter was a high school graduate, and was attending technical school to become a medical assistant. She intended to move to her own apartment. The son was also a high-school graduate, and was apprenticed to his father's company. These two elder children were not involved in the research because they were past school age.

Mother was a high school graduate, and had taken nurses' training to obtain her LPN license. She had been a nurse until they started their family. Just 3 years before the interview, Mother had returned to part-time work at her sister-in-law's candy store. Although she worked only about 8 hours a week, it was obviously very important to her. She was a member of the local MS Society support group.

Father graduated from high school, and then served a 4-year apprenticeship in sheet metal and heating and air conditioning. He had worked in that field for 23 years, owning his own business for the past 8 years. He worked from 50 to 60 hours per week. He belonged to the local Masonic Lodge and Shriner's Club, volunteering often for both.

The younger daughter (Daughter) had just entered the ninth grade in the private Catholic high school from which her mother and siblings had all graduated. She belonged to

the Spanish Club at school, and intended to be a cheerleader the next year.

Diagnosis and Acceptance

Although Father and Daughter were both reported as healthy, Father pointed out that the men in his family had all died before the age of 60, apparently due to heart problems. Father seemed to be trying to take care of himself. Mother's MS was diagnosed in 1991, in what seemed to be one of the easiest processes among the sample families. Mother's first symptom had been pain and numbness in her right hip and leg, which led her to seek help from a chiropractor. After a few unsuccessful adjustments, he sent her to an orthopedic surgeon, who performed a CAT scan of her back, with normal results. She was then referred to a female neurologist who had been recommended to her by her nephew, also a patient of this doctor. Through an EMG, the physician ruled out peripheral nerve problems and had Mother take an MRI. During the initial neurological interview, Mother had noticed that the doctor had written "MS?" in the diagnosis column next to the list of her symptoms. Mother went home and began researching MS, and began to feel that this was indeed her problem. Therefore, when her doctor told her that the MRI had confirmed the presence of MS, this was verification for Mother.

Father said that, although the diagnosis appeared reasonable, he had always been a skeptic, and wanted a

second opinion "from the best MS center in the United States." His research led him to the large metropolitan clinic through which the greater part of this sample was identified. Mother's neurologist had already suggested that she seek a second opinion from a leading neurologist at this clinic. The parents were both pleased with the way in which the situation had been handled. The second opinion verified the MS and offered the parents considerable help and information. Mother continued her follow-up care with the local neurologist.

Since Mother had already suspected MS, the diagnosis was initially a relief. "I was glad to know I wasn't bonkers or had a brain tumor." As she continued to educate herself about MS, she became depressed, worrying about how bad it could get for her. Father apparently helped her reorient herself to the fact that it is not life-threatening. Father had been very supportive, according to Mother. He commented, "We kind of got in this for the long haul 25 years ago. Leaving never entered the picture." He seemed most interested in keeping up-to-date with information about MS.

The two older children were 19 and 18 at the time of the diagnosis, whereas Daughter was only 11. Mother admitted she had initially told only the older two about her diagnosis. At first, they had been very attentive to Mother; but, as Father put it, "She's so active, they've

begun taking it for granted." The son had brought home to Mother a vial of anointing oil which had been blessed by his school principal, a priest. This was fondly remembered by Mother. Daughter soon began asking questions because Mother walked a little differently. As she did not believe that Daughter was old enough to understand, Mother did not offer much explanation. Daughter stated, "I'm just now understanding it."

Both sets of parents of Mother and Father had died prior to the diagnosis. This did not seem to significantly affect Mother's discussion of her acceptance. Mother's siblings "babied" her at first, which she did not appreciate. Most have since adjusted to her needs. Her brother's wife was the owner of the candy shop where she worked, and had given her freedom to adjust her hours as her health requires. One of Father's sisters was an RN and had, herself, been in very poor health. She had been very supportive.

Although the family belonged to a church, they did not seem to have found a strong source of support there. Mother stated that she had only recently shared the diagnosis with a limited group of people in the church. The priest often inquired as to her health; but Mother seemed uncomfortable expecting more from him. "There are so many people who need more help than I do."

When discussing friends, Mother pointed out that a good

friend and neighbor had been diagnosed with MS about the same time as she had. Although the friend's condition was worse, they continued to support each other. Both parents believed that they had maintained the majority of their friends through these years. Father said, "Your true friends are your friends no matter what."

It is important to point out that Mother did not like the term "acceptance." She believed she had learned to continue to live healthfully with the disease. To accept, in her mind, was to give up.

This family did not seem to have been forced to make many changes. Father had only once had to adjust his working hours, when Mother was in the hospital. At the time of diagnosis, the older children were at the stage in adolescence when they were beginning to separate, so the parents did not seem to have expected much involvement from them. Daughter shared her disappointment in how Mother had had to limit involvement in her activities. Mother was missing her daily walks around the neighborhood, hiking with the family on vacations, and waterskiing. She said she was pleased to simply ride in the family boat. Mother and Father agreed that their relationship is stronger as a result of the situation.

Symptoms

After Mother began experiencing problems with her right leg, she also experienced numbness in her left thumb and

index finger. These problems had remained. She slowly lost the vision in her right eye, then slowly regained it. Her sense of balance had been affected, and she experienced chronic fatigue. She spoke of pain in her limbs more than the other subjects had. She also had experienced sleeplessness and headaches, which are also uncommon in MS patients. Mother was on numerous medications for her varied symptoms. She was defensive about a few medications which are normally used for depression and anxiety, saying they were for her pain and sleep problems. There was no evidence in her walking of typical MS problems or the pain which she was experiencing. In fact, by mere observation, one would not have suspected that she had MS.

Assistance

Father discussed how Mother tended to overdo herself, with consequent exhaustion. He had tried to encourage her to slow down, but was largely unsuccessful. He had, however, recently convinced her to employ a housekeeper. Mother's medical insurance was through Father's business. There had been no alcohol or drug problems, and no one in the family had sought professional counseling.

Description of Daughter by Parents

Daughter had been an average student, who was adjusting to her new school and "not doing as well as I want." She expressed sincere interest in going to college, unlike the

pattern of the rest of the family. The parents believed she was too talkative, especially on the phone, due to her having a large group of friends. She had never been a troublemaker, and her parents believed she was "a normal 14-year-old girl."

The Family Tests

All family members participating in the study took all tests. When the tests were distributed, the same instructions were given as for the previous families, indicating that they were to fill them out with regard to the entire family. As the family was responding, it became evident that the instructions were confusing because the two older children, although still living at home, were no longer contributing to the family structure. The tests were completed with obvious frustration on the part of Mother and Father.

When the tests were reviewed shortly following the first session, it became apparent that the two older children's separation from the family had led to very skewed results, which did not seem consistent with my impression of the family that had been gleaned from the initial interview. Therefore, it was decided to ask the family, at the time of the final interview, if they would be willing to redo the tests, considering only Mother, Father, and Daughter as the family. The family was very agreeable, and it is the second set of test results which is discussed

here. Later, when working with two families in a similar situation, the amended instructions were used. Table 37 gives the results from the second administration.

Family Hardiness Index

Even though Father's FHI score was slightly higher than Mother's, both were above the average of the norming sample. They totally agreed in their level of confidence in the family's cooperativeness and mutual adequacy, and their positive views of the challenges of life. They both felt that little control was exerted by external factors out of their control, and had strong faith in their joint internal strength. There were no items on this instrument to which the parents' responses differed markedly.

Daughter's extremely low FHI score indicated a very low level of confidence in the family and its ability to cope with stress. All four subareas were low. There were, however, six items to which all three gave an identical response. Items of interest are shown in Table 38. By reviewing Daughter's other responses, it appears as if she did not feel appreciated; felt responsible for problems that occurred; felt that good things did not balance the bad things; and that the family was boring. Whereas the response "Not Applicable" had been used only once among the previous families, Daughter used it three times, in response to items 2, 5 and 9.

TABLE 37

FAMILY 208--FAMILY TESTS

Scale	Subscale	Maximum Score	Patient (Mother)	Spouse (Father)	Daughter Gd. 9.1
FHI					
	Cooriented-Commitment	24	20	21	13
	Confidence	12	11	11	5
	Challenge	15	13	13	9
	Control-External	9	6	7	4
	Total	60	50 (63)[a]	52 (80)	31 (02)
F-COPES					
	Acquiring-Social Supp.	45	22 (20)[b]	25 (40)	24 (26)
	Reframing	40	35 (87)	33 (77)	24 (12)
	Seeking-Spirit. Sup.	20	15 (28)	12 (13)	16 (65)
	Mobilizing	20	11 (31)	11 (43)	4 (05)
	Passive-Appraisal	20	18 (99)	17 (99)	9 (49)
	Total	145	101 (69)	98 (67)	77 (12)
FACES-II					
	Cohesion	80	61 (5)[c] z=-0.46	65 (6) z=0.01	36 (02) z=-2.21
	Adaptability	70	44 (4) z=-0.89	44 (4) z=-0.89	26 (1) z=-2.46
	Family Type	-	(4.5)	(5)	(1.5)

[a] Numbers in parentheses are percentile ranks from the appropriate norms: One overall norm for total score only. [b] Numbers in parentheses are percentile ranks from the appropriate norms: norms are for adults or adolescents, male or female. [c] Numbers in parentheses are from Linear Scoring Model (figure 2).

TABLE 38

FAMILY 208--SELECTED FHI RESPONSES[a]

	False	Mostly False	Mostly True	True	Not Applic
2. It is not wise to plan ahead and hope because things do not turn out anyway.	P	Sp			D
5. We have a sense of being strong even when we face big problems.				P,Sp	D
6. Many times I feel I can trust that even in difficult times things will work out.				All	
9. We believe that things will work out for the better if we work together as a family.				P,Sp	D
11. We strive together and help each other no matter what.			All		
13. We listen to each other's problems, hurts and fears.			All		
16. It is better to stay at home than go out and do things with others.	All				
17. Being active and learning new things are encouraged.				All	
18. We work together to solve problems.			All		

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

Family Crises Oriented
Personal Scales

The F-COPES instrument continued to indicate that Daughter differed markedly from her parents in how she handled stress. Both parents were slightly above average overall, whereas she was well below. The parents' score profiles were very similar. Both scored very high on the Passive Appraisal subscale, indicating that neither would resort to giving up or ignoring problems. On Reframing, the scores indicated that they were able to look at situations in a more positive light, making life easier to handle. Although Father was below average, Mother was well below average on Acquiring Social Support and Mobilizing Family to seek and accept help. Both were very low on Seeking Spiritual Support. This last was the one subscale on which Daughter scored above average. She was average on Passive Appraisal, and much below average on Acquiring Social Support, Reframing, and Mobilizing the Family, the last being extremely low.

It is of interest to note five of the six items on which the parents differed significantly from each other. Items of interest are delineated in Table 39. (On the first administration, 20 of the 30 items yielded markedly different responses.) Their seemingly contradictory responses to items 2 and 16 are intriguing.

Daughter differed markedly from one or both of her parents--most often both--on 14 of the 30 items. Six of

TABLE 39

FAMILY 208--SELECTED F-COPES RESPONSES[a]

	Strongly Disagree	Moderate Disagree	Neither	Moderate Agree	Strongly Agree
1. Sharing our difficulties with relatives.		P	D		Sp
2. Seeking encouragement and support from friends.		P		Sp,D	
3. Knowing we have the power to solve major problems.		D			P,Sp
4. Seeking information and advice from persons in other families who have faced the same or similar problems.				All	
8. Recieving gifts and favors from neighbors.	All				
10. Asking neighbors for favors and assistance.	All				
11. Facing the problem "head-on" and trying to get solution right away.	D			Sp	P
14. Attending church services.		Sp		P,D	
16. Sharing concerns with close friends.		Sp		P,D	
18. Exercising with friends to stay fit and reduce tension.	P,Sp			D	
21. Seeking professional counseling and help for family difficulties.		D		P	Sp
22. Believing we can handle our own problems.	D			P	Sp
27. Seeking advice from a minister.		P,Sp		D	
28. Believing if we wait long enough the problem will go away.	P,Sp			D	
29. Sharing problems with neighbors.	All				

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

these warrant discussion and are shown in Table 39. She was in obvious disagreement with her parents in her belief that the family did not have the strength to deal with problems or the desire to seek help.

The entire family agreed on four items, which were 4, 8, 10 and 29.

Family Adaptability and
Cohesion Evaluation
Scale-II

Once again, Mother's and Father's scores indicated similar views of the family, whereas Daughter saw it very differently. Mother and Father both saw the family as connected on the Cohesion dimension and structured on the Adaptability dimension. Mother's family type was on the border between moderately balanced and mid-range, and Father's was moderately balanced. Daughter had them disengaged and rigid, with an extreme family type.

The parents differed markedly in their responses to five items, whereas on the first administration, they had differed on 16 of the 30 items. Items of interest are displayed in Table 40. By reviewing Daughter's pattern of response, particularly the 23 items where her response differed greatly from that of one or both parents (generally both), a frustrated, isolated picture emerges. She felt that her parents were pairing up, excluding her from decision making and thus from the family. She felt that the discipline was too punitive, and that she could be closer to

TABLE 40

FAMILY 208--SELECTED FACES RESPONSES[a]

	Almost Never	Once in Awhile	Some-times	Freq-uently	Almost Always
10. We shift household responsibilities from person to person.	All				
11. Family members know each other's close friends.					All
16. In solving problems, the children's suggestions are followed.	D	P		Sp	
17. Family members feel very close to each other.			P,D		Sp
21. Family members go along with what the family decides to do.	D		P		Sp
24. It is difficult to get a rule changed in our family.	Sp		P		D
28. Family members are afraid to say what is on their minds.	All				
29. Family members pair up rather than do things as a total family.		P		Sp	D

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

people outside the family than to those within.

Individual Testing of Daughter

Mother warmly welcomed my assistant and me when we returned for the second session. Daughter quickly settled down for the testing and was cooperative. All the age-appropriate assessment instruments were administered. The school very quickly returned the report of her latest IQ standard score. Using an unspecified Scholastic Testing Service, Incorporated instrument, Daughter's IQ was reported as 105, which was average. It is my opinion that this score may be somewhat depressed as a result of her obvious problems with the family as previously mentioned.

Table 41 gives the results of Daughter's objective tests.

Empathy scale

Daughter was administered the Emotional Empathetic Tendency Scales. Her score reflected an above average ability to empathize.

Survey of Interpersonal Values

On the value of Benevolence subscale of the SIV, Daughter's score was extremely high in relation to the norming group. The other subscale on which her score was almost as high was the value of Receiving Recognition. The third subscale on which her score was above average was the

TABLE 41

FAMILY 208--CHILD TESTS

Scale	Subscale	Maximum Score		Daughter Gd. 9.1
EMPATHY			M[a]	89
				z= 2.14
PIERS-HARRIS	Behavior	16		10 (25)[b]
	Intellect	17		5 (06)
	Physical	13		6 (25)
	Anxiety	14		3 (03)
	Popularity	12		9 (52)
	Happiness	10		7 (39)
	Total Scale	80		44 (27)
SIV				
	Support	45	**[c]	19 (79)[d]
	Conformity	45		12 (34)
	Recognition	39		18 (92)
	Independence	48		10 (34)
	Benevolence	45		26 (94)
	Leadership	48		5 (15)

[a]M = Mehrabian overall norms with score range = -132 to +132. [b]Figures in parentheses are percentile ranks for the complete norming population. [c]** = Grade 9 vocational norms, male or female; * = Grade 11 and 12 norms, male or female. [d] Figures in parentheses are percentile ranks for the appropriate norms.

value of feeling Supported. The two subareas on which she scored slightly below average were the values of Independence and Conformity. Her lowest score, well below average, was the value she places on Leadership.

Piers-Harris Children's Self-Concept Scale

The profile of Daughter's scores on the Piers-Harris Children's Self-Concept Scale is included in appendix D. Daughter's self-concept was within the low average range. She felt most comfortable with her popularity, which was just above average. Her expressed sense of happiness and satisfaction, her physical appearance and attributes, and her behavior lay within the average range. Her concepts of her intellectual and school status and freedom from anxiety were well below average.

Projective tests

Daughter hesitated initially with the drawing tasks, claiming "I can't draw; it probably won't even look like a person." After encouragement, and assurance that artistic ability was not being judged, she complied without complaint.

Daughter's HFD reflected emotional concerns rather than a lack of artistic skill. Her drawing suggested that she felt out of balance with her life. She felt insecure, self-conscious, and introverted. There appeared to be a sense of helplessness due possibly to a restrictive or

limiting environment. Normal sexual concerns due to adolescent adjustment were extremely inflated for this girl.

For the KFD, Daughter drew her entire family of origin. Her older sister and Mother were drawn next to each other, sunning on beach towels, with Father, off to the side, talking to them. Daughter and older brother were "playing together" in the sand, with their backs toward the rest of the family, lower in the picture. She and her brother were not very close together. No one in the picture was looking at anyone else. They were drawn as stick figures, even though there had been a specific request that this not be done. Daughter apparently felt very separated from the family, but felt some connection to her brother. Mother, Father, and her sister seemed to be a family unit within the family, that kept even Father on the periphery.

Throughout the RATC, Daughter's stories tended to grow in length. She seemed to focus on something bad happening and the inability to properly deal with that situation, resulting in the problem continuing to grow. The profile of her RATC scores is included in appendix E. The Adaptive scale suggests that her problem-solving ability was below average, and she tended to resolve things in an immature fashion. She seemed to have average reliance on others and the ability to turn to herself for support. However, her support for others score was extremely low, in contrast to her empathy and value of benevolence scores. This could be

because her stories seemed to agitate her, causing an extremely high aggression score on the Clinical scale. Depression, feelings of rejection, and unresolved feelings were also above average. Only anxiety was within the average range, in contrast to the indication from the Piers-Harris that she did not feel free from anxiety. She may have been perceiving the tension from her aggressive tendencies as anxiety.

After the testing was completed, I talked briefly with Daughter, due to the concern raised by her stories. She gave no indication that the family "punishments" were extreme. She did, however, admit that she was "yelled at an awful lot." When asked who did the yelling, she merely shrugged her shoulders and said "Everyone." She shared that, in her opinion, Mother's MS had not changed life much. "They still go places," meaning her parents. She finished by very quietly saying, as if it were a secret, "When Mom doesn't feel good, she's in a bad mood."

Exit Interview

Although there was a longer than normal gap between the second and third sessions, my assistant and I were welcomed just as warmly into the home by Father. During this period, the eldest daughter had moved out of the house, much to the relief of Father and Daughter. There was little discussion about the first interview, as everyone felt that it was fine. Mother was excited to share that she had been

selected to participate in an experimental treatment program, beginning the following summer.

Father commented that the worst thing about their family was that they did not care enough about Mother. Since her condition was mild, the MS was probably taken for granted. Mother added that it was hard to get any sympathy around the house. I had sensed a trace of blame which is unhealthy, but not unusual in families with MS. When this was brought up, Father nodded and shared that he was "trained early" for blame. Father's father had died at a young age, leaving Father very angry and blaming his father for his own death. Only after the family history of heart problems was recognized, was he able to forgive his father. He said he was trying hard to be supportive of Mother, and she nodded agreement. They said, "It is a day-by-day proposition," meaning their ability to deal with the MS.

Father was very interested in seeing the results of the study. He said he knew that good children come from good families, but wondered what it was that made a family good and work well. He asked that, when the results were sent to the participant families, I should let them know whether the scores of the two sets of family tests differed greatly. I agreed to do this.

I commented that the house was beautifully decorated for the holidays. Mother was proud to point out the various decorations that she had personally made. Father seemed

very proud, not only of her artistic ability, but of her desire to keep the house festive and attractive. Mother jokingly added, "The reason I have a 21-year-old son still living at home is to decorate my 40-foot trees out front." Daughter quickly protested with, "Hey, I help," and Father agreed. One could sense Daughter's feeling of being unappreciated.

I left with no serious concerns about this family, but did feel that Daughter was unhappy. Once all the tests results were reviewed, it became obvious that there were more problems than could be simply observed. As with the boy in Family 202, I intend to contact the parents and inform them of my concerns that Daughter could benefit from an intervention. This intervention should clearly be on the part of another professional.

Family Summary

Family 208 consisted of the mother patient, the father, two daughters, ages 22 and 14, and a son, age 21. Only the younger daughter participated in the study. She was 11 at the time of diagnosis. Since Mother was not noticeably suffering from the MS, the family seemed to overlook the hidden symptoms, such as fatigue, which can be disabling in themselves. Mother seemed good natured about this, but frustrated. Father appeared caring and supportive. Daughter was introverted, but cooperative.

The family tests revealed that the parents believed in

their joint family hardiness, whereas Daughter had very low confidence in the family. The parents felt they were well able to cope with difficult situations, but Daughter did not agree. Mother and Father saw the family as of a favorable family type, whereas Daughter saw them as of an extreme type.

The individual testing indicated that Daughter had an average cognitive ability, with an above average sense of empathy, and she placed a very high value on altruism. Her self-concept was low average. Her value system was developing normally. She did not demonstrate an ability either to identify problems, or to resolve them, in a mature fashion. Emotional concerns for this girl were extreme, with aggressive and depressive tendencies, feelings of rejection and unresolved feelings. She appeared to be isolated from the family unit, suffering a sense of helplessness.

Family 209

The mother of family 209 learned about the research project while in an MS support group meeting, when she overheard the mother of family 208 discussing it with the father of a family attempting to schedule appointments with me. When she was contacted by telephone to verify her interest, she offered her family immediately. A packet of information was sent to her which she returned very promptly. The family lived in a small town in a rural

community. They had a small modest home in a pleasant residential area.

Demographics

Family 209 consisted of the mother (the patient), age 35; the father, age 38; the son, age 11; and the daughter, age 8. The parents were married in August of 1979. Son was in the fifth grade at the local elementary school; Daughter was in the second grade at the same school. Mother had a B.A. degree in art education and had been a preschool teacher; later she worked as a library clerk for 4 years. She quit when Father graduated from college. Father had a B.S. degree in electrical engineering and had been a computer programmer for 11 years in the same steel company. He worked 40 or more hours per week.

Diagnosis and Acceptance

Father and children were reported as healthy. Mother believed that she had had the MS since the age of 17, because of various symptoms she had begun experiencing at that time. The MS was not professionally diagnosed until February of 1984 when the symptoms had worsened. Her general practitioner had suspected the MS and referred her to a neurologist for further testing. The neurologist administered a Visual Evoked Potential, a Brainstem Auditory Evoked Response, and a spinal tap. Mother's positive results on these tests verified the MS. She was told by the

neurologist that she had "textbook MS," and should think twice about having other children. Son was 2 at the time of diagnosis. Mother shared that she was not comfortable with that doctor, so she returned to her GP for continued care. That physician was very supportive, and gave her information about the disease, and where to go for help. She felt he was very compassionate because his own mother had MS. Sometime within the 2 years prior to this interview, he referred her to a different neurologist for care of her MS because of her deterioration.

Mother had been overjoyed when she was given her diagnosis, because for years doctors had told her it was in her head. She said she had kept telling herself, "I'm not nuts." She admitted to not having followed up on some of the doctor's recommendations for reading up on the disease, because it did not matter. She was so relieved to get a diagnosis that initially she did not care much about what she had. Eventually, she immersed herself in reading material.

Father shared that he knew something was wrong with Mother, and he also was relieved to get the diagnosis. He pointed out that Mother's condition was not very bad at the time of the diagnosis. "Her progressive deterioration has been a learning process through experience."

Because Son was so young, he had no memory of the diagnosis. He shared that Mother had "always been this

way." Mother and Father decided to have their second child, as they had planned, after discussing it with their GP. He was very supportive of the idea.

The parents had shared the diagnosis with friends and both of their families. Mother said her parents were in total denial. "You didn't get it from me" had come from both of her parents. It was only in the 3 years prior to the interview that they had begun to accept it and to offer support. Her grandmother and an aunt have been very caring.

Father shared that he was not close emotionally or geographically to his family. His mother had had severe arthritis since he was a child. His father had suffered a stroke and was in a VA hospital with brain damage. "They had their own problems to deal with." Mother's siblings are younger and had backed her throughout her problems. Father's brother was a very busy owner of a private business, but readily came to their aid when needed. He built a ramp to the door of their house, for example.

When the children were asked about how Mother's MS had affected them, Son became talkative. He shared that it had bothered him quite a bit when he was younger, but as he had grown up it had bothered him less. Mother said she regretted that she could not attend a lot of his sports activities. Son seemed surprised, and said, "But you do." It became evident that Mother had an image of the "perfect mother" which she could not fulfill. When I suggested this,

Mother commented about her very full childhood and her mother. "I just want to give my children the same opportunities I had." She seemed disappointed that she could not also be the kind of mother her mother was for her. Daughter said that she liked her Mother that way. "She walks slower than Dad so I can keep up with her." She also let Daughter ride her motorized cart, which is "great fun."

As the nuclear family, everyone was helping around the house. Mother said, without any apparent guilt, that the children had a lot more responsibility than most children their age. Father did more around the house than most fathers might. He did the shopping and all of the yard work, although the children added that they helped him with both. Mother shared that she did the laundry and the cooking, with the children's help.

Father did not believe that Mother's MS interfered with his work. His job allowed him the freedom to take off time if she should need him.

The family attended church regularly, but they rarely discussed Mother's MS there. The church had allowed her to borrow a walker while Medicare was deciding if they would pay for one.

The parents' friends did not know much about MS. Most remained friends. Mother described a rather intricate network of friends which had developed into a support system. Since she did not have a job, she served as the

"telephoner" for all these working mothers. In return, they helped transport her children.

Symptoms and Treatment

Mother's first symptom, when she was only 17, had been the loss of her peripheral vision, which eventually returned. She then described a progression of symptoms. She had been numb from the waist down, but that also remitted. At times she had been color blind, and had had muscle spasms. At the time of the interview, she was experiencing tingling in her legs, a lack of balance, a neurogenic bladder, left-side weakness, and cognitive weaknesses. These included difficulty with auditory figure-ground, memory, and "I can think faster than I can speak." She regularly took numerous medications, in which she placed great value.

Assistance

Mother's head seemed to pull to the left whether sitting or walking, and she walked in a bent-over fashion with the help of a walker. Her gait was very hesitant and slow. She periodically received occupational therapy and physical therapy from the Visiting Nurse Association, which had helped her purchase a motorized cart. She had progressed from a cane to a walker for the home. When outside the home, she had used a manual wheelchair until her weakness forced her to purchase the cart. She expressed her

appreciation for the generosity of a stranger who had given her a lift chair when he found out she needed it for comfort and standing.

Mother had a cleaning woman come in once a week to dust and vacuum. If she needed help with child care, either Father or her mother would help. Mother was on Father's health insurance. She received Social Security disability and Medicare hospitalization. The family had not sought any professional counseling. It was at this point that Mother shared that she and Father had jointly initiated a local MS support group. After 1 year, it was dissolved due to lack of attendance, and they began to attend a support group in the nearby city.

Emotional Issues

Mother revealed that she no longer drives. Earlier that year she had become unable to brake with her foot, so she decided she was an unsafe driver. I pointed out the benefit of hand controls. Mother thought they had to be on the left side which was her weak side, but I said they could be on either side. After thinking about it, Mother added that she was afraid the weakness in her left hand would interfere with her control of the steering wheel.

When asked if there was anything else the family wanted to share, Mother said, "I want to know if [Father] is resentful" (clearly meaning toward herself and the MS). I pointed out that I try to elicit such information if it

should seem appropriate. Father, however, had not indicated any anger or frustration; Father smiled, and responded "No, I'm not resentful." He continued to explain that, by growing up with a mother who had arthritis, he did not resent illness or the problems it can cause a family. At that point, Mother began quietly crying, as if in relief, and Daughter immediately was at her side hugging her.

Description of Children by Parents

Son was a straight-A student who, according to the parents, was very socially aware. He had no behavioral problems; but Father was aware of some minor changes as Son was nearing adolescence. He had many friends, who felt comfortable coming to his house.

Daughter had been diagnosed with a learning disability while in kindergarten, and was receiving special education in reading and spelling. She was an A student, who liked art and math. The parents said she was a good girl and had a lot of friends, who also liked to come to the house.

Mother proudly said, "They are very independent children." They shared a one-day-a-week paper route, folding and delivering the papers together. The parents had them save part of their profits. The children seemed pleased that they were allowed to use some of the money, and were glad that they were saving for college. My assistant and I found both children very warm and friendly after the

easing of the initial tension upon meeting strangers.

The Family Tests

Table 42 gives the results of the family members on these tests. The two children took only FACES-II.

Family Hardiness Index

Both parents scored low on the Family Hardiness Index, in relation to the norming sample, largely due to very low scores on two subscales. Both responded in a fashion which suggested that they felt control was exerted by external factors out of their control. Neither viewed the challenges of life in a positive manner. However, they both were very confident in the family's sense of cooperation and mutual adequacy, and had faith in their joint internal strength.

Of the 20 items, there was only 1 on which their responses differed greatly. Mother responded "Mostly true," whereas Father responded "Mostly false," to item 19, "Most of the unhappy things that happen are due to bad luck." They gave identical answers to 11 of the remaining items. These basically reflect their belief in the family's ability to work together.

Family Crisis Oriented Personal Scales

Mother scored very high overall on the Family Crisis Oriented Personal Scales, with Father scoring well above average. Their most positive problem-solving attitude

TABLE 42

FAMILY 209--FAMILY TESTS

Scale	Subscale	Maximum Score	Patient (Mother)	Spouse (Father)	Son Gd. 5	Daughter Gd. 2
FHI						
	Cooriented-Commitment	24	23	19	Too	Too
	Confidence	12	10	10		
	Challenge	15	8	8	Young	Young
	Control-External	9	2	5		
	Total	60	43 (24)[a]	42 (20)		
F-COPES						
	Acquiring-Social Supp.	45	36 (93)[b]	25 (40)		
	Reframing	40	35 (87)	35 (88)	Too	Too
	Seeking-Spirit. Sup.	20	17 (57)	12 (13)	Young	Young
	Mobilizing	20	15 (81)	8 (16)		
	Passive-Appraisal	20	13 (95)	19 (99)		
	Total	145	116 (95)	99 (70)		
FACES-II						
	Cohesion	80	66 (6)[c] z=0.13	63 (5) z=-0.23	51 (3) z=-0.58	71 (7) z=1.60
	Adaptability	70	55 (7) z=0.77	49 (5) z=-0.14	45 (4) z=-0.05	51 (6) z=0.71
	Family Type	-	(6.5)	(5)	(3.5)	(6.5)

[a]Numbers in parentheses are percentile ranks from the appropriate norms: one overall norm for total score only. [b]Numbers in parentheses are percentile ranks from the appropriate norms: norms are for adults or adolescents, male or female. [c]Numbers in parentheses are from Linear Scoring Model (figure 2).

was on the Passive Appraisal scale, where they both scored very high. Neither would resort to ignoring a problem or giving up. They both believed they were well able to reframe situations to make them more manageable. Mother found much of her strength through acquiring social support, and mobilizing the family. She was the one who had a large network of friends who helped her and whom she helped. She also was the one who kept the family organized. Father was near average in his desire to acquire social support, but much below average in mobilizing the family. He was observed to be the one who ran the errands for the family while Mother was caring for the children. Mother sought spiritual support at an average level, whereas Father was much below that.

Their responses differed greatly on 8 of the 30 items. Seven of these reflected Father's disinclination to turn to neighbors or friends for help. Item 26, "Feeling that no matter what we do to prepare, we will have difficulty handling problems," brought a response of "Strongly agree" from Mother and "Strongly disagree" from Father. By examining the seven items to which they responded identically, it is obvious that they had tremendous confidence in the strength of their family facing and dealing with problems, and accepting that such difficulties are a part of life.

Family Adaptability and
Cohesion Evaluation
Scales-II

The entire family responded to the FACES-II instrument, with it being read to Daughter. She seemed to understand the questions very well. The family's scores indicated that Mother and Daughter believed their family type was on the border between moderately balanced and balanced, and Father believed they were moderately balanced; but Son believed they were mid-range. Mother had the family connected on the Cohesion dimension, and very flexible on the Adaptability dimension. Daughter saw them as very connected and flexible, whereas Father viewed them as connected and flexible. Son stood alone by rating them as separated and structured.

It is interesting to note that the four items on which the parents disagreed the most were ones that demonstrated Mother's organizing of the family. There were 10 items on which the children responded very differently. Their pattern suggested that Son did not feel as if he was a valuable member of the family; but this may be a function of early adolescent rebellion. Daughter appeared to have a more idealistic concept of the family than did the other members. There are four items on which the family's responses were identical as shown in Table 43.

TABLE 43

FAMILY 209--SELECTED FACES RESPONSES[a]

	Almost Never	Once in Awhile	Some-times	Freq-uently	Almost Always
12. It is hard to know what the rules are in our family.	All				
17. Family members feel very close to each other.					All
22. In our family, everyone shares responsibilities.					All
25. Family members avoid each other at home.	All				

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

Individual Testing of Children

Vineland Adaptive Behavior Scale

Both of the children's teachers rapidly returned the Vineland Scales. According to Son's scale, his teacher rated him within the average range in Communication (94), the borderline range in Daily Living Skills (74), and the above average range in Socialization (113). The Adaptive Behavior composite was average at 92. The sub-domains about which the teacher was most concerned were Personal and Domestic Daily Living Skills. By reviewing the specific questions, it appeared as if the teacher hesitated estimating anything if he had not observed the performance. It was obvious to both my assistant and me that Son was very capable within the domestic sub-domain, and should have scored at least adequate, bringing the overall Adaptive Behavior higher within the average range. The teacher's comments were only positive, discussing how intelligent, motivated and caring Son was. He respected others and rules, and was very eager to please. He worked at or above grade level in all his subjects.

Daughter's teacher rated her average in Communication (91) and in Daily Living Skills (103). The Socialization domain was above average (116). The Adaptive Behavior composite was average at 103. The only sub-domain where problems were noted was Written Communication, which seemed to be a direct reflection of her diagnosed learning

disability. Two areas of strength were her Expressive Communication, compensating for the learning disability, and Domestic Living Skills. Both she and her brother were given above average ratings for Coping Skills, within the Socialization domain. The teacher's written comments indicated that she was supportive of Daughter. She saw her as a very compliant child, eager to help, motivated to learn, and intelligent. She was special because she was so friendly and sociable. The teacher believed that she was a pretty normal second-grade child.

When my assistant and I returned for the second session, the children were finishing dinner. Daughter rapidly consumed her meal so she could get started, and was animated throughout the session. Son was more leisurely, both in finishing dinner and completing the tests. Total cooperation was given by both children. The children's scores on the objective tests are shown in Table 44.

Empathy scale

Son's score on the Bryant Index of Empathy scale was above average on the grade 4 male norms. The test was read to Daughter, who also scored above average on the grade 1 female norms.

Piers-Harris Children's
Self-Concept Scale

The profiles of the children's scores on the Piers-Harris Children's Self-Concept Scale are included in

TABLE 44

FAMILY 209--CHILD TESTS

Scale	Subscale	Maximum Score	Son Gd. 5.1	Daughter Gd. 2.1
EMPATHY			B4[a] 15 z= 1.02	B1 16 z= 0.75
PIERS-HARRIS	Behavior	16	16 (95)[b]	16 (95)
	Intellect	17	17 (98)	15 (81)
	Physical	13	12 (91)	11 (84)
	Anxiety	14	14 (97)	12 (81)
	Popularity	12	11 (86)	9 (52)
	Happiness	10	10 (90)	10 (90)
	Total Scale	80	75 (98)	72 (95)
SIV				
	Support	45		
	Conformity	45	Too	Too
	Recognition	39		
	Independence	48	Young	Young
	Benevolence	45		
	Leadership	48		

[a]B1 = male or female norms for Grade 1 on Y/N Bryant Scale with score range = 0-22. B4 = male or female norms for Grade 4 on Y/N Bryant Scale, range = 0-22. [b]Figures in parentheses are percentile ranks for the complete norming population.

appendix D. Son's profile demonstrated a very positive, solid self-concept. In all areas, he was well above average. The test was read to Daughter. She also demonstrated a very positive self-concept, with all areas well above average, except her confidence in her popularity, which was just above average.

Projective tests

Son's HFD was of a powerful, confident-looking boy. Son appeared to be a well-behaved young man, who was trying very hard to inhibit impulsive behavior, controlling his aggression so that he was merely assertive. There appeared to be a conflict over this control, as well as over normal dependency issues versus a desire for independence. Daughter's HFD, which was of her best friend, "who is just like me," was indicative of minimal brain dysfunction. Daughter felt out of balance between her striving for achievement and her learning disability. There was a defensive quality to her drawing.

Both children's KFD's had the family watching television together. Son drew them in the family room, lying around. Mother was drawn first, lying on the couch, while Son commented,"Dad's usually on the couch and Mom's in the kitchen." Therefore, he purposely kept Mother as an integral part of the family. Father and Daughter were lying in front of Mother, separated from each other by the coffee table. Son placed himself in the most distant position,

separated from everyone by that table. Although no one was looking at another, Son and Father were facing each other, and Mother and Daughter were facing one another. He viewed Daughter as a rather helpless child, and had Mother reaching out for her. Daughter's KFD had the family watching television, lying together in one bed. She commented that they do this a lot, and then proceeded to develop a story as she drew her picture. She drew a table with cards, explaining that they had just finished some games and "it's time to go to bed." The family was drawn left to right as Father, Mother, Son, and herself. She said, "They are watching a good program when the phone rings." She then drew a table with a phone ringing. "Dad says, 'Don't answer it,' and Mom is happy." Daughter appeared to have an appropriate, positive image about her family and their relationship with one another.

Son's responses to the RATC tended to be short and somewhat incomplete. His stories often had the theme of a child getting into trouble, causing parental disappointment. The Adaptive scale suggested an average reliance on others, an ability to support others, an ability to set limits, and an ability to identify problems. His ability to resolve problems was immature for his age. His sense of self-sufficiency was above average. The Clinical scale indicated a very high level of depression, but a low level of anxiety. Aggression, feelings of rejection, and unresolved feelings

were all within the average range. Daughter's RATC stories were unusually long and creative. It was difficult for me to keep up with the notes as the stories were being told. Daughter commented that she did not like stories to end badly. This contributed to the length of her stories, as she tried to find happy endings to obviously sad pictures. Daughter's profile indicated a very positive, if not overly optimistic, outlook. She was somewhat dependent on others, yet had a very strong sense of self-sufficiency, within the Adaptive scale. She had an above average ability to support others, set limits, and to identify problems. Her ability to resolve was strongly average. Within the Clinical scale, her level of depression was slightly above average, and her anxiety was very low. Feelings of aggression and rejection, and unresolved feelings were average for her age. The profiles of the children's RATC scores are included in appendix E.

As my assistant and I prepared to leave, Daughter animatedly said, "Come and see us soon."

Exit Interview

When my assistant and I returned for the final interview, Father and the children followed us into the house, as the children were just returning from dental appointments. After the children excitedly shared good reports with Mother, the family quickly settled down for the interview. When asked to react to the sessions, Father

began by commenting that he had had no problem with his involvement. Son said he also had had no problems, but Art was not his favorite subject. Daughter interjected that it was hers, and she had had a lot of fun. Mother's response indicated that she had been thinking, not only about their involvement, but also about the project as a whole. "This is something that really needs to be done. We've strived really hard, and we're real pleased." She continued, with some uneasiness in her voice, to say that she wanted to make sure that they were "really O.K." seeking reassurance that what they as a family were doing to cope was the right thing. She had requested copies of the scored family tests, and they were given to her at that time. I was very comfortable in pointing out the family agreements, while indicating that Son's variance from this was normal at his age. Father and Son smiled, while Mother's eyes began filling with tears in apparent relief and happiness. Daughter immediately ran to her elbow to comfort her. Mother assured Daughter that the tears were from happiness.

Mother shared her concern about Father and all he had to do for the family. "He doesn't spend enough time for himself." She added that the children were helping more in an effort to "ease up" time for Father. She also wanted to be sure that I knew that Son had asthma. Daughter's learning disability had been focused on in the initial interview, when discussing any problems the children might

have, and Son had been overlooked.

This family was one of the most difficult to leave. Daughter was disappointed that there were no other sessions, and Mother and Father asked if they could keep in touch.

Family Summary

Family 209 consisted of the mother patient, the father, a son age 11, and a daughter age 8. Son was 2 at the time of diagnosis. Although fairly disabled, Mother was a very positive, strong, hopeful person. Father was loving and supportive. Son was openly frustrated by the behavioral requirements necessitated by Mother's condition, but still pleasant and cooperative. Daughter was outgoing and happy.

The family inventories indicated that the parents believed in the family's joint internal strength, but questioned their overall hardiness. They felt very capable of coping with stress, complementing each other in their coping strategies. All four viewed the family as of a favorable family type.

The individual testing suggested that Son had at least average cognitive ability, with strong socialization skills, an above average level of empathy, and a very positive self-concept. He was respectful and well behaved. Although well adjusted, he had trouble with problem-solving abilities, and displayed depressive tendencies. Daughter had average cognitive ability, with a diagnosed learning disability, strong socialization skills, an above average level of

empathy and a very positive self-concept. She was compliant and motivated, with a positive image about her family and the interrelationships. She seemed very well adjusted, with superior problem-resolution ability. Mild depressive tendencies were evident.

Family 210

Family 210 was among the first to respond to the initial mailing from the metropolitan clinic. The initial inverview was fairly easy to arrange, even though it was the holiday season. My assistant and I were warmly welcomed into their pleasant condominium in the suburbs of a city.

Demographics

Family 210 consisted of the mother (the patient), age 51; the father, age 51; a daughter, age 28; a son, age 26; a daughter, age 24; and a daughter, age 19. Father was a stepfather, having married Mother in July of 1990, although he had been a close family friend since 1984. Only the youngest daughter still lived in the home. When this family had volunteered for the study and been accepted for inclusion, the youngest daughter was a senior in high school. It was not realized until the first interview that in the intervening period she had graduated. She had, in fact, moved out of the home briefly, and then moved back home out of a sense of responsibility toward her mother. As she was still of high school age and living in the home, I

decided that she could offer information related to the upper limit of the designated age sample. Her siblings also were high school graduates. The eldest daughter had a family, and worked as grocery clerk and waitress; the son had a new baby, and worked erecting signs for a billboard company; the middle daughter was married, and worked as a medical assistant. All three continued to live within a few miles of home. These three elder children were not involved in the research because they were past school age and not in the home.

Mother was a high school graduate, and had taken computer training. She had been a part-time beautician until the necessary standing became a problem due to her MS. At the time of the interview, she had recently taken a new job as a part-time word processor. She worked 25 hours a week, and occasionally did beautician work in her home. She was a member of the local MS Society support group, where one of the members had made her aware of this research. When she received the packet of materials from the clinic, therefore, she and the family readily accepted and returned their materials.

Mother volunteered with a multidenominational organization, whose mission is to clothe the needy. Father graduated from high school. He had been the supervisor of crowd control for the large, local university for 14 years, working 50 to 60 hours per week. He said this did not allow

him time for other activities.

Prior to public high school, the youngest daughter (Daughter) had received a private Catholic education through the eighth grade. Since graduation, she had been searching for a job, and began one, as a computer record keeper for a trucking company, between the first and second sessions. Her only volunteer work was to babysit for her brother's infant. In fact, she was not present at the initial interview, because she had made a commitment to babysit, without consulting her mother, who claimed she had consulted with Daughter before arranging the appointment. Using a portable telephone, I was able to involve Daughter in the interview.

Diagnosis and Acceptance

Father and Daughter were reported as enjoying good health, although Daughter had had asthma as a child. Mother's MS was diagnosed in 1985. Mother had undergone back surgery a few years earlier. Thus, when she began to experience lower back problems, she suspected it was related to that surgery. She returned to her neurosurgeon, who suspected MS, and referred her to a neurologist. That physician initiated a serious physical therapy program, which seemed to worsen her condition. Father, at that time a close friend to Mother, had been seeking answers, and located a neurologist in the large metropolitan clinic. This physician hospitalized Mother, and ran numerous tests

"to rule out other problems." He confirmed the MS. Mother was given an MRI, a spinal tap, a myelogram, auditory and visual evoked potentials, and CAT scans, a rather unusual combination of older and newer diagnostic procedures.

Although Mother felt more confident about this last physician, she believed that doctors should have a better way "to break it to you" than to say "I think you have MS." Father believed that a pamphlet could be helpful in such situations, and Mother agreed. Mother tried to find as much information as possible as soon as she had received the diagnosis. "I was not afraid to talk about it to anyone who would listen."

Father seemed reluctant to respond to the question of how he dealt with the diagnosis, finally answering, "OK, I guess." As he continued, it became clear that he had been worried about Mother. Mother added that he had been very supportive. The oldest child was 20, and already out of the home, at the time of the diagnosis. The son was 18, the middle daughter, 16, and Daughter was 11. Although Mother said she shared the diagnosis with the children, neither Daughter nor the son, who stopped in briefly, gave me the impression she actually had. Mother seemed in awe when she discussed how the middle daughter had kept their home together while Mother was in and out of the hospital, and upon her final return home. Daughter remembered her sister as being "very bossy, but organized."

Mother's father had been diagnosed with cancer within 2 months of her diagnosis. She began crying, as she shared how difficult that time had been for her mother, because she wanted to be with both husband and daughter. Father quickly provided Mother with a tissue. Her siblings had been supportive, but mostly through the telephone. Father's brother and sister-in-law helped with food and child care while Mother was in the hospital. Father's mother was supportive and concerned.

Mother shared that the eldest daughter had left home "on a bad note," and had removed herself from the family. She "knew" about Mother's MS, but there was no explanation as to how she had gained this information. She visited, but did not offer to help in any way. Mother added that this daughter had never done much even when she was at home. Mother continued by saying that the middle daughter "just did things without being told." Father nicknamed her "Mother Two."

Daughter, being only 11 at the time of the diagnosis, seemed to be tagging along with her caregiver sister. Mother said she knew Daughter was concerned, but she did not know whether or not she was afraid. I had to ask Mother about the son, and she answered that he had done the yard work and cared for the dog. When the son briefly joined the interview, I asked what was his memory of that time. He said he did not know what his mother had. "I worry about

her a lot anyway," and he was obviously very worried at that time. "I asked somebody about whether it would kill her."

Daughter's memories were added a little later. She remembered being very afraid because her mother was in such obvious pain and she did not understand what was wrong with her.

Although the parents regularly attended church, they found no source of support there. When Mother owned her own beauty shop, the clients were physically supportive, helping hold her up as she worked on them with her poor balance. Father's employers did not complain if he needed time to help Mother. "I work so many hours, how could they?" Both parents emphasized the importance of their friends. "They came through better than the family." One had given a fund-raiser to help pay Mother's bills. They felt they did not lose any, and most became better friends.

When asked how the family might have changed as a result of Mother's MS, there was a long pause before Father replied that they have all had to realize what Mother's limits were, and they had "handled it." It had not affected his decision to marry her. He had never been married before, and had apparently gradually taken over many responsibilities even before they married.

Symptoms

Before Mother began experiencing problems with her back, her feet began to fall asleep, and then the numbness

climbed up toward her chest. There was no weakness at the time of the interview. Then her back had started hurting. She described the pain as "burning," and nothing had been able to alleviate it. The numbness stabilized along her left side and began to cause weakness, which resulted in two leg fractures due to falling. She described herself as unsteady due to her balance problems, frustrated with bladder incontinence, and feeling "real draggy." Periodically, she suffered from blurry vision, muscle spasms, and leg jerks. Mother was rather non-committal about medications, not sure exactly what she had taken and not sure whether they were useful or not. Her walking showed no obvious evidence of the chronic pain which she discussed. In observation, a slight drag of her left leg and hesitance in her walk were the only indications of the MS.

Assistance

Mother had had short-term housekeeping help as necessitated by her condition. Father and Daughter also helped. The only child-care help Mother had was with the middle daughter. She required no personal assistance, but sometimes used a cane when away from home. She was on Social Security disability until she earned too much money from her part-time computer processing job. She had tried to get back on it, but was denied, and was told by the Social Security office, "You are not, and have never been,

disabled." This infuriated Mother and Father.

Mother received medical insurance coverage through Father's job. No one had received counseling, although Mother said her ex-husband, the children's father, had had "an alcohol problem." Before the testing began in the second session, Mother asked to speak privately with me, explaining that her ex-husband had been an alcoholic and had died from complications of that disease. The son was very protective of his father, and had, himself, suffered from some alcohol problems. Mother had not wanted to discuss this in front of the son for fear of starting an argument.

Description of Daughter by Parents

According to Mother, for a teenager, Daughter could be very mature and level-headed, although she had made a few poor choices in her life. Of all her children, Daughter was the "most caring and sensitive." Academically, Daughter was on the honor roll most of the time. She behaved very well at school, and never had any problems there. Although she was very social, she tended to have only one good friend at a time. Mother added that, when she fell, she found her best coping skill to be laughter. Daughter became very angry when Mother laughed at her own clumsiness. "She's hurt herself in the past, and I'm worried about her."

The Family Tests

All family members included in the study took all

tests. The instructions given were as amended for family 208. Table 45 gives the results of the family tests.

Family Hardiness Index

Father's FHI scores were well above average, and well above Mother's and Daughter's. Considering the circumstances, it seemed as if he was trying very hard to become a member of the family and to give the appearance of a strong, united family. Mother and Daughter, however, appeared more realistic with scores slightly above and below average, respectively. Both Mother and Daughter, like Father, scored high in their beliefs that they were mutually strong. Mother and Father had more confidence in the family than did Daughter. Mother and Father also scored higher than Daughter on approaching the challenges of life in a positive manner. Father and Daughter felt less subject than Mother to external forces over which they had little control.

There are only 2 items of the 20 where Mother's and Father's answers differed greatly. Both relate to the degree of control exerted by external factors. Of the 5 items on which Daughter differed greatly from one or both parents, 2 are those just mentioned, on which she was closer to Father. The other 3 are delineated in Table 46. The last 2 are clearly a function of her growing independence.

All three gave identical responses to seven items. They are all related to the family's strength, working

TABLE 45

FAMILY 210--FAMILY TESTS

Scale	Subscale	Maximum Score	Patient (Mother)	Spouse (Father)	Daughter Gd. 13
FHI					
	Coorienting-Commitment	24	19	22	20
	Confidence	12	11	12	8
	Challenge	15	13	14	10
	Control-External	9	6	9	8
	Total	60	49 (59)[a]	57 (99)	46 (42)
F-COPES					
	Acquiring-Social Supp.	45	38 (97)[b]	30 (71)	37 (95)
	Reframing	40	32 (69)	36 (92)	34 (90)
	Seeking-Spirit. Sup.	20	13 (13)	18 (79)	10 (09)
	Mobilizing	20	19 (99)	16 (94)	11 (62)
	Passive-Appraisal	20	16 (99)	14 (97)	17 (99)
	Total	145	118 (97)	114 (95)	109 (93)
FACES-II					
	Cohesion	80	59 (4)[c] z=-0.70	68 (6) z=0.37	46 (2) z=-1.12
	Adaptability	70	46 (5) z=-0.59	52 (6) z=0.32	38 (2) z=-0.94
	Family Type	-	(4.5)	(6)	(2)

[a] Numbers in parentheses are percentile ranks from the appropriate norms: One overall norm for total score only. [b] Numbers in parentheses are percentile ranks from the appropriate norms: norms are for adults or adolescents, male or female. [c] Numbers in parentheses are from Linear Scoring Model (figure 2).

TABLE 46

FAMILY 210--SELECTED FHI RESPONSES[a]

	False	Mostly False	Mostly True	True	Not Applic
2. It is not wise to plan ahead and hope because things do not turn out anyway.	P,Sp		D		
5. We have a sense of being strong even when we face big problems.				All	
6. Many times I feel I can trust that even in difficult times things will work out.				All	
8. We do not feel we can survive if another problem hits us.	All				
11. We strive together and help each other no matter what.				All	
12. When our family plans activities we try new and exciting things.	D		P	Sp	
14. We tend to do the same things over and over...it's boring.	All				
15. We seem to encourage each other to try new things and experiences.		D	P,Sp		
16. It is better to stay at home than go out and do things with others.	All				
17. Being active and learning new things are encouraged.				All	

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

together, and seeking ways to keep life interesting.

Family Crisis Oriented
Personal Scales

On the F-COPES, all three showed a very high level of problem-solving abilities. They all effectively accepted the problematic issues which faced them, minimizing reactivity. Mother and Daughter utilized social support as a coping skill at an even greater level than did Father, who was well above average. Mother and Father were much more likely to mobilize the family to acquire and accept help, though Daughter was still above average. Although Mother was above average in her ability to redefine stressful events in order to make them more manageable, Father and Daughter were much above average. Father, who proudly discussed his Irish Catholic upbringing during the first session, felt strongly about utilizing spiritual beliefs for support, whereas Mother and Daughter placed a low value on this.

There were six items on which Mother's and Father's responses disagreed greatly, whereas Daughter was in close agreement with one or the other. Items of interest are shown in Table 47. Daughter was in agreement with Mother, in opposition to Father, on items 5, 26 and 27. On item 25, Daughter and Father were in opposition to Mother. There were three items to which all three gave identical answers. These were items 3, 20 and 28.

TABLE 47

FAMILY 210--SELECTED F-COPES RESPONSES[a]

	Strongly Disagree	Moderate Disagree	Neither	Moderate Agree	Strongly Agree
1. Sharing our difficulties with relatives.		Sp			P,D
3. Knowing we have the power to solve major problems.					All
5. Seeking advice from relatives.		Sp			P,D
20. Doing things with relatives.					All
25. Asking relatives how they feel about problems we face.		P		Sp,D	
26. Feeling that no matter what we do to prepare we will have difficulty handling problems.	P	D		Sp	
27. Seeking advice from a minister.	D	P			Sp
28. Believing if we wait long enough the problem will go away.	All				

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

Family Adaptability and
Cohesion Evaluations
Scales-II

Differences were most evident on the FACES-II. Mother and Father both saw the family as flexible on the Adaptability dimension. Mother believed they were separated, whereas Father saw them as connected on the Cohesion dimension. Mother's family type was on the border between mid-range and moderately balanced, whereas Father's was moderately balanced. Daughter saw the family as disengaged on the Cohesion dimension and as rigid on Adaptability, giving a family type of extreme.

Of the six items on which the parents' responses differed greatly, three are displayed in Table 48, with other items of interest. Although Mother felt comfortable discussing her problems with other people (for example her clients), she did not necessarily feel close to them. Of the 30 items on the instrument, there were 17 on which Daughter was in strong disagreement with one or both parents, usually both. The majority of these seem to be a reflection of her natural separation from the family proper. There were two items of interest, numbers 2, and 22. Item 25 was the only one on which their responses were in complete agreement.

Individual Testing of Daughter

The high school from which Daughter had recently graduated quickly returned the requested information of the

TABLE 48

FAMILY 210--SELECTED FACES RESPONSES[a]

	Almost Never	Once in Awhile	Some-times	Freq-uently	Almost Always
2. In our family, it is easy for everyone to express his/her opinion.	D			Sp	P
3. It is easier to discuss problems with people outside the family than with other family members.		Sp	D	P	
19. Family members feel closer to people outside the family than to other family members.	P,D		Sp		
22. In our family, everyone shares responsibilities.		D		P	Sp
25. Family members avoid each other at home.	All				
26. When problems arise, we compromise.		D	Sp		P

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

latest IQ standard score. This was 107, which was average, based on the California Test of Basic Skills, form 4, Test of Cognitive Skills.

When my assistant and I returned for the second session, Mother and Father left for a holiday party. Due to Daughter's age, this was no problem. Table 49 gives the results of Daughter's objective tests.

Empathy scale

Daughter was administered the Mehrabian Emotional Empathetic Tendency Scale. Her score was well above the mean, indicating a very strong ability to empathize.

Survey of Interpersonal Values

On the Benevolence subscale of the Survey of Interpersonal Values, Daughter scored very much above average, demonstrating a very highly developed sense of altruism. This was the only value on which she placed above average importance. The values of Receiving Recognition, Feeling Supported, Independence, and Conforming were somewhat below average. The value of Leadership was much below average.

Piers-Harris Children's Self-Concept Scale

The profile of her scores on the Piers-Harris Children's Self-Concept Scale is shown in appendix D. Overall, Daughter had a positive self-concept. However, she

TABLE 49

FAMILY 210--CHILD TESTS

Scale	Subscale	Maximum Score		Daughter Gd. 12.9+
EMPATHY			M[a]	92
				z= 2.29
PIERS-HARRIS	Behavior	16		16 (95)[b]
	Intellect	17		11 (38)
	Physical	13		9 (60)
	Anxiety	14		5 (11)
	Popularity	12		4 (09)
	Happiness	10		8 (56)
	Total Scale	80		52 (46)
SIV				
	Support	45	*[c]	16 (40)[d]
	Conformity	45		14 (36)
	Recognition	39		12 (45)
	Independence	48		12 (38)
	Benevolence	45		29 (97)
	Leadership	48		7 (27)

[a]M = Mehrabian overall norms with score range = -132 to +132. [b]Figures in parentheses are percentile ranks for the complete norming population. [c]** = Grade 9 vocational norms, male or female; * = Grade 11 and 12 norms, male or female. [d]Figures in parentheses are percentile ranks for the appropriate norms.

felt more anxious and less popular than the average adolescent. She felt very confident about her behavior, and was in the average to slightly above average level of confidence concerning physical appearance, happiness and satisfaction, and intellectual status.

Projective tests

Daughter was pleasant and comfortable during the Projective testing, easily discussing herself and her family. Within the prior 6 months, she had broken a long-term relationship and had returned to the home. Although she admitted that she struggled to recover from the break-up, she claimed she had returned home out of guilt and responsibility toward Mother. She admitted to not particularly liking Father, and to fearing that he was not caring for Mother in the fashion she needed.

Daughter's HFD suggested that she felt unbalanced, if not unstable, in her life. There were indications of striving for power and a desire for open interaction. She realized, while drawing, that her figure looked "deformed," and she tried to correct this, but was unsuccessful.

For her KFD, Daughter drew the family eating together at home. She said that is the only time they do something together. She stated that she did not even like to watch the television shows her parents liked. She drew herself first, on the left, smiling, and glancing to the side. Father was drawn small, in the middle, facing into the

picture, and not recognizable. She pointed out she had drawn only his head, hands, and feet. This seems to be a blatant expression of her resentful feelings toward Father and her apparent desire for him to be a non-entity in the family. Mother was drawn to the right, opposite Daughter, with a disinterested look, also glancing to the side. No one was really looking at another, but Daughter and Mother appeared to be reaching out to each other.

Although the RATC norms were not valid for this young lady, the instrument was administered to be used qualitatively, in order to maintain the consistency of the basic protocol. I was impressed with the gentle quality Daughter instilled in her stories. She seemed to be functioning in a very emotionally healthy manner, capable of coping effectively with aversive situations. She would tend to rely on herself, rather than others, to overcome problems. Her stories reflected anxiety and unhappiness, as well as strong caring for others.

When the testing was completed, Daughter discussed how Mother's MS had affected the family. She claimed she did not remember much before Mother developed the MS; but she believed that things became harder for the family. She remembered being scared because she did not understand what was wrong with Mother. Her next older sister had taken on a lot of extra responsibility, and Daughter had tried to help her as much as possible. "Anyone who lives at home now has

to pitch in more." She said that she was helping Mother with the house cleaning, laundry, dishes, dinner, and taking her places. Daughter did not seem frustrated or in the least bit angry that she was doing these things.

Exit Interview

When my assistant and I returned for the final interview, Father met us to help us over the ice and snow into the house. Mother began by pointing out that "this had brought up some feelings I'd let go." She believed that the research was needed. Father added that people tended to forget the bad times. "This gave me more perspective." Even though they had been through the difficult diagnosis and adjustment together, he admitted that he tended to take things for granted. Daughter was observed smiling as she listened.

Father continued by saying that he believed the relationship between him and Mother had grown in strides from where they had been to where they now were, and he intended to continue working on it. At that point, Mother's eyes were observed to be filling up with tears. She wiped her eyes and added that she appreciated the thoroughness of the interview. "If you'd just asked 'How was your experience?' I wouldn't have said nearly as much. Most people who ask how I'm doing really don't care." At this point, her eyes again filled with tears. Daughter said that everything had been all right with her, and she had

appreciated the opportunity to talk with someone about it.

Mother closed the interview by pointing out that she had been away from her family of origin and on her own for a number of years before her problems with the MS began. That experience had helped her cope. "It would have been a completely different situation if I had still lived near my family." She seemed to have a wistful attitude, suggesting grief over not being closer to her family; but this was balanced by an obvious sense of pride that she had accomplished so much on her own. I pointed out that raising four children on her own surely had been a difficult task, and tried to reinforce Mother in her feelings of success.

Family Summary

Family 210 consisted of the mother patient, the father, three daughters ages 28, 24 and 19, and a son age 26. Only the youngest daughter was included in the study. She was 11 at the time of the diagnosis. Father had been close to the family since before the diagnosis, and became the stepfather 3 years prior to the study.

The family tests revealed that Mother and Father had more confidence in the family than did Daughter; but Mother and Daughter had greater faith in their mutual strength. All three believed they had strong coping ability. Mother and Father viewed the family as of a favorable family type, but Daughter saw them as extreme.

Individual testing indicated that Daughter had average

intelligence, a positive self-concept, a very strong ability to empathize, and a very highly developed sense of the value of altruism. She seemed to have developed an adequate value system. Although Daughter was well adjusted, and able to cope with aversive situations in a mature fashion, she did appear to be suffering from anxiety and depressive tendencies. It is just as likely that these could have resulted from her recent termination of an engagement, and the consequent return home to a stepfather whom she did not appreciate.

Family 211

Family 211 had responded to the mailings from the local clinic. Despite the fact that I was a year and a half late in contacting the family (due to misplacing their materials), the family was still very willing to participate in the study. Because the son was very involved in athletics, there was some difficulty arranging appointments. The son had no problem giving up some of his valuable free time to participate. The family lived in a very old, rural home which they had renovated.

Demographics

Family 211 consisted of the mother (the patient), age 43; the father, age 44; a son, age 22; a daughter, age 19; and a son, age 16. Only the youngest son still lived at home. The parents were married in October of 1968. The

eldest son was in his fifth year of college, studying business. He was married and had a new baby. The daughter was in her second year of college, studying to become an elementary teacher. The youngest son (Son) was a sophomore in the local high school. He was the only one of the children included in the study, because the others were past school age. The family attended a rural Mennonite church.

Mother was a high school graduate, and had worked 13 years in the hardware store of which their family was part owner. She had always worked part time--no more than 24 hours per week. She was a clerk and buyer for the store. She served as a volunteer visitor for the church. She preferred to spend her free time sewing, gardening, and cooking at home. Father graduated from high school, and had been manager of the family hardware store for 14 years. He averaged 50 hours per week on the job. He belonged to the local retail merchants' association, was an elder of the church, and a Director of a local bank. He volunteered for many church activities, and especially enjoyed teaching Sunday School. At school, Son was in the German club, on the Student Council, and participated in cross-country, track, and basketball. He was a member of the church youth group, and worked as a bag-boy in a grocery store. He pointed out that he and Father ran together daily. Father happily agreed, and added that the family sang together every evening.

Diagnosis and Acceptance

Father was reported as healthy, but Son struggled with chronic bronchitis. Mother's MS was diagnosed in 1980. When she began to experience numbness in her left hand and arm, she sought help from the neurologist in a large city who had diagnosed her sister with MS the previous year. He placed Mother in the hospital, where they performed a spinal tap, an EEG, visual and auditory evoked potentials, and a complete neurological exam. "They weren't really sure; but, by disqualifying everything else, they told me I probably had MS." The doctor did not provide any support, and told her "there's nothing, really, that can be done." Mother changed to a local neurologist for follow-up care and, at the time of the interview, was switching to a third, because this second doctor "did not seem interested in me."

Mother believed she handled the diagnosis "pretty well, but I get really frustrated sometimes." Father added that he felt she had done admirably well. Mother tried to keep her mind busy, so she would not dwell on the problems. Father admitted he also became frustrated and impatient. "I want to be sensitive . . . and she helps me to be sensitive." Mother responded that it had been very helpful to have a loving, kind husband. Father added "Well, I'm in it for the long haul."

The children were 9, 6, and 3 at the time of diagnosis, and were not really told much about Mother. They were

basically just asked to help out around the home. It was difficult to obtain cooperation from the daughter, but she did help. Son had been the greatest help, even when very young. Mother said, "He helps me out so much." Father added that he was like a "built-in maid." When asked if all this responsibility around the home was a problem for him, Son answered, "Sometimes it bothers me; but it really doesn't take much time." As a nuclear family, they found they had to let Mother take a rest; but, from the way Father shared the information, it would appear that this was rather difficult to accomplish.

In response to the question as to how the family had changed as a result of the MS, after a brief thought, Father replied for the family. "It has kept us closer to home--we used to take off for the weekend. It has kept us closer to the church--we rely on their moral and prayer support. It has made our family closer--we keep in contact once or twice a week." Mother and Son nodded agreement, and Mother added, "My garden's smaller, and I have a riding mower."

Mother's parents had been concerned and very supportive. However, her sister had deteriorated quickly and required more attention. She pointed out this sister always had required a lot of attention and had never really helped herself. Her husband had left her because of the MS, and she was raising a son, who was a very good friend of Son. Son added that they lived nearby, and his cousin "is a

good kid, but my aunt is a complainer." His parents agreed. Mother's other sister and her brother were concerned, but physically distant and unable to do much. Father said he had never really told his parents--"they just seemed to know." They have been supportive, as have his siblings. He was the middle child of 13 in an Amish family. Although he and seven siblings had left the Amish church, they all continued to be physically and emotionally close to one another. His family rallied to help whenever needed.

As part-owners of the store where both work, they were able to adjust their hours as needed for Mother's condition and necessary appointments. The people in their church were understanding, but it was "no big issue." The church family had held an anointing service for Mother soon after the diagnosis. She seemed disappointed that she could no longer sing in the choir because of her inability to stand for long periods. When asked about friends, Mother spoke only of their Amish neighbors, with whom they were just becoming acquainted. They did not seem to have a supportive group of friends, because they focused so much on the family as the support group. Father said, "We would only ask family for help; we wouldn't let friends do anything for us." Interestingly, while the interview was being held, a plate of cookies from a neighbor appeared in their breezeway, to the delight of Mother.

Symptoms

The numbness in Mother's left hand and arm had remained, and she had begun to experience some numbness in her right side. Periodically, she experienced blurry vision. She suffered from dizziness and poor balance, combined with poor leg coordination. She had begun to experience foot and leg cramps, and bladder spasms. From the beginning of her problems, she had overriding fatigue. Although Mother had taken only few medications, she felt they had been beneficial. Although she wanted to be considered for the trial with Betaseron, her physician would not refer her, because he did not approve of the lottery approach the drug company was using to decide who could be prescribed this drug. Mother's walk was observed to be somewhat hesitant and shaky. The house was designed and the furniture arranged in such a fashion that she had something to aid her balance throughout the house.

Assistance

Father and Son felt that Mother tended to do too much. "She's a little compulsive about cleaning, when she's alone," Father shared. Mother laughed, and admitted to having been a "workaholic" before the onset of her MS. Spring cleaning was a major undertaking in this home. Father's sisters did most of it. They also helped Mother with her summer gardening. Mother's mother had helped a little with child care when the children were younger.

Mother required no personal assistance. Her medical insurance was through their business. There had been no alcohol or drug problems, and no one in the family had sought professional counseling.

Description of Son by Parents

Son said he did "pretty well" in school. Mother pointed out that he was always on the high honor roll. "Everybody likes him." Mother continued that he never got in trouble and always had a lot of friends. Father added that Son was often chosen by his peers to represent them. "He has gifts that maybe the others [siblings] had, but they never exercised them." He was described as a very self-motivated, dedicated young man. Son apologized about needing to take the family tests quickly in order to meet an appointment. After he had left, the parents explained that he was taking a friend to a movie. This young man had very few friends, and those he had were a bad influence. Son had met this friend through track, and wanted to try to be a help to him. This information reinforced the positive impression which my assistant and I had formed of Son.

The Family Tests

All family members included in the study responded to all tests. The instructions given were as amended for family 208. Table 50 gives the results of the family tests.

TABLE 50

FAMILY 211--FAMILY TESTS

Scale	Subscale	Maximum Score	Patient (Mother)	Spouse (Father)	Son Gd. 10
FHI					
	Cooriented-Commitment	24	21	22	21
	Confidence	12	11	12	11
	Challenge	15	11	14	8
	Control-External	9	6	8	4
	Total	60	49 (59)[a]	56 (95)	44 (29)
F-COPES					
	Acquiring-Social Supp.	45	38 (97)[b]	30 (71)	37 (96)
	Reframing	40	26 (15)	29 (35)	32 (77)
	Seeking-Spirit. Sup.	20	19 (86)	17 (66)	20 (99)
	Mobilizing	20	17 (94)	12 (57)	16 (98)
	Passive-Appraisal	20	16 (99)	19 (99)	17 (99)
	Total	145	116 (95)	107 (87)	122 (99)
FACES-II					
	Cohesion	80	73 (7)[c] z=0.96	74 (8) z=1.08	71 (7) z=1.60
	Adaptability	70	57 (7) z=1.08	53 (6) z=0.47	48 (5) z=0.33
	Family Type	-	(7)	(7)	(6)

[a] Numbers in parentheses are percentile ranks from the appropriate norms: One overall norm for total score only. [b]Numbers in parentheses are percentile ranks from the appropriate norms: norms are for adults or adolescents, male or female. [c]Numbers in parentheses are from Linear Scoring Model (figure 2).

Family Hardiness Index

Mother and Father differed considerably on their overall FHI percentile rank. Whereas she was above the average for the norming sample, he was well above that. Both parents had a positive belief that the family was mutually strong and had confidence in their family. Father scored slightly higher than Mother in approaching the challenges of life in a positive manner, and on not feeling subject to external forces over which they had little control. Son scored below average on the total scale. This was due mainly to fairly low scores on the Challenge and Control External subscales. He apparently felt more overwhelmed by the challenges of life and less in control of external factors. Like his parents, however, he had confidence in his family and believed they were mutually strong.

In comparing responses to specific items, there was only one on which the parents' responses disagreed greatly. This was item 1, "Trouble results from mistakes we make," to which Mother responded "True" and Father responded "Mostly false." Son agreeed with Father on this item. There were two items on which both parents responded "False," but Son failed to commit himself by responding "Not applicable." These were item 16, "It is better to stay at home than to go out and do things with others;" and 20, "We realize our lives are controlled by accidents and luck." There were 13 items to which the parents responded identically, and on 8

of these Son was in complete agreement with them. Basically, these items reflected the family's positive outlook on life and the members' strong sense of togetherness as they coped with stress.

Family Crisis Oriented
Personal Scales

The entire family scored extremely well on the Family Crisis Oriented Personal Scales, indicating well-developed problem-solving and coping skills. The only subarea which was below average for the parents was Reframing, where Mother was even lower than Father. The subarea reflecting their strongest mutual coping ability was Passive Appraisal, effectively accepting problematic issues, minimizing reactivity. Mother and Son utilized social support as a coping skill at a greater level than Father, who still saw it as important. Mother and Son believed more strongly than Father in the value of mobilizing the family to acquire and accept help. Although all family members had expressed, during the first interview, the importance of their spiritual beliefs, this was reflected more strongly by Son and Mother than by Father, who was still above average.

On the seven items to which the parents' responses differed greatly, Son was in close agreement with Mother on five and with Father on two. The five reflect Mother's and Son's greater willingness than Father's to seek and request help, although they were less willing than Father to seek

help from professional sources. The other two are items 12 and 15 as displayed in Table 51, which shows some items of interest. There are three items on which the parents' responses were in total agreement, but Son varied greatly. Two seem important to mention, items 22 and 26. There were nine items to which the family members responded identically. Six of these were related to their strong belief in the importance of relatives, close friends and God as sources of support. The other three were items 17, 28 and 24.

Family Adaptability and Cohesion Evaluation Scales-II

The FACES II instrument clearly demonstrated how well the family worked together as a unit. Mother and Father saw the family type as balanced, and Son saw it as moderately balanced. They all viewed the family as very connected on the Cohesion dimension. On the Adaptability dimension, Father and Son saw the family as flexible, and Mother saw it as very flexible. Table 52 delineates items of interest.

Mother's and Father's responses differed greatly on only three items. These were in items 6 and 30, where Son agreed with Father; and item 15, where Son was closer to Mother. Son disagreed markedly with both parents on three other items, numbers 4, 20 and 24. On eight items, their responses were identical. These items reflect the family's supportiveness of one another and togetherness, and their

TABLE 51

FAMILY 211--SELECTED F-COPES RESPONSES[a]

	Strongly Disagree	Moderate Disagree	Neither	Moderate Agree	Strongly Agree
1. Sharing our difficulties with relatives.				All	
2. Seeking encouragement and support from friends.				All	
7. Knowing we have the strength within our own family to solve our problems.				All	
12. Watching television.	Sp,S			P	
15. Accepting stressful events as a fact of life.	P			Sp,S	
16. Sharing concerns with close friends.				All	
17. Knowing luck plays a big part in how well we are able to solve family problems.	All				
22. Believing we can handle our own problems.		P,Sp		S	
24. Defining the family problem in a more positive way so that we do not become too discouraged.				All	
25. Asking relatives how they feel about problems we face.				All	
26. Feeling that no matter what we do to prepare we will have difficulty handling problems.		P,Sp		S	
28. Believing if we wait long enough the problem will go away.	All				
30. Having faith in God.					All

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

TABLE 52

FAMILY 211--SELECTED FACES RESPONSES[a]

	Almost Never	Once in Awhile	Some-times	Freq-uently	Almost Always
1. Family members are supportive of each other during difficult times.					All
4. Each family member has input regarding major family decisions.		S		P	Sp
6. Children have a say in their discipline.			Sp,S		P
7. Our family does things together.				All	
15. We have difficulty thinking of things to do as a family.	Sp		S	P	
17. Family members feel very close to each other.					All
19. Family members feel closer to people outside the family than to other family members.	All				
20. Our family tries new ways of dealing with problems.	P	Sp	S		
24. It is difficult to get a rule changed in our family.	P	Sp	S		
25. Family members avoid each other at home.	All				
26. When problems arise, we compromise.					All
27. We approve of each other's friends.					All
28. Family members are afraid to say what is on their minds.	All				
30. Family members share interests and hobbies with each other.			P		Sp,S

[a]P=Patient; Sp=Spouse; D=Daughter; S=Son; All=All family members.

ability to be individuals within the strong family.

Individual Testing of Son

The high school which Son attended returned the letter requesting the latest IQ standard score with the information from the Indiana Statewide Testing for Educational Progress. His IQ was 126, which was within the superior range.

When my assistant and I returned for the second session, the family was just returning from a restaurant and three of Son's friends were also waiting for him. Without hesitation, he kindly asked them to leave, because he had another obligation. Son reportedly had been very ill during the time between sessions, and was still suffering some of the symptoms. Despite this, he warmly welcomed us and readily began working. Table 53 gives the results of Son's objective tests.

Empathy scale

Son was administered the Mehrabian Emotional Empathic Tendency Scale. He scored above the mean, indicating a strongly developed sense of empathy.

Survey of Interpersonal Values

On the Benevolence subscale of the Survey of Interpersonal Values, Son scored above the 99th percentile, indicating that he highly valued altruistic behavior. The values of Conformity and Feeling Supported were above

TABLE 53

FAMILY 211--CHILD TESTS

Scale	Subscale	Maximum Score		Son Gd. 10
EMPATHY			M[a]	33 z= 0.45
PIERS-HARRIS	Behavior	16		16 (95)[b]
	Intellect	17		16 (90)
	Physical	13		11 (84)
	Anxiety	14		10 (58)
	Popularity	12		10 (69)
	Happiness	10		9 (72)
	Total Scale	80		72 (95)
SIV				
	Support	45	*[c]	17 (61)[d]
	Conformity	45		18 (65)
	Recognition	39		11 (37)
	Independence	48		10 (14)
	Benevolence	45		29 (99)
	Leadership	48		5 (06)

[a]M = Mehrabian overall norms with score range = -132 to +132. [b]Figures in parentheses are percentile ranks for the complete norming population. [c]** = Grade 9 vocational norms, male or female; * = Grade 11 and 12 norms, male or female. [d] Figures in parentheses are percentile ranks for the appropriate norms.

average, whereas the value of Receiving Recognition was below average. The values of Independence and Leadership were well below average.

Piers-Harris Children's Self-Concept Scales

According to the Piers-Harris Children's Self-Concept Scales, Son had a very positive self-concept. The profile of his scores on the Piers-Harris Children's Self-Concept Scales is included in appendix D. He was above average on all of the subscales, with Behavior, Intellectual and School Status, and Physical Appearance and Attributes being well above average. Happiness and Satisfaction, Popularity, and Freedom from Anxiety also demonstrated a very positive level of comfort with himself.

Projective tests

Son was very pleasant and open in his discussion. The HFD of the Projective tests indicated that Son had strong inner control and positive interpersonal relationships. Dependency issues were beginning to cause a sense of imbalance, as he entered adolescent striving.

As Son began drawing his KFD, he commented that he liked to draw; but his cousin, whose mother also had MS, was an excellent artist. He said that the art teacher had told his cousin he could probably get an art scholarship to college, which was a relief to his family. Son drew the family eating dinner, first carefully drawing the table and

food. Then he drew Mother on the left, himself in the middle, and Father on the right, facing Mother. He pointed out that these were really their positions at the table. The drawing is most indicative of Son's organizational tendencies.

Although Son's responses throughout the RATC were short, they were very complete. His stories had helpful, patient parents and hard-working children. The profile of his RATC scores is included in appendix E. The Adaptive scale demonstrated that Son had good resources to cope with aversive situations. He had above average reliance on others, but also had a very strong ability to depend on himself. He had an average ability to support others. With very strong limit-setting skills and problem-solving ability, he was able to resolve problems in an appropriate, mature fashion.

The Clinical scale indicated an above average level of depression and anxiety, which seemed to have resulted from his drive to succeed and please others. This level of anxiety revealed by the projective test was in contrast to the self-reported feeling free from anxiety on the Piers-Harris. There was also an above average level of feeling of rejection, which was apparently based on peer relationships, particularly with girls. He had commented, at one point, that "girls are really hard to figure out." Feelings of aggression, and unresolved feelings, were within the

average range.

Son reported that he had been the only child at home for the preceding year and a half, but did not believe much had changed. I said that I had gotten the impression that Son had always been a great help in the home. He nodded, but made no reference to whether his siblings had helped much while living there. He did not think that the family changed much after Mother's diagnosis, admitting that the changes may have occurred slowly and subtly. He shared that he was very scared about his Mother at first, because of his aunt's condition. He slowly realized that MS came in different forms. When asked if he had ever worried about Mother dying, he claimed he had not, then added, "But I really didn't want to think about it." He felt that he and his cousin were great support for each other. They did not talk about it; each just understood what the other was going through. When asked if his cousin had to do a lot to help his homebound mother, he said "No, she has help that comes in; but he's there for her."

Exit Interview

My assistant and I were welcomed as old friends as we were met at the door by the entire family. Son was first to respond to the opening questions. He said everything was fine, and that he could understand why the questions were asked. However, he could not figure out why the RATC was given. I briefly explained objective and projective tests,

and the need for both. He smiled, as if with understanding, and said, "That makes sense." He also wanted me to know he was not complaining.

Mother was glad they could help out, and she hoped that their family had contributed to the research. She was assured that they had done so. She commented that she had learned some things as well. She then asked if she could ask an unrelated question. She wanted to know if forgetfulness was part of MS, and seemed greatly relieved to know that it could be.

Father commented that he had not known what to expect, but he had found it enjoyable. He said they had tried to be honest. "If I can help any more, I will. Just let me know."

Mother served more cookies from their neighbor, allowing time for casual conversation, which everyone seemed to appreciate. Son was planning to go to college, and was considering becoming a teacher/coach, or a doctor of sports medicine. "I don't know yet what I want to be when I grow up." He hoped he would receive academic and athletic scholarships. Mother and Father shared that they had known each other most of their lives, having gone through 12 years of school together. Father said he had fallen in love with Mother when they were very young, but they did not start dating until they were juniors in high school. Everyone found it difficult to close the session and say "Goodbye."

My assistant and I were assured that we would always be welcome in the home.

Family Summary

Family 211 consisted of the mother patient, the father, two sons, ages 22 and 16, and a daughter, age 19. Only the youngest son was living in the home and was included in the study. He was 3 years old at the time of diagnosis. The family was mutually supportive and uplifting of one another.

The family inventories revealed confidence in themselves as a family. Son, however, felt more overwhelmed by the challenges of life. The family believed they had well-developed coping skills and were of a very favorable family type.

Individual testing indicated that Son had superior cognitive ability, a very positive self-concept, and strongly developed senses of empathy and of the value of altruism. He appeared to be developing a solid set of values. He was well adjusted, highly motivated, and well able to resolve problems in a mature fashion. However, he was experiencing anxiety, depressive tendencies, and feelings of rejection. Some of these emotional indicators appeared to have resulted from normal adolescent insecurity, as well as his gifted drive.

Summary

This chapter has reported the individual case studies

of the 13 sample families. The major thrust of chapter 5 is to analyze the data and interpret the findings.

CHAPTER 5

ANALYSIS

The purpose of this chapter is to analyze the data which has been presented in chapter 4 as 13 individual case studies. In the sample, there were 10 families where the mother was the patient. In these families there were 5 elementary-age daughters, 4 elementary-age sons, 4 secondary-age daughters, and 1 secondary-age son. In the 3 families where the father was the patient, there was 1 elementary-age daughter, 1 elementary-age son, 2 secondary-age daughters and 2 secondary-age sons. The data are analyzed in respect to each individual instrument, for the whole group and by appropriate subgroups. It must be emphasized that all analysis relates only to the sample.

Family Tests

Three family tests were administered. Of the 20 children, 10 responded, with their parents, to the Family Hardiness Index and the Family Crisis Oriented Personal Scales, and 19 responded to the Family Adaptability and Cohesion Evaluation Scale.

Family Hardiness Index

Table 54 shows the frequency distribution of FHI scores below average, average and above average. For the total score, average was defined for this purpose as PR = 40 to 60. As norms were available for only the total score, I tentatively defined "average" for the subscales by assuming equivalent distributions on all. Therefore, only the distribution on the total score should be considered reliable.

On examination of Table 54, a clear pattern emerges with both parents in all the families. There is a clear tendency for them to be positive about their families' hardiness. This trend is seen more strongly in the spouses than in the patients. It appears as if this strength is derived in the main from their belief in their families' mutual strength and their overall confidence in their families' ability to cope, rather than by approaching the challenges of life in a positive manner or by feeling less subject to external forces over which they have little control. The small sample of only 10 children provides slight evidence of a similar trend.

Family Crisis Oriented Personal Scales

Table 55 shows the distribution of score frequencies on the F-COPES. The definition of average for this instrument and each of its individual subareas was again PR = 40 to 60. The manual provides norms for each subarea.

TABLE 54

DISTRIBUTION ON FHI

Family member	Subscale	Mother patient			Father patient			All		
		-[a]	0	+	-	0	+	-	0	+
Patient	Cooriented Commit.	1[b]	4	5	0	1	2	1	5	7
	Confidence	2	4	4	0	0	3	2	4	7
	Challenge	5	2	3	0	2	1	5	4	4
	Control External	7	1	2	3	0	0	10	1	2
	Total Scale	4	3	3	0	1	2	4	4	5
Spouse	Cooriented Commit.	0	4	6	0	0	3	0	4	9
	Confidence	0	3	7	1	1	1	1	4	8
	Challenge	4	2	4	1	1	1	5	3	5
	Control External	3	3	4	2	1	0	5	4	4
	Total Scale	2	1	7	0	1	2	2	2	9
Both parents	Cooriented Commit.	1	8	11	0	1	5	1	9	16
	Confidence	2	7	11	1	1	4	3	8	15
	Challenge	9	4	7	1	3	2	10	7	9
	Control External	10	4	6	5	1	0	15	5	6
	Total Scale	6	4	10	0	2	4	6	6	14
Daughters	Cooriented Commit.	1	1	2	1	1	0	2	2	2
	Confidence	2	0	2	1	0	1	3	0	3
	Challenge	2	1	1	1	1	0	3	2	1
	Control External	2	1	1	2	0	0	4	1	1
	Total Scale	1	1	2	1	1	0	2	2	2
Sons	Cooriented Commit.	0	0	2	0	1	1	0	1	3
	Confidence	0	0	2	0	0	2	0	0	4
	Challenge	1	0	1	0	1	1	1	1	2
	Control External	2	0	0	1	0	1	3	0	1
	Total Scale	1	0	1	0	0	2	1	0	3
All children	Cooriented Commit.	1	1	4	1	2	1	2	3	5
	Confidence	2	0	4	1	0	3	3	0	7
	Challenge	3	1	2	1	2	1	4	3	3
	Control External	4	1	1	3	0	1	7	1	2
	Total Scale	2	1	3	1	1	2	3	2	5

[a]- = Below Average; 0 = Average; + = Above Average.
[b]Numbers are score frequencies.

TABLE 55

DISTRIBUTION ON F-COPES

Family member	Subscale	Mother patient			Father patient			All		
		-[a]	0	+	-	0	+	-	0	+
Patient	Acquir. Soc. Supp.	5[b]	0	5	1	0	2	6	0	7
	Reframing	4	0	6	0	1	2	4	1	8
	Seek. Spir. Supp.	6	2	2	1	0	2	7	2	4
	Mobilizing Family	4	1	5	2	0	1	6	1	6
	Passive Appraisal	0	0	10	0	0	3	0	0	13
	Total Scale	2	0	8	1	1	1	3	1	9
Spouse	Acquir. Soc. Supp.	1	3	6	0	0	3	1	3	9
	Reframing	1	2	7	0	0	3	1	2	10
	Seek. Spir. Supp.	4	3	3	1	0	2	5	3	5
	Mobilizing Family	1	5	4	2	0	1	3	5	5
	Passive Appraisal	0	0	10	0	0	3	0	0	13
	Total Scale	0	0	10	0	1	2	0	1	12
Both Parents	Acquir. Soc. Supp.	6	3	11	1	0	5	7	3	16
	Reframing	5	2	13	0	1	5	5	3	18
	Seek. Spir. Supp.	10	5	5	2	0	4	12	5	9
	Mobilizing Family	5	6	9	4	0	2	9	6	11
	Passive Appraisal	0	0	20	0	0	6	0	0	26
	Total Scale	2	0	18	1	2	3	3	2	21
Daughters	Acquir. Soc. Supp.	1	0	3	0	0	2	1	0	5
	Reframing	1	0	3	0	1	1	1	1	4
	Seek. Spir. Supp.	3	0	1	1	0	1	4	0	2
	Mobilizing Family	2	0	2	1	0	1	3	0	3
	Passive Appraisal	0	1	3	0	0	2	0	1	5
	Total Scale	1	0	3	0	0	2	1	0	5
Sons	Acquir. Soc. Supp.	0	0	2	1	0	1	1	0	3
	Reframing	0	0	2	0	0	2	0	0	4
	Seek. Spir. Supp.	0	1	1	2	0	0	2	1	1
	Mobilizing Family	0	0	2	2	0	0	2	0	2
	Passive Appraisal	0	1	1	0	0	2	0	1	3
	Total Scale	0	0	2	1	0	1	1	0	3
All Children	Acquir. Soc. Supp.	1	0	5	1	0	3	2	0	8
	Reframing	1	0	5	0	1	3	1	1	8
	Seek. Spir. Supp.	3	1	2	3	0	1	6	1	3
	Mobilizing Family	2	0	4	3	0	1	5	0	5
	Passive Appraisal	0	2	4	0	0	4	0	2	8
	Total Scale	1	0	5	1	0	3	2	0	8

[a]- = Below Average; 0 = Average; + = Above Average.
[b]Numbers are score frequencies.

A definite pattern emerges upon examining this table. The data for both parents in all the families indicates definite strengths in coping with problems. The greatest strengths for the total group are in redefining stressful events in order to make them more manageable and in refusing to give up or ignore problems. The spouses also cope by effectively acquiring social support. Male spouses also tend to mobilize the family to seek help more than female spouses do. Overall, the least effective coping strategy, particularly for the female patient, is seeking spiritual support.

Examination of the scores of the 10 children reveals a similar pattern of strengths in reframing and not succumbing to passive appraisal, as is found in the total parent group. They also acquire social support as a coping mechanism, similar to the spouse group. As children, they appear equally divided on mobilizing the family. Like their parents, seeking spiritual support does not seem to serve to help them cope.

Family Adaptability and Cohesion Evaluation Scales-II

Table 56 shows the distribution of scores for FACES-II. As indicated in chapter 3, the middle two categories on each of the dimensions is considered by the authors as the most favorable. This table clearly indicates that the sample consider themselves well-adjusted families. The daughters of

TABLE 56

DISTRIBUTION ON FACES-II

Family member	Dimension	Mother patient Level[a] 1	2	3	4	Father patient Level 1	2	3	4	All Level 1	2	3	4
Patient	Adaptability	0[b]	2	4	4	0	2	0	1	0	4	4	5
	Cohesion	1	2	6	1	0	0	2	1	1	2	8	2
	Family Type	0	3	6	1	0	1	1	1	0	4	7	2
Spouse	Adaptability	0	2	7	1	0	1	1	1	0	3	8	2
	Cohesion	0	0	6	4	0	0	2	1	0	0	8	5
	Family Type	0	0	9	1	0	0	2	1	0	0	11	2
Both parents	Adaptability	0	4	11	5	0	3	1	2	0	7	12	7
	Cohesion	1	2	12	5	0	0	4	2	1	2	16	7
	Family Type	0	3	15	2	0	1	3	2	0	4	18	4
Daughters	Adaptability	4	0	4	1	0	0	3	0	4	0	7	1
	Cohesion	2	4	1	2	0	1	2	0	2	5	3	2
	Family Type	2	3	3	1	0	0	3	0	2	3	6	1
Sons	Adaptability	0	3	2	0	0	0	1	1	0	3	3	1
	Cohesion	0	1	3	1	1	1	0	0	1	2	3	1
	Family Type	0	3	2	0	0	1	1	0	0	4	3	0
All children	Adaptability	4	3	6	1	0	0	4	1	4	3	10	2
	Cohesion	2	5	4	3	1	2	2	0	3	7	6	3
	Family Type	2	6	5	1	0	1	4	0	2	7	9	1

[a]Levels 1,2,3,4 refer to the four levels, from lowest to highest, in the model (figure 2): these are, for Adaptability--rigid, structured, flexible, very flexible; for Cohesion--disengaged, separated, connected, very connected; for family type--extreme, mid-range, moderately balanced, balanced. [b]Numbers are score frequencies.

mother patients are the one subgroup where this pattern is not completely in evidence. Although they do appear to have faith in the family's cohesiveness, this is not evident with respect to the family's adaptability.

Individual Testing of Children

The projective tests were administered to all the children. Each objective test was administered only to those children for whom it was age-appropriate.

Adaptive and Cognitive Scores

The distribution of frequencies of teachers' ratings of the elementary-age children on the Vineland Adaptive Behavior Scales is given in Table 57. In this table, average is indicated as adequate, in accordance with the terminology of the Vineland manual, where it is defined as within one standard deviation above or below the mean.

Overall, these children are seen as adapting adequately. The teachers tended to give higher ratings to the girls than to the boys. No area stands out as a problem. Although the written comments by teachers were generally very positive, two concerns were observed. Several girls were thought to be overly social. Both boys and girls were frequently described as immature, seeming to be over-protected or dependent.

For the secondary-age children, standard scores were provided by the schools. These children are average to

TABLE 57

DISTRIBUTION ON THE VINELAND

Patient	Domain	Girls			Boys			All		
		[a]-	0	+	-	0	+	-	0	+
Mother	Communication	[b]1	4	1	1	2	1	2	6	1
	Receptive	1	3	2	0	3	0	1	6	2
	Expressive	0	3	3	0	3	0	0	6	3
	Written	2	4	0	0	3	0	2	7	0
	Daily Living	0	4	2	2	1	0	2	5	2
	Personal	0	3	3	1	2	0	1	5	3
	Domestic	0	3	3	1	2	0	1	5	3
	Community	0	5	1	1	2	0	1	7	1
	Socialization	0	4	2	1	1	1	1	5	3
	Interpersonal	1	5	0	1	2	0	2	7	0
	Play	0	4	2	1	2	0	1	6	2
	Coping	0	5	1	1	1	1	1	6	2
	Motor	-	-	-	-	1	-	-	1	-
	Gross	-	-	-	-	1	-	-	1	-
	Fine	-	-	-	-	1	-	-	1	-
	Overall	0	5	1	1	2	0	1	7	1
Father	Communication	1	0	0	0	1	0	1	1	0
	Receptive	0	1	0	0	1	0	0	2	0
	Expressive	1	0	0	0	1	0	1	1	0
	Written	1	0	0	0	1	0	1	1	0
	Daily Living	0	1	0	0	0	1	0	1	1
	Personal	0	0	1	0	0	1	0	0	2
	Domestic	0	1	0	0	0	1	0	1	1
	Community	1	0	0	0	1	0	1	1	0
	Socialization	0	1	0	0	1	0	0	2	0
	Interpersonal	0	1	0	1	0	0	1	1	0
	Play	0	1	0	0	1	0	0	2	0
	Coping	0	1	0	0	1	0	0	2	0
	Motor	-	-	-	0	0	1	0	0	1
	Gross	-	-	-	0	0	1	0	0	1
	Fine	-	-	-	0	0	1	0	0	1
	Overall	1	0	0	0	1	0	1	1	0

Table 57--Continued

Patient	Domain	Girls			Boys			All		
		-	0	+	-	0	+	-	0	+
Either	Communication	2	4	1	1	3	0	3	7	1
	Receptive	1	4	2	0	4	0	1	8	2
	Expressive	1	3	3	0	4	0	1	7	3
	Written	3	4	0	0	4	0	3	8	0
	Daily Living	0	5	2	2	1	1	2	6	3
	Personal	0	3	4	1	2	1	1	5	5
	Domestic	0	4	3	1	2	1	1	6	4
	Community	1	5	1	1	3	0	2	8	1
	Socialization	0	5	2	1	2	1	1	7	3
	Interpersonal	1	6	0	2	2	0	3	8	0
	Play	0	5	2	1	3	0	1	8	2
	Coping	0	6	1	1	2	1	1	8	2
	Motor	-	-	-	0	1	1	0	1	1
	Gross	-	-	-	0	1	1	0	1	1
	Fine	-	-	-	0	1	1	0	1	1
	Overall	1	5	1	1	3	0	2	8	1

[a]- = Below average; 0 = Average; + = Above average.
[b]Numbers are rating frequencies.

superior in cognitive ability.

Empathy Scales

Table 58 provides the score distribution of 8 children on the Bryant Index of Empathy, and of 11 children on the Mehrabian Emotional Empathic Tendency Scale. For both scales, average is defined as a z-score of plus or minus one-half standard deviation. Of the 14 children of a mother patient, 11 were average and above, and 3 were below average in their levels of empathy. The father patient group of only 4 children are the 2 daughters of the emotionally positive middle-school history teacher, who are average and above in empathy, and the 2 sons of the critical, extremely disabled father, who are both below average in levels of empathy.

Survey of Interpersonal Values

The distribution of scores of 10 secondary-age children on each of the six subscales of the SIV is shown in Table 59. A PR from 40 to 60 is designated as average. The Benevolence subscale was used to investigate the level of altruism. This sample is clearly above average in its valuing of altruism. As a forced-choice test, being so high in that one value automatically reduces the probability of many other high scores. Of the six values, clearly altruism is consistently the most highly regarded. The value of being supported is seen as next in importance. The least

TABLE 58

DISTRIBUTION OF EMPATHY

Patient	Form	Daughters					Sons					All				
		--[a]	-	0	+	++	--	-	0	+	++	--	-	0	+	++
Mother	Bry[b]	1[c]	0	0	2	1	1	0	0	0	2	2	0	0	2	3
	Mehr	1	0	1	0	3	0	0	2	0	0	1	0	3	0	3
	Both	2	0	1	2	4	1	0	2	0	2	3	0	3	2	6
Father	Bry	0	1	0	0	0	0	0	0	0	0	0	1	0	0	0
	Mehr	0	0	1	0	1	1	1	0	0	0	1	1	1	0	1
	Both	0	1	1	0	1	1	1	0	0	0	1	2	1	0	1
Either	Bry	1	1	0	2	1	1	0	0	0	2	2	1	0	2	3
	Mehr	1	0	2	0	4	1	1	2	0	0	2	1	4	0	4
	Both	2	1	2	2	5	2	1	2	0	2	4	2	4	2	7

[a]-- = z<-1; - = z from -1 to -.5; 0 = Average (z=-.5 to +.5); + = z from .5 to 1; ++ = z>1. [b]Bry = Bryant's Index of Empathy; Mehr = The Mehrabian and Epstein Emotional Empathic Tendency Scale. [c]Numbers are score frequencies.

TABLE 59

DISTRIBUTION ON SIV

Patient	Subscale	Daughters			Sons			All		
		-[a]	0	+	-	0	+	-	0	+
Mother	Support	2[b]	1	2	0	0	1	2	1	3
	Conformity	2	1	2	0	0	1	2	1	3
	Recognition	2	2	1	1	0	0	3	2	1
	Independence	4	1	0	1	0	0	5	1	0
	Benevolence	0	0	5	0	0	1	0	0	6
	Leadership	2	2	1	1	0	0	3	2	1
Father	Support	0	0	2	0	1	1	0	1	3
	Conformity	2	0	0	1	0	1	3	0	1
	Recognition	0	0	2	1	0	1	1	0	3
	Independence	1	1	0	2	0	0	3	1	0
	Benevolence	1	0	1	0	0	2	1	0	3
	Leadership	0	1	1	2	0	0	2	1	1
Either	Support	2	1	4	0	1	2	2	2	6
	Conformity	4	1	2	1	0	2	5	1	4
	Recognition	2	2	3	2	0	1	4	2	4
	Independence	5	2	0	3	0	0	8	2	0
	Benevolence	1	0	6	0	0	3	1	0	9
	Leadership	2	3	2	3	0	0	5	3	2

[a]- =Below average; 0 = Average (PR = 40-60); + = Above average. [b]Numbers are score frequencies.

value is placed upon independence. The group as a whole is divided with respect to the value the individuals place on conforming, receiving recognition and being in leadership.

Piers-Harris Children's Self-Concept Scale

Table 60 gives the distribution of scores of 16 children on the Piers-Harris. The term "average," as used in this table, is assumed from the profile form, where the "average" band ranges from PR of 16 to PR of 50 (see profiles in appendix D).

The table uses a fourth column indicating scores above a PR of 84. This is shown because the authors of the scale advise caution in the interpretation of scores at that level, and the majority of the overall scores from this sample are at that level. The authors point out that although a score this high may be a true indicator of a child's positive self-concept, it may also represent an over-inflated ego or an inability to look at oneself critically.

By evaluating Table 60, the only problem area, minor as it appears, is the feeling of anxiety by 2 of the 4 secondary-age daughters of mother patients. One of 4 elementary-age daughters of mother patients had a low sense of comfort with her physical attributes. With these two exceptions, the table indicates very positive overall self-concepts, with very positive feelings about physical attributes, behavior, and happiness. Feelings about their

TABLE 60

DISTRIBUTION ON PIERS-HARRIS

Patient -School	Scale	Daughters				Sons				All			
		-[a]	0	+	++	-	0	+	++	-	0	+	++
Mo[b]-Sec	Overall	0	2	1	1	0	0	0	2	0	2	1	3
	Behavior	0	1	0	3	0	0	1	1	0	1	1	4
	Int.& Sch.	1	1	2	0	0	0	1	1	1	1	3	1
	Physical	0	1	1	2	0	0	1	1	0	1	2	3
	Anxiety	2	1	1	0	0	0	2	0	2	1	3	0
	Popularity	1	1	2	0	0	0	2	0	1	1	4	0
	Happiness	0	1	1	2	0	0	1	1	0	1	2	3
Fa--Sec	Overall	0	0	1	1	0	0	0	2	0	0	1	3
	Behavior	0	1	1	0	0	0	0	2	0	1	1	2
	Int.& Sch.	0	1	0	1	0	0	0	2	0	1	0	3
	Physical	0	0	0	2	0	0	0	2	0	0	0	4
	Anxiety	0	1	0	1	0	0	1	1	0	1	1	2
	Popularity	0	0	1	1	0	0	1	1	0	0	2	2
	Happiness	0	0	1	1	0	0	1	1	0	0	2	2
All Sec	Overall	0	2	2	2	0	0	0	4	0	2	2	6
	Behavior	0	2	1	3	0	0	1	3	0	2	2	6
	Int.& Sch.	1	2	2	1	0	0	1	3	1	2	3	4
	Physical	0	1	1	4	0	0	1	3	0	1	2	7
	Anxiety	2	2	1	1	0	0	3	1	2	2	4	2
	Popularity	1	1	3	1	0	0	3	1	1	1	6	2
	Happiness	0	1	2	3	0	0	2	2	0	1	4	5
Mo--El	Overall	0	1	0	3	0	0	1	1	0	1	1	4
	Behavior	0	2	1	1	0	0	1	1	0	2	2	2
	Int.& Sch.	0	1	2	1	0	0	1	1	0	1	3	2
	Physical	1	0	1	2	0	0	1	1	1	0	2	3
	Anxiety	0	0	2	2	0	1	0	1	0	1	2	3
	Popularity	0	0	3	1	0	0	1	1	0	0	4	2
	Happiness	0	1	1	2	0	0	0	2	0	1	1	4
All	Overall	0	3	2	5	0	0	1	5	0	3	3	10
	Behavior	0	4	2	4	0	0	2	4	0	4	4	8
	Int.& Sch.	1	3	4	2	0	0	2	4	1	3	6	6
	Physical	1	1	2	6	0	0	2	4	1	1	4	10
	Anxiety	2	2	3	3	0	1	3	2	2	3	6	5
	Popularity	1	1	6	2	0	0	4	2	1	1	10	4
	Happiness	0	2	3	5	0	0	2	4	0	2	5	9

[a]- = Below average; 0 =" Average" (On Piers-Harris profile = PR of 16-50); + = Above average; ++ = PR>84. [b]Mo=Mother patient; Fa=Father patient; Sec=Secondary School children; El=Elementary School children; [c]Numbers are score frequencies.

intellectual and school achievements, and freedom from anxiety, are evenly spread between average and high.

Human Figure Drawing

In performing an overall analysis of the individual DAPs, utilizing the Koppitz variables, certain patterns emerge. Of the 20 children, 11 drew pictures indicating a sense of being imbalanced in their lives. Four other negative indicators are seen four times each. These are impulsive tendencies, feeling inadequate in some aspect of life, dependency, and difficulty reaching out. Concerning the last of these indicators, these four drawings also suggest that the children desire interaction.

Positive indicators are not as frequently found with this test, because it was designed to investigate problems. Therefore all the positive indicators found in the drawings should be mentioned. Assertiveness and assertive potential were suggested four times. Positive interpersonal relationships and high intellectual aspirations with achievement striving were both found three times. Normal adolescent sexual adjustment, good behavior, and parental support are each seen twice. An overall evaluation of the 20 DAPs suggests that 13 had basically well-adjusted personalities, 3 were mildly questionable, and 4 reflected more serious concerns.

Kinetic Family Drawing

When the 20 children drew their KFD's, the family activity most frequently illustrated was passively watching television (5). The next most common activity was eating (4), then shopping (3), and being outside doing something, not necessarily together (3). Utilizing several of the Burns and Kaufman variables, an interesting picture appears.

Family communication is actively indicated in 8 of the drawings. Cooperation is indicated in 10. Only 5 suggest family nurturance. All accurately represent the number of their family members; but the relative figure size is inaccurate in 12 of the drawings. The figure which was drawn inordinately large is thought to represent the center of attention or power. The 12 evenly divided the enlarged figure among the patient, the caregiving spouse, and the child artist. Twelve of the drawings have barriers of some sort between family members. Two of the barriers are large canes, and 2 are wheelchairs, separating the patient from the rest of the family. Several problem indicators are also evident. Seven pictures demonstrate encapsulation or compartmentalization, suggesting isolation of the child, or a lack of cohesion of the family. Six pictures, including 4 of the above 7, contain lining, representing a sense of insecurity and desire for a better foundation in the family. Fifteen of the drawings treat all the figures similarly, indicating a sense of equity within the family.

The Roberts Apperception Test for Children

Table 61 shows the frequency distributions of RATC ratings for children 6 to 12 years old. Because there are only 11 children in this group, and very few in 2 of the subgroups (Father patient), attention is not given to those subgroups. Adequate, on this table, is determined by the age-related scoring profiles (see appendix E).

Among the total group, reliance on others and support of others show an even distribution over the rating range. Self-assurance shows a definite strength, reflecting the positive Piers-Harris results. Limit-setting is high, indicating good self-discipline. These children are able to identify problems well, and to resolve them, but not necessarily with as much maturity as would be expected for their age and intelligence. Anxiety is low, aggressive tendencies are normal, but depression is high. Rejection and unresolved feelings are higher than average. Among girls with mother patients, the only departure from the above pattern is that anxiety is spread across the rating range. Among the boys with mother patients, reliance on others is somewhat less, and feelings of rejection are not as strong. Looking at the total girls, in comparison to the total boys, they are more reliant on others, are somewhat more self-assured, have much stronger limit-setting skills, and slightly more ability to identify problems. The boys are slightly less anxious, less aggressive and less

TABLE 61

RATC DISTRIBUTION--6 TO 12 YEARS OLD

Patient	Variable	Girls			Boys			All		
		[a]-	0	+	-	0	+	-	0	+
Mother	Reliance--others	[b]0	3	2	2	1	1	2	4	3
	Support--others	2	1	2	1	2	1	3	3	3
	Support--child	1	1	3	1	1	2	2	2	5
	Limit setting	0	0	5	1	2	1	1	2	6
	Problem identific.	1	1	3	0	2	2	1	3	5
	Resolution 1	0	2	3	1	1	2	1	3	5
	Resolution 2	2	2	1	2	1	1	4	3	2
	Anxiety	1	2	2	2	1	1	3	3	3
	Aggression	0	4	1	1	3	0	1	7	1
	Depression	1	0	4	0	2	2	1	2	6
	Rejection	0	2	3	0	3	1	0	5	4
	Unresolved	0	3	2	0	2	2	0	5	4
Father	Reliance--others	0	0	1	0	1	0	0	1	1
	Support--others	1	0	0	0	1	0	1	1	0
	Support--child	0	0	1	0	1	0	0	1	1
	Limit setting	0	0	1	0	1	0	0	1	1
	Problem identific.	0	0	1	0	1	0	0	1	1
	Resolution 1	0	0	1	1	0	0	1	0	1
	Resolution 2	0	1	0	0	1	0	0	2	0
	Anxiety	1	0	0	1	0	0	2	0	0
	Aggression	0	0	1	0	1	0	0	1	1
	Depression	0	0	1	0	1	0	0	1	1
	Rejection	0	1	0	0	0	1	0	1	1
	Unresolved	1	0	0	0	0	1	1	0	1
Either	Reliance--others	0	3	3	2	2	1	2	5	4
	Support--others	3	1	2	1	3	1	4	4	3
	Support--child	1	1	4	1	2	2	2	3	6
	Limit setting	0	0	6	1	3	1	1	3	7
	Problem identific.	1	1	4	0	3	2	1	4	6
	Resolution 1	0	2	4	2	1	2	2	3	6
	Resolution 2	2	3	1	2	2	1	4	5	2
	Anxiety	2	2	2	3	1	1	5	3	3
	Aggression	0	4	2	1	4	0	1	8	2
	Depression	1	0	5	0	3	2	1	3	7
	Rejection	0	3	3	0	3	2	0	6	5
	Unresolved	1	3	2	0	2	3	1	5	5

[a]- = Low; 0 = Adequate; + = High. [b]Numbers are rating frequencies.

depressed, than the girls in this sample.

Table 62 shows the frequency distribution of RATC ratings for children 13 years of age and older. Again, there are only 8 children in this group, and therefore very few in the subgroups. Only the marginal cells are discussed.

In regard to the total group, reliance on others is adequate, supporting others is less than adequate, and self-assurance is higher than adequate. Limit-setting, again, is high. The children's ability to identify problems is adequate; but they, too, resolve them without the degree of maturity that would be expected for their age and intelligence. As with the younger children, depression is high, and rejection is higher than average. With this group, however, anxiety and aggressive tendencies are also higher than average. Unresolved feelings are average.

Comparing all 5 girls to all 3 boys, the girls seem to have a slightly more mature problem solving ability, but feel somewhat more rejected. The boys seem somewhat more self-assured, but slightly more depressed. Comparing the children with mother patient to those with father patient, the former are slightly more reliant on others. The latter have slightly better problem solving skills.

TABLE 62

RATC DISTRIBUTION--13 TO 18 YEARS OLD

Patient	Variable	Girls			Boys			All		
		[a] -	0	+	-	0	+	-	0	+
Mother	Reliance--others	[b] 0	2	1	0	0	1	0	2	2
	Support--others	1	1	1	0	1	0	1	2	1
	Support--child	0	2	1	0	0	1	0	2	2
	Limit setting	0	0	3	0	0	1	0	0	4
	Problem identific.	1	2	0	0	1	0	1	3	0
	Resolution 1	0	1	2	0	0	1	0	1	3
	Resolution 2	1	2	0	0	1	0	1	3	0
	Resolution 3	0	3	0	0	1	0	0	4	0
	Anxiety	0	2	1	0	0	1	0	2	2
	Aggression	0	1	2	0	1	0	0	2	2
	Depression	0	1	2	0	0	1	0	1	3
	Rejection	0	2	1	0	0	1	0	2	2
	Unresolved	0	2	1	0	1	0	0	3	1
Father	Reliance--others	0	2	0	0	2	0	0	4	0
	Support--others	1	1	0	1	1	0	2	2	0
	Support--child	0	1	1	0	0	2	0	1	3
	Limit setting	0	1	1	0	1	1	0	2	2
	Problem identific.	0	2	0	0	2	0	0	4	0
	Resolution 1	0	0	2	0	0	2	0	0	4
	Resolution 2	1	1	0	1	1	0	2	2	0
	Resolution 3	0	0	2	0	2	0	0	2	2
	Anxiety	1	0	1	0	2	0	1	2	1
	Aggression	1	1	0	0	1	1	1	2	1
	Depression	0	1	1	0	0	2	0	1	3
	Rejection	0	0	2	0	2	0	0	2	2
	Unresolved	0	2	0	0	2	0	0	4	0
Either	Reliance--others	0	4	1	0	2	1	0	6	2
	Support--others	2	2	1	1	2	0	3	4	1
	Support--child	0	3	2	0	0	3	0	3	5
	Limit setting	0	1	4	0	1	2	0	2	6
	Problem identific.	1	4	0	0	3	0	1	7	0
	Resolution 1	0	1	4	0	0	3	0	1	7
	Resolution 2	2	3	0	1	2	0	3	5	0
	Resolution 3	0	3	2	0	3	0	0	6	2
	Anxiety	1	2	2	0	2	1	1	4	3
	Aggression	1	2	2	0	2	1	1	4	3
	Depression	0	2	3	0	0	3	0	2	6
	Rejection	0	2	3	0	2	1	0	4	4
	Unresolved	0	4	1	0	3	0	0	7	1

[a]- = Low; 0 = Adequate; + = High. [b]Numbers are rating frequencies.

Summary

This analysis of the data from the 13 families in the sample has certainly revealed a number of interesting patterns. These will be discussed in chapter 6.

CHAPTER 6

SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

This chapter is divided into three major sections. The first section summarizes the problem and purpose of the study, the literature review, the methodology and the findings. The second section discusses the findings in relation to previous literature and seeks to draw conclusions. The final section includes recommendations for practice and for further research.

Summary

Problem and Purpose

Research into the psychological effects of multiple sclerosis (MS) has focused on how the chronically ill adult deals with the disease, with less attention paid to the spouse and caregiver. Minimal research has been undertaken with the children of a multiple sclerotic parent. Such research initially concentrated on the negative effects of the disease upon the children. Only in more recent years has attention been given to investigating the positive effects.

The purpose of this study was to investigate certain aspects of the personality of children 5 to 19 years old who

have a parent diagnosed with MS. Particular attention was given to family dynamics, cognitive ability, social and emotional health, self-concept, empathy and altruism/prosocial behavior. The importance of studying the positive aspects of the personality of a child with a multiple sclerotic parent became of particular interest to me when I, as a parent with MS, observed the development of such positive tendencies in my own child.

Literature Review

In searching all the available psychological, medical and educational research, only a few references were found dealing with families and children where a parent had MS. The research on families consistently reported that MS is stressful to the family (Moore, 1959), causing role changes (Bruhn, 1977; Rintell, 1985; Yuditsky & Kenyon, 1979), and overall modifications of family relationships (Braham et al., 1975; Hanson, 1982; Luft, 1975; McSweeney et al., 1982; Parsons, 1977; Power, 1979; Schmitt & Neubeck, 1985; Sjogren & Fugl-Meyer, 1982; Stuifbergen, 1988/1989; Sullivan, 1974/1975). These effects can be moderated by clear and open communication about the illness (Stuifbergen, 1988/1989); the stage of family development (Carter & McGoldrick, 1980); and by the influence of their cultural beliefs on their approach to chronic illness (Wishner & O'Brien, 1978). Factors contributing to the family's adjustment include pre-illness family relationships,

previous success in coping with stress, "role complementarity," and their beliefs about the illness (Power, 1979). Maintenance of the maximum possible independence (Power, 1975, 1985), with the acceptance of a dependent role as necessary (Monroe, 1988/1989) lead to healthier adaptation.

Findings of the research with children of a multiple sclerotic parent have not been so consistent. Earlier studies focused on the negative effects on the child. These included false maturity and compliant behavior, dependency needs, social alienation and rejection, dysphoric feelings, hostility and anxiety (Arnaud, 1959); fear, guilt and resentment (Yuditsky & Kenyon, 1979); body image concern (Arnaud, 1959; Olgas, 1974; Rintell, 1985; Sullivan, 1974/1975). Arnaud (1959) accepted that, despite the continued stress of parental illness, normal ego integration may occur. This was supported by later research, which focused on positive adjustment (Carpio, 1981; Peters & Esses, 1985; Power, 1984; Rintell, 1985; Solomon, 1981). Solomon (1981) found adolescents with an MS mother were better adjusted than those whose father had MS. Carpio (1981) and Sullivan (1974/1975) supported this finding. Rintell (1985) found that adolescents who were older at the onset of the parent's symptoms, or at the time of the research were closer to the onset, had better body images. He believed that participation in family decision making and

help from a local MS clinic resulted in better overall adjustment. Power (1984) found adolescents adjusted well using "positive denial" to reduce anxiety. He concluded that an adolescent's adjustment is determined by the family understanding of the illness, family expectations of one another, the family's positive adjustment, and religious involvement. Peters and Esses (1985) found the adolescents felt more conflict, less cohesion, less intellectual-cultural orientation, less moral-religious emphasis, and less organization than did a comparison group with healthy parents. Blackford (1992) found the children had higher potential for mature friendship relationships, with a high degree of sensitivity to others.

Very little relevant research was identified relating to the development and measurement of empathy and altruism/prosocial behavior. As children mature, their capacity for abstract thinking, which leads to moral reasoning, also develops (Eisenberg, 1979, 1982; Feshbach, 1978, Kohlberg, 1969). Eisenberg found that young children lack prosocial reasoning, due to their egocentricity; but it develops as they enter school age, and matures with them. She feels that young children do have early empathic reasoning as a part of their needs orientation. She believes that the connection between empathy and altruism is strengthened as the child matures. Eisenberg et al. (1983) recommended that parents encourage children to understand

the views of others and to participate in decision making, as a means of developing more effective moral reasoning. Mehrabian and Epstein (1972), whose Emotional Empathic Tendency Scale was used in this research, found that highly empathic subjects showed less aggression.

Methodology

This qualitative research used the case study approach with 13 families where one parent has multiple sclerosis, the other parent or step-parent is present, and there are school-age children, ages 5 through 19. The families were identified through the dissemination of a packet of materials through a local neurologist and a major MS clinic in the Midwest to their diagnosed MS patients. Interested families who returned the consent form and were qualified were then contacted by letter and telephone. Three interview sessions were used with each family. I visited the families in their home and was accompanied by a research assistant who was responsible for the transportation and assisted with the administration of the objective tests. During the first session, the entire family was interviewed about the onset and diagnosis of the disease, and the resulting reactions and changes. The children's individual development and adjustment were also discussed. At the conclusion of the interview, all age-appropriate family members responded to three family inventories: (1) the Family Adaptability and Cohesion Evaluation Scales-II,

(2) the Family Hardiness Index; and (3) the Family Crisis Oriented Personal Scales. The parents signed a release of information form so that the school(s) could provide the most recent standardized cognitive ability score for the secondary-age children and complete the Vineland Adaptive Behavior Scales for the elementary-age children.

At the second session, a combination of projective and objective tests, as were age-appropriate, were administered to the children. These included the Human Figure Drawing; the Kinetic Family Drawing; the Roberts Apperception Test; either the Mehrabian and Epstein Emotional Empathic Tendency Scale or the Bryant Index of Empathy; the Survey of Interpersonal Values; and the Piers-Harris Children's Self-Concept Scale.

The third session was an exit interview, again involving the entire family. Each family member was asked to respond to his or her involvement in the study. Related discussion, frequently yielding further valuable information, concluded the active participation of each family.

The information obtained from the interviews was first reported as 13 individual case studies. The data were than analyzed with respect to each instrument, for the whole group and by appropriate subgroups.

Findings

In reviewing the findings, it must be emphasized that

these are based upon information from 13 intact families who were both willing to participate and sufficiently confident in their ability to do so. There were 10 families where the mother was the patient. These families had 5 daughters and 4 sons of elementary age, and 4 daughters and 1 son of secondary age. The 3 families where the father was the patient had 1 daughter and 1 son of elementary age, and 2 daughters and 2 sons of secondary age.

Interview

Predominant positive features which were evident during the initial and final interviews include open communication or a willingness to become open, respect for each individual's contributions to the family, and willingness to accept role changes in a joint effort to continue the successful functioning of the family. Many of the families actively reassess their situation in a conscious effort to remain flexible and adaptable. In all but one of the families, no matter how disabled the patient is, the family tries to normalize the patient's continuance as a contributing member of the family, while accepting the presence of the MS and the consequent changes in family functioning. The families continue to try to find opportunities to do things together. A common problem admitted by most families is in remembering to respond to the special needs of the patient at times when the disease is not so evident. A number of the patients shared regret

that their children were having to accept more responsibility than most children their age, yet none of the children expressed resentment about this. Based upon my almost two decades of clinical experience working mainly with children, I sensed that all the children of this sample, with two obvious exceptions, appeared positive, friendly, open and contented.

Family Tests

There is a clear tendency for both parents in all families to be positive about their families' hardiness. This trend is stronger in the spouses than the patients. The strength is largely derived from their belief in their families' mutual strength and their overall ability to cope. A slight evidence of the same trend is seen in the 10 participating children.

The data for both parents in all the families indicate definite strengths in coping with problems. The families' most effective coping strategies are in reframing and refusing to give up or ignore problems. The spouses also cope by effectively acquiring social support. Male spouses tend to mobilize the family to seek help more than female spouses do. This sample did not consider seeking spiritual support as an effective coping strategy. The 10 children responding to this instrument reveal a pattern similar to that of the spouse group.

The sample clearly consider themselves well-adjusted

families, with good cohesion and adaptability, demonstrating relatively balanced families. The daughters of mother patients do not appear to believe as strongly in the family's cohesiveness. The fact that these families were all intact could be considered a contributing factor to the overall healthiness. In a population where divorce is more common due to the onset of a chronic illness, these families seem to make conscious efforts to remain intact. Five spouses of female patients made emphatic comments regarding their determination to stay together "for better or for worse." The 2 new spouses of female patients made it very clear that the MS did not interfere with their decision to marry.

Individual Testing of Children

The elementary-age children are seen by their teachers as adapting adequately, with the girls being rated higher than the boys. Written comments were generally very positive. The only two concerns that were mentioned were that several girls were considered to be overly social, and both boys and girls were frequently described in a fashion that suggested over-protection or dependent behavior. The secondary-age children are average to superior in cognitive ability.

The children of a mother patient tend to have average and above levels of empathy (11 out of 14). The father patient group is split, with 2 daughters showing average or

above average empathy, and 2 sons below average. The secondary-age children are well above average in their valuing of altruism. The value of being supported is next in importance to them, with the value of independence the least important. The majority of the 16 children taking the self-concept scale scored very high in overall self-concept, with very positive feelings about physical attributes, behavior, and happiness. Feelings about their intellectual and school achievements and freedom from anxiety are evenly spread between average and high.

All 20 children in the sample responded to the three projective tests. Eleven children feel unbalanced in their lives. Four other negative indicators, each appearing four times, are impulsive tendencies, feeling inadequate in some aspect of life, dependency, and a difficulty reaching out with a desire for interaction. Assertiveness and assertive potential are suggested four times. Positive interpersonal relationships and high intellectual aspirations with achievement striving are both found three times. Normal adolescent sexual adjustment, good behavior, and parental support are each seen twice. These results are consistent with the finding of basically well-adjusted personalities.

The families were drawn more often in passive, though joint, activities. Half demonstrate cooperation, and less than half have active family communication and nurturance. Over half have one inordinately large figure, thought to

represent the center of attention or power, evenly distributed among the patient, the caregiving spouse and the child artist. Four of the pictures each include more than one serious problem indicator, suggesting isolation, lack of family cohesion and a sense of insecurity. Fifteen of the drawings indicate an appropriate sense of equity within the family.

For the total group of 6 to 12 year olds, the projective stories resulted in an even distribution over the rating range for reliance on others and support of others. Self-assurance is a definite strength. Limit setting is high, indicating good self-discipline. Although these children can identify problems well and resolve them, it is not necessarily with as much maturity as would be expected for their age and intelligence. Anxiety is low, aggressive tendencies are normal, but depression is high. Rejection and unresolved feelings are higher than average. Girls with mother patients have anxiety spread across the rating range. Boys with mother patients are somewhat less reliant on others, and have more normal feelings of rejection. Of the 6-to-12-year-old group, girls as a whole are more reliant on others, but are also more self-assured than boys, have much stronger limit-setting skills, and are slightly more able to identify problems. The boys are slightly less anxious, less aggressive and less depressed, than the girls in this sample

For the total group of 13 to 18 year olds, a similar

picture emerges, with the exception of adequate reliance on others, less than adequate supporting of others, and higher than average anxiety and aggressive tendencies, with average unresolved feelings. In the small sample of 5 girls and 3 boys, the girls seem to have slightly more mature problem solving ability, but feel a little more rejected. The boys seem somewhat more self-assured but a little more depressed. Those with mother patient are slightly more reliant on others; those with father patient have slightly better problem solving skills. The 19-year-old daughter, whose responses could not be compared to the norms, reflected anxiety, unhappiness and a strong caring for others.

Discussion and Conclusions

Many of the findings of this study of 13 families are of particular interest and merit further discussion. Some are discussed in relation to past research findings. The interpretations suggested are based on the combination of the results from several instruments and the interviews.

The Family

Each family in this study was sufficiently confident in its strength to be willing to participate. The results indicate that, on the whole, this confidence was justified. The couples and the children were generally positive about their family hardiness, with the well spouse being especially positive. This belief comes from their mutual

strength and the family's strong ability to cope. They seem to cope most effectively using reframing (redefining a difficult situation to make it less stressful), and by refusing to ignore problems or to give up. They appear to actively reassess their family's constantly changing situation in an effort to manage and deal with the effects the MS has on their family system. This is consistent with one of Monroe's (1988/1989) findings. This reassessment includes a willingness to adjust roles and responsibilities as required, which is described by Power (1979) as "role complementarity." Agreeing again with Monroe and also with Power (1975, 1985), I found that the family tries to normalize the patient's continuance as a contributing member, no matter how disabled the patient is. With the patient remaining as active as possible, yet accepting his or her limitations, and the family recognizing when help is needed, the family is respecting and supporting the patient's individuality and dignity.

Agreeing with Power (1975, 1985), but in opposition to Sullivan (1974/1975), these families make a concerted effort to do things together, even though they admit that it is at times difficult to include the handicapped parent. Sullivan's sample included parents with some obvious disability, apparently making them less able to participate with the family. The spouses and the children, as Carpio (1981) found, acquire social support also as an effective

coping strategy. Male spouses seem to mobilize the family for problem solving more than female spouses do. Contrary to Power (1984), but in agreement with Peters and Esses (1985), the majority of these families do not use spiritual support to help them cope. This was surprising, because the majority of the families reported church affiliation. Of the 9 Catholic families, 2 indicated strong spiritual support, 2 average, and 5 low. Of the 3 Protestant families, 2 were strong and 1 was low. One family reported no church affiliation and little spiritual support. Several of the Catholic families seemed surprised when I asked how the church had given support, even questioning why it should be expected that it would give support. The church seemed to them to be an institution rather than a source of spiritual support. The families in this study consider themselves well-adjusted, adaptable, and balanced. Apart from the daughters of mother patients, these families, in contrast to Peters and Esses, also consider themselves cohesive. Peters's and Esses's subjects felt an overall lack of family togetherness. The resulting willingness to be open with one another, and with others including myself, further aids in moderating the impact of the illness on the family. This is parallel to Stuifbergen's (1988/1989) findings.

As Monroe (1988/1989) found, these parents recognize their children have more responsibility than most of their

peers. However, unlike Sullivan (1974/1975) and Yuditsky and Kenyon (1979), 18 of the 20 children in these families showed no resentment toward the ill parent in relation to this increased responsibility. There was an acceptance of this responsibility as being normal. In fact, during the interviews, these children, particularly the middle and younger children of a family, demonstrated obvious nurturance of not only the ill parent, but also the well spouse. Yuditsky's and Kenyon's results reflect the dysfunction of families who had labelled the patient member as "disabled." This was the case in only 1 of these 13 families, where the father was actually very disabled. The sons continued to show nurturance even though resentment was obvious. The family with a very disabled mother gave no impression of so labelling her. In one family where the mother was mildly affected and occasionally used a motorized cart, the son showed resentment and anger, based on his perception of her disability, and asked her not to attend his school functions. As Power (1979) found, the families' previous successful experience of coping with stress increases their ability to deal effectively with the additional stress resulting from the MS. These families confirmed Power's assertion that chronic illness enhances a family's prior pathology or, as in most of these families, their healthiness.

The Children

The children in this study perceive their families as basically equitable and well-adjusted. They recognize that, although the majority of their family activities may be passive, the family is involved together in them. The children do not recognize the family communication and nurturance which the parents believe exist. There are definite lines of communication, which frequently allow a family member to feel left out. Over half of the children recognize that one individual family member stands out as the strongest or most in need of attention.

As Power (1984), Rintell (1985) and Solomon (1981) all reported, these children have basically well-adjusted personalities, and are generally adapting adequately to life, with the girls in this study adapting slightly better than the boys. Even though they may feel imbalanced in their lives, they indicated strong self-assurance and extremely high self-concept, whereas Rintell's sample was close to the mean. The authors of the Piers-Harris test caution that scores as high as were obtained from this sample may represent an over-inflated ego or an inability to look critically at oneself. It is my opinion, in light of all the results of the projective and objective tests and the interviews and observations, that this could be true of only 1 of the 10 children in this sample who are at that extremely high level. Because of Carpio's (1981), Rintell's

(1985), and Sullivan's (1974/1975) findings of adequate and appropriate body image, and Arnaud's (1959) and Olgas's (1974) findings of poor body image, the extremely high physical self-concept of the children in this study may appear more open to question. However, again, the overall picture gained from the results of this study, together with the obvious pride of a number of the children in their athletic accomplishments, lead me to believe they are accurately assessing themselves. These children also have extremely positive self-concepts regarding their behavior and their sense of happiness. Their feelings regarding their intellectual and academic achievements range from average to high, consistent with the school ratings of cognitive ability from average to superior.

In agreement with Carpio (1981) and Blackford (1992), but in contrast to Arnaud (1959), these children have good interpersonal relationships, and may tend to be overly social. Those who appear to have difficulty reaching out do have the desire to interact. Again in contrast to Arnaud, only a small proportion are considered over-protected or dependent. Arnaud's study appeared to focus on the negatives, based on the negative outlook of that time regarding the effects of MS on the patient and, therefore, the family. Of the children of mother patients, 78% have average to above empathy, as found by Blackford (1992). In this study, daughters of father patients have average to

above average empathy, whereas the sons of father patients are below average. Only adolescents could be tested about their social values. In this study, the highest value was placed upon altruism. The value of being supported was next in importance, consistent with Sullivan's (1974/1975) findings of its importance to adolescents. The adolescents in this study do not value independence. Although this seems contrary to normal development and the adolescent need for individuation, it is consistent with these children's apparent unresentful acceptance of their responsibilities within the family.

The children in this study have high limit-setting ability, indicating good self-discipline. Although they can identify problems well, their maturity in resolving them is not necessarily consistent with their age and intelligence. The children tended to try to solve problems in an over-controlling fashion of "this is the way it should be," or a laissez-faire fashion of "ignore it and it will go away." The children whose parents obviously made attempts to have them participate in family problem solving demonstrated definitely greater skill, taking more care to effect a positive solution. The older children seem to have developed a more appropriate reliance on others, and seem to recognize their need, as a part of normal individuation, to become less supportive of others. In several of the families, the oldest adolescent shared the belief that the

next child should now be assuming more responsibility in the home so he or she could proceed with his or her own life.

Anxiety is higher than average in the adolescents, as was found by Yuditsky and Kenyon (1979), and in contrast to Arnaud (1959). Similar to Arnaud, however, the adolescents have above average aggressive tendencies. The younger children have low anxiety and normal aggressive tendencies, in contrast to Arnaud's findings. The children generally, across the age range, seem to have high depressive tendencies, in agreement with Arnaud. The majority of the children in this study worry about their parents, both patient and spouse. The younger children worry whether the ill parent will die, and what will happen to them. This may seem in conflict with the earlier finding that they report themselves as satisfied with their happiness. The depressive tendencies, however, were revealed through projective techniques. Therefore, the children may not even be aware of these feelings. The older children admit to denying many aspects of their situation such as Power's (1984) "positive denial," seeking to fulfill daily responsibilities yet still desiring to attend to their own needs for the future. These children appear to be coping quite well, but at a cost. The psychic energy necessary to maintain their outward healthiness drains internal reserves, making them more vulnerable to feelings of imbalance, anxiety and depression. In general, these children have

above average feelings of rejection, but the high level of unresolved feelings in the younger children is reduced in adolescence.

Research Questions

The study sought answers to a number of research questions, as stated in chapter 1. Answers to these questions are suggested in the findings.

Question 1: How do children with multiple sclerotic parents perceive their families? Overall, the children perceive their families as well-adjusted, hardy, coping, adaptable and balanced. They recognize that one family member is very strong or the center of attention.

Question 2: How do these children perceive themselves, their physical image, their self-concept and their place within the family? Generally, they have very positive physical images and self-concepts. Some of the children feel a sense of rejection, apparently resulting from the focusing of attention on the patient, and the intense marital relationship the parents have developed.

Question 3: As the families have adjusted their structure, roles and expectations, support systems and financial situation as a response to the disease affecting one of the productive adults, how have the children related to these adjustments? In the main, these children have adapted as the family has adjusted. They seem to accept their new responsibilities as natural; but, as they grow

older, there is a desire to pass some of these responsibilities to a younger sibling, so they can begin their normal separation process. The youngest child in the unit did seem to be experiencing more internal conflict as they reached adolescence and had no younger sibling to whom the responsibilities could be passed.

Question 4: Is the emotional and social development of these children following a normal developmental pattern, specifically with respect to the development of empathy and altruism/prosocial behavior? In the main, these children were reported as experiencing normal development. They exhibit average and higher levels of empathy and the adolescents value altruism very highly.

Question 5: If the children are developmentally delayed or accelerated, is it the apparent result of the multiple sclerosis in the family? It would appear that the high levels of empathy and altruism could well be a function of the situation which demands that the children extend themselves for the benefit of a parent and that generates nurturance in well-adjusted families. Anxiety, depressive tendencies, and feelings of rejection also seem a logical result of the continual stress the illness places on the family, and the concern for and attention paid to the ill parent.

Recommendations

Professionals, such as physicians, teachers, counselors

and ministers, who come in contact with families where a parent has MS, need to be aware of the additional stresses being placed on the family system, as well as on the individual family member. By recognizing the findings of this and previous studies identifying how well-adjusted families have successfully coped with the situations caused by the MS, they may be better able to provide appropriate support to families dealing with MS.

It is essential that the professional community become aware that the children in such families are basically normal and adjusted. While they may suffer negative effects from the stress, they may also benefit in their social development of empathy and altruism.

The potential for research in this field is limited by several factors: (1) the difficulty gaining access to the population for research purposes, (2) the lack of sufficient confidence in many families to allow for participation, and (3) the small proportion of intact families. However, further research is essential. The present study should be replicated with a larger sample over a larger geographic area. A similar study should be undertaken with families who are not coping as well with the MS. This should include families with a single parent. A study needs to be undertaken that can delineate how the age and stage of development of the child at the onset of the parent's symptoms are related to their eventual adjustment. Further

research related to the sex of the patient and the children would also be useful. Similar research should be undertaken with non-Caucasian families.

APPENDICES

APPENDIX A

Demographic Questionnaire Package and Approval Forms

- Introductory Letter
- Questionnaire
- Consent Form
- Letter Acknowledging Receipt
- HSRB Approval
- Letters of Support
- Letter to St. Luke's
- St. Lukes' HSRB Approval
- St. Lukes' Letter of Introduction

Date

Hello,

My name is Jean McCutchan and I am a doctoral student at Andrews University in Berrien Springs, Michigan. I am working toward a Ph.D. in counseling psychology. I was a school psychologist for ten years, then resigned due to problems caused by the onset of multiple sclerosis. I changed occupations and have been a part-time family therapist for seven years.

There has been a lot of research done on multiple sclerosis and the people who have it. But there has been minimal research done on the families involved, especially the children. Since my areas of specialization are families and health issues I am doing research to complete my Ph.D. on families which have a parent with multiple sclerosis and school-aged children. I am investigating the social and emotional development of the children as to whether they are affected by having a parent with M.S. I am looking at both positive and negative effects.

If you and your family would be interested in participating in the project, please fill out the attached questionnaire and consent form and return them in the enclosed stamped and addressed envelope. You will be contacted further as the research progresses only if you return the questionnaire.

An assistant and I need to be able to meet with you and your family in your home if you become part of the study. We would need to meet with the entire family at least once and each individual separately and/or in small groups at least once.

Following the interviews with your family and individual members of the family, the interview schedules and forms will be identified only by an ID number, so that materials from a family may be kept together. The family name will not be attached to these forms. No family names will be mentioned in the research report. Confidentiality is thus assured.

If at any time during the study you should wish to withdraw, this is your right. As a counselor, and a fellow sufferer from multiple sclerosis, I take it as my responsibility to conduct the research in such a manner as to avoid causing discomfort to your family or any individual member of your family.

Thank you for considering your contribution to research on families dealing with M.S. If you have further questions, please feel free to call me at 219-262-0019, evenings.

Sincerely,

JEAN A. MCCUTCHAN

Enclosures:

1. Multiple Sclerosis Study - Population Identification Questionnaire - to be filled out and returned in the enclosed envelope.
2. Andrews University, Information and Consent Form - to be filled out. Return the white copy with the questionnaire and keep the yellow copy.

MULTIPLE SCLEROSIS STUDY

POPULATION IDENTIFICATION QUESTIONNAIRE

1. Please give the complete names and ages of all who live in the home. Give the grade in school for the children.

		Age	School Grade
MOTHER	_____	___	
FATHER	_____	___	
DAUGHTER(S)	_____	___	_____
	_____	___	_____
	_____	___	_____
	_____	___	_____
SON(S)	_____	___	_____
	_____	___	_____
	_____	___	_____
	_____	___	_____
			Relationship
OTHERS	_____	___	_____
	_____	___	_____

2. Please give the complete names, ages and relationship of any other family members not living at home.

_____

_____

_____

3. Which parent has multiple sclerosis? _____

4. What year was it diagnosed? _____

5. Who diagnosed it? NAME(S) _____

_____

6. What symptoms are you experiencing on a daily basis? _____

_____

_____

7. To participate in this study every family member must be willing to be interviewed as part of a group and possibly individually. Would everyone in your family be willing to participate?

   Yes_____ If yes, go to #8.

   No_____ If no, I am sorry, but your family cannot participate in the study without full cooperation from everyone. Thank you for your time.

   Uncertain____ If uncertain, may I contact you to help you you make your decision? Yes_____ No_____

8. It will be necessary for me and an assistant to visit in the home of each participating family. We believe you would be most comfortable being interviewed in the familiar surroundings of your own home. Is this agreeable to your family?

   Yes_____ If yes, go to #9.

   No_____ If no, would you be willing to meet in another mutually agreeable location?
   Yes_____ If yes, go to #9.

   No_____ If no, your questionnaire will be kept on file in case circumstances change in the study. Please go to #9.

9. Because of the nature of the study it may be necessary to spread the interviews with a particular family over a period of several months. Is this agreeable to your family?
   Yes_____ No_____

10. Please give the following information:

    ☐ Home address:_____

    _____

    ☐ Home phone number:_____

    ☐ Wife's work phone number:_____

    ☐ Husband's work phone number:_____

Please indicate how you can best be contacted by checking the appropriate box(boxes) on the left above.

11. On what day of the week and at what time of day is it most convenient to make contact?

	Day	Time
Home:	_____	_____
Wife's work phone:	_____	_____
Husband's work phone:	_____	_____

12. If you have any additional comments feel free to write them in the space at the bottom of this page.

13. Please turn to the next page, which is an information and consent form, and fill it out completely if you are willing to participate in the study.

Thank you very much for your time and willingness to be considered for participation in this study.

Kindly return this questionnaire in the stamped, addressed envelope provided.

Please be sure to include your completed information and consent form.

You will be contacted further within one month of receipt of your filled-out questionnaire.

Signed

Full name of person completing the questionnaire (please print):_____

Signature_____ Date_____

ANDREWS UNIVERSITY

INFORMATION AND CONSENT FORM

Dear Family Members,

I have explained to you that as a doctoral student at Andrews University, I am investigating the social and emotional development of children who have a parent with multiple sclerosis. By responding to the questionnaire you have provided some personal information which I have assured you will be held in strict confidence. If you have indicated your willingness to participate in the study you have done so with the understanding that the research will involve family group and individual interviews, which may involve measures of attitude toward self, toward other family members, about self within the family and toward other people. As few as one or as many as all of these measures could be administered. The study will be conducted in your home. You have agreed to participate under the following safeguards:

Since your participation in this study is voluntary, you may withdraw at any time.

All information will remain confidential. Although the descriptions and findings may be published, at no time will your name(s) be used.

There is no cost for participation in this study.

As the researcher, I take it as my responsibility to conduct the research in such a manner as to avoid causing discomfort to the family or individual family members and to avoid subjecting anyone to an overlengthy and tiring period of questioning.

Investigator_____ Date_____

Jean A. McCutchan

If you have any further questions, please call me at 219-262-0019, evenings, or write to me at 22660 Remington Court, Elkhart, Indiana 46514.

Please sign in the appropriate spaces below. Please tear off the yellow back copy and keep it for your records, then send this original with your completed questionnaire in the envelope provided.

To be signed by each family member and by a witness who is anyone other than a family member:

We, the undersigned, have read, understood and accept the above information and conditions. We have received a copy of this form. We agree to participate as a family in this study under the conditions outlined.

Mother's signature_____ Date_____

Father's signature_____ Date_____

Children's signatures_____ Date_____

_____ Date_____

_____ Date_____

_____ Date_____

Witness' signature_____ Date_____

22660 Remington Court
Elkhart, IN 46514

July 23, 1993

The ---------family

Dear ----------family:

I have received your returned materials. Thank you very much for filling them out and being willing to participate.

I am reviewing the returns as they come in and will eventually be able to make a selection of families for the sample in such a way as to allow me to limit the possible extensiveness of such a study.

Your record will be held in strict confidence and I will be contacting you as soon as I am able to determine my sample families.

If you have any questions, feel free to contact me at 219-262-0019, evenings.

Sincerely,

Jean A. McCutchan

PS. I am returning the yellow back copy to you for your records.

Encls.

ANDREWS
UNIVERSITY

May 26, 1992

Jean A. McCutchan
22660 Reminton Ct.
Elkhart, IN 46514

Dear Jean:

The Human Subjects Review Board has reviewed your proposal, "Social and Emotional Development of School-aged Children of a Parent with Multiple Schlerosis," under the full review procedure. You have been given clearance to proceed with your research plans.

If there are any modifications to the proposed research protocol or consent form, or you encounter problems as a result of the study, please notify us in writing. Feel free to contact us if you have any questions.

If your research is going to take more than one year, you must request an extension of your approval in order to continue with this project. The present approval duration is for one year. We wish you success on this project.

Sincerely

Kent R. Randolph
Assistant to the Director,
Office of Scholarly Research

kr

c: Dr. Wilfred Futcher

STATEMENT OF SUPPORT

I, Thomas R. Vidic, M.D., am willing to help with Jean A. McCutchan's doctoral dissertation study in the following manner:

I will send Jean's cover letter, questionnaire and consent form to my multiple sclerosis patients together with a cover letter of my own introducing Jean, explaining she is not associated with the Elkhart Clinic, but that she is a professional person worthy of their confidence.

Thomas R. Vidic, M.D.

Date 16 April 95

NATIONAL MULTIPLE SCLEROSIS SOCIETY
[illegible] NEW YORK, N.Y. 10017 (212) 986 3240 FAX (212) 986 7981

May 4, 1992

Jean A. McCutchan, M.A.
Psychological & Family Consultants
926 E. Jackson Blvd.
Elkhart, IN 46516

Dear Ms. McCutchan:

Per our telephone conversation this afternoon, attached is a statement indicating the support offered to you for your dissertation research by the National Multiple Sclerosis Society.

Sincerely yours,

Robert Enteen, Ph.D.
Director, Health Research and
Policy Programs

attach.

STATEMENT OF SUPPORT

The National Multiple Sclerosis Society is willing to help with Jean A. McCutchan's doctoral dissertation study in the following manner:

We will furnish to Jean a list of state and local chapters. If they agree, through their auspices she may send individual members her letter and questionnaire. These chapters will introduce Jean's study and her questionnaire by a cover letter or any other means they choose. She will abide by any conditions or limitations they require, in order to protect member confidentiality.

Robert Enteen, Ph.D. — Name

5/4/92 — Date

Signature

Director, Health Research & Policy Programs — Office

22660 Remington Court
Elkhart, IN 46514

August 10, 1992

Floyd Davis, M.D.
MSC Neurological Consultants
(Rush-Presbyterian St. Luke's Medical Center)
1725 W. Harrison Street, Suite 330
Chicago, IL 60612

Dear Dr. Davis:

Dr. Tom Vidic, my neurologist, suggested that I write you to ask for assistance in locating potential subjects for my study. I am a doctoral student at Andrews University in Berrien Springs, Michigan and am completing my Ph.D. in counseling psychology. I am presently beginning to work on my dissertation and am searching for families who have a parent with multiple sclerosis. I plan to study the families and their school-aged children. I have enclosed a packet of information which Dr. Vidic helped me disseminate to all of the Elkhart Clinic M.S. patients. To protect their confidentiality Dr. Vidic wrote a cover letter. He had one of his staff members identify via the computer the M.S. patients that had been diagnosed as having M.S. over the past year, then address and stuff the envelopes I provided with the materials I had collated for them. Therefore, I only know names if a family returns a packet showing interest in participating in the study. Dr. Vidic felt that you and your colleagues have a large population of M.S. patients and might be willing to assist me in a similar fashion.

I had the pleasure of meeting you ten years ago this summer when you helped my physicians diagnose my M.S.

I would like an opportunity to talk with you to discuss the possibility of your help with my dissertation. I will plan on calling your office in the morning of Wednesday, August 19. If you could leave a time with your secretary which would be a good time to reach you, I will call back at that time. You are welcome to call me at your convenience at 219-674-0157 during the day and 219-

262-0019 after 5:30. If you would prefer to discuss this with me in person, that can also be arranged.

I hope you will find my study worthy of your assistance. I am very excited about the response so far. I look forward to talking with you.

Sincerely,

Jean A. McCutchan, M.A.

RUSH-PRESBYTERIAN-ST. LUKE'S MEDICAL CENTER
HUMAN INVESTIGATION COMMITTEE

Investigational Studies Involving Questionnaires, Survey Forms, Video Materials, Data Collection or Information Obtained from Patients' Charts

PRINCIPAL INVESTIGATOR: Jean A. McCutchan/H. Robert Abr DATE: 1/15/92

DEPARTMENT: Neurology SECTION: M.S. Center

TITLE OF PROJECT: Social and Emotional Development of School-aged Children of Parent with Multiple Sclerosis

SOURCE OF FUNDS (*If NIH, specify agency*): Self-funded (funds provided by individuals)

PROJECT PERIOD: _____

The undersigned affirmatively certify that:

Please check:

[✓] 1. This study involves answering questionnaires, completing survey forms, or reviewing videotapes;

[✓] 2. This study involves obtaining information from patients' charts, or data collection.

[✓] 3. The confidentiality of the subject information will be maintained.

That should the Human Investigation Committee feel that subjects will be at risk, the appropriate Human Investigation Committee forms will be filed prior to the initiation of the project and consent will be obtained; and that if the nature of the study changes in any material way which would modify this certification, the undersigned principal investigator agrees to notify the Office of Research Administration immediately.

(Please type name below signature line.)

SIGNATURE: Jean A. McCutchan H. Robert Abr
Principal Investigator JEAN A. MCCUTCHAN

SIGNATURE: _____
Section Director, if applicable

SIGNATURE: F McDermott MD
Department Chairperson

SIGNATURE: M.E. Arnold Janet M. Walter DATE 1-15-93
Janet M. Walter, M.D., Chairperson Human Investigation Committee

SIGNATURE: H.R. Wicklund
Authorized Institutional Official

NOTE: Please enclose protocol, questionnaire and/or survey with this form. Human Investigation Committee approval is valid for one year only.

2/87

OMB No. 0925-0637

DEPARTMENT OF HEALTH AND HUMAN SERVICES

PROTECTION OF HUMAN SUBJECTS ASSURANCE/CERTIFICATION/DECLARATION

☒ ORIGINAL ☐ FOLLOWUP ☐ EXEMPTION (previously undesignated)

☐ GRANT ☐ CONTRACT ☐ FELLOW ☒ OTHER

☒ New ☐ Competing continuation ☐ Noncompeting continuation ☐ Supplemental

APPLICATION IDENTIFICATION NO. (if known)

POLICY: A research activity involving human subjects that is not exempt from HHS regulations may not be funded unless an Institutional Review Board (IRB) has reviewed and approved the activity in accordance with Section 474 of the Public Health Service Act as implemented by Title 45, Part 46 of the Code of Federal Regulations (45 CFR 46—as revised). The applicant institution must submit certification of IRB approval to HHS unless the applicant institution has designated a specific exemption under Section 46.101(b) which applies to the proposed research activity. Institutions with an assurance of compliance on file with HHS which covers the proposed activity should submit certification of IRB review and approval with each application. (In exceptional cases, certification may be accepted up to 60 days after the receipt date for which the application is submitted.) In the case of institutions which do not have an assurance of compliance on file with HHS covering the proposed activity, certification of IRB review and approval must be submitted within 30 days of the receipt of a written request from HHS for certification.

1. TITLE OF APPLICATION OR ACTIVITY

Social and Emotional Development of School-Aged Children of a Parent with Multiple Sclerosi

2. PRINCIPAL INVESTIGATOR, PROGRAM DIRECTOR, OR FELLOW

ABER, W. Robert, Ph.D.

3. FOOD AND DRUG ADMINISTRATION REQUIRED INFORMATION *(see reverse side)*

4. HHS ASSURANCE STATUS

☒ This institution has an approved assurance of compliance on file with HHS which covers this activity.

M 1385 Assurance identification number 01 IRB identification number

☐ No assurance of compliance which applies to this activity has been established with HHS, but the applicant institution will provide written assurance of compliance and certification of IRB review and approval in accordance with 45 CFR 46 upon request.

5. CERTIFICATION OF IRB REVIEW OR DECLARATION OF EXEMPTION

☒ This activity has been reviewed and approved by an IRB in accordance with the requirements of 45 CFR 46, including its relevant Subparts. This certification fulfills, when applicable, requirements for certifying FDA status for each investigational new drug or device. *(See reverse side of the form.)*

1/18/93 Date of IRB review and approval. *(If approval is pending, write "pending." Followup certification is required.)*
(month/day/year)

☐ Full Board Review ☒ Expedited Review

☐ This activity contains multiple projects, some of which have not been reviewed. The IRB has granted approval on condition that all projects covered by 45 CFR 46 will be reviewed and approved before they are initiated and that appropriate further certification *(Form HHS 596)* will be submitted.

☐ Human subjects are involved, but this activity qualifies for exemption under 46.101(b) in accordance with paragraph _____ *(insert paragraph number of exemption in 46.101(b), 1 through 5)*, but the institution did not designate that exemption on the application.

6. Each official signing below certifies that the information provided on this form is correct and that each institution assumes responsibility for assuring required future reviews, approvals, and submissions of certification.

APPLICANT INSTITUTION	COOPERATING INSTITUTION
NAME, ADDRESS, AND TELEPHONE NO. Rush-Presbyterian-St. Luke's Medical Center 1653 West Congress Parkway Chicago, Illinois 60612 (312) 942-5479	NAME, ADDRESS, AND TELEPHONE NO.
NAME AND TITLE OF OFFICIAL *(print or type)* W. Randolph Tucker, M.D. Director, Research Administration	NAME AND TITLE OF OFFICIAL *(print or type)*
SIGNATURE OF OFFICIAL LISTED ABOVE *(and date)* W. Randolph Tucker 1/18/93	SIGNATURE OF OFFICIAL LISTED ABOVE *(and date)* 1/18/93

HHS 596 (Rev. 1/82) *(If additional space is needed, please use reverse side under "Notes.")*

RUSH-PRESBYTERIAN-ST. LUKE'S MEDICAL CENTER
Office of Research Administration
PROCESSING CHECK-LIST

ORA # 92/1058

INVESTIGATOR(S): Jean J. McCutchan / W. Robert Ober AGENCY DEADLINE: _____
DEPARTMENT/SECTION: Neurology / N.S. Center EXTENSION: 2-5811 LOCATION: Jr. Bldg.
PROJECT OR PROTOCOL TITLE & NO.: Social and Emotional Development of School-aged Children of a Parent with Multiple Sclerosis FAX #: _____

FUNDING AGENCY (*If NIH, Specify Institute*): _____

TYPE OF APPLICATION (*Check One*): ☐ Grant ☐ Contract ☑ Departmental ☐ Other _____

The Investigator Should Obtain the Following Approvals Where Appropriate:

	Initials:	Date:	Commen
1. Approved by Department Chairperson or Admin. Officer (M.F. Cento)	FAO.	10-22-92	
2. Is Recombinant DNA used in this Project? ☐ Yes ☑ No If yes, submit DNA form with this project.			
3. Are animals involved in this project? ☐ Yes ☑ No if yes, initial and indicate date of submission of appropriate documentation to the Animal Care & Use Committee (2-6576)			
4. Are Radioisotopes used in this project? ☐ Yes ☑ No If yes, initial and indicate date of submission of "Authorized Radioisotope User" form to Radiation Safety Officer (2-5763)			

The Office of Research Administration will Obtain the Following Approvals:

	Initials:	Date:	Commer
5. Received by the Office of Research Administration (ext. 2-5498)	DD	11/5/92	
6. Budget Reviewed by Office of Research Administration	N/A		
7. Reviewed by Eva M. Wimpffen, Office of Research Administration	[illegible]	11/9/92	✓
8. Reviewed by Dr. Tucker, Office of Research Administration	[illegible]	11/12/92	
9. Human Investigation ☐ Yes ☐ No Approved by the Human Investigation Committee (Minutes Sept 14 '93)	JW	1-15-93	
10. Approved by Other Review Groups as appropriate: _____	HC	1-18-93	
11. Approved by Office of the Dean	[illegible]	1-21-93	
12. Reviewed and approved by Authorized Official			
13. Returned to Investigator	Dm	1 22 93	

PLEASE CONTACT THE OFFICE OF RESEARCH ADMINISTRATION, EXTENSION 2-5498, AT LEAST TH WEEKS PRIOR TO ANY DEADLINE IF YOU HAVE ANY QUESTIONS OR NEED ASSISTANCE.

Sec. 450, 5

MSC NEUROLOGICAL CONSULTANTS
RUSH-PRESBYTERIAN-ST. LUKE'S MEDICAL CENTER
1725 WEST HARRISON STREET, SUITE 309, CHICAGO, ILLINOIS 60612
PHONE (312) 942-8011

FLOYD A. DAVIS, M.D.
DUSAN STEFOSKI, M.D.
LEA H. BATMAN, M.D.
JAMES D. STEWART, Ph.D.
W. ROBERT ABER, Ph.D.
KIMBERLY A. DOUGLASS, R.N.
LINDSEY L. BARNES, OTR/L

February 15, 1993

Dear Rush M.S. Center Patient,

I am forwarding the enclosed information concerning this research study through our office in order to preserve your confidentiality. Although Jean McCutchan is not directly affiliated with the Rush M.S. Center, I am acquainted with her and know her to be an ethical and caring professional. Please consider participating in this study, as this area of research is an important one that has been given little attention historically. I do want to stress, however, that your decision to participate (or not to participate) will have no effect on your treatment here at the M.S. Center or on your relationship with your physician.

If you have questions concerning this or any other issue, please feel free to call me at (312) 942-8011.

Sincerely,

W. Robert Aber, Ph.D.
Clinical Psychologist

APPENDIX B

INTERVIEW INSTRUMENTS

- Family Interview Schedule
- School Request Forms
- Recommendation of FACES-II over FACES-III
- FACES-II
- FCOPES
- FHI
- Vineland Adaptive Behavior Scale
- Mehrabian Letter
- Bryant Index of Empathy
    - Yes/No Response Scale
    - 9-point Response Scale
- Survey of Interpersonal Values
- Piers-Harris Children's Self-Concept Scale
- Roberts Apperception Test for Children

1

FAMILY INTERVIEW Family #_____

Names - this page will be destroyed
Star M.S.

Parents

A. Mother _____ BD _____ Educational Level _____

Occupation _____ How long there? _____

Hours of work _____

B. Father _____ BD _____ Educational Level _____

Occupation _____ How long there? _____

Hours of work _____

Marriage Date _____

Children	M/F	BD	School	Grade	Teacher
C.					
D.					
E.					
F.					
G.					

Others living in home	Relationship	Age	In Home How Long
H.			
I.			

Family #_____

Church affiliation(s) _____

_____

Organizations (who and what) _____

_____

_____

Volunteer work _____

_____

_____

Other activities _____

_____

_____

M.S. was diagnosed when? _____

where and by whom? _____

_____

how _____

how told of diagnosis _____

_____

doctor's support _____

_____

age of children at diagnosis _____

_____

_____

Who has the diagnosis been shared with?_____

_____

]

Family #_____

How was diagnosis dealt with by self _____

_____

_____

Spcuse _____

_____

_____

Parents and in-laws of self _____

_____

_____

Siblings of self _____

_____

_____

Children _____

_____

_____

As the nuclear family _____

_____

_____

_____

Work _____

_____

Church _____

_____

Friends _____

_____

4

Family #_____

How supportive has each individual group been? _____

Spouse _____

Parents and in-laws _____

Siblings _____

Children _____

Work _____

Church _____

Friends _____

Family #_____

First symptoms/problems, what and when? _____

_____

_____

List all symptoms:

Initial, but stopped	Initial, still present	Additional but stopped	Additional, still present

List all treatments and medications, specify ones presently used:_____

_____

_____

Home help and assistance: Who, How often, How paid

Housekeeping _____

_____

Child care _____

_____

Personal assistance _____

_____

Financial assistance _____

_____

_____

Family #_____

Medical insurance coverage for patient _____

_____

_____

Counseling: for whom, by whom, for how long, related to diagnosis or other

_____

_____

_____

How has the family changed? As individuals in relationships to one another and responsibilities:

_____

_____

_____

_____

How are the children doing in school academically, behaviorally, socially

_____

_____

_____

_____

Any other data or comments:_____

_____

_____

_____

_____

TEACHER RELEASE FORM

As the parent of _____, I give my permission for their teacher to fill out the Vineland Adaptive Behavior Scale on my child and to provide any additional information as requested.

_____ _____
Signature Witness

_____
Date

TEACHER LETTER

Dear _____:

This child, _____, is involved in a doctora dissertation study with his/her family investigating how childre are affected by having a parent with Multiple Sclerosis. I woul appreciate it if you would fill out the enclosed Vineland Adaptiv Behavior Scale regarding this child, but please do not identif yourself or the child on the form. It is coded to maintain th family's confidentiality. Please include on the Scale's cover th child's most recent IQ score as recorded in their cumulativ folder, incidating the measure used to determine the IQ.

If you have any questions please call me at 219-522-0481 or 800 257-4837. Feel free to write on a separate sheet any comments yo feel may be helpful. Please return in the enclosed SASE as soon a possible.

Jean McCutchan

Encls.

To the Principal

Dear Sir:

Our child, _____, is a student in Grade __ in your school.

As a family, we are participating in a research by Jean McCutchan into the personality, social and cognitive development of children in a family where a parent has multiple sclerosis.

We are hereby authorizing you to release to Mrs. McCutchan information from your records on our child.

Would you kindly have the appropriate person provide on the lower part of this page, the latest IQ standard score obtained for our child, stating also the scale (instrument) on which it was measured.

Please detach that part of the page, and send it, in the stamped, addressed envelope provided, to Mrs. McCutchan. Please do not put a name on the form. It is number coded so that the information may be attributed to the correct individual.

Thank you.

Yours sincerely,

_____ Father

_____ Mother

Family ID _____

Child ID _____

IQ _____

Scale (Instrument) _____

UNIVERSITY OF MINNESOTA

Twin Cities Campus

Family Social Science
College of Human Ecology

290 McNeal Hall
1985 Buford Avenue
St. Paul, MN 55108
612-625-7250
Fax: 612-625-4227

June, 1991

USE OF FACES II VERSUS FACES III

We at the Family Inventory Project currently find ourselves in a state of transition. Work is underway to test the reliability and validity of FACES IV. Until we are confident of our results and can provide you with the completed instrument and manual, we are recommending that you now use FACES II.

Although FACES III is the most recent version of FACES, and has been effectively used in hundreds of research projects, many findings have suggested that FACES II has some advantages over FACES III.

First, the alpha reliability is higher in FACES II because it contains more items. The following table illustrates the differences in reliability when test items were reduced from 15 in FACES II to 10 in FACES III. Cronbach Alpha figures for the two versions are as follows:

	FACES II	FACES III
Cohesion	.87	.77
Adaptability	.78	.62
Total Scale	.90	.68

Second, the correlation between adaptability and cohesion and social desirability in FACES II is less problematic than anticipated. Although the correlation between cohesion and adaptability is considerably higher in FACES II, the common variance has not been problematic, and the unique variance did work well. The correlation of adaptability, cohesion, and social desirability for FACES II and FACES III is reported below:

		FACES II		
		Cohesion	Adaptability	Social Desirability
FACES III	Cohesion	---	.65	.39
	Adaptability	.03	---	.38
	Social Desirability	.35	.00	---

Third, the concurrent validity for FACES II is higher than for FACES III, especially for family adaptability. That is, other instruments which measure constructs similar to cohesion and adaptability correlate higher with FACES II than FACES III. Hampson, Hulgus and Beavers (1991) compared the Dallas Self-Report Family Inventory (SFI) with both FACES II and FACES III. They found the following correlations between the SFI global measure of family health and FACES II and FACES III:

	FACES II		FACES III	
	Cohesion	Adaptability	Cohesion	Adaptability
SFI				
Health	.93**	.79**	.84**	.45**

** = p. < .01

Hampson, R. B., Hulgus, Y. F., & Beavers, W. R. (1991). Comparisons of self-report measures of the Beavers Systems Model and Olson's Circumplex Model. Journal of Family Psychology, 4(3), 326-340.

SUMMARY

Therefore, in light of these recent reliability and validity comparisons, we recommend that you use FACES II. You will note in the March, 1991 issue of Family Process (30:74-79) that the Circumplex Model has been theoretically updated. Recent empirical evidence supports a linear scoring of FACES II and III and a curvilinear scoring of the Clinical Rating Scale (CRS). In short, we believe you will have better success with your research by using FACES II and the linear scoring and data analysis.

Faces II: Family Version
pgs. 417 - 436

University Microfilms International

Albert Mehrabian, Ph.D.

Dear Ms McCutcheon,

Your are hereby given permission to duplicate and use the Emotional Empathic Tendency test for use with subjects who you will be running in your ow experimental studies. Please note you are not allowed to reproduc any items of the scale listed above in any medium for distributic to others (e.g., dissertation, journal article, book, compute program, or another test or test manual). Others in you department or school who may wish to use the scale listed abov need to contact me at the address below for permission to use it

Best wishes,

Albert Mehrabian

*1130 Alta Mesa Road * Monterey, CA 93940 * Telephone (408) 649-5710*

APPENDIX C

DATA FILE

APPENDIX C

Data File

Row 1	Column	
	1-3	Family ID
	4	1 = Patient; 2 = Spouse; 3 = Child 1; 4 = Child 2, etc.
	5	1 = Male; 2 = Female
	6-35	FACES-II responses
	36-55	FHI responses
	56-85	F-COPES responses
Row 2	**Column**	
	1-5	as for row 1
	6-7	FACES-II score on Cohesion
	8-9	FACES-II score on Adaptability
	10-11	FHI score on Cooriented Commitment
	12-13	FHI score on Confidence
	14-15	FHI score on Challenge
	16-17	FHI score on Control External
	18-19	FHI Total Score
	20-21	F-COPES score on Acquiring Social Support
	22-23	F-COPES score on Reframing
	24-25	F-COPES score on Seeking Spiritual Support
	26-27	F-COPES score on Mobilizing Family
	28-29	F-COPES score on Passive Appraisal
	30-32	F-COPES total score
	33-34	Bryant Scale (Yes/No) score
	35-37	Bryant Scale (-4 to +4) score

Row 2	Column	
	38-40	Mehrabian Scale score
	41-42	Piers-Harris score on Behavior
	43-44	Piers-Harris score on Intellectual/ Academic
	45-46	Piers-Harris score on Physical Appearance and Attributes
	47-48	Piers-Harris score on Anxiety
	49-50	Piers-Harris score on Popularity
	51-52	Piers-Harris score on Happiness and Satisfaction
	53-54	Piers-Harris total Self-Concept score
	55-56	SIV score on Support
	57-58	SIV score on Conformity
	59-60	SIV score on Recognition
	61-62	SIV score on Independence
	63-64	SIV score on Benevolence
	65-66	SIV score on Leadership
	68-72	Age at date of testing (11.08 = 11 years 8 months
	74-78	Grade at date of testing (+ in column 5 = completed)
	80-85	Date of testing (m d y)

```
10112542451545331451444223452134115222224413144412144113342235344225233224224222311451
101126748191013 8502529101216 92
10121551551441151521354135553143215211344414143423334214252545545542533214443435523125
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10132442345351441254324315421215355
101325548                              18                                          6.11  1.8   41293
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20612664620100806443227181414105
20621541551451151341254164432144214311444444143414144444344445344235554444553434141 15
20621724724091401483331181615113
20631531522321353125153155531125515
206316542                              15          15151108091064                 9.02  3.9+  82493
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20732223543535353553555235535235335
207326249                              12                                         7.11  1.9+  82493
20741                PROJECTIVES ONLY
20741                PROJECTIVES ONLY                                           5.08  K.9+  82493
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210624638200810084637341011171 09 092161109050408521614121229 07 19.09 12.9+ 121393
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APPENDIX D

PIERS-HARRIS PROFILES

APPENDIX D

Piers-Harris Profiles

Profiles included for:

Family 102	-	Daughter 1
	-	Daughter 2
Family 201	-	Daughter
Family 202	-	Son
Family 203	-	Daughter
Family 204	-	Daughter 1
	-	Daughter 2
	-	Daughter 3
Family 205	-	Son 1
	-	Son 2
Family 206	-	Son
Family 208	-	Daughter
Family 209	-	Son
	-	Daughter
Family 210	-	Daughter
Family 211	-	Son

The Piers-Harris Children's
Self-Concept Scale
Profile Form
pgs. 458 - 473

APPENDIX E

RATC PROFILES

APPENDIX E

RATC PROFILE ABBREVIATIONS

REL = Reliance on Others

SUP-O = Support-Other

SUP-C = Support-Child

LIM = Limit Setting

PROB = Problem Identification

RES-1 = Resolution (level) 1

RES-2 = Resolution (level) 2

RES-3 = Resolution (level) 3

ANX = Anxiety

AGG = Aggression

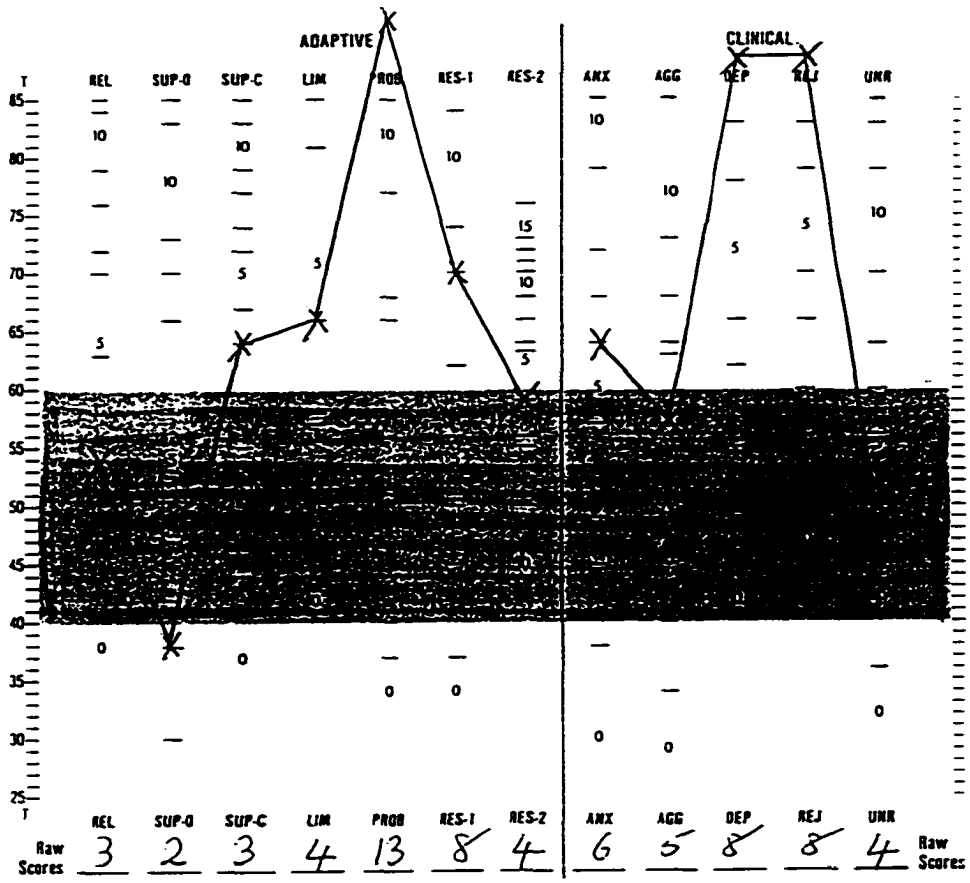
DEP = Depression

REJ = Rejection

UNR = Unresolved

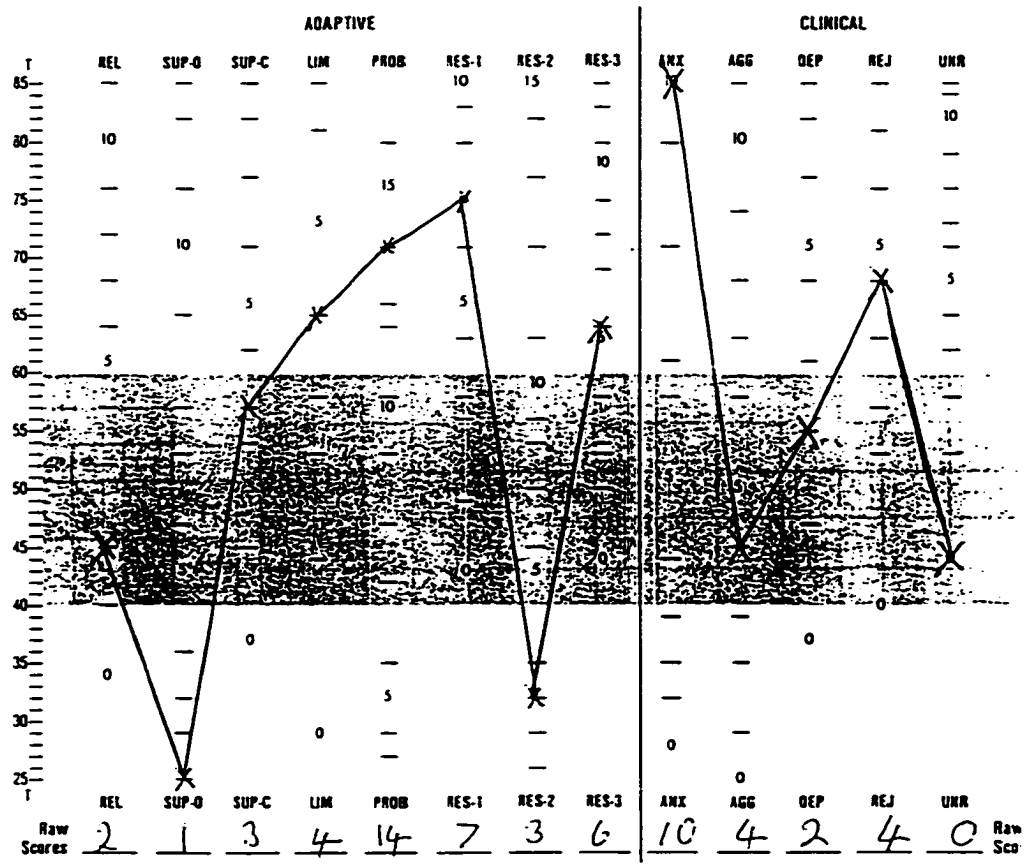
Family 101--Daughter

Ages 6-7



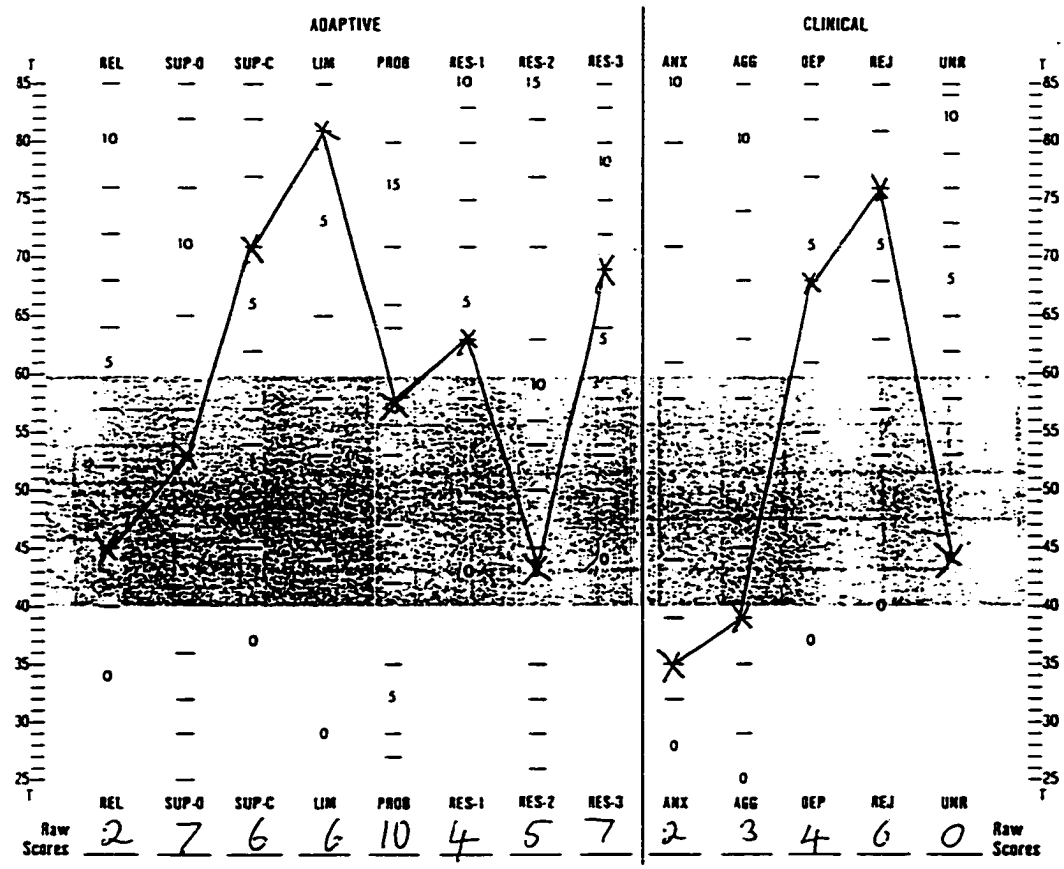
Family 102--Daughter 1

13-15



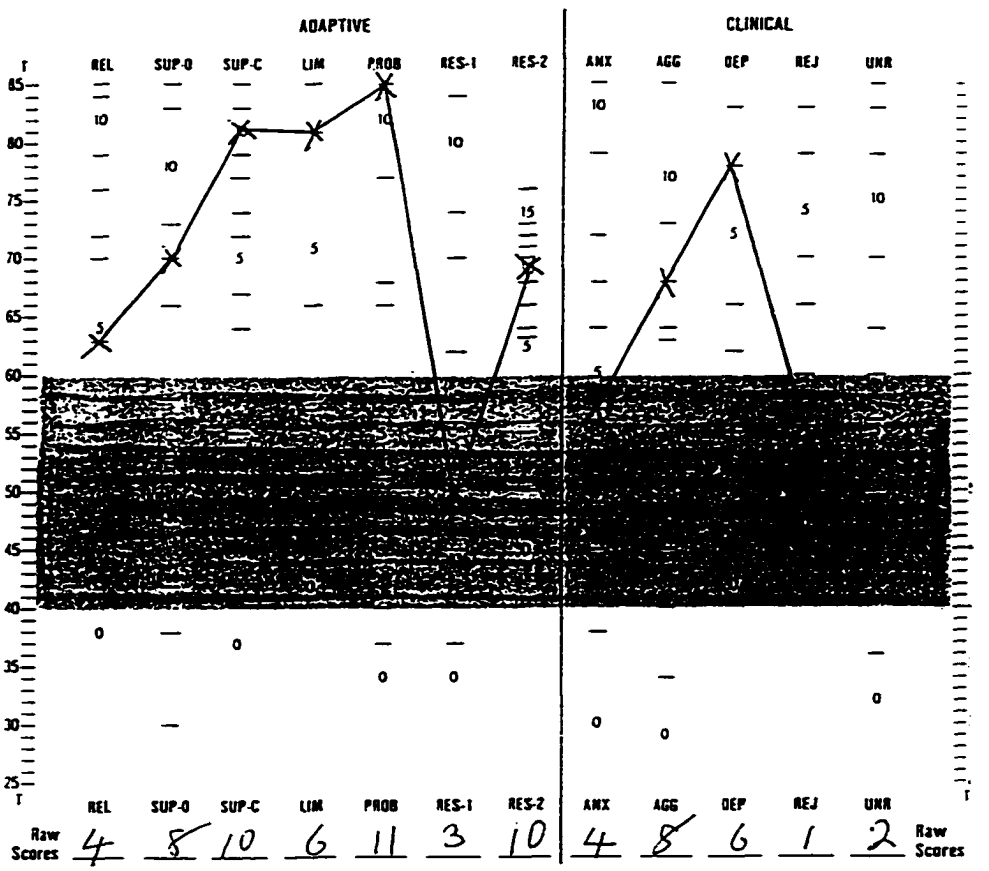
Family 102--Daughter 2

13-15



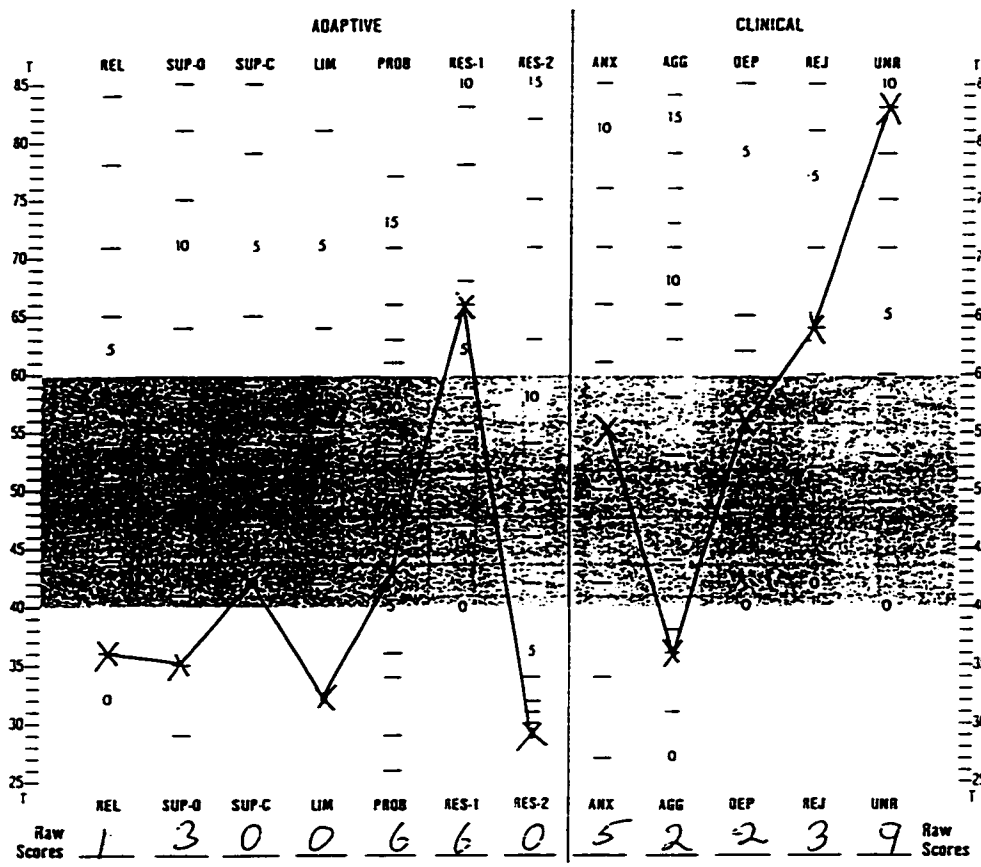
Family 201--Daughter

Ages 6-7



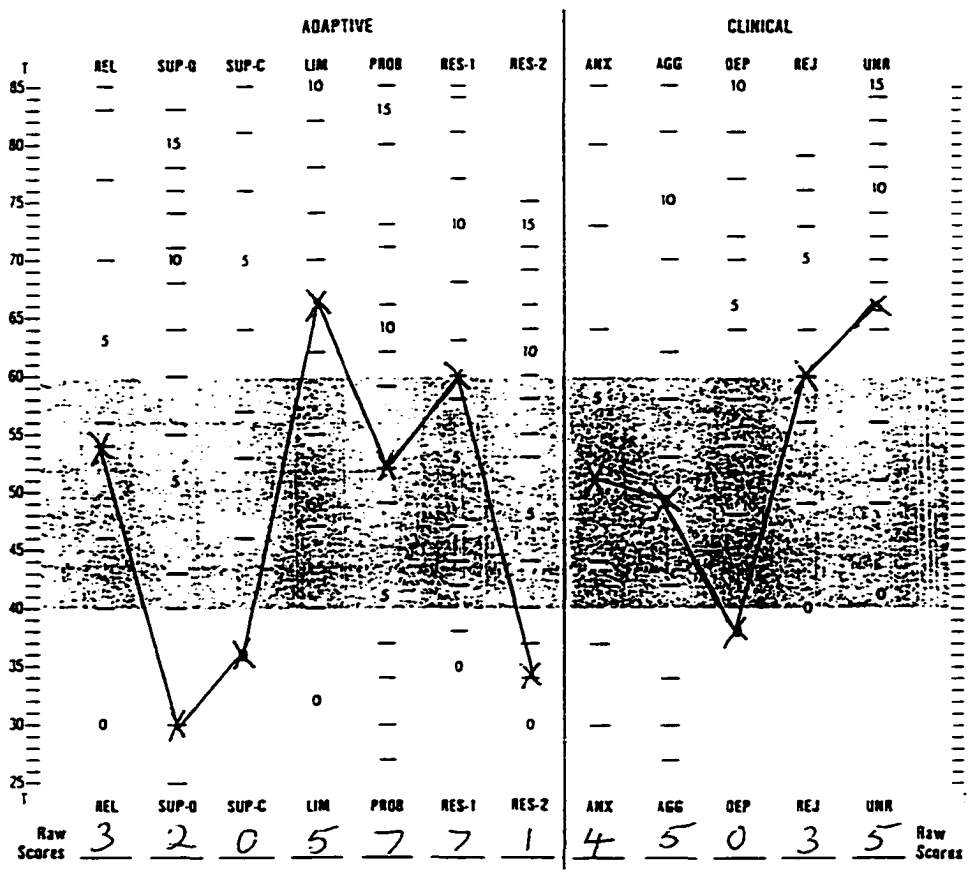
Family 202--Son

Ages 10-12



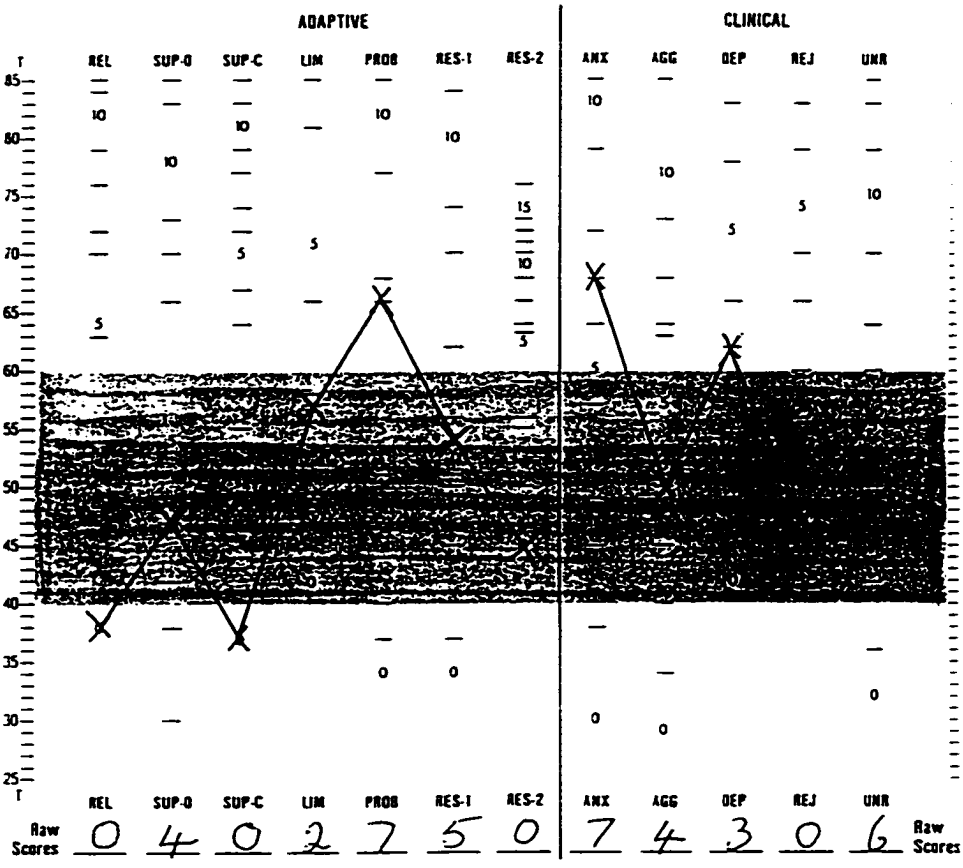
Family 203--Daughter

Ages 8-9



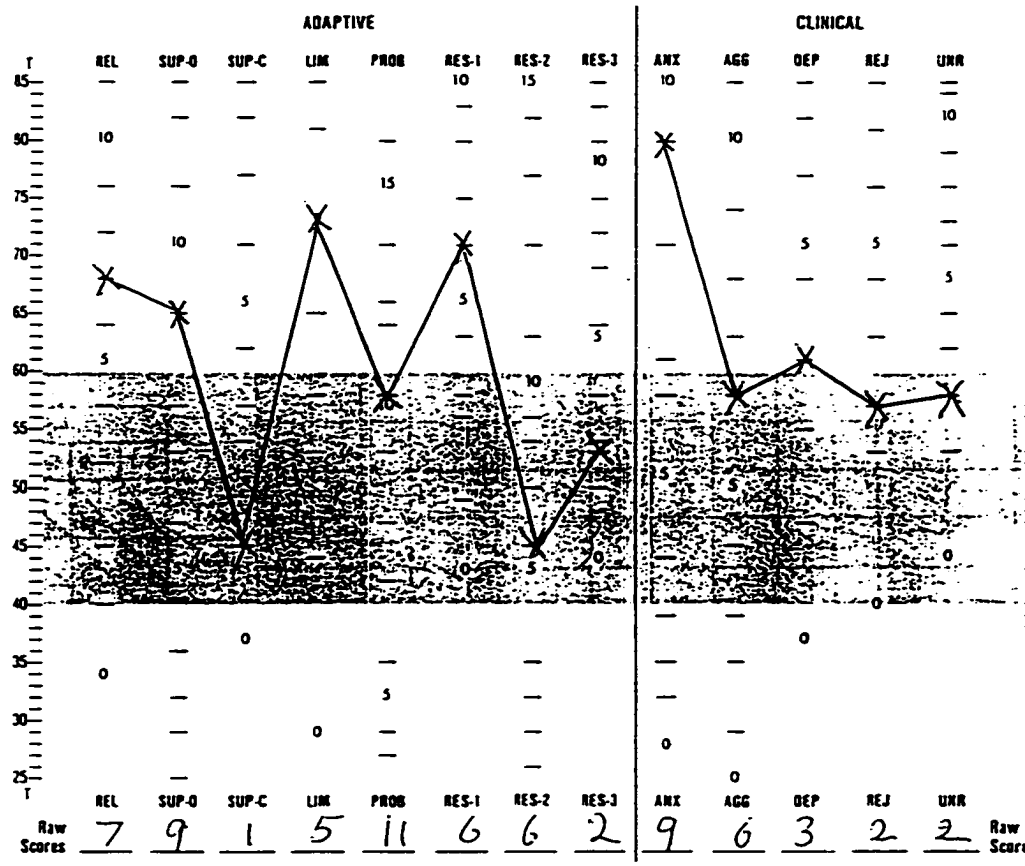
Family 203--Son

Ages 6-7



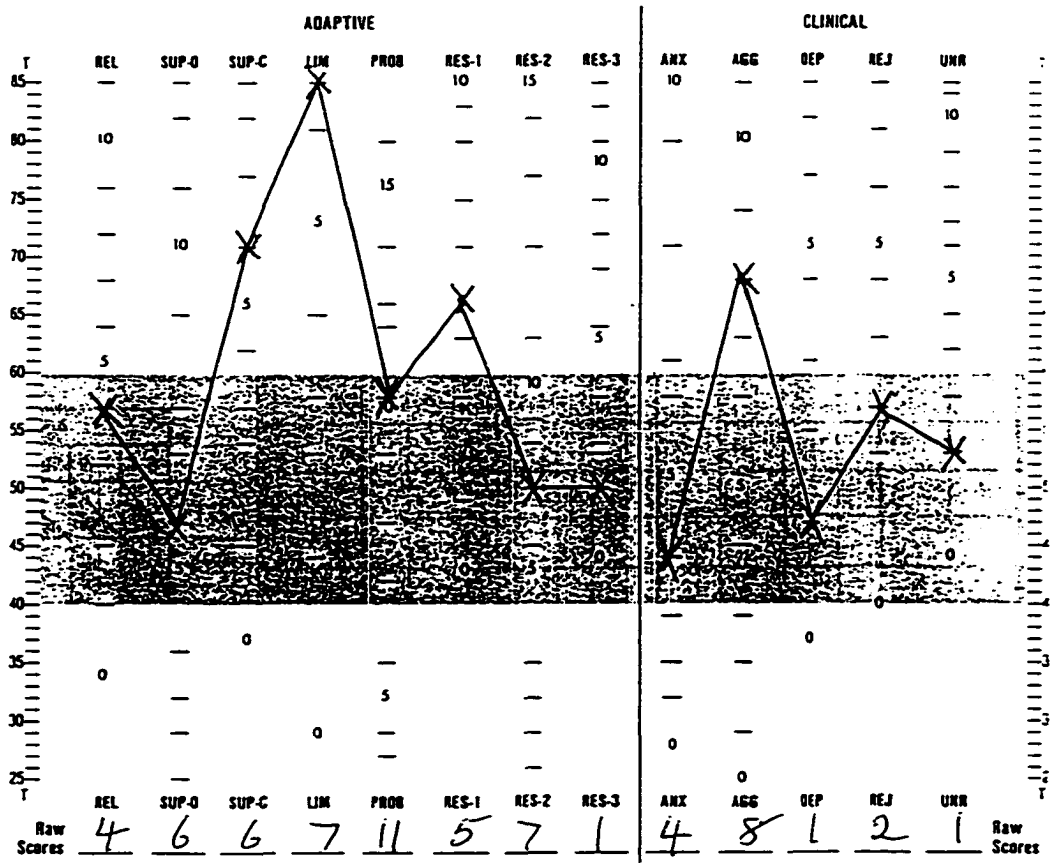
Family 204--Daughter 1

13-15



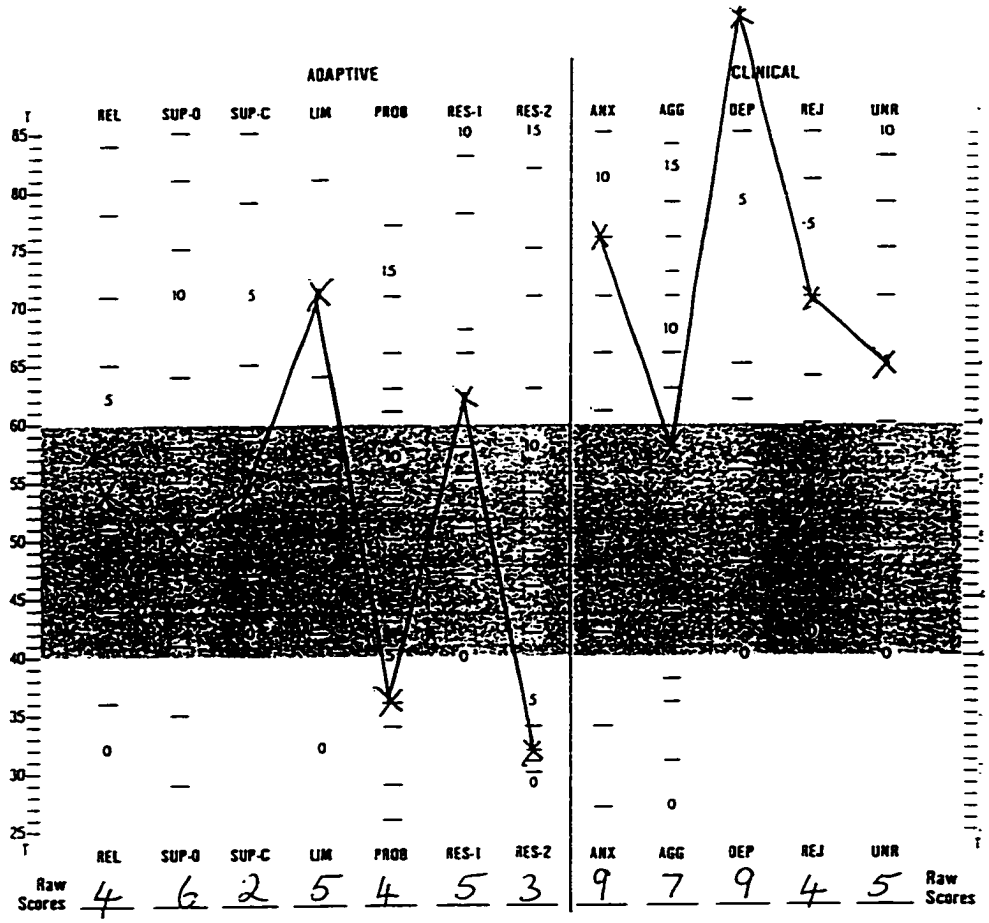
Family 204--Daughter 2

13-15



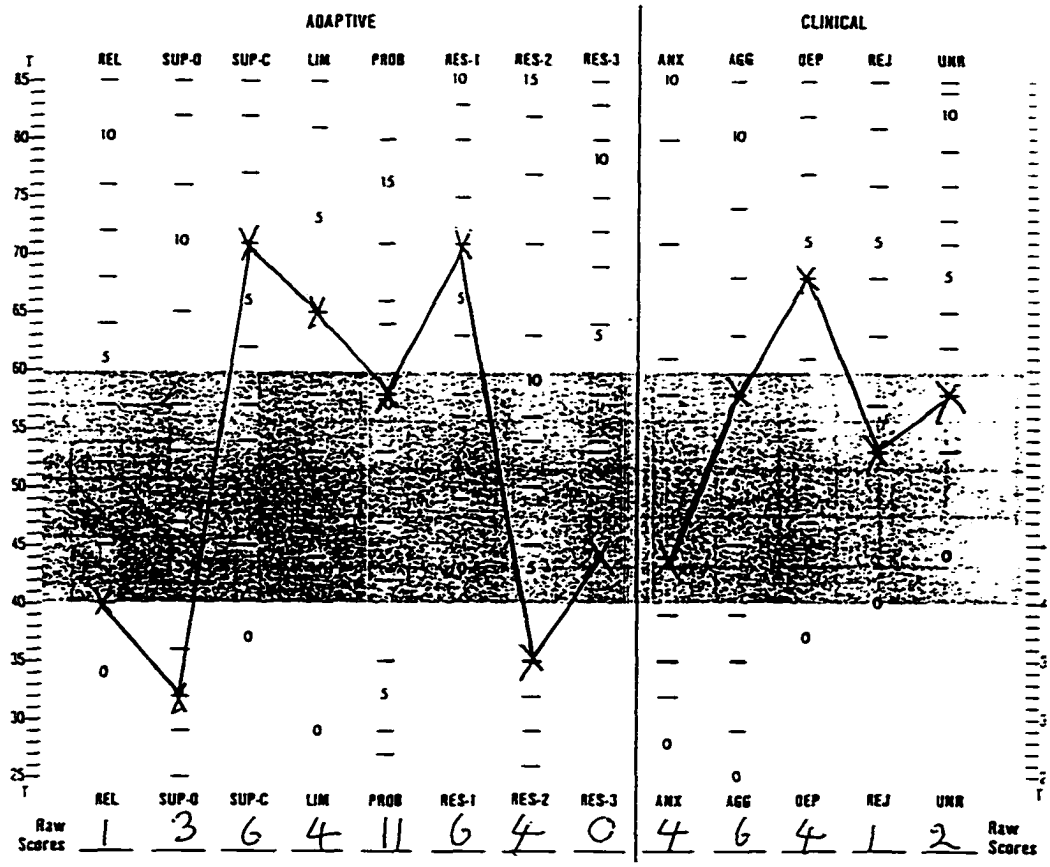
Family 204--Daughter 3

Ages 10–12



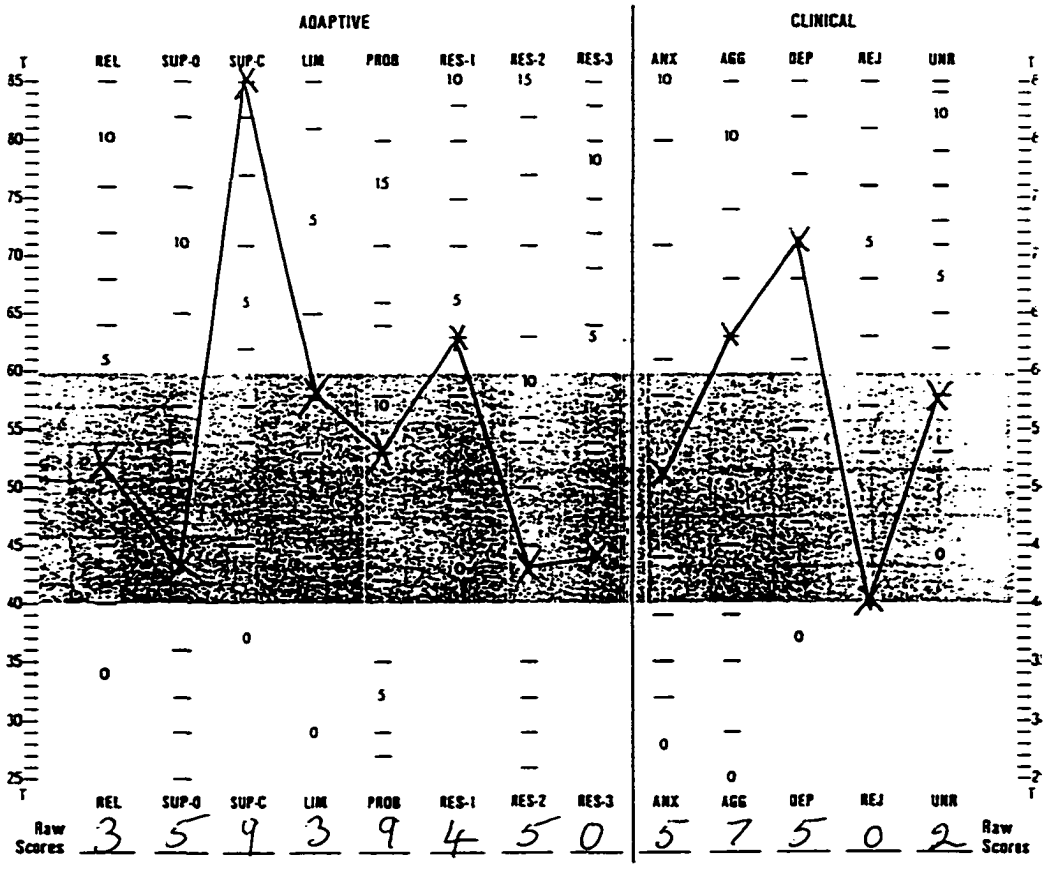
Family 205--Son 1

13-15



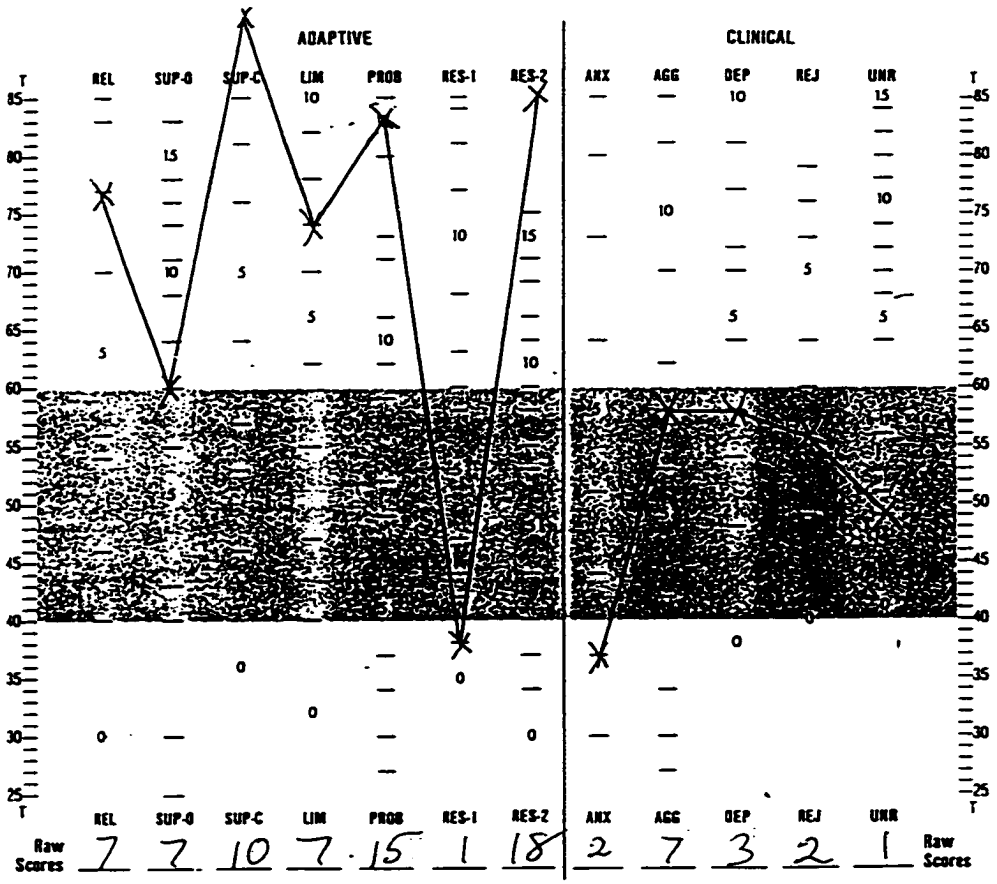
Family 205--Son 2

13-15



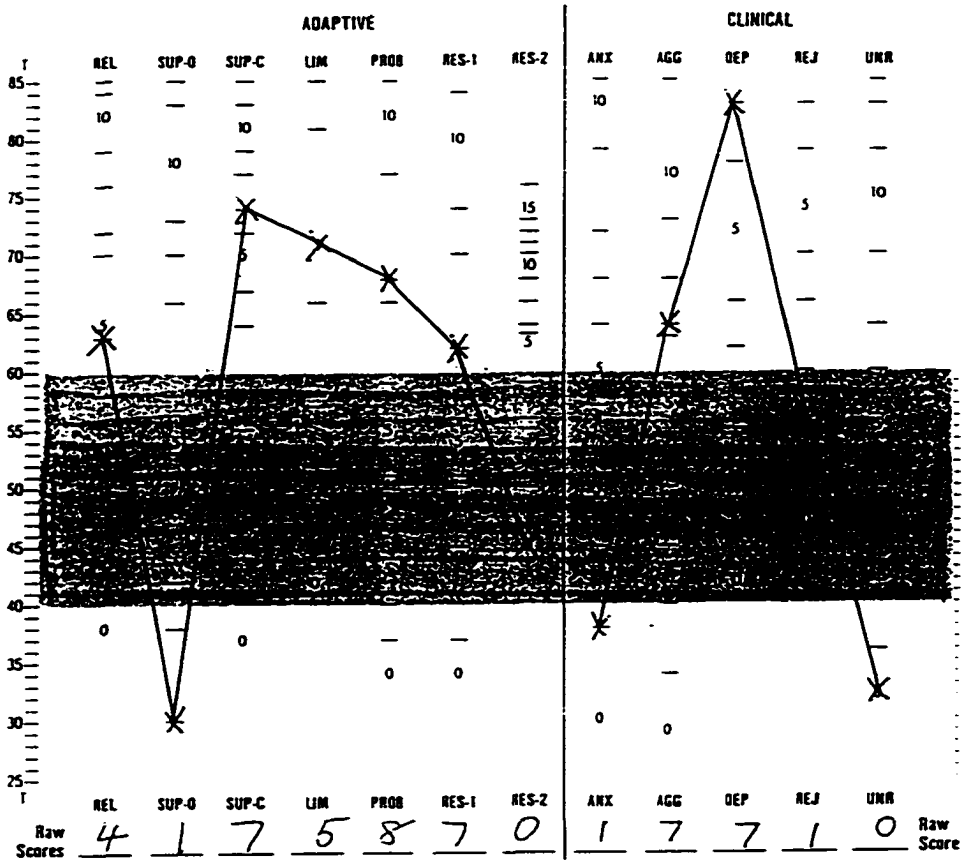
Family 206--Son

8-9



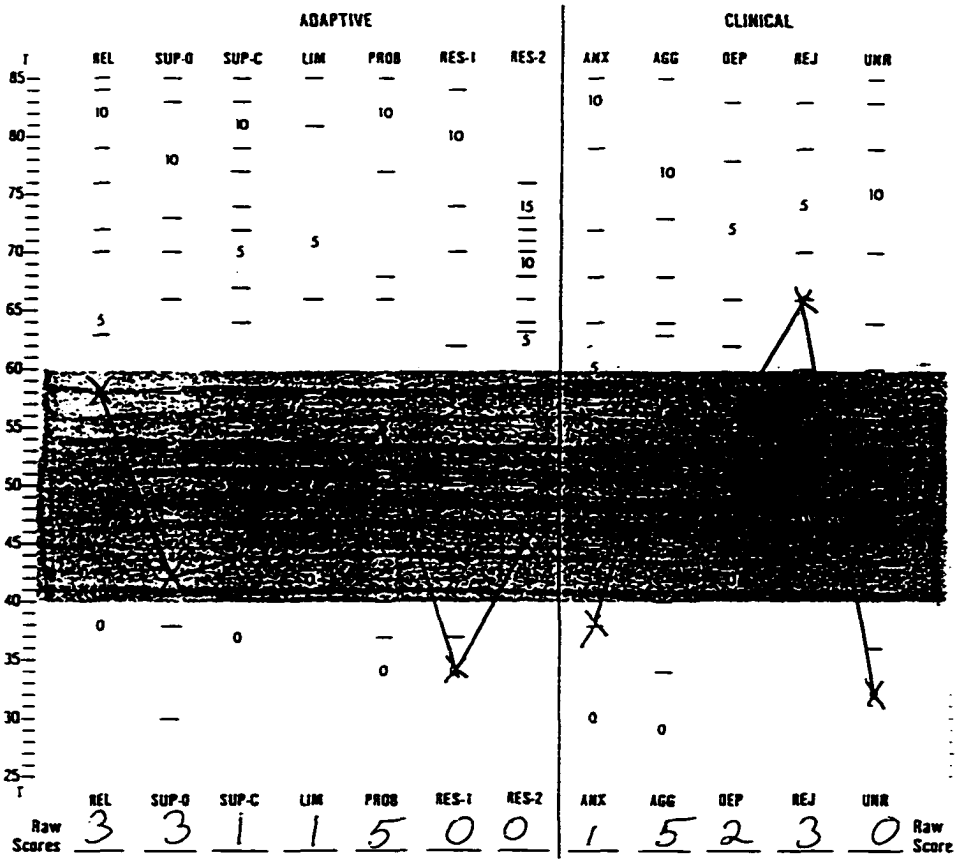
Family 207--Daughter

Ages 6-7



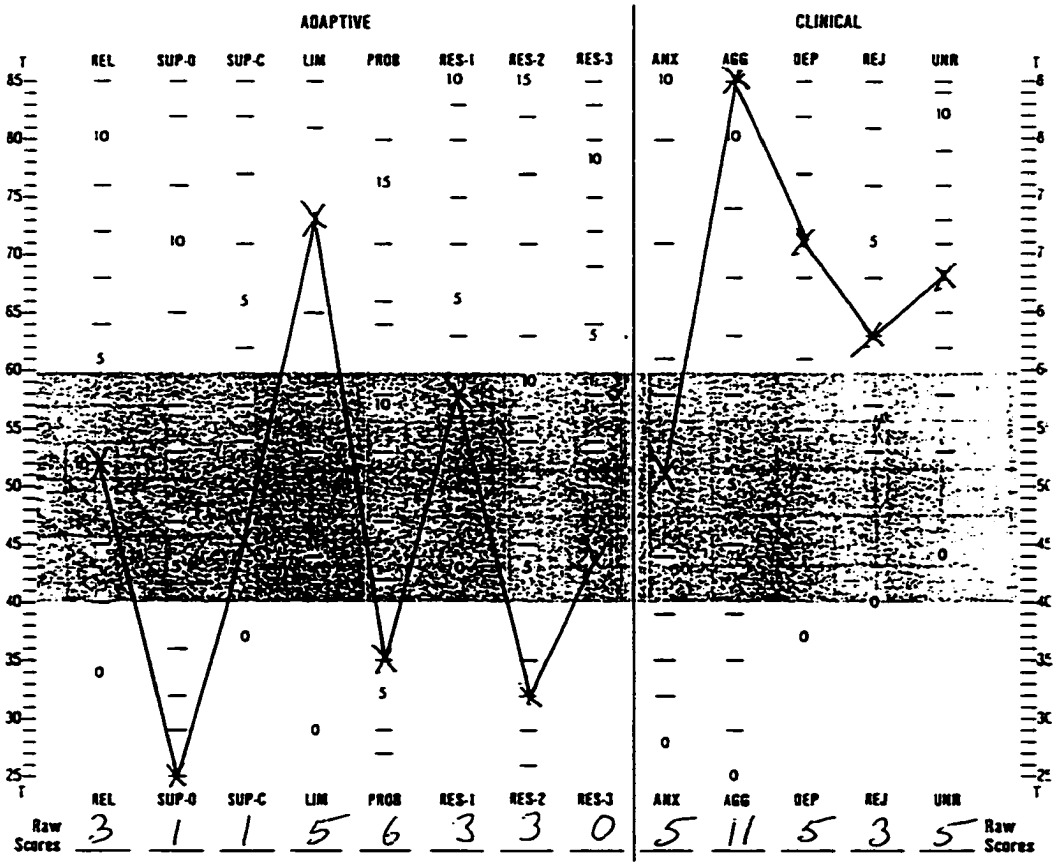
Family 207--Son

Ages 6-7



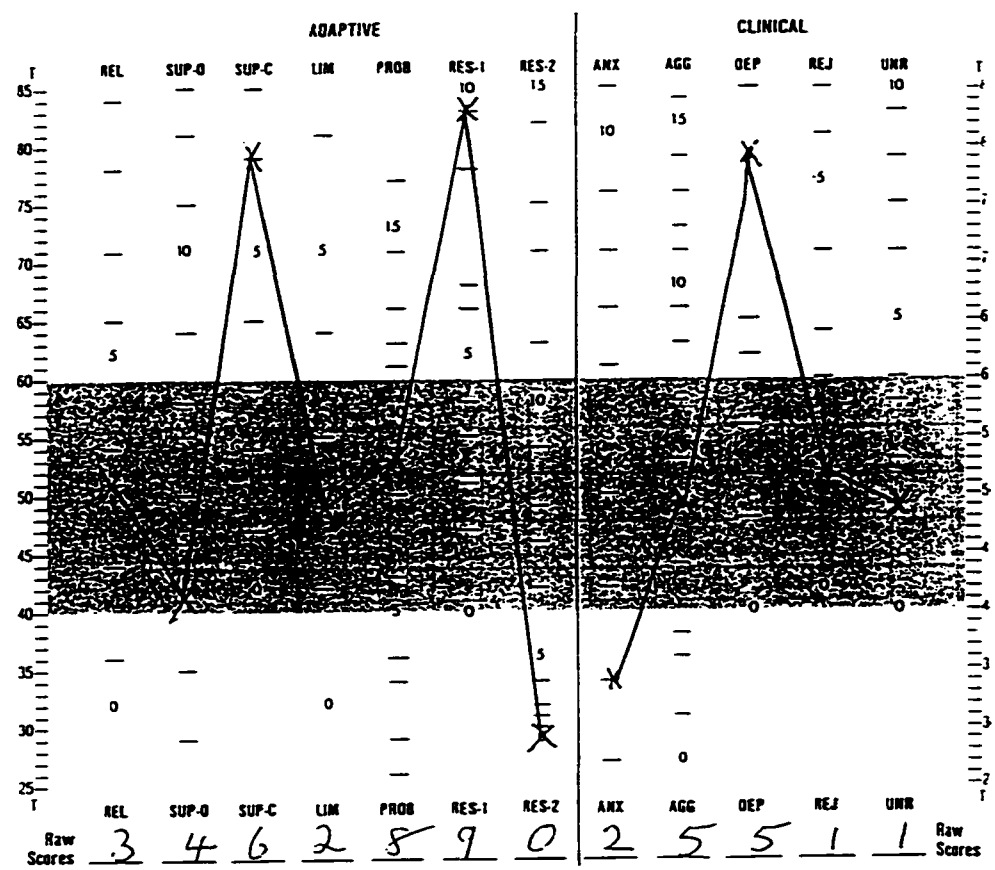
Family 208--Daughter

13-15



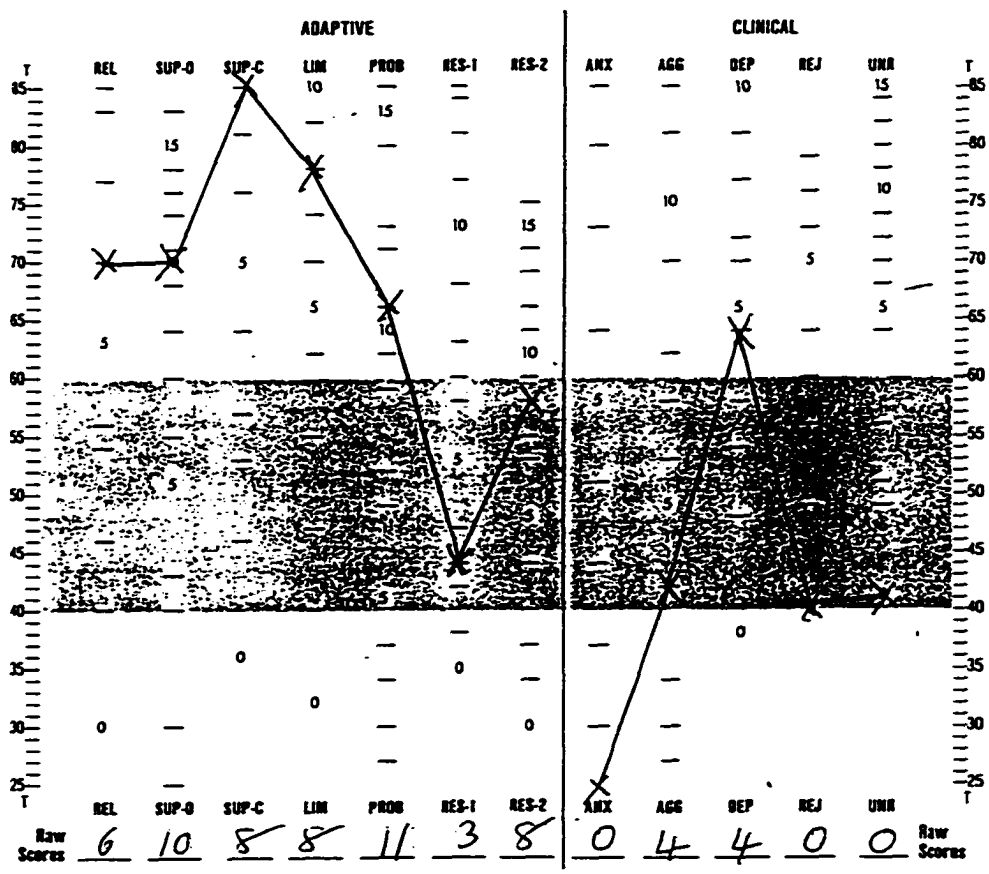
Family 209--Son

Ages 10-12



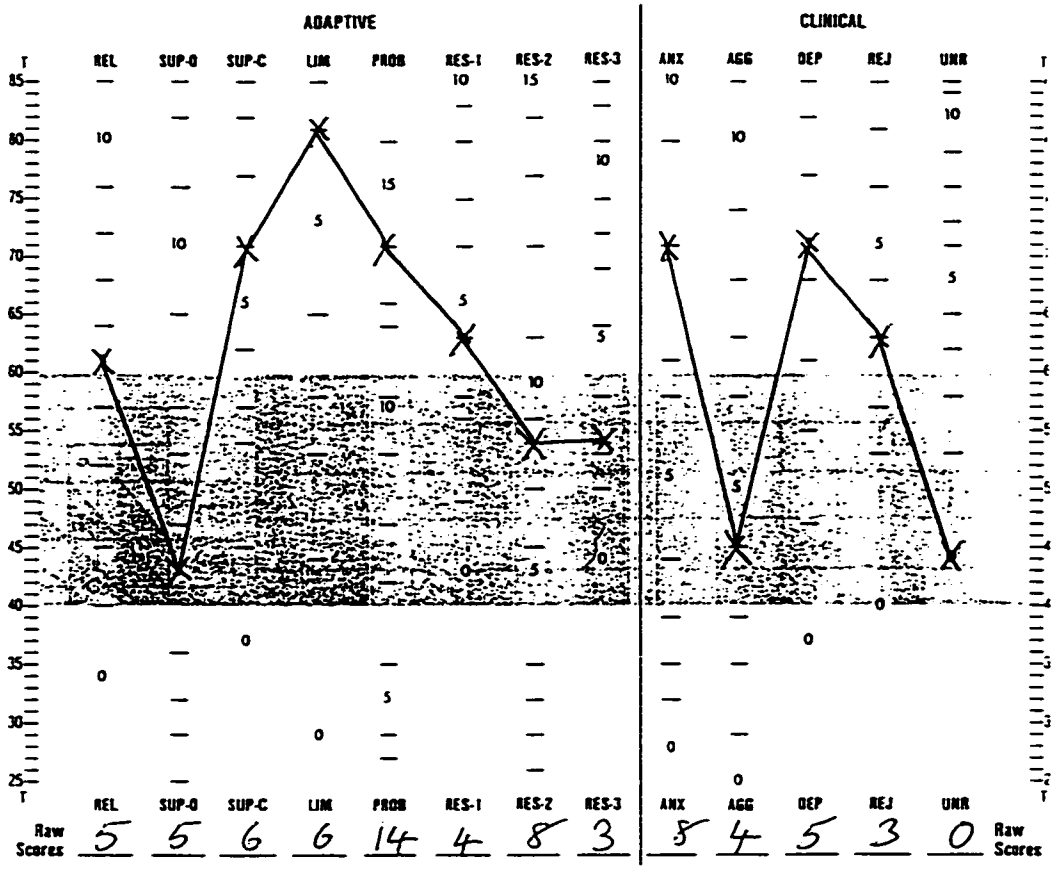
Family 209--Daughter

8-9



Family 211--Son

13-15



APPENDIX F

MEDICATIONS

Medication	F A M I L Y												
	101	102	201	202	203	204	205	206	207	208	209	210	211
ACTH		x			x		x		x			x	
Anti-biotics	x										x		
Anticon-vulsants				x						x			
Antide-pressants				x						x			
Antivert									x				
Baclofen/ Lioresal	x			x	x			x		x	x		x
B-vitamins		x	x					x					
Cytoxin						x	x						
Dantrium											x	x	
Daypro											x		
Diazepam		x											
Ditropan								x					x
Ibuprofen										x			
Imodium	x												
Imuran					x		x				x		
Inderal				x									
Medrol						x	x			x		x	
Midrin										x			
Prednisone	x		x	x	x	x					x	x	x
Symadine/ Symmetrol					x			x	x		x	x	
Valium									x	x	x		
Vivactyl			x										

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1974-75	Ball State University	M.A. - Educational Psychology
1970-74	Manchester College	B.A. - General Psychology and Peace Studies

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School Psychologist I	Life
Director of Special Education	Life

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9/91 - present	Psychological & Family Consultants Elkhart, IN	Family therapist and private practice school psychologist
8/85 - 8/91	Family Learning Center Elkhart, IN	Family therapist and private practice school psychologist
8/80 - 8/85	Wa-Nee, Baugo and Concord Special Education Cooperative Nappanee, IN	Director of Special Education and Psychological Services
8/75 - 8/80	Same Cooperative	School Psychologist

COMMUNITY SERVICE

8/75 - present	Elkhart Community, Andrews University and Indiana University in South Bend, IN	Speaker, instructor and seminar leader