Title
An investigation of the relationship between family functioning and the impact of stress from impending loss of a family member

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AN INVESTIGATION OF THE RELATIONSHIP BETWEEN FAMILY FUNCTIONING AND THE IMPACT OF STRESS FROM IMPENDING LOSS OF A FAMILY MEMBER

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ABSTRACT

This exploratory, descriptive study was designed to examine the relationship between stress and the overall level of family functioning in families who were threatened with the imminent death of a member from cancer. The theoretical framework was based on an integration of family systems theory and theories of grief, dying and bereavement. The Moos Family Environment Scale was used to examine family functioning. To measure the amount of subjective stress experienced by individual family members, the Horowitz Impact Stress Scale was administered. The specific purpose of the study was to establish a tentative relationship between the impact of stress and family functioning.

The sample consisted of seven families with a total of 24 individuals, in which each family constituted one unit of analysis. Criteria for family selection specified that one parent in the nuclear family had to have been diagnosed with cancer and have been informed that the disease was terminal with only palliative care available. The Moos and Horowitz instruments were selected to determine the relationship between the stress of terminal illness of the parent in the family and the level of family functioning. These paper-and-pencil instruments were administered to each available member of the family.

The study demonstrated that the means of all families in the sample clustered around the mean of Moos' nonclinical sample on the Family Environment Scale. However this study's total sample mean of 27.3 on the stress scale, as compared to Horowitz' stress score mean of 39.5 in a sample of individuals seeking psychotherapy, suggests that this study's sample experienced a lesser degree of measurable stress. Due to the small sample size, no statistically significant relationships could be

established between the impact of stress and family functioning. The study did indicate that the family members in this sample agreed with each other about their family environment despite the fact that one of their members was dying. The low stress score possibly reflected adaptation and coping resources within the families to accomodate a boundary change. Over time, these normative families adjusted to this life event.

This study has significance for nursing because it attempted to open communication in a family experiencing an extremely stressful event. It also demonstrates the need to recognize that illness affects not only the individual family member, but the entire family system as a whole, and that the entire family needs to be assessed as a unit. Nurses are in a unique position to assist families to develop their own resources for coping with the stress of losing a member from death due to cancer.

Further research needs to be done on a larger sample using qualitative methods to gain data over time from which hypotheses can be formulated.

Although the results of this study are inconclusive, it does challenge the assumption that all families define death as a stressful event, and that they experience greater than average stress at the possibility of losing a member from death by cancer. This study leads to further speculation as to whether families whose boundaries change by losing a member through death, a normal transition of the family life cycle, experience greater stress or become less functional than the average family. This implication needs further investigation. Knowledge gained from such a study can contribute to the development of theory that serves as a foundation for the science and art of family nursing.

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CHAPTER I

THE PROBLEM

The serious illness and subsequent death of any family member inevitably leads to disruption of the family's equilibrium. When a family member is diagnosed with a terminal illness, all other family members begin to examine their relationship with the diagnosed member. Though the impact of the illness will be different for each member of the family, each will experience a sense of loss. The degree of stress generated by the potential loss of another family member affects relationships within the entire family system.

Purpose, Problem, and Specific Aims

The purpose of this exploratory study was to measure levels of family functioning, primarily cohesion and stress, and to examine the relationship between these variables at a time shortly before the death of a family member. How each family member relates to the rest of the family at the time of this impending loss was described by examining family functioning. The impact of impending loss, indicated by measures of subjective stress, which family members were experiencing was compared with the overall level of family functioning.

The problem posed for research was to examine the relationship between the impact of the stressful event (i.e., terminal illness) and family functioning. Originally a working hypothesis had been formulated, which postulated a positive relationship between levels of family cohesion and levels of stress. This hypothesis was eventually discarded in the development of this study because of the preliminary nature of this work, the limited size of the sample, and the inherent difficulty of assessing

family cohesion as a single variable. Instead, the following aims served as guidelines for directing this exploratory research:

1) To examine family functioning using the Moos Family Environment Scale (Moos, 1974);

2) To measure the amount of subjective stress experienced by individual family members using the Horowitz Impact of Event Scale (Horowitz, 1979);

3) To establish a tentative predictive relationship between the impact of stress and family functioning.

Definition of Terms

Family, as defined by Nolan (1980), is "viewed as an emotional operating system of interrelationships on a nuclear level (husband, wife, children) and on an extended level across generations (parents, siblings, grandparents), so that changes in any aspect of the system are met with complementary changes throughout the system" (p. 9).

Family Functioning describes the patterns and processes represented by relational behavior for each family member. In this study, family functioning was measured using the Moos Family Environment Scale.

Subjective Stress indicates the distress perceived by persons experiencing a serious life event, such as a life threatening illness. Subjective stress, in this study, was measured by the Horowitz Impact of Event Scale.

Background of the Study

The family systems theory formulated by Bowen (1976) provided a theoretical underpinning for observing families in this study. Bowen

views the level of functioning of individuals to be indicated by the quality of their emotional relationships within their families. He identifies this level of functioning as "differentiation," a term he uses to describe the ability of individual members to maintain their separate boundaries while remaining emotionally connected with one another. Family units characterized by such high level functioning are comprised of members of high differentiation who are able to maintain a cohesive group relationship within their families without observing the boundaries of individual family members.

Bowen further claims that the real test of individual family members' ability to maintain their level of differentiation occurs when the family is beset with stressful events accompanied by high anxiety. It is at times such as these that family members who are less differentiated tend to blur the boundaries between their own intellectual and emotional processes and, at the same time, blur the boundaries between themselves and other family members. In so doing, members are said to "fuse" themselves with one another so that the family unit becomes identified as an "undifferentiated family ego mass."

Several other authors have attempted to measure family functioning. Notable among these is Moos who developed the Family Environment Scale (FES) to measure family functioning. The FES is divided into three dimensions examining: 1) the relationship between and among individual family members; 2) the personal growth of family members; and 3) the ability of the system to maintain itself as a family.

Theories about the functioning of families as a unit of analysis, specifically from a perspective of family systems, have only begun to

be tested. Furthermore, there has been little integration of family systems theory with previous knowledge of dying and bereavement. Studies of death in relation to individuals have been extensively reported. For example, Lindemann's pioneer studies of reaction to grief (1965) with the Coconut Grove fire served as a starting point for researchers to study the stages of loss following death of a loved one. More recent authors, such as Bowlby (1980), Kubler-Ross (1969), and Paul (1969), have further delineated stages of grieving. These authors describe the process experienced by individuals faced with the prospects of imminent death. The stages of this process include a time of disbelief or denial, a period of anger, an experience of intense depression, an attempt at bargaining, and finally an acceptance of the inevitability of death. It has been the observation of the investigator that persons in close contact with someone who is dying go through similar stages of grieving in preparation for the loss.

When a family is about to lose one of its members through death, a redistribution of roles occurs. One way of examining some elements of this family dynamic process is to use the interactional view and role theories which focus on the role of individuals in a family. Jackson, who first developed these theories (1977), stated that the family is a rule-governed system and that its members behave among themselves in an organized, repetitive manner. This patterning of behaviors can be abstracted as a governing principle of family life. The rules of family relationships ascribe a role to each family member to complement other roles within the family. This process occurs outside the awareness of family members. For example, when a family unconsciously assigns one member the role of patient, someone else assumes a non-patient role.

In order for the family to maintain its equilibrium, a delicate balance between these roles must be established.

The principle governing the relation of roles to one another within a family assumes that the alteration of one member's role because of terminal illness has an impact on all of the family relationships. Family systems theory supports this assumption. Bowen (1976), Carter and Orfanidis (1976), and Fogarty (1978) describe family relationships as functioning on a physical, emotional, and social level, so that a change in one part of the system is followed by compensatory changes in other parts of the system.

These same authors stipulate that a multigenerational approach including at least three generations is required for an adequate examination of the functioning of a family. Bradt (1980) concurs with this view in describing the family as being organized on a relationship axis intersected horizontally with the nuclear family and vertically with the family of origin. Thus the balance of the family lies on a multigenerational plane. A highly stressful event, such as terminal illness, can create an instability in the relationships among family members and in the functioning of the family system that reverberates across several generations.

A death in the family affects the survivors both as individuals and as members of the family as a whole. Bowen (1976), when discussing the impact of death on the family, claims that no other life event can incite more emotionally directed thinking in a person and more emotional reactiveness in people surrounding the individual. This emotional reactiveness to the loss of a member affects the equilibrium of the entire family unit. The intensity of the emotional reaction is governed

by the level of differentiation of the individuals within the family.

The degree of disruption to the family system is affected by a number of factors described by Cattel (1969), Herz (1980), and Marcowitz (1973). These variables include the timing of the death, the nature of the illness, the openness of the family system, and the position in the family of the dying member. The manner in which the bereaved persons act also depends on the nature of earlier resolutions of the emotional issues surrounding separation and loss.

Some clinicians even suggest that later disruptions in families are directly related to inadequate mourning and resolution of earlier losses. The underlying hypothesis of Paul (1969) is that there is a direct relationship between abrasive relationships within a family and unresolved grief over the death of a loved one at some earlier time. This implication suggests that health care providers who are aware of the possible relationship between family problems and unresolved grief can intervene for families by creating a setting in which such losses are explored and feelings are resolved.

CHAPTER II

REVIEW OF THE LITERATURE

This study examined the impact on family functioning of a stressful event such as terminal illness. The theory of family systems that serves as a foundation for this study holds that the family is a complex system of interacting subsystems. Serious illness or disability represents a crisis that threatens family equilibrium by disturbing the structure of roles and their interrelationships within the family (Abrogast, 1978).

Similarly, Mailick (1979) states that a major task of the family experiencing disruptive illness is the management of role shifts. He specifies tasks related to role changes within the family that are unique to the diagnostic phase of the disease, the chronic phase, and the end stage. Different defenses and coping capacities are required by family members at each of these disease phases.

Families who lose a member through death are deprived of the role functions of that member. Krieger (1975) theorizes that families need to identify the functions no longer performed by the missing member in order to function in a healthy way. The family can then either redistribute these functions to other members or reorganize itself to compensate without them.

The effect of serious illness and death is said to ripple between and across generations within the family system (Bowen, 1976). Winder and Elam (1978) explain the dynamic of the ripple effect. Because the family is an intricate emotional, communicational and cognitive system, changes in one part require reorganization throughout the rest of the family system. The stress experienced by the family of the terminally

ill cancer patient can be understood within this framework. Winder and Elam elaborate that a new relational balance in the family must be created and that all members must redistribute the feelings among themselves that were previously held for and received from the patient.

Cohen (1977) identified families experiencing the catastrophic illness and subsequent death of a member to be in a state of chronic stress. His study was of 29 middle class families who had lost a young parent from cancer. To collect the data, Cohen used a semi-structured family interview, a 25-item multiple choice questionnaire, and a brief clinical description of the family based on the impressions of the interviewer. The results of his study indicated that the prolonged illness of a parent means that certain role responsibilities can no longer be performed. The way role changes are made depends on the family's pattern of functioning and communication, its definition of roles, and the assignment of tasks within the family.

Cohen concluded that the communication patterns of families have little to do with the utilization of external support systems and more to do with increasing utilization of internal resources within the families. The study also confirmed that the more family members were able to communicate with each other, the greater the likelihood of an effective adjustment during the period following death.

Baider, et al. (1980) elucidated the process of coping in families experiencing death by examining two Appalachian families who suffered the loss of infants. Their small study indicated that when death occurs, each surviving member bears the pain of grief, and the entire family must restructure the meaning of its relationships. The way individual family members react after a death has occurred depends on several

factors: previous experiences of loss, ability to cope with crisis, and available sources of support. Baider stated that in every family a crisis and its aftermath have different meanings not only for each individual but also for the family as a whole. He thereby affirms the adage that the whole is different from the sum of its parts. The assessment of the impact of death on the family should include the developmental status of each individual, the structural characteristics of the family and the transactions that occur between family members and other social systems.

Kaplan, et al. (1976) did a study that attempted to predict the impact of severe illness on families. Their purpose was to relate different family coping reactions observed early in the crisis with stress outcomes after the death of a child. They interviewed forty families in which a child received medical treatment for leukemia. They included whole families in their study because they believed in the unique role the family plays in mediating stress for all its members, and because severe illness often has harmful effects on those members who do not suffer from the disease themselves. Kaplan refers to these harmful effects as maladaptive coping. These particular coping behaviors are manifested by marital problems, sibling problems, health problems, and morbid grief reactions. Kaplan proposed that intervention must be initiated early in the acute stages of the crisis in order to prevent a poor stress outcome as a result of these behaviors.

Stein and Riessman (1980) developed a scale in an effort to measure the impact of stress on the family from chronic childhood illness. Their scale consisted of 24 items on a paper-and-pencil questionnaire which was administered to the mother of the child. Their assumption was that

changes occur in the family because of the illness, forcing adaptations in the family environment. The illness can have either a negative influence on family life or it can serve as a catalyst for unifying the family. Stein and Riessman conceptualized the negative influences on structure and function of familial relationships in terms of losses. These losses are reflected in extra financial burden, restrictions in social life, less time for other family members, and increased subjective distress or strain. The impact on family scale quantified the impact along four dimensions of response: 1) the financial situation; 2) social interaction; 3) subjective distress felt by the parent; and 4) a sense of mastery which emerged from coping with the stress. In their study, only mothers were tested, which limited the applicability of the results to the entire family and, especially, the fathers.

There exists a need for further study of the family that experiences the death of a member from chronic illness. It is especially important in include as many members of the family as possible to such studies in order to learn more about how the family as a unit copes with the loss of a member. The present study is a beginning effort to fill this need.

CHAPTER III

METHODOLOGY

RESEARCH DESIGN

This was a pilot study of an exploratory, descriptive nature using quantitative and qualitative methods to compare the effects of stress from loss of a family member with the overall level of functioning of the family. A small convenience sample was selected from a population of families in the San Francisco Bay area.

SAMPLE

Human Subjects Assurance

The research proposal was submitted to and approved by the Committee on Human Research at the University of California, San Francisco. Participants were asked to sign a consent form (Appendix A) informing them of their rights and protection as research subjects.

Size

The sample consisted of seven families in which each family constituted a unit of analysis. There was a total of 24 individuals in the sample. The family size varied from two to five members.

Criteria

The principal criterion for family selection in the sample was that each family have one member, specifically one of the parents in the nuclear family, who had been diagnosed with terminal cancer. In addition, subjects had to be English-speaking who could read and write to answer the questionnaires. The diagnosed person must have been informed that there was no medical cure for the cancerous condition, that only palliative care remained, and that the illness would ultimately result in death.

TECHNIQUES OF DATA COLLECTION

Procedure

Sources for gaining access to potential subjects were selected on the basis of feasibility and availability. The sample was drawn from families either attending an outpatient clinic or involved in a hospice home-care program. The two institutions selected for obtaining subjects were the Hospice of San Francisco and the Oncology Clinic at the University of California, San Francisco.

To obtain access to the hospice, the Director was contacted and an appointment was made for the investigator to explain the details of the study to the staff. After acceptance by the hospice staff, the investigator attended weekly case conferences held by the staff in order to select families who met the criteria for the study. The investigator then contacted each family by phone and explained the study. If the family members agreed to participate, an appointment was made for a home visit. On arriving at the home, the investigator explained the study to the other available family members. All family members who were present and who agreed to participate were asked to fill out the consent form and the questionnaires. In several cases, absent family members who previously agreed to participate by phone, mailed the questionnaires back to the investigator.

In addition, families who met the sample criteria at the Oncology Clinic were first approached by the head nurse who asked their permission for the investigator to contact them by telephone. The investigator described the study over the telephone. Of the three families who agreed to participate, one answered the questionnaires in the clinic, while the other two families obtained the questionnaires at the clinic and mailed

them back to the investigator.

After administering the questionnaires, the investigator conducted an informal, unstructured interview to obtain a basic profile of each family. When information about the family's feelings about death or the loss of a loved one was volunteered, it was included in the profile of the family. The family profile also included the investigator's clinical evaluation of the family.

DESCRIPTION OF THE QUESTIONNAIRES

A short questionnaire for demographic data was devised (Appendix B) to obtain descriptive information about each subject and family. The data included sex, age, cultural background, religious preference, approximate date the diagnosis was known, what the nature of the diagnosis was, the number of persons in the nuclear family and the role of each person in the family (e.g., husband, principal wage earner, daughter, etc.).

A description follows of the two quantitative questionnaires that were selected to measure the relationship between the stress of the terminal illness of the parent in the family and the level of functioning of the family.

The Impact of Event Scale

Evaluation of life events is thought to be possible through a questionnaire that lists situational changes and yields a quantitative estimate of the impact of this event on an individual. The Impact of Event Scale was developed by Horowitz and others (1979) to measure the degree of subjective stress experienced as a result of a specific catastrophic event (Appendix C).

The Horowitz scale consists of 16 statements, each of which describes

a possible subjective response to the catastrophic event. These items were derived from statements most frequently used to describe episodes of distress by persons who had experienced a serious recent life change. Examples of the statements are, "I thought about it when I didn't mean to," and, "I tried not to talk about it." Respondents are instructed to rate each statement as applied to themselves on a Likert-type scale according to frequency categories of "Not at All," "Rarely," "Sometimes," or "Often." Scoring weights of 0, 1, 3, and 5 were assigned respectively to each of these categories. A subject's total score was derived by counting the number of responses in each category, multiplying this frequency by the category scoring weight, and adding these together to yield a single score.

In the original Horowitz study, the mean total stress score for 66 subjects was 39.5 (SD = 17.2; range = 0-69)(Horowitz, et al., 1979, p.213). The 16 items in the Horowitz scale were selected for their internal reliability because they empirically clustered and had signficant item-to-subscale correlations beyond the .01 level of significance. Test-retest reliability was established by administering the scale twice with a one-week interval. The results indicated a correlation of 0.87 for the total stress scores (Horowitz, 1979).

In the present study, the Horowitz scale was used to obtain a family subjective stress score. This was done by administering the questionnaire to each member of the family, adding the individual scores and dividing them by the number of respondents in the family, to yield a total family mean score.

The Family Environment Scale

The Family Environment Scale (FES) was developed by Moos (1974) to assess the social climate of all types of families (Appendix D). "It focuses on the measurement description of the interpersonal relationships among family members, on the direction of personal growth which is emphasized in the family, and on the basic organizational structure of the family" (p. 3).

The FES consists of 90 items arranged into ten subscales that are further grouped according to three dimensions. The relationship dimension consists of the subscales of cohesion, expression and conflict. These subscales assess the extent to which family members feel that they belong to and are proud of their family, the extent to which there is open expression of feelings within the family, and the degree to which conflictual interactions are characteristic of the family.

The dimension of personal development and growth includes the subscales of independence, achievement orientation, intellectual-cultural orientation, active recreational orientation, and moral-religious emphasis. These subscales measure the amount of emphasis a family places on certain developmental processes which may be fostered by family living.

The system maintenance dimension is comprised of the subscales of organization and control. These subscales are system-oriented to obtain information about the structure or organization within the family and about the degree of control which is usually exerted by family members with one another.

The internal consistencies for the Moos FES are all in an acceptable range. The item-subscale correlations ranged from moderate (0.45 for independence) to substantial (0.58 for cohesion). Test-retest

reliabilities calculated on 47 family members in nine families who took the FES twice with an 8-week interval were acceptable, ranging from a low of 0.68 for independence to a high of 0.86 for cohesion (Moos, 1974).

Subjects were instructed to answer "True" or "False" to each of the 90 FES items according to the degree the statement was considered to apply to the subject's family. The FES was scored by placing a transparent plastic template over the answers. The template groups the answers according to subscales, and indicates which items receive a score of zero or one. One point is assigned for each True item marked true, and for each False item marked false. An example of an item for which the subject receives a score of one when answered True is: "Family members really help and support one another." Or, when a subject responds False to an item like the following, a score of one is given: "We don't do things on our own very often in our family." A True item marked false and a False item marked true receive a score of zero. True and False items are randomly mixed on the FES to avoid subject response set. Raw scores for each of the ten FES subscales were converted to standard scores using the tables of equivalency in the manual.

The FES was also used to evaluate the extent to which all pairs of family members disagreed about their family climate. This factor was termed the family incongruence score (FIncS). It was derived from the difference between scores for each possible pair of family members on each of the ten FES subscales. The differences of these ten subscale scores were summed, indicating the extent to which a pair of family members disagreed about their family climate (i.e., their incongruence). The mean of these incongruence scores for each pair of members was then calculated to yield a family incongruence score (Moos, 1974).

Family incongruence scores (FIncS) were calculated for 285 families in Moos' normative sample. The mean FIncS was 16.74 (SD = 5.38). In the present study, the mean FIncS for the seven families was compared with the mean of the 285 families in Moos' original sample.

CHAPTER IV

RESULTS AND DISCUSSION

To investigate the relationship between family functioning and the impact of stress from impending loss, the investigator administered the Moos Family Environment Scale (FES) and the Horowitz Impact of Event Scale to seven families. The Moos FES and Horowitz questionnaires were supplemented with a short unstructured interview to obtain further descriptive data.

This chapter reports a description of the sample based on the demographic data. Using data from the unstructured interviews, the investigator compiled a profile of each family that included both the investigator's clinical impression of the family as well as information about the family's feelings about the impending loss of a dying loved one. Raw data from the Moos FES and Horowitz scales are then reported. The statistical correlations between the data from the two instruments are presented, and trends indicated. Data from the present Miller study are compared with data from the original Moos and Horowitz studies. The chapter concludes with a section discussing these findings.

THE FAMILIES

The sample in this study is a culturally diverse group of White, Jewish, Black and Asian families drawn from the San Francisco Bay area. Each family had one member who was terminally ill with cancer. The Oncology Clinic at the University of California, San Francisco, provided access to three of these families and the Hospice of San Francisco provided the other four. Although the design of the study called for participation of all members of each family, the sample was actually

limited to those members who were available and willing to participate. The mean family size was four members, but the mean number of respondents was 3.4. The age of the dying member ranged from 47 to 81 years, with a mean age of 63. Varying lengths of time had elapsed between the time of diagnosis and the time of participation in the study. Families averaged 18.3 months between discovering the terminal nature of the illness and participating in the study, with a range from 6 to 37 months. Three of the seven terminally ill members have died since the completion of the study. The demographic data from this sample of families are summarized in Table 1.

Profiles of the Families

The following profiles of the families are a narrative description based on interview data.

Family #1: The Chinese American Family

This was an inner city Chinese family of seven members, without any religious preference. The identified patient was an 81-year-old widower who was cared for by his son who was a 52-year-old single, retired teacher. Because of his advanced osteogenic cancer, the patient was barred from participating in the study by his son. This son and two other siblings participated in the study. The caretaking son described his relationship with his father as "symbiotic." He said that he was greatly affected by his father's illness, but he did not speak of death or cancer as such during the interview. However, his father died shortly after the data were collected.

As evidenced by the family incongruence scores (FIncS), the members in this family were in greater disagreement with each other about their

TABLE 1

Demographic Information on the
Seven Families in the Miller Sample

DEMOGRAPHIC DATA

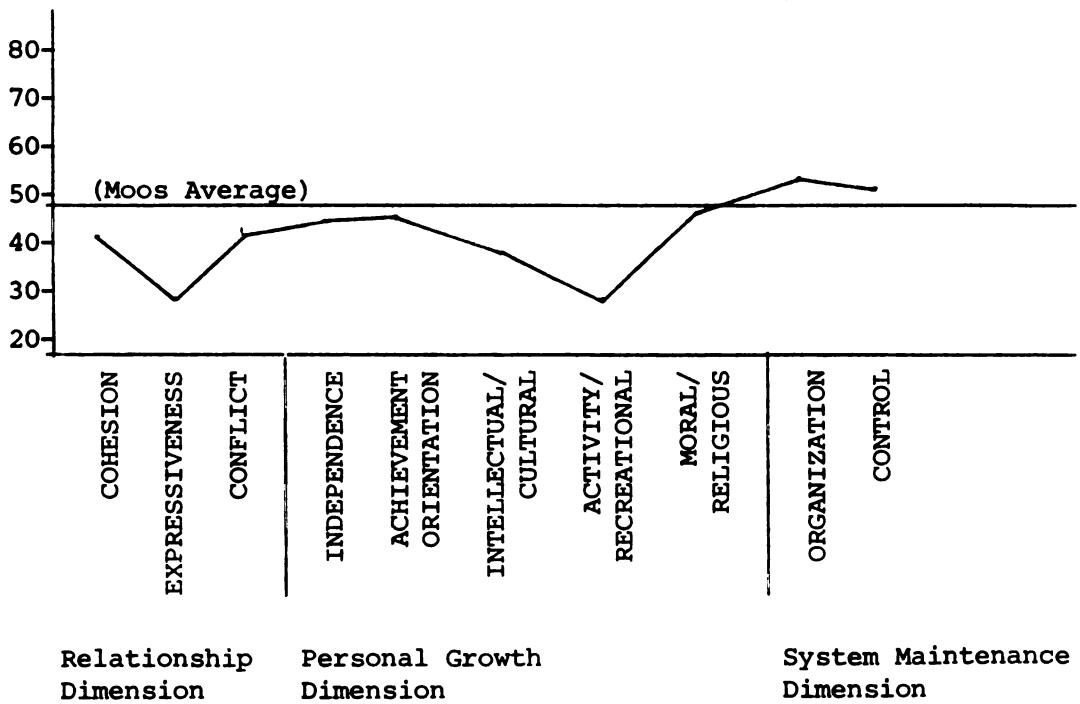
Family	Size	Age of Patient	Role	Religion	Ethnicity	Type of Cancer	Date of Diag.	Time Since Diag.
1	7	76	Father Retired	None	Chinese	Bone	4/81	6 mo.
2	3	58	Mother Non-bread winner	Catholic	White Irish	Lung	9/78	37 mo.
3	2	81	Father Retired	Epis.	Black	Bone	7/80	15 mo.
4	5	58	Father Bread-winner	Catholic	White Italian	Brain	3/81	19 mo.
5	3	47	Mother Non-bread winner	None	White	Breast	1/80	21 mo.
6	4	71	Mother Non-bread winner	Catholic	White	Lymphoma	4/80	18 mo.
7	4	51	Mother Non-bread winner	Jewish	White	Breast	10/80	12 mo.

family environment (FIncS = 21.3) than the norm in Moos' sample (FIncS = 16.74). However, using the Horowitz scale, this family seemed to experience much less subjective stress in relation to the father's illness (11.7) than that expressed in the original Horowitz sample (39.5).

On the Moos Family Environment Scale (FES), this family scored low on cohesion, was very non-expressive, and appeared below average on conflict, in comparison to the means in the norm of Moos' sample. All of the personal growth dimensions were below average. Values of organization and control were not emphasized in this family. The data from the FES on this family are compared with the data from Moos' sample and summarized in Figure 1.

FIGURE 1

Comparison of Miller and Moos Standardized Scores on FES
Family #1: The Chinese American Family



Family #2: The Irish Catholic Family

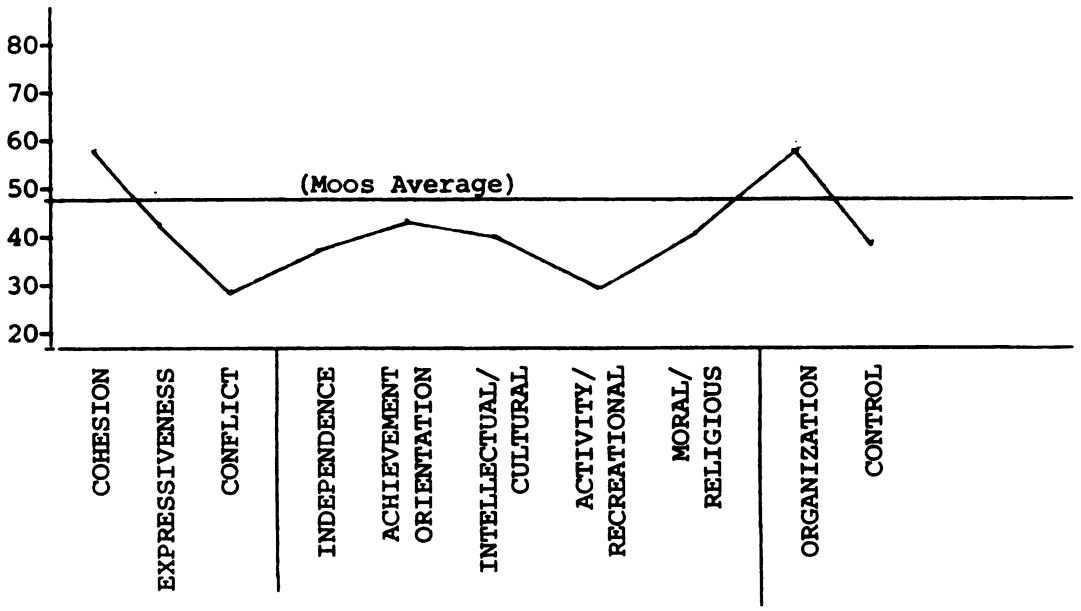
There were three members in the Irish Catholic Family. The identified patient was the mother, aged 58, who was diagnosed with lung cancer three years previously, and who felt she would die within a few months. Her husband, aged 54, and son, aged 34, were both lawyers. Her son was single and lived in Los Angeles, but kept in close contact with his parents by frequent telephone calls and visits. The mother sat at home alone all day and thought a great deal about dying. She stated that she "is ready to die and is trying to help her husband accept her death." Six months before the study, she started a macrobiotic diet so that she could "live healthily until she dies." At the time of this study, she was refusing all pain medication and any chemical treatments. She said she was happy to have extra time, that is, the diet made her feel better and possibly was prolonging her life a bit longer.

The FIncs of 15.3 of this family was closely correlated with the FIncS of 16.75 for Moos' norm. However, their stress score of 24.5 was considerably lower than the score of 39.5 from the Horowitz sample.

This family was slightly above average in cohesion, and was not characterized by conflict or expressiveness. Control was not emphasized at all, and organization was only slightly above the norm. These data are summarized in Figure 2.

FIGURE 2

Comparison of Miller and Moos Standardized Scores on FES
Family #2: The Irish Catholic Family



Family #3: The Black Episcopalian Family

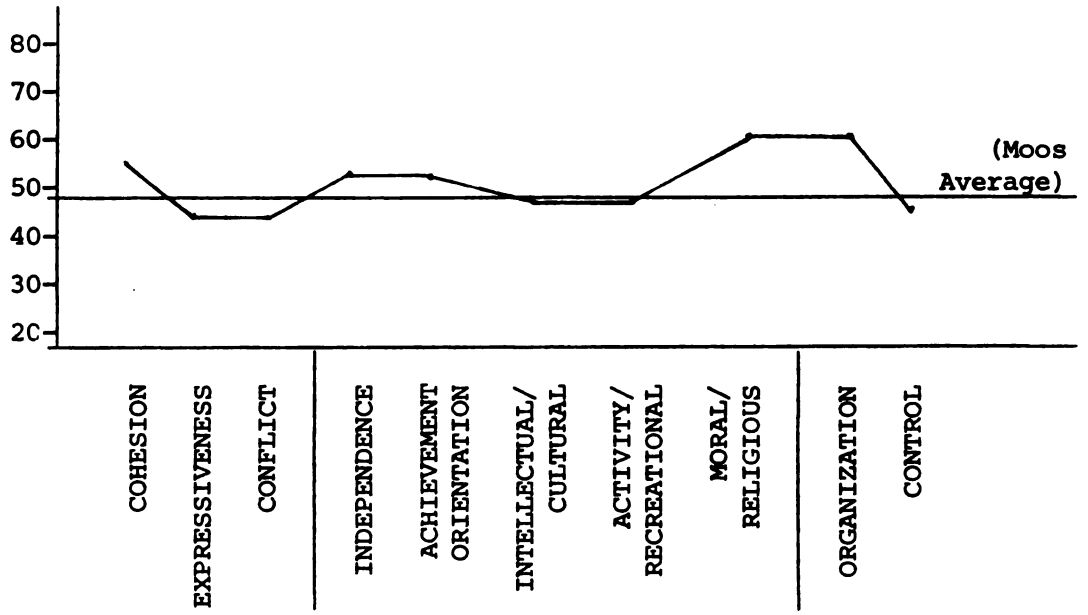
The Black Episcopalian Family consisted of only two people, an 81-year-old father and his single daughter who was 49. He was dying from osteogenic cancer diagnosed one year earlier. His wife died just before he was diagnosed the year before. His daughter was single and worked full-time as a social worker. She moved back to San Francisco from New York when her mother died. The father was very aware that he was dying and spoke of it often and openly with his daughter. He cried throughout the interview and expressed frustration with his changing body image and about leaving his daughter. She too shed some tears about losing her remaining parent. In fact, the interviewer learned that this man died a few weeks after the interview.

The FIncS for this family was only 9.5, the lowest FIncS in the entire sample. Their impact of stress score was 50.0, the highest stress score in the sample.

They scored slightly above average on the FES subscale of cohesion and slightly below on the subscales of expressiveness and conflict. Based on the interview data, one would have expected a higher expressiveness score, and a lower conflict and higher cohesion score because of their low FIncS. All of the personal growth dimensions, except moral/religious, on the FES were below the Moos average. Organization was stressed in this family, but control was not. The data for this family are summarized and compared with the Moos norms in Figure 3.

FIGURE 3

Comparison of Miller and Moos Standardized Scores on FES
Family #3: The Black Episcopalian Family



Family #4: The Italian Catholic Family

The Italian Catholic Family had three sons, two married and one single, all of whom lived in the San Francisco Bay area. The father, aged 58, had brain cancer diagnosed a year earlier in August, 1981. He was cared for at home by his wife, aged 49, and was receiving radiation therapy. Throughout the interview, the dying father often cried and stated how alone and frustrated he felt. He was frustrated about the effects of cancer and his feelings of disability and inadequacy. He felt completely helpless because he could not take care of his daily needs. He stated that he was afraid of dying and wished that someone would talk openly with him about what was happening. He was angry and hurt because he thought people were whispering about him and his condition behind his back. His wife, in fact, did whisper to the interviewer that her husband was often upset and that she was afraid to say anything to him for fear of hurting him more. Despite family attempts at secrecy, the man frequently used the word "cancer" to describe his illness.

Two of his sons were born-again Christians and completely denied their father's illness and prognosis. Their avoidance behavior caused both their parents much anguish. It also prevented family members from openly discussing among themselves the issues and problems facing them.

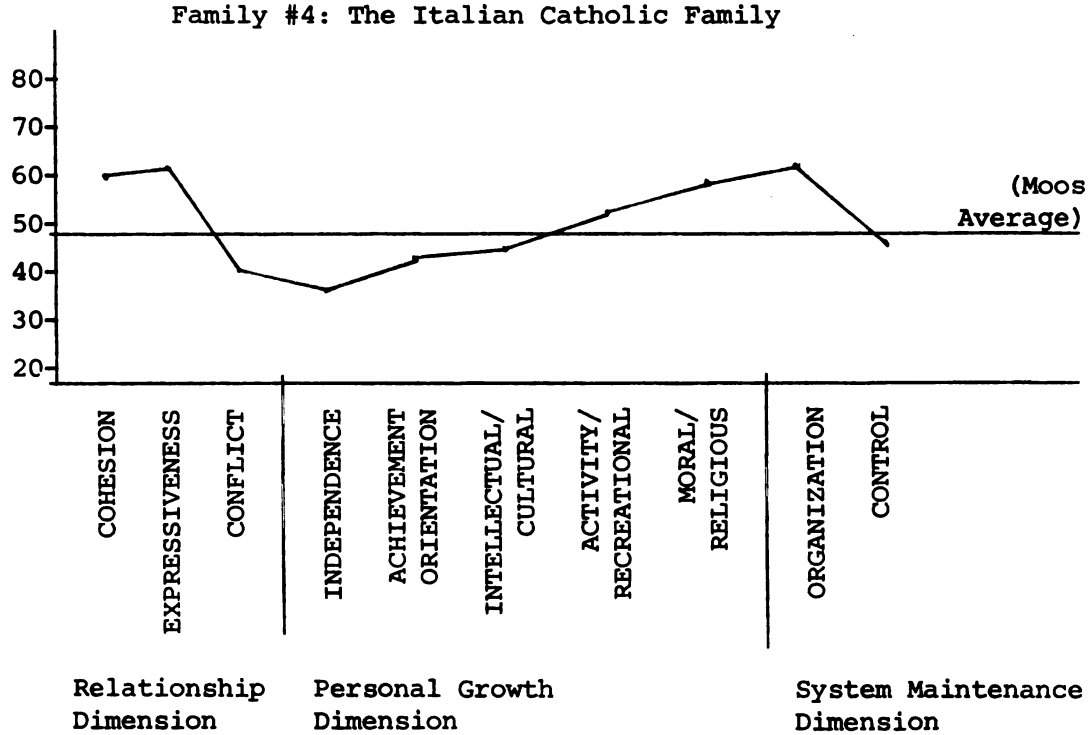
Interestingly, the interviewer learned that the wife had left the family six years previously, divorcing the patient and marrying another man. This second marriage lasted only six months and the wife moved back with her family to remarry her first husband shortly after his diagnosis with cancer. The interviewer noted that two other members of the patient's extended family were also diagnosed with cancer.

The family's FIncS of 15.9 was almost average, and their stress score of 31 was only slightly below the average of 39.5 on the Horowitz sample.

Despite the interview data, the family scored above average in expressiveness and cohesion and below average in conflict. All of the scores on the personal growth dimensions except moral/religious were below average. Organization was highly emphasized, but control was average. These data are summarized in Figure 4.

FIGURE 4

Comparison of Miller and Moos Standardized Scores on FES
Family #4: The Italian Catholic Family



Family #5: The White Middle-Class Family

The White Middle-Class Family of three members indicated no religious preference. The mother, aged 47, had been diagnosed 21 months earlier, in January, 1980, with breast cancer, and metastasis was discovered a year later. The father was breadwinner, aged 53. The daughter, aged 24, was single and lived alone two blocks away. She was in law school. This family experienced the death of their only son, aged 24, in September, 1980, from testicular cancer. It was nine months before this that the mother had discovered a lump in her breast. However, it was only after the death of her son that she submitted to a mastectomy. The mother stated that she was too busy with her son's illness and the stress she experienced from his death to pay attention to herself. She felt that this stress related to her son was a significant factor in the exacerbation of her own cancer. She was currently receiving chemotherapy.

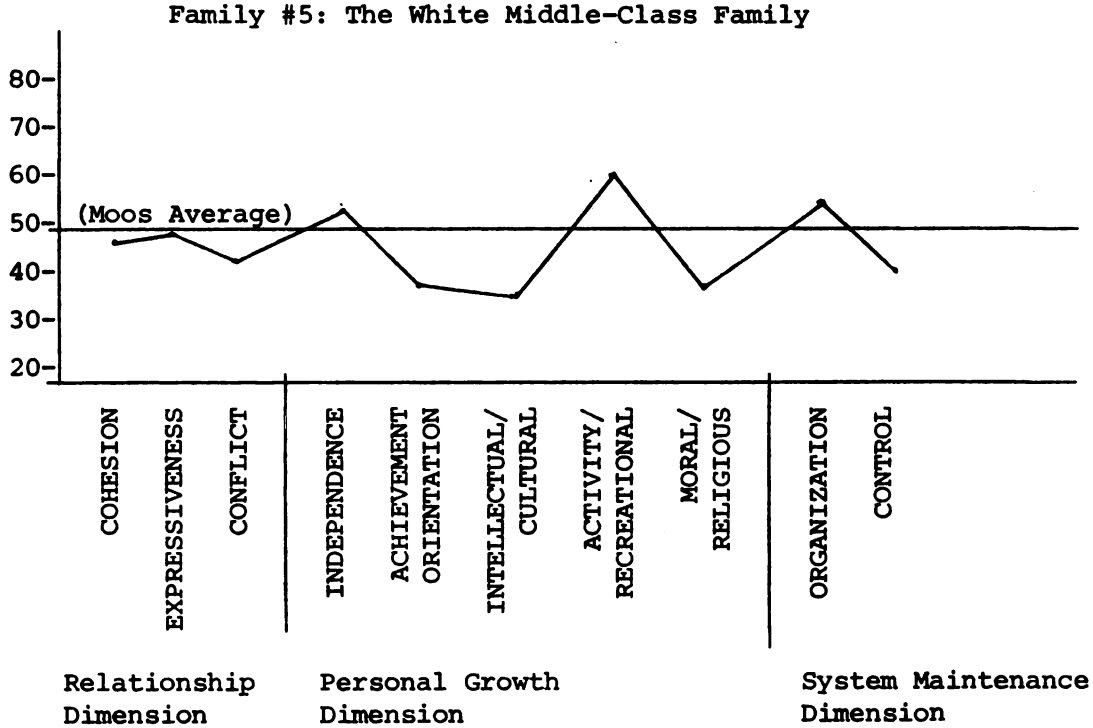
During the interview, her husband cried several times and expressed his bitterness about not only losing his only son, but also his wife. He also said that he had never resolved his feelings of bitterness about losing his father from testicular cancer when his father was only 32. The man in this study used physical labor, outdoor activities, and work to relieve some of his stress. He said the whole family often participated in sports together to relieve tension.

The FIncS of this family was 30.0, the highest FIncS in the sample. Their disagreement lay in cohesion, expressiveness, independence, and organization. Their stress score of 44.3 was second highest in the study, and was higher than the average score of 39.5 on the Horowitz sample. They scored below average on the FES subscale of conflict and on the intellectual/cultural, achievement, and moral/religious subscales,

but above average on activity/recreation. Organization was stressed only slightly more than control in the system maintenance dimension. The FES data from this family are compared with the mean data from the Moos sample and summarized in Figure 5.

FIGURE 5

Comparison of Miller and Moos Standardized Scores on FES
Family #5: The White Middle-Class Family



Family #6: The Poor White Family

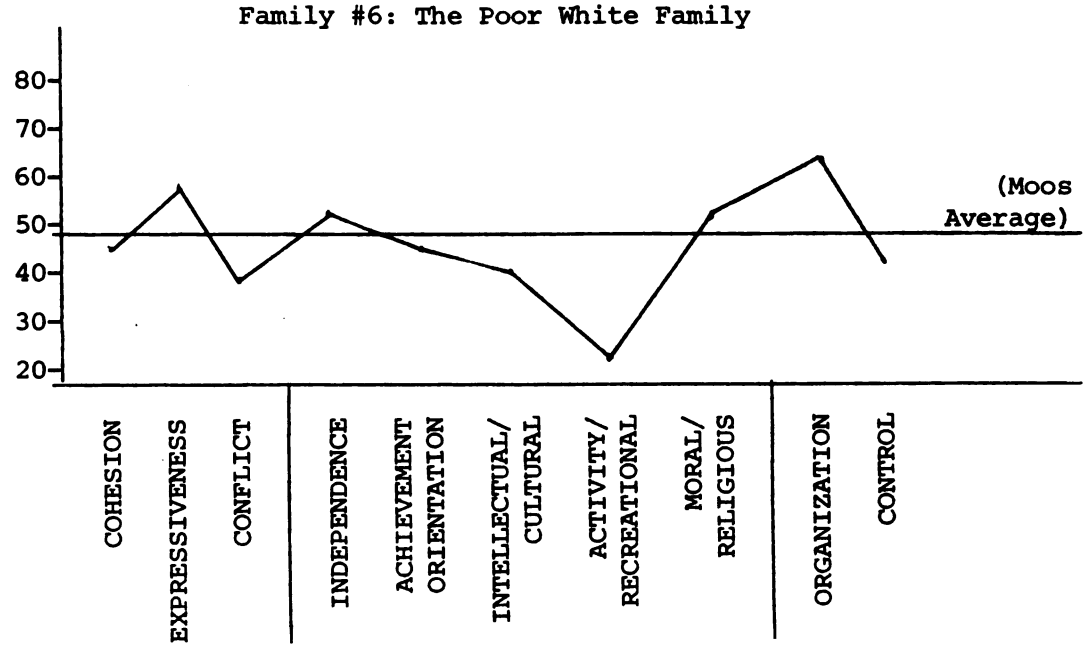
This was a white, lower middle-class Catholic family of four members. The mother, aged 71, was widowed, and had been diagnosed with Hodgkins lymphoma since April, 1980, about 18 months before the study. Four months prior to the interview, she was diagnosed with metastasis to the liver and was currently receiving chemotherapy and radiation therapy. Her daughter supported the family as a postal clerk and was the sole breadwinner. The patient's son-in-law quit his job four months earlier to care for her. He drove her to appointments and did all the domestic work for both households. The patient's son, aged 37, was single, unemployed and lived one block away. The mother described him as "having his head buried in the sand." This description was validated by the following direct quote written on the son's data form: "She may get significantly better, or the cancer may be cured. But I believe her to be strong and the cancer will not significantly shorten her life." In fact, she died three weeks after the data for this study were collected.

The family FIncS was 27.8, which was moderately above the Moos norm of 16.74. Disagreement was noted between the daughter and son-in-law, and between the son and the rest of the family. The stress score of 22.3 was below the Horowitz norm of 39.5.

Despite the family's high incongruence score, their score on the conflict scale was below average. Predictably, their cohesion score was slightly below average. The personal growth dimensions were all at average or below. Organization was highly emphasized within the family while control was slightly below average. Figure 6 represents a summary of these data.

FIGURE 6

Comparison of Miller and Moos Standardized Scores on FES
Family #6: The Poor White Family



Family #7: The Jewish Family

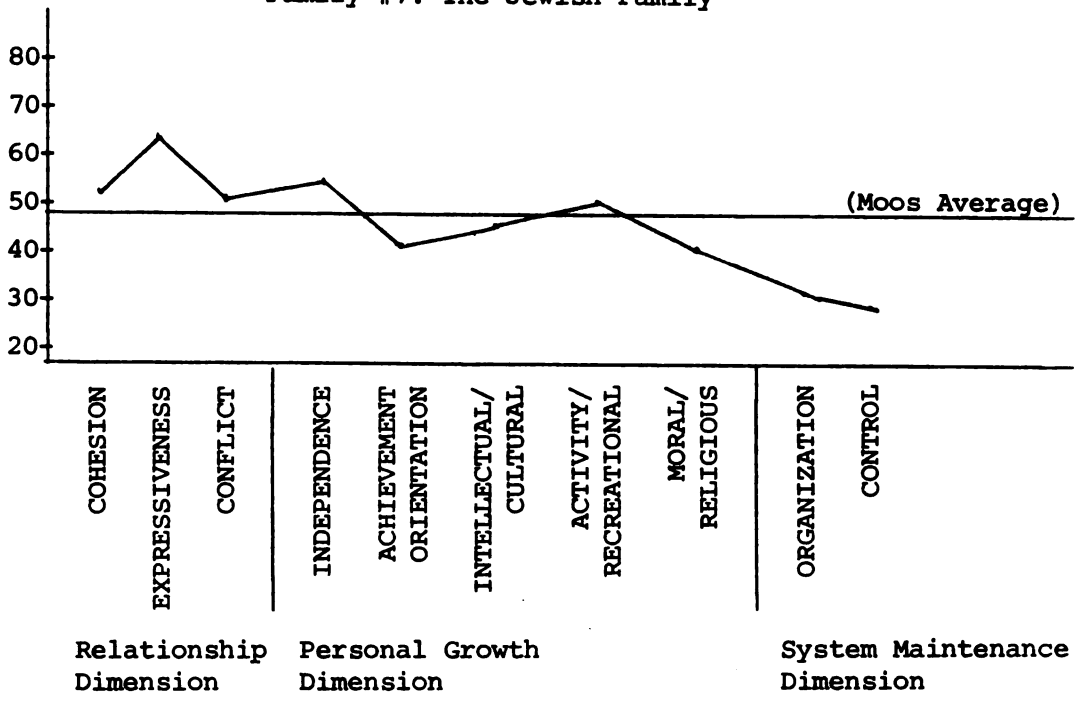
The patient in the Jewish Family of four members was the mother, aged 51, who was diagnosed with breast cancer a year earlier. She lived with her husband, aged 56, and two daughters, aged 15 and 19. The mother felt that the shock of her illness lessened over time and that the stage of grief was a big variable affecting the family's coping and stress behaviors. She said that time was the most important factor allowing her to come to terms with her life and death. She did not feel that her condition was terminal at the time of the interview. She was quite functional and was able to work and go to school. Currently, she was undergoing chemotherapy treatment.

The FIncS of 13.3 for this family was the second lowest of all the families in this sample. There was substantial agreement among all members on the FES subscale scores. The scores on all subscales were markedly similar, but the daughters disagreed between themselves on the subscales of cohesion and expressiveness. Furthermore, the family stress score was only 7.5, by far the lowest stress score of all the families in the sample, and lower than the mean stress score of 39.5 on the Horowitz sample.

This family was very expressive in its relationship dimension, but had a below average score for organization and control. Achievement orientation and moral/religious factors did not seem to receive much emphasis in the family. These data are summarized in Figure 7.

FIGURE 7

Comparison of Miller and Moos Standardized Scores on FES
Family #7: The Jewish Family



FINDINGS AND DISCUSSION

The family incongruence scores (FIncS) indicating the extent to which all pairs of family members disagreed about their family environment, were calculated for each of the seven families. The mean FIncS of the seven families in this study was 19.0, with a range of 9.5 to 30, compared to the FIncS mean of 16.74 in the original Moos sample. In addition, the mean stress score of the total family sample in this study is 27.3, with a range of 7.5 to 50, compared to the stress score of 39.5 in the Horowitz sample. These data are summarized in Table 2.

TABLE 2

Miller Sample Mean Scores on the
Moos Family Incongruence Score (FIncS) and
the Horowitz Impact of Stress Scale

	MEAN SCORES	
Family	FIncS	Stress
1	21.3	11.7
2	15.3	24.5
3	9.5	50.0
4	15.9	31.0
5	30.0	44.3
6	27.8	22.3
7	13.3	7.5
TOTAL MEAN	19.0	27.3

Note: Moos sample mean for FIncS = 16.4; Horowitz sample mean for Stress = 39.5.

These same data are plotted in Figure 8 to provide a visual comparison between the Miller and Moos samples of the mean FIncS scores derived from the FES, and between the Miller and Horowitz samples of the mean scores of the Impact of Stress Scale.

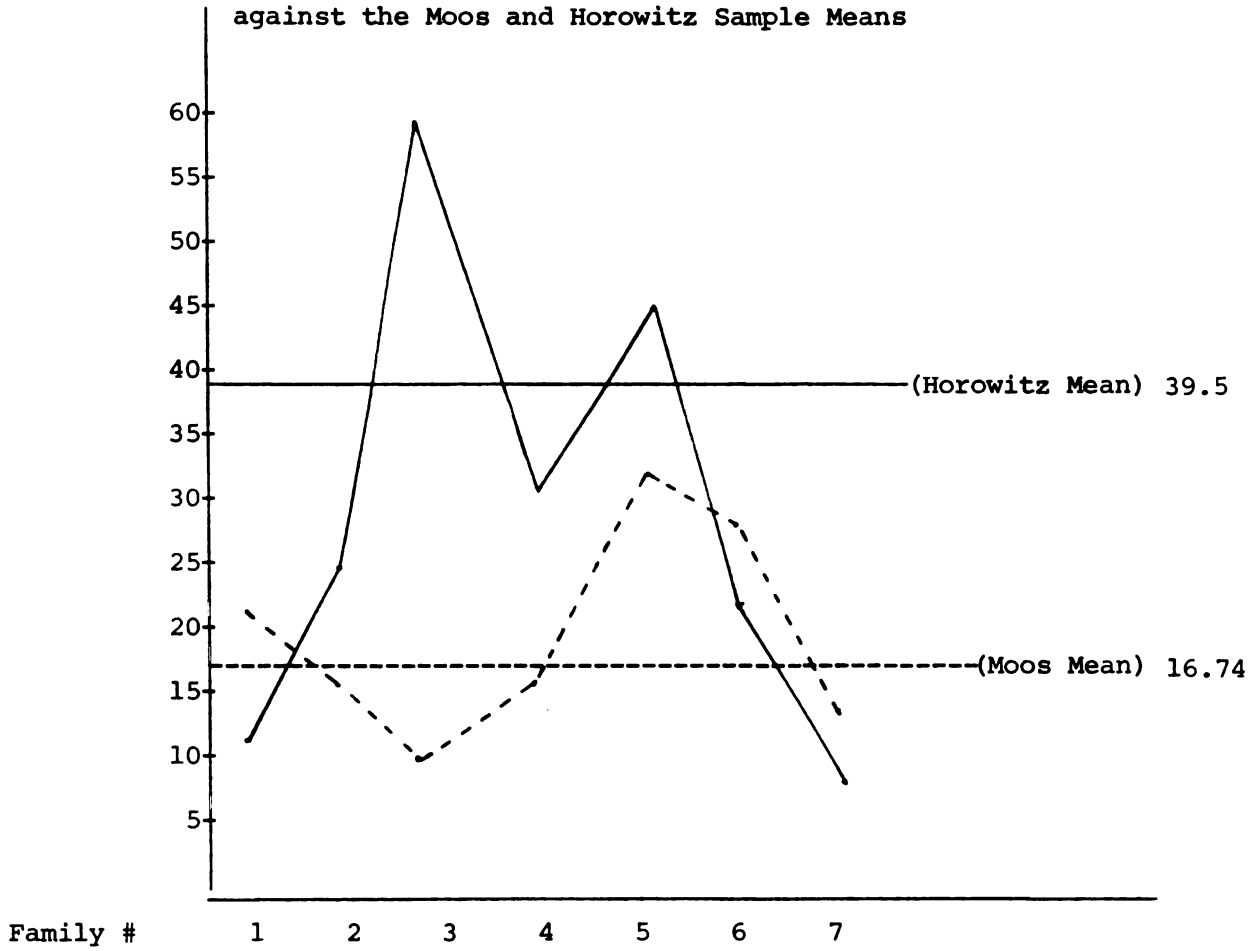
The mean FIncS and the mean stress scores for all seven families in this sample were correlated to yield a coefficient of .004, which was not statistically significant. Apparently, in spite of, or even because of terminal illness, the members of each family agreed with each other about their family environment, as demonstrated by the slight difference in FIncS (19.9 for the Moos sample and 16.74 for Miller's sample) and the lack of relationship between measures of family functioning and the impact of stress.

Table 3 illustrates the difference between the mean scores of the Moos and Miller samples on the FES and also the correlation between the Miller sample stress scores and Miller FES scores. Although there is no statistically significant difference between this study's FES means with the means of the Moos sample, there are several interesting trends. The areas of major difference between the Miller and Moos samples were found on the subscales of conflict, organization, intellectual/cultural, and activity/recreational. There was the greatest difference between the Miller sample mean of 2.81 and the Moos sample mean of 4.65 on the conflict subscale. The lower Miller conflict score suggests that the open expression of anger, aggression and generally conflictual interactions are not characteristic of the cancer families in the sample.

The subscales for intellectual/cultural and activity/recreational on the FES showed a slight trend of difference between the scores of the Moos sample and the scores of the Miller sample. In the Miller sample,

FIGURE 8

Plot of Miller's Sample Mean Scores
on the FIncS and Horowitz Stress Scale
against the Moos and Horowitz Sample Means



Note: Horowitz Scores = ————————————

Moos Scores = ----------

TABLE 3

The Difference Between the Mean Scores
of Moos and Miller on the Family Environment Scale (FES)
and the Correlation Coefficient
Between the Miller Sample Scores and the FES Subscales

FES Subscales	Total Sample Mean[a] Moos	Miller	Difference (Moos - Miller)	Correlation Between Miller Stress Score[b] & Miller FES Subscales
Cohesion	6.36	6.70	+0.34	+0.35
Expressiveness	5.43	5.34	-0.09	-0.07
Conflict	4.65	2.81	-1.84	-0.14
Independence	6.67	6.37	-0.30	+0.03
Achievement Orientation	5.64	5.01	-0.63	+0.05
Intellectual/Cultural	6.15	4.73	-1.42	+0.01
Activity/Recreational	6.19	4.98	-1.21	+0.51
Moral/Religious	4.55	4.28	-0.27	+0.31
Organization	5.27	6.33	+1.06	+0.57
Control	4.80	3.90	-0.90	+0.36

[a]Moos N = 285
Miller N = 7

[b]Miller sample mean on Horowitz Stress Scale = 27.3

each family had a member who was physically disabled by either the cancer itself or as a result of the therapy. Family activities outside the home were restricted not because of problems related to family functioning, but by physical limitations. To lend support to these findings, there is a slight positive correlation ($r = .51$) between the activity/recreational scores and the impact of stress scores. In the Miller sample, both the activity/recreational scores and the impact of stress scores were low. Family #5 in this study is of special interest in this regard because their activity/recreational score was the highest in the sample. This family also had a subjective stress score that was above the norm. Family #5's higher activity/recreational and stress scores are still positively correlated, suggesting that in times of moderate stress, this family coped by engaging in recreational activities.

Table 3 also demonstrates that this study's sample scored higher in organization than Moos' sample. There was also a slight positive correlation between organization and the impact of stress. Organization is a system maintenance dimension. Becoming more organized may be a means of coping with stress and maintaining the family system. Jackson (1965) supports this idea by claiming that, "The family is a rule-governed system. Members behave among themselves in an organized, repetitive manner and this pattern of behaviors can be abstracted as a governing principle of family life" (p. 6). Further on, Jackson suggests that organization of the family is a way families seek to maintain balance within themselves. "The homeostatic mechanism, the means by which norms are delimited and enforced, will function to bring the family back to the norm when disruption occurs" (p. 12).

The Miller scores for the subscales of cohesion and control are slightly elevated above the Moos norms. Olson (1979) provides an explanation through his hypothesis that a balanced degree of family cohesion is conducive to effective family functioning and to optimal individual development (p. 5). This assumption holds when there are no extremes with either stress or cohesion, as in this study.

The implication of all these findings is that the ten subscales of family functioning alone cannot explain a reaction to a stressful event in this study's sample of families. In other words, levels of family functioning, as indicated by the FES, do not necessarily explain or even influence a family's response to a catastrophic event such as the impending loss of a member through terminal illness.

Figure 8 plots the family mean score of this study's seven families against the standard mean scores of the Moos and Horowitz samples. Families #1, 2, 3, and 4 were participating in a hospice program of care, while families #5, 6, and 7 received treatment in an outpatient clinic. There is no significant difference between these two groups of families on either the FES or stress scales, so that no patterns can be established on the basis of the two different kinds of care.

Family #7 experienced the lowest subjective stress score in the sample. In Family #7, the patient was actively working full-time and attending school part-time. Her illness had not in any way changed her role in the family so that her family probably was not much affected or stressed by the fact of her cancer.

The experience of the death of a close family member within the preceding year may well account for the fact that Families #3 and #5 had the highest stress scores in the sample. Family #3 also had a below

average family incongruence score, indicating their apparent agreement with one another about their family environment during a time of high stress.

Family #5 had a high stress score but also a high family incongruence score. Further examination of this family's response on the FES reveals significant differences between the daughter's responses and those of her parents. These discrepancies were reflected in the high incongruence score for this family. The areas of disagreement occurred on the scales measuring cohesion, expressiveness, independence, and organization. This family was still grieving over the loss of a 24-year-old son one year previously. This case serves to illustrate that the family is a system and that a change in the functioning of one family member results in a compensatory change in the functioning of other members. If another death occurs before this compensatory change has taken place, symptoms can occur that indicate a dysfunction in the family system as a whole. This family's differential perception of the stressful event was reflected in a high incongruence score and suggests a potential dysfunction.

The results of this study confirmed for the investigator the necessity of including basic background information about a patient's family in an initial nursing assessment of the patient. This background information needs to include data about previous deaths experienced by the patient and family members and how they responded to these losses. Another important factor for assessment is the patient's and family's readiness for death. These kinds of questions can provide rich data that nurses could use to plan and provide more comprehensive, functional interventions with dying patients and their families.

CHAPTER V

SUMMARY AND CONCLUSIONS

SUMMARY

The purpose of this study was to examine families experiencing the imminent loss of a family member through death from cancer, to identify possible relationships between the impact of stress and the level of family functioning. The Moos Family Environment Scale was used to measure the level of family functioning, and the Horowitz Impact of Stress Scale was used to measure stress. These instruments were administered to a small convenience sample of seven families with a parent diagnosed with terminal cancer. No statistical significance was found in the relationship between impact of stress and the level of family functioning. There were no statistically significant differences between the mean stress scores of the sample in this study and the mean scores from the Horowitz sample. Neither were any statistically significant differences found between the mean family environment scores in this sample and the Moos sample. However, a number of interesting trends were noted about the scores of the Family Environment Scale subscales as used in this study that uniquely characterize several specific features of the "cancer families" in this study.

The subscales reflecting the major differences between this study's sample and that of Moos were measures of conflict, organization, intellectual/cultural and activity/recreation. The greatest difference between the Moos sample and the Miller sample was on the conflict subscale. Open expressions of anger, aggression and conflictual interactions were not characteristic of the cancer families in this study.

Organization, on the other hand, was higher for this study's sample. Organization is a dimension of system maintenance serving to maintain a balance within the family that assisted with effective family functioning.

The subscale scores of activity and recreation were lower for the cancer families in this study which were probably related to the family's physical limitations and disruption due to radiation and chemotherapy treatments rather than a reflection of poor family functioning. The subscales of cohesion and control were only slightly elevated, further indicating the ability of these cancer families to cope and adapt.

That there were no statistically significant relationships in the present study might be explained in part by the limited sample size. However, there are authors whose research supports the findings of this study that there are no differences between the level of functioning of the family with a member dying from cancer and the level of functioning of families from a "normal" population. One of these is Cohen (1977) who reported that the communication patterns of families are directly related to the family's ability to utilize internal support. He stated that the more family members were able to communicate, the greater the likelihood of an effective adjustment. Cohen's findings lend credence to the findings in this study that the communication patterns in the study were indicative of normal family functioning, and that the adjustment of these families was reflected in lower than average impact of stress scores.

It would have seemed likely that the families in the present study would have a higher impact of stress score than the average. But the data in this study indicate that there was actually a lower total mean stress score than average. There are several possible explanations for

this. Horowitz, in his original study, administered the stress questionnaire to individuals who had sought psychotherapy following a stressful event. The average time of testing after the event for his 66 subjects was 25 weeks. By contrast, the sample in the present study represented average families from a non-psychiatric population who were undergoing a normative transition in the family life cycle, i.e., loss of a member through death. Further, the unit of analysis in this study was the entire family as opposed to the individuals in the sample Horowitz used. Because family members' scores were averaged to yield one score for the entire family, the effect of extreme scores of individual members was muted.

Although the identified stressful event in the present study was loss of a family member through death which, like birth, is a normative process in the family life cycle, it seems that these families adjusted fairly "normally" to the life event. Apparently, through their ability to adapt and use functional coping resources, these families pulled together their reserves to accommodate a boundary change. Perhaps the most significant finding of this study is that the loss of a family member is not the massively disruptive event to family functioning that people outside the family system would expect it to be. The families in this study had an average time of illness of 18.3 months during which to stabilize their relationships. In other words, families seemed to have time to adapt to the change. Possibly the impact of stress on family functioning would be different if the time of data collection followed more immediately the time of diagnosis. At any rate, the impact felt by the shifting role responsibilities after a member was stricken with terminal illness in this study was less stressful than the investigator

expected.

The family's definition or perception of the stressful nature of an event is a most significant factor influencing how the family responds to the event (McCubbin, 1981). The complexity of family life is such that little can be explained or predicted by merely examining a single life event. The clinical investigator needs to take into account the unique meaning each family gives to a stressful event, and the context of the entire family system in order to understand and explain the meaning of current events in the life cycle of the family. For example, in Family #3, the Black Episcopalian Family, the identified patient was 81 years old. Because this was a time in the life cycle when death is more likely to occur, it might be assumed that this family would experience a lower impact of stress score than a family losing a younger member. However, the opposite was true; this family's stress score was quite high. Apparently, the stage of advanced individual development of the patient does not contribute an explanation for the high stress score.

Similarly, in Family #5, the White Middle-Class Family, the identified patient continued to work and function in her role as mother and housewife. One might expect that this family's stress score would be lower because the family functioning hadn't been disrupted by the need to redistribute roles. But instead, this family's stress score was also quite high. It seems that role theory alone does not account for this family's response to the diagnosis of cancer.

Upon further assessment, it was learned that both of these families had experienced deaths of close significant family members within the previous year. These families were probably still experiencing, each

in their own way, the grieving process related to these deaths. The possibility of losing another family member so soon after a previous death further exacerbated their grief and so intensified their experience of stress. A detailed, comprehensive examination of the significant events in a family's life cycle history seems to be critical in understanding how a family responds and adapts to potential crises in its present negotiation of life cycle transitions.

It is not enough to test the impact of a single isolated event on the functioning of a family. In Family #7, the Jewish Family, the investigator anticipated a high stress score because the identified patient was a young mother with children still living at home. Instead, this family had the lowest stress score in the sample. Several explanations are possible. Maybe the family was still using denial as a coping mechanism to deal with the mother's diagnosis of cancer. Perhaps the mother's role had not yet changed, since her chemotherapy treatments and outpatient clinic visits did not yet interfere with her functioning role in the family. The family did not seem to perceive the illness as a disruptive threat to their security functions and life style at this time. Or, even though their family routine may have changed a bit, they may have coped with the hope that the situation would eventually improve after therapy was finished.

SIGNIFICANCE AND IMPLICATIONS FOR NURSING

Although there were no relationships sufficiently strong enough to be substantiated with statistical significance in this study, important inferences can be made for nursing. Merely providing subjects in this study an opportunity to talk about their experiences related to the

cancer was a way of opening communication among family members themselves and with an outside resource in the person of the investigator. Families consistently verbalized their relief and gratitude to the investigator for her time and interest in them and for giving them an opportunity to share their feelings. This was further validated by their eager willingness to discuss their feelings about death and serious illness. This finding was in contrast to the expectations of several health providers who controlled access to potential subjects, and even to some members on the UCSF Human Rights Committee!

Nurses are frequently in the position of providing care to people who are seriously ill and facing death. Nurses can play an invaluable role by empathically understanding the feelings of family members experiencing significant loss. This is an area of research especially relevant to nursing because it contributes to further knowledge about how families function in time of crisis in terms of their resources and coping behaviors. If health care providers, with added knowledge of how family systems function in crisis, could predict more accurately the possible impact of a stressful event on family functioning, they could be significant change agents facilitating open communication to lessen the impact of the stress.

Nurses can be a source of support to families in assisting them to cope with crisis. This study demonstrates the need to recognize that serious illness affects not only the individual but the entire family as a unit. The most significant result of this study is the implication that only a very comprehensive assessment of families can yield sufficient data to be useful in facilitating family functioning. The study suggests that some families, probably more than one might expect, are capable of

managing their own resources to adapt to the crisis of stressful events such as the diagnosis of cancer. It is important for the nurse to be able to identify those particular families who may need assistance to tap their own repertoire of resources in coping with this kind of stress. Nurses can be especially useful by teaching these families how to manage stress with maximum effectiveness. Interventions that are initiated early in the process of illness can prevent the maladaptive coping that leads to poor stress outcome (Kaplan, 1976).

LIMITATIONS

The following factors were identified as limitations on the study:

1) Access to subjects proved especially difficult. Sample size was constricted by factors related to the limited time and financial resources of the researcher, and by the resistance of several agency administrators to allow access to potential subjects.

2) The exclusive use of quantitative instruments to measure complex family interactions limited the amount of data obtained. It was difficult to quantify the feelings of family members and the impact on families of a stressful event. The instruments available at the time of this study were not sufficiently comprehensive to assess the valuable, rich information that these families had to offer.

3) Although the Moos Family Environment Scale was potentially useful because it purported to measure the family as a unit, it was designed to examine family functioning while children were still present in the household. Thus its face validity was limited in the present study because the older population in the sample had grown children living away from the home of their parents. Moreover, the sample for

Moos' study was mainly drawn from middle and upper class families who had facilities for "camping," "theatre," and "baseball." These facilities were not available or of value to all of the people in the sample in this study. Therefore, the usefulness of the FES to poorer families or families with different cultural backgrounds is questionable. Moos was able to retest the instrument in his sample over a time span of eight weeks. This was not possible in the sample in the present study because the person with cancer was terminal at the time of the interview and, in three cases, died shortly after the time of data collection.

4) The Horowitz stress questionnaire was administered to individuals and was designed to test reactions of these individuals to a stressful event. In this study, the stress scale was administered to individuals within a family, and a family mean was calculated to yield a total family score. This raises the question of whether the mean of the sum of individual member scores can truly represent the score of the family as a unit of analysis.

FURTHER RESEARCH

On the basis of the study, the following recommendations are made for further research:

1) In order to provide the most comprehensive data describing a family system, it would be useful to supplement quantitative instruments with a semi-structured interview. An interview would detect further inferences and gradations of impact that were not revealed by the instruments in this study.

2) If instruments are to be used, a larger sample would allow for more robust correlations that might be statistically significant.

3) A study done over time, with data collection at several points during the process of illness (e.g., immediately after the diagnosis, during the time of dying, immediately following the death) would yield more comprehensive data about family functioning during different stages of grieving.

CONCLUSION

Although the results of this study are inconclusive, they challenge the assumption that all families define death as a stressful event, and that families experience greater than average stress at the possibility of losing a member from death by cancer. This study leads to further speculation as to whether families whose boundaries change by losing a member through death, a normal transition in the life cycle, experience greater stress or become less functional than the average family. This implication needs further investigation. Knowledge gained from such a study can contribute to the development of theory that serves as a foundation for the science and art of family nursing.

APPENDIX A

SUBJECTS' CONSENT FORM

University of California
Department of Family Health Care Nursing

CHR Approval Number 939193-01

CONSENT FORM

Mary Alice Miller, R.N., graduate student at the School of Nursing University of California, is doing a study to evaluate factors that affect a family's reaction to a serious illness.

If I agree to participate in the study, I will be asked to fill out two (2) questionnaires which will take approximately 20 minutes. Everyone in the family who agrees to participate will be included in the study. Any information collected will be kept as confidential as possible.

I understand some of the questions asked may cause some discomfort due to the sensitive nature of the subject matter. Participation in this study is voluntary and I have the right to refuse to answer any questions and I may withdraw from the study at any time.

If I have questions at any time concerning the study, I can call Ms. Miller at (415) 753-1676.

Date_____ Participants_____

_____

_____

_____

_____

_____

APPENDIX B

DEMOGRAPHIC QUESTIONNAIRE

DEMOGRAPHIC DATA

NAME:_____

DATE:_____

LOCATION:_____

SEX:_____

AGE:_____

CULTURAL BACKGROUND:_____

RELIGIOUS PREFERENCE (if any):_____

APPROXIMATE DATE YOU KNEW OF THE SERIOUS ILLNESS:_____

WHAT DO YOU THINK IS THE DIAGNOSIS OF THE SERIOUS ILLNESS?_____

_____

_____

NUMBER OF PERSONS IN YOUR FAMILY:_____

YOUR ROLE IN THE NUCLEAR FAMILY. For example, grandfather, mother, shared breadwinner, son, breadwinner, head of household, etc.

_____

APPENDIX C

THE HOROWITZ IMPACT OF STRESS SCALE

IMPACT OF EVENT SCALE

This questionnaire is designed to get information about the impact of serious illness on the family. The questionnaire is designed both for the person with the serious illness and the other family members.

DIRECTIONS: Below is a list of comments made by people after stressful life events. The stressful life event in this case is the serious illness in your family. Read each item and decide how frequently each item was true for you DURING THE PAST SEVEN (7) DAYS. If the item did not occur during the past seven days, choose the NOT AT ALL option. Make a checkmark on the line under the heading which best describes that item. Please complete each item.

	NOT AT ALL	RARELY	SOME-TIMES	OFTEN
1. I thought about it when I didn't mean to.	____	____	____	____
2. I had trouble doing other things because the event kept coming into my mind	____	____	____	____
3. I avoided letting myself get upset when I thought about it or was reminded of it.	____	____	____	____
4. I tried to remove it from memory.	____	____	____	____
5. I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind.	____	____	____	____
6. I had waves of strong feelings about it.	____	____	____	____
7. I had dreams about it.	____	____	____	____
8. I stayed away from reminders of it.	____	____	____	____
9. I felt as if it hadn't happened or wasn't real.	____	____	____	____
10. I tried not to talk about it.	____	____	____	____
11. Pictures about it popped into my mind.	____	____	____	____
	(0)	(1)	(3)	(5)

		NOT AT ALL	RARELY	SOME-TIMES	OFTEN
12.	Other things kept making me think about it.	____	____	____	____
13.	I was aware that I still had a lot of feelings about it, but I didn't deal with them.	____	____	____	____
14.	I tried not to think about it.	____	____	____	____
15.	Any reminder brought back feelings about it.	____	____	____	____
16.	My feelings about it were kind of numb.	____	____	____	____
		(0)	(1)	(3)	(5)

APPENDIX D

THE MOOS FAMILY ENVIRONMENT SCALE (FES)

FAMILY ENVIRONMENT SCALE

FORM R

RUDOLF H. MOOS

INSTRUCTIONS

There are 90 statements in this booklet. They are statements about families. You are to decide which of these statements are true of your family and which are false. Make all your marks on the separate answer sheets. If you think the statement is *True* or mostly *True* of your family, make an X in the box labeled T (true). If you think the statement is *False* or mostly *False* of your family, make an X in the box labeled F (false).

You may feel that some of the statements are true for some family members and false for others. Mark T if the statement is *true* for most members. Mark F if the statement is *false* for most members. If the members are evenly divided, decide what is the stronger overall impression and answer accordingly.

Remember, we would like to know what your family seems like to *you*. So *do not* try to figure out how other members see your family, but *do* give us your general impression of your family for each statement.

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1. Family members really help and support one another.
2. Family members often keep their feelings to themselves.
3. We fight a lot in our family.
4. We don't do things on our own very often in our family.
5. We feel it is important to be the best at whatever you do.
6. We often talk about political and social problems.
7. We spend most weekends and evenings at home.
8. Family members attend church, synagogue, or Sunday School fairly often.
9. Activities in our family are pretty carefully planned.
10. Family members are rarely ordered around.
11. We often seem to be killing time at home.
12. We say anything we want to around home.
13. Family members rarely become openly angry.
14. In our family, we are strongly encouraged to be independent.
15. Getting ahead in life is very important in our family.
16. We rarely go to lectures, plays or concerts.
17. Friends often come over for dinner or to visit.
18. We don't say prayers in our family.
19. We are generally very neat and orderly.
20. There are very few rules to follow in our family.
21. We put a lot of energy into what we do at home.
22. It's hard to "blow off steam" at home without upsetting somebody.
23. Family members sometimes get so angry they throw things.
24. We think things out for ourselves in our family.
25. How much money a person makes is not very important to us.
26. Learning about new and different things is very important in our family.
27. Noboby in our family is active in sports, Little League, bowling, etc.
28. We often talk about the religious meaning of Christmas, Passover, or other holidays.
29. It's often hard to find things when you need them in our household.
30. There is one family member who makes most of the decisions.
31. There is a feeling of togetherness in our family.
32. We tell each other about our personal problems.
33. Family members hardly ever lose their tempers.
34. We come and go as we want to in our family.
35. We believe in competition and "may the best man win."

36. We are not that interested in cultural activities.
37. We often go to movies, sports events, camping, etc.
38. We don't believe in heaven or hell.
39. Being on time is very important in our family.
40. There are set ways of doing things at home.
41. We rarely volunteer when something has to be done at home.
42. If we feel like doing something on the spur of the moment we often just pick up and go.
43. Family members often criticize each other.
44. There is very little privacy in our family.
45. We always strive to do things just a little better the next time.
46. We rarely have intellectual discussions.
47. Everyone in our family has a hobby or two.
48. Family members have strict ideas about what is right and wrong.
49. People change their minds often in our family.
50. There is a strong emphasis on following rules in our family.
51. Family members really back each other up.
52. Someone usually gets upset if you complain in our family.
53. Family members sometimes hit each other.
54. Family members almost always rely on themselves when a problem comes up.
55. Family members rarely worry about job promotions, school grades, etc.
56. Someone in our family plays a musical instrument.
57. Family members are not very involved in recreational activities outside work or school.
58. We believe there are some things you just have to take on faith.
59. Family members make sure their rooms are neat.
60. Everyone has an equal say in family decisions.
61. There is very little group spirit in our family.
62. Money and paying bills is openly talked about in our family.
63. If there's a disagreement in our family, we try hard to smooth things over and keep the peace.
64. Family members strongly encourage each other to stand up for their rights.
65. In our family, we don't try that hard to succeed.
66. Family members often go to the library.
67. Family members sometimes attend courses or take lessons for some hobby or interest (outside of school).

68. In our family each person has different ideas about what is right and wrong.
69. Each person's duties are clearly defined in our family.
70. We can do whatever we want to in our family.
71. We really get along well with each other.
72. We are usually careful about what we say to each other.
73. Family members often try to one-up or out-do each other.
74. It's hard to be by yourself without hurting someone's feelings in our household.
75. "Work before play" is the rule in our family.
76. Watching T.V. is more important than reading in our family.
77. Family members go out a lot.
78. The Bible is a very important book in our home.
79. Money is not handled very carefully in our family.
80. Rules are pretty inflexible in our household.
81. There is plenty of time and attention for everyone in our family.
82. There are a lot of spontaneous discussions in our family.
83. In our family, we believe you don't ever get anywhere by raising your voice.
84. We are not really encouraged to speak up for ourselves in our family.
85. Family members are often compared with others as to how well they are doing at work or school.
86. Family members really like music, art and literature.
87. Our main form of entertainment is watching T.V. or listening to the radio.
88. Family members believe that if you sin you will be punished.
89. Dishes are usually done immediately after eating.
90. You can't get away with much in our family.

FAMILY ENVIRONMENT SCALE

DIRECTIONS

Look at your test booklet and check the Form printed on it here:

Form R____ E____ I____

Please provide the information requested below.

Your Name _____ Age _____

Address _____ Sex: M F (circle)

Please indicate your position in the family (check one):

Mother (wife)____ Father (husband)____ Son or Daughter____

Other____ (Please specify): _____

Today's Date _____ Other _____

Now, please read each statement in your booklet and then, in the boxes on the other side of this sheet, mark T (true) if you think the statement is true of your family, and F (false) if the statement is not true of your family.

Use a heavy X, as in the example: Please use a pencil with an eraser, not a pen. Be sure to match each number in the booklet with each one on this sheet.

EXAMPLE ONLY

	1	2
T	X	
F		X

START HERE

T/F											T/F
T	1	2	3	4	5	6	7	8	9	10	T
F											F
T	11	12	13	14	15	16	17	18	19	20	T
F											F
T	21	22	23	24	25	26	27	28	29	30	T
F											F
T	31	32	33	34	35	36	37	38	39	40	T
F											F
T	41	42	43	44	45	46	47	48	49	50	T
F											F
T	51	52	53	54	55	56	57	58	59	60	T
F											F
T	61	62	63	64	65	66	67	68	69	70	T
F											F
T	71	72	73	74	75	76	77	78	79	80	T
F											F
T	81	82	83	84	85	86	87	88	89	90	T
F											F

do not mark below this line

	C	Ex	Con	Ind	AO	ICO	ARO	MRE	Org	Ctl
R/S										
S/S										

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