

PARENTS OF PEDIATRIC CANCER PATIENTS:
PSYCHOLOGICAL PROFILE AND IMPACT
ON DRUG COMPLIANCE

By

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INTRODUCTION AND REVIEW OF LITERATURE

The diagnosis, treatment, and acceptance of outcome for childhood cancer may be a tragic complex of events not only for the patient but for the patient's family as well. To care for a dying child bespeaks an undeniably intensive level of psychological stress for these families. Childhood cancer has inherent psychological stresses for both the patient and their family. These stress factors have historically been related to death and the dying process. While treatment methodologies have greatly improved the expected life-span for many of these children, the remissions and relapses associated with this prolongation of life have added to the ambiguity with which these patients and families must cope.

Kaplan et al. (1973) found that families with a leukemic child were a high risk group psychologically. They noted 87 percent of the families in their study failed to cope adequately with the consequences of childhood leukemia. This resulted in many personal problems in addition to the stress precipitated by the leukemia. This is compatible with Binger's (1969) findings which revealed the need for psychiatric intervention for at least one family member in 50 percent of the families with a fatally ill child. As Holland (1977) pointed out, it is the family member closest to the patient who bears the strain of the illness with the patient. When the patient is a child this strain is borne by one or both of the parents. A range of difficulties in coping and signs of psychological stress in parents of children with cancer have been

noted. Many parents utilize denial of the child's illness for varying lengths of time (Bozeman et al., 1955; Pearse, 1977; Stehbins and Lescari, 1975). Orbach et al. (1955) in their early work found greater magnitudes of rage and despair in the mothers of these children.

Friedman (1967) and Adams (1978) also noted hostility and anger as often seen in these parents. Parents frequently feel guilt at not recognizing the disease sooner (Kirkpatrick, 1974; Friedman et al., 1963). Wright et al. (1979) speak of the feelings of helplessness of these parents due to their lack of control over their child's disease process.

After the onset of the child's illness when support is needed most, it appears these parents tend to isolate themselves from friends and relatives while friends and relatives also abandon them (Bozeman et al., 1955; Heffron et al., 1973; Pearse, 1977; Lansky, 1974). Parents are often deprived of luxuries as well as being stressed in meeting basic needs due to the financial burden of caring for their child with cancer (Lansky et al., 1979).

While authors agree that there is significant psychological stress for these parents, what is needed is an improved understanding of this stress. As Wright et al. (1979) suggest, most of the behavioral data on these parents tends to be impressionistic and subjective. Very few studies have sought to quantify the behavior and level of psychological adjustment of these parents. This information would be important not only for improvement of psychological management of these parents, but possible effects on the medical management of the child's illness. As Friedman (1967) pointed out, these parents must protect themselves from being overwhelmed to effectively function in both the medical and psychological management of their child. The focus of this

review will be on the components of medical management which may be affected by the parent's psychological state. It is not the intent of this research project to investigate necessary psychological interventions.

A relatively broad approach to conceptualizing psychological factors which affect medical management has been presented by Becker et al. (1972) in terms of a Health Belief Model. They explain this Health Belief Model in terms of an individual's views concerning susceptibility to a disease, severity of that disease, and the benefits and costs associated with the paths of action that could be taken to prevent it. Children of mothers who believed that her child was susceptible to the disease, that the disease was severe, and that the treatment was worth the cost consistently showed higher levels of compliance to the medical regimens. However, no study has undertaken the assessment of the Health Belief Model for parents of pediatric cancer patients and its effect on the medical management of those children.

Another factor found to affect compliance with medical management and which would be important for this population has to do with adequacy of coping mechanisms. Gillum and Barsky (1974) reported that those without adequate coping mechanisms could not harness their fear to organize and initiate action to counterattack the perceived threat but were instead immobilized by the threat. With the high level of stress parents of childhood cancer patients appear to be experiencing, this process might be expected to interfere with the provision of medical care for the child.

Medical management of childhood cancer primarily utilizes chemotherapy. Chemotherapy often results in agents being combined to

increase their therapeutic effect. Complicated dosage and schedules exist for many chemotherapeutic agents which allow the agents to exert their antineoplastic effect (Minich and Grindey, 1977). Therefore, the agent, dosage, and scheduling may be crucial to the successful outcome of treatment. This places the primary emphasis on the agent dimensions in contrast to compliance with the regimens. The assumption which followed was that treatment failures were due to the drugs rather than to a lack of compliance. Only one study has evaluated levels of compliance in a pediatric cancer population (Smith et al., 1979). This study found a striking 33 percent of the population not in compliance with their medication regimen. No study of a pediatric cancer population has attempted to simultaneously study drug compliance and possible psychological factors related to that compliance.

The present study sought to gain a more thorough understanding of parents of pediatric cancer patients in a quantified manner utilizing standardized psychological instruments. It was expected that in comparisons with normal adult populations these parents would exhibit greater levels of tension and apprehension. It was also expected they would tend to be more isolated and to be more willing to give up control of decisions to others.

Drug compliance for these children is an extremely important aspect of their medical regimen. Since studies have shown parent's personality and attitudes to play an important part in that compliance, drug compliance for this population was measured for these children. Parents of compliant patients were compared with parents of noncompliant patients for possible differences. In addition to the standardized psychological measures, an experimental questionnaire was utilized which

concerns the parent's adherence to the Health Belief Model discussed earlier. It was expected that parents of compliant patients would exhibit a greater adherence to the Health Belief Model, would be more relaxed and be better able to cope with their difficulties.

It has been shown with other diseases that as time in remission lengthens, there are changes in how one views the illness and need for treatment (Sackett and Haynes, 1976). To examine this dimension with this population, parents studied when their children had been in remission less than six months were compared with parents studied when their child was in remission more than six months. It was expected that parents with children in remission longer might become less tense, less isolated, and become more willing to take control of their decisions.

The last subgroup analysis compared parents of patients who relapsed after testing to parents of patients who remained in remission throughout the study. At this time little is known as to possible personality traits or beliefs which might interact with a child's tendency to relapse. This analysis explored this dimension.

METHODOLOGY

Subjects

The subjects were the parents of 31 pediatric outpatients of the Hematology-Oncology clinic of Oklahoma Children's Memorial Hospital. Outpatients in this study ranged in age from six months through 17 years of age, were receiving at least one oral antineoplastic medication, were judged by the clinic physicians not to be in the acute phase of their disease, and returned to the clinic at one to three week intervals. Diagnoses included solid tumors and lympho-leukemic neoplasms. In each case the parent who was primarily involved in the child's treatment was tested resulting in responses from 30 adult females and 1 adult male.

Procedure

Each parent-subject was administered four evaluation instruments. The Sixteen Personality Factor (16 PF) Questionnaire (Cattell et al., 1970) and Fundamental Interpersonal Relations Orientation - Behavior (FIRO-B) Questionnaire (Schultz, 1967) supplied information as to the informants preexisting personality structure and attitudes. To evaluate how the parent evaluates the relative importance of internal versus external control, the Rotter (1966) I-E locus of control scale was employed. Additionally, the parents were administered an experimental questionnaire, the Medicine Information Satisfaction Survey (MISS), to assess their attitudes toward medication, medical health professionals, their child's illness and other facets of the Health Belief Model. The 16 PF, FIRO-B, and Rotter I-E were all administered

one time to each patient's parent at the beginning of the study. The MISS was administered at both the beginning and end of the study to assess possible changes in the parent's health belief model.

RESULTS

Analysis #1

Parents of Patients Compared to Normative Data

The entire group of parents (n=31) responding in this study were compared to normative data by means of scores on the 16 PF, FIRO-B, and Rotter I-E. Student's t-values demonstrated significant differences between these two groups on five of the factors of the 16 PF and on four of the six FIRO-B scales. Scales of the 16 PF found to significantly differentiate the two groups were: (1) Factor E, Humble versus Assertive, with these parents scoring more in the humble direction; (2) Factor M, Practical versus Imaginative, with parents scoring more in the practical direction; (3) Factor O, Placid versus Apprehensive, parents' scores were greater in the apprehensive direction; (4) Factor Q₂, Group-Dependent versus Self-Sufficient, with parents scoring more in the self-sufficient direction; (5) Factor Q₄, Relaxed versus Tense, with parents scoring toward the tense dimension. Significant 16 PF factors and their associated t-values are listed in Table I.

The four FIRO-B scales significantly differentiating these parents as a group from the general adult population were: (1) Expressed Inclusion, (2) Wanted Inclusion, (3) Expressed Control, and (4) Wanted Control. These parents admitted to wanting and expressing less inclusion and control than did the comparison group. FIRO-B scales found to be significant and their associated t-values are given in Table II. Mean values for significantly differentiating factors of the 16 PF and FIRO-B are provided in Table III.

TABLE I
 VARIABLES SIGNIFICANTLY DIFFERENTIATING PARENTS OF
 PATIENTS FROM ADULTS IN THE GENERAL POPULATION

Variable	t-Value
16 PF Factor E Humble versus Assertive	2.947**
16 PF Factor M Practical versus Imaginative	3.649**
16 PF Factor O Placid versus Apprehensive	2.705*
16 PF Factor Q ₂ Group-Dependent versus Self-Sufficient	2.564*
16 PF Factor Q ₄ Relaxed versus Tense	2.877**

*p < .02, df = 27, t = 2.473

**p < .01, df = 27, t = 2.771

TABLE II

FIRO-B VARIABLES SIGNIFICANTLY DIFFERENTIATING PARENTS
OF PATIENTS FROM ADULTS IN THE GENERAL POPULATION

Variable	t-Value
FIRO-B E ^I Expressed Inclusion	3.163**
FIRO-B W ^I Wanted Inclusion	2.549*
FIRO-B E ^C Expressed Control	5.454***
FIRO-B W ^C Wanted Control	2.987**

*p < .02, df = 30, t = 2.457

**p < .01, df = 30, t = 2.750

***p < .001, df = 30, t = 3.646

TABLE III
 MEAN VALUES OF FACTORS SIGNIFICANTLY DIFFERENTIATING
 PATIENTS' PARENTS FROM NORMATIVE DATA

Variable	\bar{X} Parents	\bar{X} Normative Data
16 PF Factor E	4.54	5.5
16 PF Factor M	4.29	5.5
16 PF Factor O	6.21	5.5
16 PF Factor Q_2	6.46	5.5
16 PF Factor Q_4	6.57	5.5
FIRO-B E^I	4.07	5.2
FIRO-B W^I	2.23	3.4
FIRO-B E^C	1.32	3.1
FIRO-B W^C	3.87	5.1

Analysis #2Parents of Compliant Patients Versus
Parents of Noncompliant Patients

This division concerned adherence of the patients to their anti-neoplastic medication regimen. Medication history interviews were conducted at three consecutive clinic visits with each parent by a registered pharmacist. Compliance for each antineoplastic agent was based on the accuracy with which the patient adhered to the dosage and interval prescribed. A compliance percentage was calculated for each drug by dividing the number of doses taken correctly by the number of doses prescribed. Patients were categorized as compliant if they complied with their medication schedule at the rate of 80 percent or above for each drug as suggested by the work of Meyers et al. (1975) as expected compliance for chronic illnesses. If their rate was less than 80 percent for any of their prescribed antineoplastic drugs, they were considered noncompliant. Eight of the 31 parents tested were excluded from this analysis due to insufficient compliance information, an incomplete test battery or both. Of the 23 remaining subjects, 14 were the parents of compliant patients while 9 were parents of noncompliant patients. Compliance on individual medications ranged from 0% to 100%.

A step-wise discriminant function analysis with 1 and 21 degrees of freedom (Klecka, 1978) compared the subjects in these two groups. Twenty-four variables were used of which six were found to be individually significant in differentiating the two groups. These variables indicated that the parents of compliant patients and noncompliant patients' parents differed in the areas of: (1) 16 PF Factor H in which the parents of noncompliant patients showed themselves to be more shy and restrained than parents of compliant patients who were more

venturesome and spontaneous; (2) FIRO-B Expressed Affection with the parents of compliant patients expressing more affection than those of noncompliant patients; (3) 16 PF Factor N with parents of noncompliant patients scoring in the shrewd and calculating direction; (4) FIRO-B Expressed Inclusion with parents of compliant patients expressing more inclusion behavior; (5) FIRO-B Wanted Affection with parents of compliant patients wanting more affection; (6) 16 PF Factor C with parents of compliant patients scoring more in the direction of emotionally stable and facing reality. These results with their associated F values are summarized in Table IV.

Utilizing the step-wise process of the discriminant function analysis, a set of three predictor variables was generated which significantly differentiated the two groups. These three variables were (1) 16 PF Factor H, Shy versus Venturesome; (2) FIRO-B Expressed Affection; and (3) 16 PF Factor N, Forthright versus Shrewd. These variables, their associated F-values, and the significance level of the prediction system as each variable was added are given in Table V.

Analysis #3

Studied at <6 Months in Remission Versus Studied at >6 Months in Remission

For purposes of this analysis, parents were divided into those studied (tested) when their child's illness had been in remission six months or less and those parents who were studied (tested) when their child's illness had been in remission more than six months. The range of time in remission for these children was one month to thirty-two months at the time of testing. Only those parents whose child was in a first remission were used in this analysis. Of the 25 parents meeting

TABLE IV
 VARIABLES SIGNIFICANTLY DIFFERENTIATING PARENTS OF COMPLIANT
 PATIENTS FROM PARENTS OF NONCOMPLIANT PATIENTS

Variable	Compliant \bar{X}	Noncompliant \bar{X}	F-Step 0
16 PF Factor H Shy versus Venturesome	6.00	3.44	11.01**
FIRO-B E ^A Expressed Affection	4.21	2.11	7.349*
16 PF Factor N Forthright versus Shrewd	5.00	7.11	6.668*
FIRO-B E ^I Expressed Inclusion	4.57	3.00	4.947*
FIRO-B W ^A Wanted Affection	5.36	3.67	4.617*
16 PF Factor C Affected by Feelings versus Emotionally Stable	6.14	4.44	4.613*

* $p < .05$, $df = 1, 21$; $F = 4.30$

** $p < .01$, $df = 1, 21$; $F = 7.95$

TABLE V
 DISCRIMINANT FUNCTION PREDICTOR VARIABLES FOR THE PARENTS OF
 COMPLIANT PATIENTS VERSUS PARENTS OF NONCOMPLIANT
 PATIENTS

Variable	F-Step 0	F-Entered	Significance	d.f.
16 PF Factor H	11.01	11.013	0.0033	1,21
FIRO-B E ^A	7.349	12.919	0.0003	2,20
16 PF Factor N	6.668	16.774	0.0000	3,19

this criterion, 7 were studied at six months or less while 18 were studied at over six months in remission.

These two groups were compared utilizing a step-wise discriminant function analysis with 1 and 24 degrees of freedom. In this analysis one variable was found which individually significantly differentiated the two groups. Factor N of the 16 PF demonstrated the parents of patients in remission less than six months at the time of the study scored more toward the forthright dimension than the parents of patients studied at more than six months in remission who scored more toward the shrewd dimension. Values for this segment of analysis #3 are given in Table VI.

Chosen by the step-wise portion of the discriminant function analysis were five variables which combined to significantly differentiate the two groups studied. These variables were: (1) 16 PF Factor N, Forthright versus Shrewd; (2) FIRO-B Expressed Control; (3) 16 PF Factor Q_4 , Relaxed versus Tense; (4) 16 PF Factor F, Sober versus Happy-Go-Lucky; (5) FIRO-B Wanted Inclusion. These predictor variables, their associated F-values, and the significance of the prediction system as each variable was added are given in Table VII.

Analysis #4

Remission Versus Relapse

After testing, during the course of the study, seven of the participating patients relapsed. Test data from the parents of these patients were compared with the parents of those 20 patients who remained in their first remission throughout the study.

A step-wise discriminant function analysis was performed to compare the parents in these two groups. The analysis revealed no variables

TABLE VI

VARIABLE SIGNIFICANTLY DIFFERENTIATING PARENTS OF PATIENTS STUDIED
AT LESS THAN SIX MONTHS IN REMISSION FROM PARENTS OF PATIENTS
STUDIED AT MORE THAN SIX MONTHS IN REMISSION

Variable	< 6 Mo. \bar{X}	> 6 Mo. \bar{X}	F-Step 0
16 PF Factor N Forthright versus Shrewd	4.29	6.78	9.406*

* $p < .01$, $df = 1,24$; $F = 7.82$

TABLE VII

DISCRIMINANT FUNCTION PREDICTOR VARIABLES FOR PARENTS OF PATIENTS
STUDIED AT LESS THAN SIX MONTHS IN REMISSION VERSUS PARENTS
OF PATIENTS STUDIED AT MORE THAN SIX MONTHS IN REMISSION

Variable	F-Step 0	F-Entered	Significance	d.f.
16 PF Factor N	9.406	9.406	0.0055	1,23
FIRO-B E ^C	1.929	6.524	0.0060	2,22
16 PF Factor Q ₄	0.9129	5.671	0.0055	3,21
16 PF Factor F	0.2364	5.094	0.0054	4,20
FIRO-B W ^I	0.5340	5.010	0.0043	5,19

which individually significantly differentiated the two groups. The step-wise portion provided six variables which combined to form a prediction system which significantly differentiated the two groups. These six variables, all 16 PF Factors, were: (1) Factor Q_1 , Conservative versus Experimenting; (2) Factor F, Sober versus Happy-Go-Lucky; (3) Factor I, Tough-minded versus Tender-minded; (4) Factor Q_3 , Undisciplined versus Controlled; (5) Factor L, Trusting versus Suspicious; (6) Factor M, Practical versus Imaginative. Parents of patients who later relapsed scored more in the direction of conservative, sober, tough-minded, controlled, trusting, and practical. These factors, their associated F-values, and the significance of the prediction system as each variable was added are given in Table VIII.

Analysis #5

Individual MISS Items

This analysis examined the ability of scores on individual MISS items to differentiate the two subgroups used in each of analyses #2, #3, and #4. These comparisons were accomplished by means of Student's t-tests.

This analysis found no individual MISS items were significant in differentiating between parents of compliant patients versus parents of noncompliant patients, parents of patients studied at >6 months versus parents of patients studied at <6 months in remission, or parents of patients who maintained their remission throughout the study versus parents of patients who relapsed during the course of the study.

Analysis #6

Pre-MISS Scores Versus Post-MISS Scores

Scores on the MISS from its first administration at the beginning of the study were compared with MISS scores from its administration at

TABLE VIII

DISCRIMINANT FUNCTION PREDICTOR VARIABLES FOR PARENTS OF
 PATIENTS WHO RELAPSED AFTER TESTING VERSUS PARENTS
 OF PATIENTS WHO REMAINED IN REMISSION AFTER
 TESTING

Variable	F-Step 0	F-Entered	Significance	d.f.
16 PF Factor Q_1	3.244	3.244	0.0838	1,25
16 PF Factor F	2.540	2.249	0.1273	2,24
16 PF Factor I	1.260	1.905	0.1569	3,23
16 PF Factor Q_3	0.383	1.884	0.1490	4,22
16 PF Factor L	2.323	2.397	0.0790	5,21
16 PF Factor M	0.1455	2.663	0.0459	6,20

the end of the study. Student's t-tests for correlated measures were employed for these comparisons.

One MISS item showed a significant difference between pre-MISS and post-MISS scores. This was item number two concerning the parent's understanding of why the medication was given to their child. Parents reported an improved understanding at the conclusion of the study. For this item, $t = 3.00$, $df = 15$, $p < .01$.

DISCUSSION

Results of this study indicate that parents of pediatric cancer patients are not grossly maladjusted nor highly deviant in personality. They have made some adjustments in their outlook and beliefs which allow them to cope with their situational stress.

These results lend support to observations noted earlier (Adams, 1978; Binger, 1969; Friedman, 1963; Pearse, 1977) that parents of pediatric cancer patients as a group are more tense and isolated than parents in general. Considering the stress they are experiencing, it is not surprising that they were found to be more tense and apprehensive than normal control adults. It might also be expected that in order to cope with the situation in which they find themselves it would be necessary for them to direct their focus of energy and emotional resources within the family thereby leaving little energy for outside interactions, hence the isolation evidenced by these parents. Another dimension of coping would revolve around their lack of control of their child's illness. To attempt to assert and maintain control would be less adaptive in their situation than to place belief and control with others. These parents are evidencing less desire for control than the comparison group of adults. Another facet of positive coping could be the greater concern with practical issues which would be necessary for the daily management of their child's illness and which these parents are manifesting.

These parents consistently endorsed items on the MISS in the direction of ascribing to the Health Belief Model. According to compliance

work with this model (Becker et al., 1972; Becker et al., 1977a; Becker et al., 1977b; Radius et al., 1978), it would be expected that these parents would be more likely to carry through in the provision of medical treatment for their child. Since only those parents whose child was in remission were studied, all the parents in this study had stayed with medical treatment long enough to help bring their child through the acute phase of their illness. This would imply a selected set of parents, that is, those who have the belief system and coping skills to provide their child with treatment for the illness. Therefore, the profile we see of a parent who is more practical, and experiencing tension, apprehension, isolation, and reduced control is probably the profile of the parent who mobilized their emotional resources in such a way as to be more successful in coping with the child's illness.

The stress experienced by these parents might be expected to be present in a more intense form for those parents whose child has most recently experienced the acute phase of their illness. These are the parents who most recently have attempted to cope with the threatened loss of their child. It was hypothesized that these parents would experience the feelings of stress, isolation, and need for control more intensely than those parents whose children had achieved a greater distance of time into remission. For the most part these hypotheses were supported. Parents with a child in remission less than six months were more tense, sober, less questioning, and expressing less control than parents whose child had been in remission more than six months. The only result counter to this idea was that of parents with a child in remission less than six months desired more inclusion with others than did the parents with a child more than six months removed from their acute

phase. While these parents desired more interaction with others, they were not involved in these interactions to a significantly greater extent than were the parents of the children more than six months into remission. One explanation might be that the parents who were less removed from their child's acute phase experience more need for support by means of interactions with others while still exhibiting the reduced interaction necessary for the conservation of their emotional resources, hence the greater desire for inclusion without a significant difference in the expressed inclusion level.

Feelings as to interactions with others also proved to be important in the delineation of another subset of parents. In the comparison of parents of compliant patients with those of noncompliant patients, the parents of noncompliant patients were significantly more constricted interpersonally than were parents of compliant patients. The parents of noncompliant patients were more shy, less forthright, interacted less with others, and desired less affection. They also showed themselves to be less emotionally mature. It appears that these parents may have a tendency to overreact. In the sphere of isolation they appear to exceed what is necessary to adequately conserve needed emotional resources. This degree of constriction may prevent the kind of interaction necessary with the medical staff to assimilate adequate information and encouragement for their child's proper compliance with medication regimens. In a clinic setting where necessary medication information was already being presented carefully, repetitively, and in a supportive and encouraging fashion, these parents were still reporting less than optimal compliance by their child. When medication counseling with a registered pharmacist at each appointment and take-home medication calendars were added

(Cantrell, 1979), all but one of the parents of noncompliant patients who were still in remission reported drug compliance improved to the point that their child could be classified as a drug compliant patient. It appears that these parents have the capacity to help these children comply but require greater and a different type of intervention than do the parents of already compliant patients.

Parents of noncompliant patients subscribed to the Health Belief Model equally as well as parents of compliant patients as evidenced by the lack of significant differences on the MISS. This is contrary to what might be expected from reviewing previous work (Becker et al., 1972; Becker et al., 1977a; Becker et al., 1977b; Radius et al., 1978) which showed compliant patients endorsing the Health Belief Model to a greater extent than noncompliant patients. However, as mentioned earlier the parents included in this study appear to be a select subset of those parents of children with cancer. These parents have evidenced by their behavior a belief in the efficacy of medical treatment. This idea of support for the Health Belief Model within this population is consistent with the lack of differences on the MISS among all the various subsets of this population which were tested. These beliefs also appear to be stable for this population. The only change noted between the MISS's administered at the beginning and the end of the study was an increased understanding of why the medication was given to the child. Considering that a portion of the study utilized repeated drug counseling with a registered pharmacist, this increased understanding is not unexpected.

One set of findings in this study which must be interpreted with caution concerns differences between parents of patients who later

relapsed and parents of patients who remained in remission. Due to the small number of patients in the relapse group (n=7), the lack of variables which were individually significant, and the paucity of even observational data in this area, information on the relapse group is considered very preliminary in nature. Results suggest that as a group the parents of patients who later relapsed are more conservative, sober, tough-minded, controlled, trusting, and practical. These data suggest the possibility of differences but testing information needs to be obtained on greater numbers of these parents before an interpretation is warranted.

Results of this study have implications for both the medical and psychological management of the child with cancer and their parent. They suggest that the tension and isolation previously suspected does indeed exist for these parents. In an attempt to provide care to these children the staff must deal with a parent who is genuinely tense and apprehensive but not open to a great deal of interaction. This is especially true of parents of children in remission only a short period of time. While these parents of childhood cancer patients do not want to make their own decisions, neither are they willing for others to totally take control.

It appears that the shyness and constriction parents of noncompliant patients feel may keep them from seeking the information and encouragement they need to help their children increase their medication compliance. Identification of and special attention to these parents appears necessary to maximize compliance.

While this study has provided new information by a quantified examination of how parents of children with cancer function and has

quantified differences among parents of noncompliant patients, it has also pointed to the need for additional questions to be answered with appropriate modifications in design. An especially important question is how parents of children with cancer who do not maintain their child in treatment differ from those parents who do continue treatment for their child. What are the differences between parents with a child in the acute phase as compared with parents in remission? Do differences in parents of children who later relapse and parents whose children remain in remission hold when greater numbers of these parents are studied?

Future research in this area would be strengthened by the use of additional measures of medication compliance. While it would be well to continue the use of structured medication interviews, the use of measures of actual medication levels in the body by blood and/or urine assays would add greater precision to these estimates.

Another suggestion in the area of future research concerns the use of additional psychological evaluation. Structured interviews and the use of a projective measure such as the Thematic Apperception Test would add a further dimension to the area of psychological functioning studied. The use of a more strongly normed test such as the California Personality Inventory might also prove advantageous. Additional information in this area might begin to answer the questions of helpful psychological interventions appropriate to these parents. However, judging from the interpersonal constriction evidenced by the parents in the present study, the traditional approaches of a strong staff and/or group interventions may not be the treatment methods of choice. As these questions are addressed and information gained the goal of optimal medical and psychological management of these patients and their families will be closer to realization.

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APPENDIX A

CONSENT FORM

CONSENT FORM

I, _____, voluntarily consent for myself and my child, _____, to participate in the study entitled, "Factors Affecting Compliance in a Pediatric Hematology-Oncology Population," and understand that the study will be as follows.

1. The purpose of this project is to determine the extent of acceptance of the medical regimens prescribed by the physician and the factors which may affect acceptance. Behavioral, psychological, and medical information are to be collected to aid in understanding your view of the medications and its effects. This information will assist in developing procedures for increasing a child's compliance in following the necessary regimen.

2. The procedures used in this study have been adapted from previous work involving other medical problems. The questionnaires and techniques are standardized, accepted scientific procedures from medical and psychological disciplines. Some of the procedures are investigational in purpose (for example, examining the personality of the patient). However, none are contrary to the regular control of your child's illness. There are no known or expected adverse effects of a parent's or a child's participation in this project.

3. While this study has the complete support of the physicians and staff of the Hematology-Oncology clinic, they will not have access to any information that I or my child provide as related to my/my child's name. All data will be released by group membership rather than with my/my child's name. Our participation in this study will consist of completing questionnaires at the beginning of the project, once during the project, and at the end of the project, returning medication

containers with each clinic visit, and at times being in contact with the project personnel by appointment, mail, or telephone. My child's participation will consist of completing questionnaires and providing information at his/her regularly scheduled clinic appointments. The hospital records concerning my child's illness will be made available to the project personnel. I understand that strict confidentiality will be observed of all data collected as a result of participation by my child or myself under the guidelines established by the Public Health Service and the American Psychological Association. Complete anonymity will be preserved and no patient's names will be released with the data collected. The project will continue no longer than ten clinic visits.

4. The participation in this study should help my child and me in managing his/her illness through a definite procedure to maximize compliance to medical regimens. Through increased compliance, the control of the disease will hopefully improve. The information gained should also benefit other pediatric hematology-oncology patients.

5. As noted above, there are no known or expected risks to me or to my child as a result of participating in this study.

6. Should I and my child decline to participate in this study, medical treatment of the condition will continue in the manner heretofore followed by them without discrimination or denial of services by caretakers.

7. Whereas no assurance can be made concerning results that may be obtained (since results from investigational studies cannot be predicted), the principal investigator will take every precaution consistent with the best medical psychological practice. By signing this consent form, I have not waived any of my legal rights or released

this institution from liability for negligence. I may revoke my consent and withdraw from this study at any time. Should any problems arise during this study, I may take them to:

The Director of Research Administration
 Room 362, Biomedical Sciences Building
 Telephone: 271-2090

 Patient's Name

Jeannie Masters
 Pat Cantrell

 Principal Investigators

 Signature of Witness

H. Steven Caldwell, Ph.D.
 L. Kay See, M.S.

 Investigators

 Signature of Parent or Legal
 Guardian of Patient

 Date

OKLAHOMA CHILDREN'S MEMORIAL
 HOSPITAL

APPENDIX B

16 PF, ROTTER I-E, AND FIRO-B RELIABILITY,
VALIDITY AND NORMATIVE GROUP INFORMATION

16 PF, Rotter I-E, and FIRO-B Reliability,
Validity and Normative Group Information

16 Personality Factor

Cattell believes that the most important of the several varieties of reliability coefficients is the "dependability coefficient: the correlation between two administrations of the same test when the lapse of time is insufficient for people themselves to change with respect to what is being measured." Using this criterion, scale reliabilities ranged from 58 to 83 for Form A of the 16 scales.

Concept validity is measured by correlating the scale with the factor it is supposed to measure. Utilizing this approach, scale validities ranged from a low of 53 to a high of 94 on the 16 scales.

Raw scores from the 16 PF are converted to sten scores from 1 through 10, with the population average fixed at sten 5.5. Stens 5 and 6 extend, respectively, a half standard deviation below and above the mean. Females from the group of parents tested were compared with norms based on age 30 years and created by the testing of 729 young women using Form A of the 16 PF. The one male parent's score was compared with norms based on age 30 years and created from the testing of 2,255 young men on Form A of the 16 PF.

(Reliability and validity information taken from Handbook for the 16 PF, 1970. Normative information from the Tabular Supplement No. 1 to the 16 PF Handbook, 1967-68 Norms.)

Rotter I-E

In Rotter's 1966 work he reviews eight studies which show the reliability of his I-E to range from .49 to .79. His studies of validity correlating the I-E with the Marlowe-Croune Social Desirability Scale ranged from -.07 to -.35 and from -.22 to .03 with

intellectual measures indicating a good discriminant validity. He says that the "most significant evidence of the construct validity of the I-E scale comes from predicted differences in behavior for individuals above and below the median of the scale or from correlations with behavioral criteria." This group of parents scores were tested against his group of 605 female undergraduates at Ohio State University whose mean score was 8.42 with a standard deviation of 4.06.

FIRO-B

Reliability of the FIRO-B by means of test-retest stability ranged from .71 to .82 with a mean coefficient of .76 for the six scales. Coefficients of internal consistency produced a mean of .94 for the six scales.

According to Schultz (1967) "if the theory underlying the use of Guttman scales is accepted, then content validity is a property of all legitimate cumulative scales, and therefore of all FIRO-B scales."

The FIRO-B has no overall population norms as the authors believe it more meaningful to examine how individual groups manifest themselves on the dimensions of the FIRO-B. After consultation with the publishers of the FIRO-B (Consulting Psychologists Press, Inc.), it was decided that the group closest in make-up to the group of parents tested was a group of 677 teachers. The majority of these teachers were female and a parent. Their scores on the six scales were as follows:

<u>Scale</u>	<u>M</u>	<u>SD</u>
E ^I	5.2	1.96
W ^I	3.4	3.42
E ^C	3.1	2.38
W ^C	5.1	1.93
E ^A	3.7	2.07
W ^A	4.3	2.36

APPENDIX C

MEDICINE INFORMATION SATISFACTION SURVEY

Medicine Information Satisfaction Survey

On the following pages you will be asked to read statements.

Below each statement you will find:

Totally False							Totally True
0	1	2	3	4	5	6	

OR

Totally Incomplete							Totally Complete
0	1	2	3	4	5	6	

Please circle the number closest to your belief about the statement.

For example, if you read a statement and completely agreed with it you would circle 6. If you completely disagreed with it you would circle 0.

Or if in another statement the term Totally Complete best fit your belief you would circle 6 while if Totally Incomplete best fitted your belief you would circle 0. If your belief is somewhere in between the two extremes, you would circle the number in between which best fitted your belief. Remember, circle the number which best fits your belief.

Medicine Information Satisfaction Survey

1. The information given me by the doctor about my (my child's) illness was:

Totally Incomplete						Totally Complete
0	1	2	3	4	5	6

2. I understand why this medication was given.

Totally False						Totally True
0	1	2	3	4	5	6

3. If this medication does not seem to be working, I will feel comfortable in talking to the doctor about it.

Totally False						Totally True
0	1	2	3	4	5	6

4. The directions about my (my child's) medicine were:

Totally Incomplete						Totally Complete
0	1	2	3	4	5	6

5. The medication given me (my child) will cure this illness.

Totally False						Totally True
0	1	2	3	4	5	6

6. The medication given me (my child) is only for this illness.

Totally False						Totally True
0	1	2	3	4	5	6

7. The successful treatment of my (my child's) illness depends only on the medicine.

Totally False						Totally True
0	1	2	3	4	5	6

8. Taking more than one kind of medicine shows that the doctors know what to do about this illness.

Totally False						Totally True
0	1	2	3	4	5	6

9. Medicine prescribed for other illnesses have helped.

Totally False						Totally True
0	1	2	3	4	5	6

10. The medicine prescribed for this illness is worth what it costs.

Totally False						Totally True
0	1	2	3	4	5	6

11. The medicine prescribed for this illness is worth the problems that go with it.

Totally False						Totally True
0	1	2	3	4	5	6

12. Following the exact directions about my (my child's) medicine is important.

Totally False						Totally True
0	1	2	3	4	5	6

13. Medicine is not as helpful when taken late.

Totally False						Totally True
0	1	2	3	4	5	6

14. Taking an extra dose of medicine is harmful.

Totally False						Totally True
0	1	2	3	4	5	6

15. Forgetting to take a dose of medicine is harmful.

Totally False						Totally True
0	1	2	3	4	5	6

16. Unless the doctor's orders are followed my (my child's) illness may return.

Totally False						Totally True
0	1	2	3	4	5	6

17. I feel my (my child's) doctor in this clinic has been warm and understanding in his dealings with me (my child).

Totally False						Totally True
0	1	2	3	4	5	6

18. I believe my (my child's) illness is serious.

Totally False						Totally True
0	1	2	3	4	5	6

19. I feel the staff in this clinic has been warm and understanding in their dealings with me (my child).

Totally
False

Totally
True

0 1 2 3 4 5 6

20. My (my child's) treatment in this clinic is everything I hoped it would be.

Totally
False

Totally
True

0 1 2 3 4 5 6

APPENDIX D

MEANS AND STANDARD DEVIATIONS FOR ALL PARENTS
ON THE 16 PF, FIRO-B, AND ROTTER I-E
AND t-VALUES FOR ANALYSIS #1

Means and Standard Deviations for All Parents
on the 16 PF, FIRO-B, and Rotter I-E
and t-values for Analysis #1

<u>Variable</u>	<u>Mean</u>	<u>Standard Deviation</u>	<u>t-value</u>
16 PF Factor A	5.29	1.76	0.644
16 PF Factor B	5.85	1.96	0.935
16 PF Factor C	5.25	1.94	0.683
16 PF Factor E	4.54	1.73	2.947**
16 PF Factor F	4.93	1.84	1.623
16 PF Factor G	5.25	1.71	0.772
16 PF Factor H	4.89	2.16	1.483
16 PF Factor I	6.14	1.96	1.738
16 PF Factor L	5.61	1.73	0.306
16 PF Factor M	4.29	1.76	3.649**
16 PF Factor N	6.18	2.25	1.599
16 PF Factor O	6.21	1.40	2.705*
16 PF Factor Q ₁	4.93	1.78	1.696
16 PF Factor Q ₂	6.46	1.99	2.564*
16 PF Factor Q ₃	5.54	1.88	0.101
16 PF Factor Q ₄	6.57	1.97	2.877**
FIRO-B E ^I	4.07	2.00	3.163**
FIRO-B W ^I	2.23	2.57	2.549*
FIRO-B E ^C	1.32	1.81	5.454***
FIRO-B W ^C	3.87	2.29	2.987**
FIRO-B E ^A	3.55	2.19	0.386
FIRO-B W ^A	4.84	2.19	1.368
Rotter I-E	9.63	3.67	1.591

*p < .02

**p < .01

***p < .001

APPENDIX E

F-VALUES AT STEP 0

F-Values at Step 0

Variable	Analysis #2 F-Value	Analysis #3 F-Value	Analysis #4 F-Value
16 PF Factor A	0.432	1.043	0.816
16 PF Factor B	0.649	1.360	0.816
16 PF Factor C	4.613*	0.745	0.383
16 PF Factor E	0.800	1.999	0.116
16 PF Factor F	0.245	0.236	2.540
16 PF Factor G	0.104	0.163	0.209
16 PF Factor H	11.010**	0.584	0.561
16 PF Factor I	0.168	0.646	1.260
16 PF Factor L	0.450	1.612	2.323
16 PF Factor M	0.488	0.815	0.146
16 PF Factor N	6.668*	9.406**	0.383
16 PF Factor O	2.837	0.236	0.157
16 PF Factor Q ₁	1.479	0.436	3.244
16 PF Factor Q ₂	0.308	0.460	0.383
16 PF Factor Q ₃	0.708	1.525	0.629
16 PF Factor Q ₄	0.310	0.913	0.219
FIRO-B E ^I	4.947*	0.137	0.388
FIRO-B W ^I	0.707	0.534	0.718
FIRO-B E ^C	0.710	1.929	0.101
FIRO-B W ^C	3.098	0.275	0.938
FIRO-B E ^A	7.349*	0.599	0.301
FIRO-B W ^A	4.617*	0.354	0.168
Rotter I-E	0.161	0.289	0.314
MISS	0.600	0.332	0.216

*p < .05

**p < .01

APPENDIX F

MISS INDIVIDUAL ITEM MEANS
AND STANDARD DEVIATIONS

MISS Individual Item Means and
Standard Deviations

Item No.	Compliant vs. Non-compliant				< 6 mo. vs. > 6 mo.				Remission vs. Relapse			
	M	SD	M	SD	M	SD	M	SD	M	SD	M	SD
#1	5.66	0.61	5.70	0.48	5.50	0.76	5.63	0.60	5.55	0.67	5.86	0.38
#2	5.66	0.62	5.70	0.48	5.63	0.52	5.58	0.61	5.59	0.59	5.71	0.49
#3	5.93	0.26	5.10	2.02	5.86	0.35	5.26	1.82	5.55	1.41	5.29	1.89
#4	5.87	0.35	5.90	0.31	5.75	0.46	5.95	0.23	5.86	0.35	6.00	0.00
#5	3.40	1.63	2.80	1.93	3.75	1.17	3.00	1.80	3.18	1.44	2.71	2.43
#6	5.13	1.77	5.30	1.75	5.13	1.36	4.84	2.03	5.90	1.87	4.71	1.60
#7	1.40	1.84	2.70	2.00	2.88	1.64	2.10	2.05	2.09	1.95	3.00	1.92
#8	3.13	2.26	3.30	2.31	3.75	1.98	3.21	2.32	3.32	2.26	3.43	2.51
#9	2.13	2.56	4.10	2.23	2.50	2.83	2.89	2.40	2.77	2.56	2.86	2.61
#10	6.00	0.00	5.70	0.95	6.00	0.00	5.84	0.69	5.86	0.64	6.00	0.00
#11	5.87	0.35	5.70	0.95	6.00	0.00	5.74	0.73	5.28	0.66	5.86	0.38
#12	6.00	0.00	6.00	0.00	6.00	0.00	6.00	0.00	6.00	0.00	6.00	0.00
#13	3.67	2.22	4.00	1.89	3.75	1.91	3.79	2.12	3.41	2.20	4.71	1.60
#14	5.87	0.35	4.90	2.33	5.88	0.35	5.05	2.12	5.41	1.62	5.14	2.27
#15	4.67	1.40	4.50	1.90	5.15	1.17	4.32	1.57	4.82	1.33	4.29	1.98
#16	5.47	0.92	4.90	1.29	5.25	1.16	5.16	1.17	5.18	1.37	4.71	1.38
#17	5.53	1.36	5.60	0.96	5.13	1.81	5.79	0.71	5.50	1.26	6.00	0.00
#18	5.93	0.26	5.90	0.31	6.00	0.00	5.89	0.32	5.95	0.21	5.86	0.38
#19	5.60	0.63	5.90	0.32	5.50	0.76	5.84	0.37	5.72	0.55	5.86	0.38
#20	5.53	0.74	5.80	0.42	5.38	0.74	5.68	0.67	5.64	0.66	5.57	0.79

APPENDIX G

PRE-MISS MINUS POST-MISS MEANS, STANDARD
DEVIATIONS, \underline{t} -VALUES, AND
SIGNIFICANCES

Pre-MISS Minus Post-MISS Means, Standard
Deviations, t-Values, and
Significances

<u>Item No.</u>	<u>Mean</u>	<u>Standard Deviation</u>	<u>t-value</u>	<u>Significances</u>
#1	0.00	1.71	0.00	1.000
#2	0.38	0.50	3.00	0.009*
#3	0.44	1.50	1.16	0.263
#4	0.19	1.60	0.47	0.646
#5	0.31	2.06	0.61	0.552
#6	0.56	1.63	1.38	0.188
#7	1.00	1.90	2.11	0.052
#8	0.94	2.46	1.52	0.149
#9	0.06	3.43	0.07	0.943
#10	0.00	0.00	-	-
#11	0.50	1.55	1.29	0.216
#12	0.00	0.00	-	-
#13	0.38	2.09	0.72	0.485
#14	0.44	1.60	1.10	0.289
#15	0.06	1.95	0.13	0.900
#16	0.50	2.10	0.95	0.355
#17	0.19	0.75	1.00	0.333
#18	0.00	0.00	-	-
#19	0.25	0.58	1.73	0.104
#20	0.13	0.50	1.00	0.333

VITA

Barbara Jean Scott Masters

Candidate for the Degree of

Doctor of Philosophy

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