

THE RELATIONSHIP BETWEEN FAMILY "HARDINESS" AND REMISSION IN LEUKEMIC CHILDREN

Study Objectives. This pilot study attempts to assess the precise nature of the relationship between family system and various outcome variables relevant to childhood cancers. Specifically, the study is designed to test the hypothesis that "hardy" families (ie., families with adaptive family function) will be positively associated with ease of induction and length of remission; with better compliance to medical regimen; with decreased patient complications and hospitalizations; and with patient and family subjective feelings of satisfaction with medical care in particular and quality of life in general.

An associated aspect of the project will be to gather data on the various coping styles employed by patients and family members in response to this condition. Specifically, five areas of coping behavior will be examined:

- 1) Communication patterns within the family
- 2) Mobilization of a support system
- 3) Information and help-seeking behaviors
- 4) Normalization of family life and integration of affected child into the family system
- 5) Cognitive interpretations about the significance of the illness.

This descriptive component will identify information which can later be integrated into clinical interventions with families determined to be particularly vulnerable to the stressor of childhood cancer.

It is hoped this study may identify a relatively unexplored factor (ie., family hardiness) as it relates to various outcome measures for child cancer patients and their families. It is also hoped that the study will identify specific behavioral and attitudinal manifestations of an effective, adaptive coping style generated in response to life-threatening illness.

Methodology. Approximately 20-30 families containing a preadolescent

leukemic or solid tumor patient will be studied. Standardized instruments (the Family APGAR and the Family Environment Scale) will be used to assess the general family system. Three personal interviews with patient and family members will also be done at various points in time to determine the impact of this particular illness on the family, as well as what family strategies have been mobilized to cope with the situation. Families will be followed for a period of one year, so that prospective data can be obtained on remissions, hospitalizations, compliance issues, medical and psychosocial complications etc.

Risks and Discomforts. Few potential risks exist in this study, provided it is conducted with an overall attitude of respect and appreciation for the families involved. Both initial assessment material and the home interview schedules will be pilot-tested on a sample of 5 families. Special attention will be paid to a consideration of family feelings, in particular defense mechanisms employed in face of the possible death of their child. As this study is descriptive, rather than interventionist in nature, no attempt will be made to change family response patterns. All subjects will sign a consent form informing them as to the nature of the study, so that they understand they may decline participation without in any way jeopardizing their access to health care. All possible care will be taken in the scheduling and conducting of the home interviews, so as not to inconvenience, threaten, or offend the families involved in the project.

PHYSICIAN QUESTIONNAIRE

1. Rate your overall impression of how you feel this family is coping with the child's current illness.

1	2	3	4	5
NOT AT ALL WELL	SLIGHTLY WELL	MODERATELY WELL	WELL	VERY WELL

2. If you are previously acquainted with this family, how would you rate the family's response to this illness as compared to other illnesses experienced by the same child in the past?

1	2	3	4	5
WORSE		SAME		BETTER

3. In your estimation, what is this family's greatest strength in coping with the child's current illness? _____

4. In your estimation, what is this family's greatest weakness in attempting to cope with the child's current illness? _____

5. How will do you feel the family will follow through on the medical regimen for the patient you outlined during this treatment session?

1	2	3	4	5
NOT AT ALL WELL	SLIGHTLY WELL	MODERATELY WELL	WELL	VERY WELL

6. Do you feel the child was brought to the clinic unnecessarily?

1	2	3	4	5
NOT AT ALL		SOMEWHAT		COMPLETELY

7. Do you feel the parent asked for medicines or other treatment unnecessarily?

1	2	3	4	5
NOT AT ALL		SOMEWHAT		COMPLETELY

8. Do you feel the child should have been brought in for treatment sooner?

1	2	3	4	5
NOT AT ALL		MODERATELY		A GREAT DEAL

9. In your judgement, to what extent has this child's illness interrupted normal family functioning?

1	2	3	4	5
NOT AT ALL		MODERATELY		A GREAT DEAL

10. In your estimation, do you perceive the parent (or other family members) to be highly stressed by the child's current illness?

1	2	3	4	5
NOT AT ALL		MODERATELY		A GREAT DEAL

11. Please estimate in days the anticipated duration of the child's current illness episode: _____

12. Please estimate to what extent you anticipate that the resolution of this particular illness episode will be uneventful and follow a normal course

1	2	3	4	5
UNEVENTFUL		MODERATELY UNEVENTFUL		MANY COMPLICATIONS

13. What complications, if any, do you anticipate? _____
