Social Work Practice with Chronically Ill Children and their Families: An Ecological Approach

MSW Practicum Report

© by: Megan Beamish

Presented to:

Prof. Ruth Rachlis
Prof. Shirley Grosser
Mr. Dick Marinelli

June 13, 1988

ISBN 0-315-51679-8

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February 27, 1989

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Sincerely,

Harvey A. Skinner, Ph.D.
Senior Scientist

HAS/rs

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929 Longview Road
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Enclosed is a copy of the scoring guidelines for the Chronicity Impact and Coping Instrument (CICI:PQ) that you requested. Towards the end of the scoring guidelines is a list of the items making up each scale.

Please feel free to contact me if you have any questions or comments about the instrument. I am in the process of revising it and welcome any feedback you may have. Thank you for agreeing to share your experiences with the instrument. They will be very useful to me.

I am available for consultation and to present inservice programs and workshops related to the care of ill or hospitalized children and their families. The fees vary with the length and nature of the consultation or presentation. If you, or others in your institution, are interested is such a program, please feel free to contact me.

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Debra P. Hymovich, Ph.D., F.A.A.N.
Lecturer/Consultant in Chronic
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SOCIAL WORK PRACTICE WITH
CHRONICALLY ILL CHILDREN AND THEIR FAMILIES:
AN ECOLOGICAL APPROACH

BY

MEGAN BEAMISH

A practicum submitted to the Faculty of Graduate Studies of the University of Manitoba in partial fulfillment of the requirements of the degree of

MASTER OF SOCIAL WORK

ABSTRACT

Chronic childhood illness is a life experience which has short and long term reverberations for the child and his/her family. Literature and experience confirm that there are a range of psychosocial issues which arise out of chronic pediatric illness.

This practicum experience provided the opportunity to develop a better understanding of this life situation and to explore the role of the social worker in facilitating the ongoing process of coping and adaptation in chronically ill children, and all family members. This practicum design which combined research and clinical intervention activities furthermore allowed the student to develop assessment and intervention skills in this area. Assessment and treatment approaches involved an integration of the broad ecological perspective with the problem centered model of family therapy (which incorporates the McMaster model of family functioning), Leventhal's model of psychosocial assessment of children with chronic childhood disease and other expressive/projective techniques drawn from the play therapy literature.

Evaluation data was based on three selected standardized measures and in depth family assessment interviews. These interviews also provided information about the impact of social work involvement and other identified needs.

The selected assessment and intervention models were found to be very helpful in illuminating the process of coping in families and in planning and implementing appropriate treatment strategies. This practicum also permitted the development of additional clinical skills

in working with chronically ill children and their families in a multi-disciplinary health care setting.

ACKNOWLEDGMENTS

There are many individuals who made this practicum possible and contributed to the quality of this experience. My committee members were invaluable in their ongoing interest and support. Special thanks to Ruth Rachlis, my primary advisor for her enthusiasm, clinical expertise and encouragement. Her support and guidance from the inception to completion of this practicum were most appreciated. I owe thanks to Shirley Grosser for expanding my views and providing inspiration and confidence in utilizing expressive and play modalities. Some of my most powerful moments incorporated stories, pictures and "radio shows". Thanks are also extended to Dick Marinelli (Social Work department director at Children's Hospital) for his ongoing support, information and advice.

In the social work department I am appreciative of all the staff who made me feel welcome and supported my work. I am particularly grateful to Marnie Bond for her typing services, endless patience with my questions and genuine interest in my work. The opportunity to partcipate in the peer consultation group was most valuable; thanks are extended to Sue Powell, Nancy McGregor, Tom Roche and Doreen Shindel for allowing me to paricipate in this process.

I would also like to thank Dr. Stan Moroz whose support and committment to my involvement in the gastroenterolgy clinic made this experience possible. His dedication to his patients and their families and his attention to their social, emotional needs was noteworthy. My thanks also to Lynn Hilliard-Thorson, the clinic nurse who offered her time and experience throughout the six months.

Lastly I would like to acknowledge my husband Richard for his unfailing faith in my abilities and patience in listening to my ongoing reflections and struggles regarding my work.

Megan Beamish

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PART I - INTRODUCTION

Chapter i - Introduction To Problem Area

Chronic illness is a term which has wide usage. Mattsson who has undertaken extensive work in this area has broadly defined chronic illness as a disorder with a protracted course which may be progressive and fatal or may be associated with a relatively normal lifespan despite impaired physical and mental functioning. He further notes that such a disease frequently shows periods of acute exacerbation requiring intensive medical attention followed by periods of management (Mattsson 1972:802). The occurrence and experience of chronic illness is particularly disruptive and difficult to accept when the patient is a child or adolescent. This is due to the frequently massive disturbance of the child's normal developmental progress and because such an event contradicts our deeply rooted beliefs and assumptions about the natural "order of things". As a society we view childhood as a time for growth, learning and as a life stage characterized by energy, freedom and vigor (Stein and Jessop, 1984:194).

Concurrently the diagnosis of serious long-term illness presents a multitude of new demands and tasks. As a result of these factors, chronic childhood illness tends to have far-reaching psycosocial and pragmatic effects which reverberate throughout the family system. In her book entitled Chronic Illness in Children, Travis attempts to define its primary features in the following comprehensive description:

> ... the child with long term illness is a psychosocial being who functions as a whole in a changing matrix of relationships and events to which she/he responds and upon which he/she reacts. The

> task is elusive because of the constancy of change. A chronic illness grows better or worse, the increasing age of the child places his/her illness in a different developmental framework: the parents bend, straighten or collapse under the stress of the child's illness and other events and relationships (Travis, 1976:1).

This definition effectively captures the complexity and multidimensional nature of the stress and tasks which confront the chronically ill child and his/her family. It is a life event which has a pervasive and dynamic impact on the child and family life. Every disease has some unique features and implications with regard to: fatality (prognosis), pain, disfigurement, impairment of daily functioning and activity patterns and the need for residential adaptations. Thus chronic illness is an umbrella term rather than a specific entity (Travis, 1976:1). Nonetheless all chronically ill children share certain common experiences such as: some pain and discomfort, the need to adhere to medical and treatment regimens, struggles related to identity (i.e.: with regard to peer group relationships) and uncertainty about the future.

The current medical approach to treatment of chronically ill children is primarily focused on the the specific features of the particular disease entity thus hampering thinking about chronic illness in more than a piecemeal fashion (Strauss, 1984:7). It is increasingly being suggested that a broader approach characterized by a shift away from the focus on medical issues and the acute phases of chronicity to the daily lives and psychosocial impacts of patients and their families would be more helpful. This would involve a reorientation of attention away from medical treatment in the health care facility to the short and long term tasks and coping strategies which must be addressed in every day family and community living (Germain, 1984:58, Bergman et al. 1979: 266-267; Leventhal, 1984:71).

The traditional medical model which has served as the foundation of treatment for the ill child and family has not adequately addressed the spectrum of psychosocial, developmental, instrumental and environmental issues which these families face. Given the broader scope of the systems based social work perspective and the particular concern with the psychosocial aspects of the illness experience, the social worker can potentially make important contributions to the overall care of the clinically ill child and his/her family. While social work Services do exist in most health care settings they often lack the credibility and status granted to other disciplines. Furthermore, due to limited resources, social work efforts often by necessity represent fire-fighting activities which are directed at alleviating crises and providing short term emotional support. As a result of these factors, limited energy has been directed into developing interventive strategies aimed at helping families to cope with the range of long term stressors, disruptions and needs they experience in an effective manner.

Chapter ii - Target Population and Rationale

As stated, the term chronic illness embraces a spectrum of conditions and diseases and tends to be utilized differentially by theorists, clinicians and researchers. The literature often includes permanent, and relatively static disorders as well as those which are usually fatal within this category. While this is appropriate in many medical contexts given that these types of diseases share some key common features with chronic illnesses (uncertainty regarding the future, distorted body image, family stresses and disruptions) there are some apparent substantial variations as well. For example, the family of a child with cancer faces some very different psychosocial issues than the family of a child with asthma or juvenile rheumatoid arthritis who may have a relatively normal expected lifespan but who requires intensive and potentially exhaustive home therapy and attention. The point being made is not to minimize the shared stresses which all families of ill children experience but rather to reinforce the need for the student to establish some conceptual parameters for the target population of interest. A degree of uniformity within the selected client group was necessary and desirable in order to draw meaningful conclusions about the impact of the illness experience and the effectiveness of treatment. Without such parameters, accurate generalizations would have been precluded by a spectrum of confounding variables.

Hagen et al (1986) discuss the issues involved in research of the young chronically ill child in depth. They suggest a non-categorical approach in understanding the impact of chronic illness. This involves identification of characteristics which exist across disease categories. They describe seven dimensions which have emerged as critical in consideration of the impact of the disease on the child and family. These include: etiology, duration, survival, management, effects on activity, visibility and economics. This model incorporates two central notions: (1) that the diagnostic label itself is relatively meaningless regarding psychosocial implications and (2) that types of disease features (i.e. fatality) affect the tasks and adjustment of the child and family (Hagen et al., 1986:52-53; Stein, 1983:54).

The features of interest which define chronic illness as it was uderstood in this practicum include:

1. an illness which has primarily physiological origins;
2. which involves continual or intermittent symptoms which are painful, bothersome, disruptive or embarassing;
3. illnesses which are not necessarily curable but are to a greater or lesser extent manageable;
4. illnesses which require ongoing medical attention, supervision and treatment;
5. diseases which have a protracted and possibly progressive course but which are not usually associated with a fatal outcome;
6. diseases which tend to have a substantial impact on the child's psychosocial, emotional, cognitive and academic development (i.e. enforced dependency, body image distortions, absences from school, limited activity);
7. illnesses that necessitate substantial adjustments or restrictions of lifestyle and family life (Mattsson, 1972:183; Travis, 1976:3; Bracht, 1979:135-137; Hagen and Anderson, 1986:52-53.

The sick child must not only cope with the range of issues faced by the chronically ill adult but, in addition, must confront powerful social and psychological consequences of the disruption of the formative years of his/her development. Bloom states that variation in the environment has the greatest quantitative effect on a characteristic during its most rapid period of change and least effect on the characteristic during its least rapid period of change (Travis, 1976:1). This principle suggests that the impact of the illness is closely associated with the child's developmental stage as well as other pre-existing individual characteristics and ecological variables. Since one of the objectives of this proposal is to gain an increased understanding of these developmental issues, the student did not limit the target population to children of a certain age category. Given the selected target population (children with inflammatory bowel disease) the anticipated age range encompassed preschool to late adolescent aged children (see Part IV, Chapter i for further information).

Chapter iii - Personal Objectives

This practicum plan was designed to assist the student in addressing the following personal learning objectives:

1. to gain a comprehensive undertanding of the impact of childhood chronic illness on the family through a review of the literature and practice experience;

2. to develop an understanding and knowledge base regarding the impact of chronic illness on the child, particularly with regard to developmental features;

3. to utilize an ecological approach in exploring the role of the social worker with these families;

4. to explore the usefulness of the problem-centered psychodynamic model of family therapy as a practice model for intervening within these family systems;

5. to develop an ability to work effectively within a multidisciplinary active treatment health care setting;

6. to systematically evaluate the effectiveness of the selected approach in working with the target population;

7. to expand and refine assessment and intervention skills in working with chronically ill children and their families.

Chapter iv - Clinical Questions

A review of the available applied and theoretical literature revealed an abundance of general discussion but also some apparent gaps in particular areas. The student attempted to summarize these gaps at the outset of the practicum experience in the following questions:

1. What are the psychosocial effects (stresses, changes, disruptions) of serious long term childhood chronic illness on the family?

2. What are the specific psychosocial effects on the ill child? How does the child's illness interact with developmental tasks?

3. What are the coping mechanisms employed by families in order to manage these stresses and demands?

4. What types of styles are associated with maximal adaptation and management of the illness?

5. Are there certain variables which moderate the employment of effective coping styles? What are they?

6. How effective is the ecological approach which incorporates multi-level (individual, family, social support network) interventions in assisting families to resolve problems and promoting adaptive coping

styles?

7. How effective and appropriate is the problem-centered psychodynamic model of family therapy as an adjunct to the ecological approach in resolving internal family systems issues?

It was not the intention or expectation of the student to undertake empirical study of these questions. Rather, these enquiries were formulated to provide conceptual clarity with regard to those features of the target population which had not been adequately examined or documented in the literature and which were therefore of particular interest. Systematic and thorough social work assessment, the application of appropriate evaluation instruments (see Part IV, Chapter ix - The Impact of Childhood Chronic Illness on the Child and Family) and the accumulation of direct experience with the selected client group provided some new understanding of these issues. It was not intended however that causal conclusions be drawn. The experience and findings of this practicum do however provide direction for clinical practice and further research in this area.

PART II - LITERATURE REVIEW

Preface

While there is a growing body of research and literature on the common psychosocial features of serious childhood chronic illness, there is still much that is not known. There is for example, an increasingly well recognized need for exploration of the differential impacts of pediatric chronic illness on family members such as the parental subsystem and siblings. Also despite the traditional categorical approach to treatment, little has been actually documented about the psychosocial impacts of specific diseases. While much has been said about typical problems, research is needed which focuses on explicating factors moderating adaptive vs maladaptive coping. Theorists and researchers have very recently begun to recognize the relevance of developmental factors in the adjustment of the ill child and his/her siblings, although understanding these variables is in its infancy (Perrin, 1986:7; Cerreto, 1986:24-25). One of the most striking gaps in the literature to date is the absence of discussion regarding interventive strategies. The tendency to "lump" children with chronic illnesses with disabled and acutely ill children creates some confusion. The looseness with which many study populations are defined renders their conclusions difficult to interpret. Comparative study of these populations is needed to clarify these questions.

The difference between the multi-disciplinary and ecological frameworks is that the former incorporates a set of specialized view points while the latter is primarily concerned with the interrelationship between dimensions. This conceptualization is in a sense metaphorical for the following literature review which attempts to integrate and summarize the body of literature regarding the experience of chronically ill children and their families. Included within this review are references from medicine, psychiatry, psychology, nursing, education, cultural anthropology and social work. While this meld of viewpoints may muddy the distinct differences in perspective which are characteristic of particular disciplines, it is felt that this integration will provide a richer, more multi-dimensional understanding of this population. The persistence in and commitment to expanding the range of vision rather than narrowing it, is in essence social work's most important contribution to the helping field.

Chapter i - Impact of Chronic Illness on the Family

(a) Overview

Chronic childhood illness is relatively common. Green and Haggerty estimate that 10-20% of all children in the United States suffer from a serious chronic disorder (Green and Haggerty. 1968 from: Bergman et al, 1979: 267; Gortmaker and Sappenfield 1984: 4). The national health survey (U.S.) provided physical examinations for a probability sample of children ages 6-11 years from 1963-1965 and youth ages 12-17 in 1966-1970. Findings revealed that one child in eight and one youth in five had one or more significant cardiovascular, neurological, musculoskeletal or other physical abnormality (Travis, 1976: 4). Some of the most prevalent chronic illnesses are: asthma, epilepsy, juvenile rheumatoid arthritis, cystic fibrosis, inflammatory bowel disease and diabetes (Mattsson. 1972: 802). A few childhood chronic diseases such as polio and rhuematic fever have been eliminated through medical advancements although most remain incurable but manageable.

Surprisingly little has been documented regarding the experience of families with chronically ill children. Three main factors have been cited as explanation of the sparseness of strong research in this area:

1. the patient populations of most medical centres is insufficient to allow valid group comparisons
2. there are few valid and reliable measurements
3. research involving multiple sources of data is difficult to analyze. (Millers and Thomas from: Tritt and Esses, 1986:2; Hagen et al., 1986: 50)

In a recent survey of the existing literature on the effects of chronic childhood illness on the family, Tritt and Esses summarize several key assertions which are predominant;

1. Childhood chronic illness represents a major stressful life event for all family members. The degree of stress is thought to be connected to such factors as: pre-morbid family functioning, financial strains, social supports and previous coping experiences. (Trute and Hauch, 1986:14 and 22)
2. Families wherein there is a chronically ill child must invariably cope with a complex new set of instrumental demands (ie: transporting the child to regular clinic appointments, carrying out home treatments) and emotional strains (ie: the need to balance attention to the ill child with other member's need for support) (Fortier and Wanlass, 1984:13)
3. Chronically ill children's reactions to stress are heavily

influenced by the coping responses of their social support networks, especially their parents (Tritt and Esses, 1986:11).

It is widely agreed that the family provides the context in which the processes of the child's adjustment take place and is the essential provider of love, support and socialization (Travis, 1976:30-33; Tritt and Esses, 1986:113; Epstein and Bishop 1981:447) This well established principle substantiates the need to nurture and uphold the family in order to assist the child to adjust. Recent documentation of clinical experience has elicited some highly relevant information about those aspects of family functioning typically effected by the presence of a chronically ill child. Those include: role strains and shifts, changes in extrafamilial and intrafamilial communication patterns, altered family alliances, readjustments in the parent-child relationships, loss of confidence in parenting skills, and disparate discipline practices for the ill versus the well siblings in the family (Drotar:1985); Johnson et al., 1985:310; Mattsson, 1972:803, McCubbin and Figley, 1983:25; Travis, 1976:44-45; Tritt and Esses, 1986:113-115).

While the demands and stresses vary to a great degree depending upon the particular disease features and other factors, certain tasks may be identified which are experienced by most families with a chronically ill child. These are; acceptance of and adherence to a medical and treatment regimen, adjustment to the loss of normality, an ongoing unpredictability about the child's health, reactions of siblings and the dynamic psychosocial adjustment of the ill child (Strauss, 1984:13-17; Travis, 1976:44; Tritt, 1983:4-6).

(b) Chronic Anxiety, Mourning and Family System Dysfunction

Other investigators in this area emphasize the common experience of prolonged feelings of guilt and associated anxiety in many parents of sick children, particularly mothers (Mattsson, 1972:806). This is predictable given that mothers remain the primary caregivers in most families. Several studies have concluded that mothers of chronically ill children frequently experience psychological disturbance. McCrae reported that 79 percent of mothers of children with cystic fibrosis described themselves as run down or depressed. Allan found that 50 percent of mothers of children with cystic fibrosis required treatment for depression. Walker determined that half of her sample of 106 mothers of children with spina bifida were worried or depressed. Many of these studies lack controls and use problematic measurement techniques. We also do not know if these psychosocial effects are also shared by fathers who were not included in the studies.

It has been reported that many families experience the stages of mourning described by Elizabeth Kubler-Ross, beginning with acute anxiety and fear followed by a period of denial, particularly if symptoms are not dramatic or subside. Feelings underlying denial often involve mourning the loss of the desired normal child (Trout, 1983:338-339; McCubbin and Figley, 1983:26). These feelings are frequently manifested through overt hostility towards medical staff and non-compliance with established routines. The stage of acceptance is described as a process thorugh which parents can verbalize and master resentful and self-accusatory feelings about having been responsible for having transmitted or caused the disease (Fortier and Wanlass, 1984:14-15; Mattsson, 1972:807).

Those parents who remain highly anxious and guilt-laden tend to cope with their emotional distress, through protecting, pampering and/or severely limiting the child's activities. These patterns predictably lead to dysfunctional adjustment in the child and in the family system as a whole (Croake, 1984:463). Undesirable behavior patterns characterized by self-destructiveness, clinginess and general apathy may result (Friedman and Hockelman, 1980:130-132; Mattsson, 1972:802). In such families it is suggested that the overprotectiveness retards the children's development of autonomy and competence.

Minuchin, Baker, Rosman, Liebman, Milmon, Todd argue that certain family interactional patterns such as enmeshment and rigidity "trigger the onset or hamper the subsidence of psychophysical processes or both" (Minuchin, Baker, Rosman, Liebman, Milmon, Todd, 1975:1033). Unresolved chronic guilt and anxiety seem to be particularly evident in the following circumstances; when the child suffered a life threatening condition at birth, when the child is afflicted by a hereditary condition which is present among relatives, when the child's illness reactivates emotional conflicts stemming from the past death of a significant other and lastly when the child was unwanted initially thus provoking a mixture of loving and rejecting feelings (Mattsson, 1972:807).

Dillon suggests utilization of the concept of "illness family" rather than patient and family as separate components in the assessment and intervention process. She is critical of practice models which tend to comprehend and respond to the patient and family as seperate diagnostic entities with many things in common rather than as inseparable parts of an interacting system" (Dillon, 1985:36). Dillon suggests for example, that we not focus on the reverberations of the patients illness on the family but also the reverberations for the patient who must adjust and respond to the family's process of dealing with the illness. Thus Dillon emphasizes the notion of reciprocity in planning intervention strategies. She further argues that the development of serious illness may be viewed as an articulation or outcome of prior family systems problems (Dillon, 1985:37). While the writer advocates the "family as a whole" perspective, this view appears somewhat simplistic and appears to overlook the organic and environmental factors in the etiology and course of serious illness.

(c) Differential Impact of Illness on Family Members

One of the emerging directions in the recent literature is the need to explore the differential impact of the illness on individual family members and subsystems. In her Ph.D. dissertation on the psychosocial adaptation of siblings of children with chronic medical illnesses, Tritt found that the healthy siblings are sometimes dramatically effected by the illness of their brother or sister, often experiencing feelings of isolation and jealousy. It is suggested that these emotions stem at least partly from the intensified relationship between the sick child and his/her parents (Burton, 1979:190-192; Tritt, 1983:6). Travis also noted that siblings often fear becoming contaminated with the illness and feel guilty about having caused it (Travis, 1976:57).

A related theme is the growing recognition that the strength and functioning of the marital dyad is a key determining factor in the adjustment of the ill child, the other siblings and the family as a whole. Some empirical research has been undertaken to examine the parent's coping and the impact of this life event on the marital relationship. These studies document a high degree of marital stress and a need for reorganization within the family. The ability of the parents to support one another, share feelings and household and child care responsibilities, and to engage in mutual decision-making seem to be essential components of successful coping (Krulik, 1980:573; McCubbin and Figley, 1983:32; Travis, 1976:49-51). In addition, the ability of the parents to define the illness in a healthy yet realistic manner seems to decrease negative feelings and interactional patterns (Anderson, 1981:428; McCubbin and Figley, 1983:31). For example, one might expect that if mother and father agree about not pampering the ill child, sibling conflict may be decreased.

There has been some discussion regarding the potentially different impacts of the illness between parents within the family of the chronically ill child. There are two obvious problems in this component of the literature; firstly there is a prevalent assumption that most families reflect the traditional nuclear structure and that single headed families are dysfunctional or unable to meet their own needs. This is reflected in the judgemental and somtimes derogatory language used to describe non-traditional family forms. Travis for example describes the dramatic difference in experience of the "intact" vs "the precariously balanced partial family". Furthermore she suggests that the single mother must "either return to her family of origin or lead the life of a welfare recipient" in order to care for the child at home

(Travis, 1976:49).

Dillon argues for a more progressive approach to assessment of the "illness system" and its supportive or reciprocal parts rather than an assumption of traditional family structure which is the basis of much social work theory. She emphasizes that social workers must adapt their frameworks to accomodate and support non-traditional and alternate family forms such as blended or divorced families, gay couples with or without children, and extended immigrant families (Dillon, 1985:37).

A second concern with the available literature on differential role stresses is that it seems to presuppose a stereotyped traditional definition of relationships and division of labor which, for many families no longer applies. Figley and McCubbin describe the mothers coping style as representing a focus on the interpersonal dimensions of family life including cohesiveness and emotional expressiveness while fathers tend to complement those efforts through attention to systems maintenance dimensions of family life (McCubbin and Figley, 1983:32-33). While the patterns identified by these theorists may be valid descriptions of some families, they are not necessarily representative of most.

The well siblings of chronically ill children have received little attention by clinical investigators. Some recent theorists have speculated that brothers and sisters of the sick child bear the greatest burden of stress since they receive less acknowledgement, support from the community and must cope with the special attention given to the ill child (Perrin, 1981:1). In addition, the well siblings experience anxiety imposed by the illness such as the fear of the sick child dying.

In a few studies, siblings of children with serious illnesses (such as cystic fibrosis, diabetes and gastrointestinal disease) have been found to be more inhibited and withdrawn than children in control groups (Lavigne and Ryan, 1979; Tow and Lawrence from: Tritt and Esses, 1986:117). Inconsistencies in research methodologies make direct comparisons between studies difficult. Also the lack of control groups, broad variation in sibling ages and third party reports (usually provided by parents) make generalization difficult. Further research efforts which incorporate strong experimental controls are needed.

(d) A Family Life Cycle View: Developmental Considerations

All families must cope with normative life transitions (such as the birth of the first child and establishing identities as parents) as they pass through the family life cycle. These anticipated developmental events require ongoing adjustment and adaptation by all family members. These transitions have long been acknowledged as stressors and potential triggers of crises depending upon how they are experienced by the family (Figley and McCubbin, 1983:xxi). One of the factors which complicates the movement of a family through the life cycle stages is the fact that each individual family member simultaneously proceeds through his/her own developmental course. Thus developmental needs may overlap in synchrony or may conflict and compete with one another (Carter and McGoldrick, 1980:4-5; McCubbin and Figley, 1983:xxiii; McGoldrick and Gerson, 1985:3; Travis, 1976:52-53). Most families are able to modify themselves through positive feedback mechanisms in order to adjust to these competing demands (Nichols, 1984:402-403).

The family with a chronically ill child must also cope with a whole set of additional demands, changes and chronic strains. Neurgarten emphasizes that the major stresses of life are "caused by events which upset the sequence and rythum of the life cycle ..." (Neurgarten from: Carter and McGoldrick, 1980:5). Thus these families are faced with addressing the usual demands of parenting, working, managing a household and finances but must also exert continuous effort to secure competent medical care, carry out treatments, initiate lifestyle changes and provide special attention to the ill child. While the child may get better or worse he/she is not a normal, healthy child; this fact often produces a chronic or recurrent grief as the child moves through various developmental stages (Wikler, 1981 from: McCubbin and Figley, 1983:24; Travis, 1976:53). It is not surprising then that this set of interlocking demands frequently produces overwhelming stress for the family (Kazak and Marvin, 1984:68-69; Tritt and Esses, 1986:115) (see Appendix 2: p. 213).

(e) Dysfunction vs Adaptation: A Changing Perspective

The conceptual foundations underlying the majority of research to date have relied heavily on the frameworks of stress, chronic sorrow, mourning and crisis (Olschansky, 1972; Tritt and Esses, 1986:111-112). These theories continue to be useful in establishing an understanding of the range of behavioral and psychosocial reactions of families with ill children in times of high stress, loss or change such as diagnosis and acute illness phases. They are limited however in that they do not address the process of adaptation which presumes the resiliences and strengths inherent in all family systems (Dillon, 1985:38-39; Longo and Bond, 1984:61). Tritt and Esses point out a recent shift from a concern with how the family system effects the child to a more systemic orientation characteried by a focus on the effects of illness on the functioning of the family system. The emerging commitment of a system based family centered approach has "put to question the utility and appropriateness of using a psychopathological model for comprehending the psychosocial impact of childhood chronic illness" (Tritt and Esses, 1986:11).

Dillon argues that since "a whole system becomes ill when one of its members does due to the shifts and breakdowns in interlocking obligations and role reciprocities, independent assessment of elements of that system runs the risk of missing crucial features" (Dillon, 1985:36). She therefore suggests the concept "of illness family" as the unit of assessment and treatment thus maintaining the social work focus on the ecology of illness and wellness (Coulton, 1981; Germain, 1978 from Dillon, 1985:37).

While this life event often represents a crisis situation with subsequent multidimensional long term psychosocial implications for all family members, these impacts are by no means uniform for all families within this population. For some families, successful negotiation of tasks and challenges involved in caring for an ill child promote family closeness, growth and well-being (Tritt and Esses, 1986:112; Mattsson, 1972:808; Carr, 1984 from Trute and Hauch, 1986:20). It has even been argued that having a handicapped child may actually function in some instances to strengthen the marital relationship (Kazak and Marvin, 1984:68). In his overview of the developmental and emotional impacts of varied chronic illnesses Perrin emphasizes the finding that most families cope surprisingly well with the ongoing stresses of the illness. He also draws attention to the fact that variation in family functioning varies as much within single diseases as it does between disease categories (Perrin, 1986:6).

The emerging awareness of the dramatic variability of family and child responses has had major implications for research and practice. Firstly there has been an acknowledgement that contemporary and future research needs to be directed towards increasing knowledge and understanding about which factors distinguish families of risk (who are likely to develop problems or symptoms) from those who cope well. This is a challenge which has been complicated by a number of variables which have been postulated as moderators of adjustment to childhood chronic illnesses. Developmental factors such as age and stages of individual family members and the family life cycle phase are for example, currently thought to dramatically effect the overall impact of this life event (Cerreto, 198:24; Hagan et al., 1986:49). Specific illness related characteristics including the illness trajectory, severity, imposed disabilities and impairment are also claimed to be predictive of adjustment although their relative importance has not been established. Pre-morbid features of the child (intelligence, social skills) and family (marital stability, financial resources, career phases) are also speculated as factors in psychosocial responses (Pless, 1986:296).

As a more holistic ecological orientation has gained favorability, increasing attention is being paid to the existence and quality of a social support system as a fundamental variable in the child and family's ability to normalize rather than become overwhelmed by the presence of chronic illness in a child (Bergman et al., 1979:273; Brandt, 1984:187; Schilling et al., 1984:47).

As a result of the growing appreciation of the multitude of variables which impact upon the family's experience and secondly the recognition that many of these families adjust well, the current direction for research and practice in this area is towards the view that illness introduces a constellation of adaptational tasks and challenges which offer opportunities for growth as well as problems in adjustment. This fundamental shift in the understanding of this target population has led to a mounting interest in and commitment to a practice approach which emphasizes health and coping rather than assuming maladjustment (Tritt & Esses, 1986:113. Rose, 1984:177-178).

A study was recently undertaken by Trute & Hauch on a group of non-clinical families who have adjusted well to the birth of a developmentally disabled child. The main goal of this research was to identify factors which were associated with positive adjustment. The central assumption underlying this research was that the identification of adaptive patterns of coping could provide a guide for intervention with families facing similar circumstances. The writer recognizes that there exist some significant variations between this population and families with chronically ill children. However the parallels in terms of the stress and demands shared by both are striking (Trute and Hauch, 1986).

Results of this study suggested that positive adjustment was unrelated to the level or severity of the child's disability, the degree of "soothability" of the child (extent to which the child could be comforted) nor was it directly linked to income level. Predominant characteristics of these families included:

1. most were two parent families with a small number of children;

2. there was a strong parental subsystem;

3. families engaged in skillful mobilization of extended family support and friendship network members;

4. the employment of coping strategies that drew heavily upon resources external to the parental subsystem (Trute & Hauch, 1986:19-20; Kazak & Marvin, 1984:69-71; Schilling et al., 1984:48-49).

These researchers assert that professional caregivers appear to maintain certain beliefs about the family impact of having a severely mentally disabled child which are inconsistent with research evidence. These assumptions are manifested in two ways. Firstly, the clinician tends to see families who are not coping and therefore misses those who cope well; this leads to an assumption that all families are maladjusted. Some theorists further argue that the ingrained belief about family dysfunction by clinicians in this field leads to the identification of problems (i.e.: denial) where none exist (Longo & Bond, 1984:63; Trute & Hauch, 1986:3-4). Secondly, there is a tendency to overestimate the impact of early experience (i.e.: crisis following diagnosis) and underestimate the later coping demands as the child grows older and his or her needs change (Trute & Hauch, 1986:4).

In Venters (1981) study on the ability of families to develop various levels of adaptive strategies, two key factors were found to be associated with positive outcome:

1. effectively sharing the burden of the childs illness among

family members;

2. the family's ability to make philosophical sense of the childs illness or disability (Travis, 1976:47).

In their comparison of families of children with cystic fibrosis Johnson et al explored the degree of adaptation in those families whose ill child was a first born compared to those whose ill child was later born. The results indicated that families with later born children with CF were functioning better. This finding was postulated to reflect the ability of more firmly established families to normalize the trauma and disruption of the illness. Those families which began without a major illness had the opportunity to develop normally as a family whereas the birth of a first born child with CF tended to produce a developmental delay (Johnson et al., 1985:310).

Other studies provide some evidence regarding parents ability to modify expectations of the ill or handicapped child. For example it has been found that parents are alert to the need to modify normal developmental expectations for their developmentally disabled children. Chronic illnesses usually imply physical impairment and symptoms rather than cognitive limitations. Nonetheless disruptions associated with chronic medical illnesses commonly alter the expected developmental tasks over time. Parents are therefore presented with the challenge of accommodating their expectations of normal developmental growth with the ebb and flow of the disease process and its secondary features. This task is further complicated by competition between or differential expectations regarding the ill child and his/her siblings (Longo & Bond, 1984:61). Further research which explores parental expectations and the consequences of these attitudes and behaviors on the ill child and siblings is needed.

(f) The Social Support System

The availability of a supportive social network appears to be an essential ingredient in effective coping. The activation of a rich network of support helps by providing instrumental assistance, information, allowing emotional catharsis, decreasing stress and reducing isolation (McCubbin & Figly, 1983:35; Slater & Wikler, 1986:387; Strauss, 1984:78). Theorists have identified three levels of support:

1. nuclear family members, close friends and relatives (and other significant persons) often representing the most basic enduring and immediate sources of support;
2. neighbors, more distant friends and relatives, key professionals and service providers;
3. supports based in social or health institutions defined by superficial and infrequent contact (Unger & Powell from Schilling, 1984:49).

As the importance of social support systems has become widely accepted, efforts have been made to develop assessment instruments which measure relevant dimensions of this structure such as density, size and stability (Brandt, 1984:190-193).

Many investigators have recently asserted that the ability to interact skillfully with others is necessary for the development and maintenance of social support systems (Hartman & Laird, 1983:157; Trute & Hauch, 1986:18-19). Schilling et al. suggest that social supports and internal coping mechanisms are closely linked and may be viewed as complementary strategies. These authors specifically suggest group programs as interventions to provide parents with the opportunity to develop the special skills (interpersonal communication, assertiveness) they require in order to mobilize these resources (Schilling, 1984:51). It is generally conceded in the literature that work with families with a chronically ill child should attend to skill building and problem solving with regard to both internal family coping and external resource building (Hartman & Laird, 1983:187; Bergman et al., 1979:265; McCubbin & Figley, 1983:34-35; Tritt & Esses, 1986:121). Unfortunately there is very little documentation of particular practice models which incorporate these emerging principles. Again the available literature seems to address the service needs of handicapped children and families; as discussed, the degree to which these populations parallel one another is unclear. Slater & Wikler for example propose a normalized family resource model (for families with a developmentally disabled child) which expands the role of the social worker to include; systems convener, systems activator, systems trainer and family therapist. They suggest that this model reflects a dynamic view of family functioning in which the normally developing family derives support on a number of levels simultaneously (Slater & Wikler, 1986:388-389).

The emerging challenges to previously deeply ingrained beliefs regarding dysfunction as a normative pattern in this population suggest some important practice directions. While many professionals are equipped to face the difficulties of acute grief reactions and to utilize crisis intervention techniques it seems that few are prepared to assess and provide services to families who demonstrate varying degrees of adaptability once the initial crisis has passed (Longo & Bond, 1984:57). Professionals need to develop opportunities to maintain contact with those healthy families in order to learn about what enables them to cope effectively. In addition even those families who function well require support information and guidance in upholding their adaptive strategies (Longo & Bond, 1984:63; Rose, 1984:178). The Trute & Hauch study discussed earlier led to the articulation of two specific needs which are likely relevant in the population of interest. These were: the need for a professional person to assist them in identifying and accessing services and resources available in their community and secondly a request for a family approach by the professional caregivers rather than the narrow advice giving directed at behavioral management that they had experienced (Trute and Hauch, 1986).

(g) Resilience and Vulnerability: Mediation of Family Stress

It has been established that the presence of a long term serious illness in a child has extensive and diverse implications for family systems. "Confronted with the ongoing stress of a chronically ill child plus additional life events and changes, some families actually appear to grow stronger and thrive. Other families grew weaker with repeated crises..." (Figley & McCubbin, 1983:26). The double ABCX model of family stress was developed as a framework to explain the variability in response to chronic illness and other stressors. It provides a way of viewing family efforts over time to adapt to multiple stressors. It is being presented briefly here. It sheds light on the variability of responses of families with ill children and because it has been applied to this population by the theorists. Within this model the ability of the family to cope effectively depends upon the interaction of:

1. the stressor (i.e.: precipitating event);
2. perceptions of this stressor;
3. the family's existing resources (pychological, social, material characteristics of the individual, family and community).

Thus whereas the occurrence of serious chronic illness may be experienced as catastrophic and overwhelming by family A; it maybe integrated with little major disruption in family B (McCubbin & Figley, 1983:27) (see Appendix 3: p. 214).

Similarly, Rose argues that effective coping of the chronically ill child depends upon levels of vulnerability (based on constitutional and acquired factors) and the support or non-support of the environment. This is further supported by Chiland who said that "...the critical factor determining vulnerability or resilience to risk is not the risk itself but rather the relationship between the risk and the person in terms of the psychobiological make up, his/her past history individual characteristics and so forth" (Chiland from Rose, 1984:181).

The concept of pile-up is central to this model and is helpful in conceptualizing the long term impacts and tasks associated with this event. It involves the notion that multiple changes and demands occur simultaneously; these combine normative changes (i.e.: birth of another child, residential moves) and the particular strains associated with the illness (Kazak & Marvin, 1984:67). Those tasks that are not resolvable (need for dietary regimens for the child with Crohns disease) become chronic strains. In their 1981 studies on children with cerebral palsy and myelomeningocele it was found that these persistent strains were judged by the families as the most problematic (McCubbin & Figley, 1983:28). Two other key sources of pile-up include the efforts to cope (i.e.: quiting a job) and ambiguity (i.e.: uncertainty regarding ill, childs future and the genetic factors related to the disease). Coping is thus the process whereby the family extends efforts to adapt and to develop an organization which meets their current needs (Figley & McCubbin, 1983:28-29).

Parental efforts (and successes) in obtaining sources of social support from the community for the child and the family are acknowledged as essential in managing the emotional and instrumental demands of living with chronic illness. The health care professionals involved including physicians, nurses, psychologists and social workers are important sources of support (Figley & McCubbin, 1983:32; Kazak & Marvin, 1984:68-69; Slater & Wikler, 1986:387; Brandt, 1984:187). In their research of families with chronically ill children, Figley & McCubbin identified three key coping strategies employed by adaptive families; each coping pattern incorporates several coping behaviors:

1. Maintaining family integration, cooperation and an optimistic definition of the situation:

   (a) doing things together as a family unit;

   (b) strengthening family relationships;

   (c) developing and maintaining a positive outlook.

2. Maintaining social support, self-esteem and psychological stability:

   (a) maintaining a sense of personal well-being through social relationships;

(b) involvement in activities which have the potential of enhancing self esteem;

(c) managing psychological tensions and strains.

3. Understanding the medical situation through communication with other parents and with the medical staff (Figley & McCubbin, 1983:32).

In summary, clinical experience and research in this area documents the far-reaching short and long term impacts of chronic illness on the family system. Additional research is needed which is aimed at:

1. elucidating the differential impacts of the illness on individual family members (and subsystems);

2. identifying variables which influence effective coping styles;

3. and which begins to assess the effectiveness of various practice models and specific interventive strategies.

A primary theme in the most recent literature is the acknowledgement of the variability of response and an awareness that many families cope remarkably well. Important practice implications emerge from these findings; families need help less with correcting dysfunctional patterns and more with promoting their abilities to cope with stress, problem-solve and mobilize inner and external resources. In view of our evolving understanding of this population the growing commitment to a social work approach which focuses on the ongoing processes of adaptation is highly appropriate.

Chapter ii - Impact of Chronic Illness on the Child

(a) Preface

The purpose of this section is to summarize the current knowledge about the impacts of serious long term illness on the individual child. As noted earlier, recent literature has documented the need to gain greater understanding of the differential impact of chronic illness on individual family members. Factors such as the relationship to and degree of care-taking responsibility (for the ill child), gender, and developmental stage have been postulated as factors which influence individual family member's experiences (Tritt & Esses, 1986:115; Travis, 1976:56). Obviously no one is more effected by the illness than the child him/herself. A substantial body of literature exists regarding the reactions and stresses of the ill child; unfortunately much of what has been written focuses on psychological problems and dysfunctional behavioral and attitudinal patterns. Based on much of this data, one might reasonably conclude that chronic childhood illness inevitably leads to maladjustment and insurmountable strains. The writer asserts that these themes reflect an historically predominant problem centered orientation to study of this population. Very recent evidence suggests that in fact many children adjust remarkably well particularly when the family system is stable and supportive (Tritt & Esses, 1986:115; Mattsson, 1972:808). Thus additional research which examines the process of adaptation, including such factors as: types of resources needed, school adjustment, presentation of self esteem despite limitations and altered body image is needed. Another major gap in the literature (which has been acknowledged by recent authors) is the impact of chronic illness on the childs capacity to work through the tasks associated with various developmental stages. Very little has been documented regarding the interaction of specific disease features (i.e.: visible vs. non-apparent symptoms) and psychosocial development. Particular attention will be paid in this section to the emerging appreciation for and understanding of these developmental issues. It should also be noted that the term child in this context is defined broadly as infancy to eighteen years. Where comments refer to specific age categories, these will be noted as such.

(b) Common Stresses of the Chronically Ill Child

Robert Louis Stevenson who had pulmonary tuberculosis once said, "Life is not a matter of holding good cards but rather of playing them well" (Mattsson, 1972:801). This proverb captures the essence of the challenges faced by the chronically ill child. These children must continually adapt and readapt to the physical, social and emotional struggles associated with their disease and its course. As one mother described, "You have to just enjoy each good day and get through each bad one." Mattsson has summarized several of the potential causes and psychological and emotional stress which are typically experienced as the result of the illness. Variables in the ecological context of the child, developmental stage and particular disease features moderate the impact of these stressors (Burton, 1975:140). They include:

1. Malaise, pain, various physical symptoms:

(a) Uncertainty as to why pain occurs is a stress for anyone but especially the preschool age child with little ability to understand causality and who may interpret pain and other symptoms as punishment for being bad (Cerreto, 1986:26-27; Schaefer & O'Connor, 1983:216).

(b) Discomfort, lack of energy may limit ability and/or inclination to participate in various activities (Travis, 1976:44).

2. Hospital admissions, nursing and other treatment procedures:

(a) Frequent and lengthy hospital stays involve separations from family, school and friends (Travis, 1976:47; Schreier, 1980:49).

(b) Feelings of helplessness, embarassment and limitation may prevail at the loss of control over self. These emotions are especially intense for adolescents.

(c) Other treatments (at home or at a clinic) interrupt play, school and other daily activities and may cause physical discomfort.

3. Change in the emotional climate (the family context):

(a) Family members reactions over time affect the child (Tritt & Esses, 1986:115).

(b) Many parents tend to become more loving and indulgent often letting up on family rules. These changes can be confusing to the child especially since developmentally he/she is striving towards independence.

4. Stress factors related to certain chronic syndromes:

(a) Specific disease entities have particular features (i.e.: the child with a convulsive disorder may fear losing consciousness or uncontrollable strange behavior while having a seizure and the child with cystic fibrosis must cope with a growing awareness of the progressive nature of his/her disease) (Figley & McCubbin, 1983:24).

5. Additional psychologic threats:

(a) The child must cope with threats of exacerbation, restrictions, painful treatments, social stigmatization and uncertainty regarding the future.

(b) As the child grows older he/she is expected to assume greater responsibility for his/her own care (Travis, 1976:65; Perrin, 1986:5; Mattsson, 1972:802-805).

Although maladjustment is certainly not the norm, as with physically healthy children there are those who experience difficulty. It is theorized that in order for a family to adjust to a serious long term illness, the patient must assume a position of centrality temporarily, necessitating temporary neglect of other family members. If the disruptions associated with the initial phase are too great the illness retains a dysfunctional central organizing focus in the family. The child or teenager engages in illness maintaining behaviors (i.e.: not complying with dietary restrictions) which, paradoxically are simultaneously self-destructive and stabilizing for the dysfunctional family system (Frey, 1984:252; Minuchin et al., 1975:1032) while this has not been explicitly suggested in the literature, one might logically argue that the ill child is able to develop a positive self image and minimize limitations to those realistically imposed by the illness to the extent that the family is able to normalize this experience.

Based on his clinical experience Mattsson has documented certain coping patterns which tend to lead to poor adjustment and severe impairment of developmental growth and lifestyle. These behavioral patterns are referred to generally throughout the literature although there has been little empirical study of the frequency and variables associated with their development. The first group are those children and adolescents who are characterized by fearfulness, inactivity, a lack of outside interests, marked dependency on family especially mothers. Parental overprotectiveness and worry are known to be characteristics of these children's family environment. The second pattern most evident in adolesents involves behaviors such as recklessness, denial of needs and realistic dangers, thereby at times challenging the risk of trauma. Mattsson suggests that this is typically a reaction to oversolicitous guilt ridden mothers. The third type is apparently predominant in older children and adolescents with congenital deformities and handicaps. These children present as shy, lonely and appear to harbor deep resentment and hostility particularly towards normal people. It is noted that these children's families tended to emphasize the handicap and to isolate them. Consequently the child internalizes this view of him or herself (Mattsson, 1972:805-806; Travis, 1976:2). While these maladjustment patterns may be accurately described it should be remembered that the evidence is largely impressionistic rather than empirically based.

Pless notes that in the past it was generally assumed that the more severe the disorder in medical terms the greater the likelihood of psychosocial maladjustment. Recent studies however suggest that the relationship is not as direct as previously thought. He suggests for example, that children with "marginal" or "ambiguous" status may be more at risk. This involves disease states which may not be visible so that the child is perceived as normal in most circumstances. However situations arise in which the child is faced with the conflict of sacrificing the medical requirements or admitting the condition to peers. The anxiety associated with hiding the medical problem may be greater for some individuals than having a more severe disability. Another variable which has been speculated to be a risk factor is episodicity. In diseases that are episodic rather than persistent, it may be that the ups and downs are more stressful than more predictable conditions (Pless, 1984:37-38; Steinhauer, 1974:825). Empirical study of these factors is only beginning to emerge; further investigation is needed to substantiate these queries.

(c) Factors Associated with Positive Coping and Maladjustment

Coping behavior has been defined as including the use of cognitive functions, motor activities, emotional expression and psychologic defenses used by an individual to master a major psychologic threat and its attendant feelings (Mattsson, 1972:805). Successful coping behavior results in a state of adaptation which involves effective individual and social functioning. As the child grows his/her increasing intellectual understanding provides a greater variety of ways for self-expression through language and activity (Travis, 1976:65). Recently theorists have begun to suggest the need to focus on the positive features of the child's efforts to adjust in order to "avoid the downward pulls of the disease" (Mattsson, 1972:806). This refers to the potentially overwhelming chronic strains of caring for a sick child (Anderson, 1981:428-429; Longo & Bond, 1984:63-64). Children who cope well seem to share certain characteristics. Many aspects of successful coping can be linked to overall family functioning and parental responses and attitudes (Tritt & Esses, 1986:115).

Positive coping characteristics include: minimal age appropriate dependence on family, little need for the secondary gains associated with the illness, assumption of maximum responsibility for self-care, the appropriate appearance of self-protection (precluding the development of helplessness and hopelessness) and the ability to find personal satisfaction in a variety of compensatory activities. Another important feature of healthy adjustment seems to be the childs ability to allow him/herself to experience and express a range of emotions (Mattsson, 1972:806-807; Pinkerton & Pless, 1975:28-29; Travis, 1976:60-61).

It has been reported that learning about and associating with others who struggle with the same problems, particularly those who have successfully overcome them is an important element of coping. These relationships normalize and provide a sense of belonging to the ill child (particularly the adolescent) which is essential in the development of a positive self image and social competence (Cerreto, 1986:33). Mattsson also points out that successful management of the disease through responsible self-care can be a source of self-confidence and feeling of mastery (Mattsson, 1972:805).

It seems clear at this point that a reciprocal relationship exists between the successful adaptation of the family system as a whole and the adjustment of the ill child (McCubbin & Figley, 1983:24). In a study of the successful adjustment of disabled children it was found that family harmony, quality of parenting, emotional support and encouragement for learning were salient factors (Slater & Wikler, 1986:385).

(d) Developmental Issues

Recent reviews of the literature and research on chronically ill children have described a lack of investigation into the pychosocial impacts of the disease process at different developmental stages (Perrin, 1986:7). Researchers have for example, commonly gathered data from samples of ill children with no attention to the developmental stages in the sample group (Anderson, 1984; Perrin & Gerrity, from Hagen et al., 1986:53).

Little research has been carried out which documents typical developmental patterns of children with chronic illnesses (Hiedman & Roth, 1986; from Perrin, 1986:7). Perrin has further identified a need to explore alternative pathways to the accomplishment of development milestones and to understanding how diseases exhibiting different characteristics affect developmental processes (Perrin, 1986; Cerreto, 1986:24). Recent studies permit a beginning understanding of illness mechanisms both among healthy children and those with chronic illnesses. It has been found for example, that older children maintain a greater internal locus of control than younger children who tend to attribute illness to external factors, i.e.: "I got a sore chest because I went out into the bad air" (Altman & Reverson, 1986:64-65). Continued research efforts should assist those who work with children by providing greater understanding of childrens cognitions, perceptions and interpretations of their illness experience.

Three relevant principles have been articulated regarding the importance of collecting and interpreting developmental information:

1. Children face specific developmental tasks at different age periods (Erikson, 1950:246; Travis, 1976:21). Consequently effective treatment plans must therefore address the distinct social, psychological (and ecological) challenges faced by ill children at different stages.

2. Secondly the child's developmental stage influences responses of family members, health care providers and school personnel towards the child and treatment responsibilities.

3. The child experiences rapid and dramatic physiological change with age; biological changes such as those which occur at puberty strongly influence the childs psychological response to illness (Coupey & Cohen, 1984 from Hagen et al., 1986:53-54).

The psychological, social and emotional impacts of an illness on the child can be best understood within a developmental framework. Review of child development literature reveals three central themes:

1. The child's growth is inevitable in that he/she will inevitably undergo identifiable social, emotional and biological changes.

2. These changes are characterized by qualitative shifts in appearance, perceptions and experience; they are not of an "add on nature" (Erikson, 1963:247-273; Travis, 1976:21-23).

3. The family provides the central context within which these processes take place (and is the essential provider of love, support and socialization) thus exerting substantial influence on the developmental process (Stein, 1986:71; Figley & McCubbin, 1983:24).

Naturalistic observation, empirical study and societal consensus have led to the delineation of physical, emotional, cognitive and educational tasks required of children within particular age ranges. These task categories incorporate anticipated typical age related behaviors and have become our yardstick for assessment of healthy growth and development (Cerreto, 1986:24). Maturation and experience interact at each stage to enable the child to achieve particular tasks and to move on to more advanced phases. Processes or events (physical, psychological, environmental) that alter or interfere with experience and/or maturation tend to disrupt the sequence of accomplishment of developmental tasks (Cerreto, 1986:25; Travis, 1976:57).

Chronic illness represents a major disruption. The child with a serious ongoing illness must confront the usual set of developmental experiences and expectations such as physical maturation, sociocultural pressures but must also cope with an added set of demands associated with his/her illness. This may involve maintenance of a special diet, medical treatment, distorted body image, activity restrictions and the uncertainty and disruption of acute illness phases. The added burden of the illness may impede or change the expected developmental course of the child (Perrin, 1986:6; Cerreto, 1986:25).

The manner and degree to which a chronic illness modifies typical developmental processes depends partly on particular details of the illness such as it's severity, its natural history, expected prognosis, degree of limitation associated with it, necessity for physical care, its impact on mental abilities and the degree to which the disease is visible. A multitude of other variables including personality characteristics, family and peer responses and the reactions and supportiveness of teachers, physicians, nurses and other health care professionals influence the magnitude and style of variations in the child's developmental process (Perrin & Gerrity, 1984:19-20; Stein & Jessop, 1984:191). Perrin & Gerrity suggest a transactional approach in understanding the dynamic and complex interplay between these variables; this "...posits that the child interacts with and influences his/her environment, in doing so changes it and this changed environment in turn influences the child and changes him/her" (Perrin & Gerrity, 1984:19). This is analogous to the ecological model of adaptation described by Germain (see Part III: Intervention Models).

Travis notes that there are three major indicators of the struggle to cope: denial, regression and depression (Travis, 1976:66-67). These signs may manifest themselves at different points in time as the child seeks to balance developmental tasks with the sometimes competing demands of the illness. Identification of the child's stage of development with regard to level of cognitive, psychological, social, emotional and biological functioning is essential for the selection of appropriate treatment strategies.

The absence of adequate investigation regarding the impact and effectiveness of treatment modalities with chronically ill children and their families has been emphasized. Recent evidence has begun to emerge which supports the notion that early interventions improve long term outcomes. As with many health conditions, optimal interventions tends to be preventive thus minimizing the negative psychological, social and physiological consequences of the disease. For the child with diabetes for example, it appears that careful control of blood sugar may diminish the serious long term complications of blindness and kidney failure

(Perrin, 1986:9). The implementation of ongoing appropriate supportive services is thus likely to enhance developmental progress (Habbes et al., 1985; Holtzman & Richmond, 1985 from Perrin, 1986:9).

The developmental task model developed by Cerreto provides a useful paradigm which enhances understanding of the manner in which chronic illness impacts on particular age related developmental tasks of childhood (Cerreto, 1986:23). It's focus on optimizing normalization for the ill child is consistent with the growing assertion in the literature that helping efforts should be adaptation rather than problem oriented. In her discussion of communication between educators and health care professionals, Stein suggests that the primary goal in all involvement with these children is to minimize biological limits imposed by the condition and to reduce restrictions and the potential social and psychological handicaps which are associated with the illness (Stein, 1986:73).

Erik Erikson's theory of psychosocial development is particularly relevant to this population of children and has been widely applied in the literature in this area (Gumaer, 1984:8-9; Travis, 1976:37; Cerreto, 1986:25; Schacter & O'Connor, 1983:220; Perrin & Gerrity, 1984:20). He emphasized the importance of external social and environmental events in influencing personality development (Perrin & Gerrity, 1984:20). Erikson theorized that each developmental stage represents a psychosocial crisis which arises and must be resolved before the child can address the next stage of crisis and growth (Erikson, 1950:151). Physical illness may be conceptualized as an event which has definite implications at each stage of development and which has the potential to either promote or discourage optimal progression from one stage to the next (Tumo, 1982:28; Mattsson, 1972:806; Perrin, 1986:10; Stein, 1986:72). The developmental sequence described by Erikson (entitled the Eight Stages of Man) has dramatic implications for chronically ill children.

Infants spend their first year and a half of life in a relationship of complete dependency with adults. With regard to psycho social development the infant begins to: establish trust in others to fill basic needs, to develop emotional ties and to experience and master the first stage of stranger anxiety and finally to develop the beginnings of intentionality. Toddlerhood is marked by the beginning of use of imagery, language memory and a fundamental ambivalance between autonomy and dependence (Cerreto, 1986:25-26). The ill toddler who is separated from his/her parents (i.e.: due to hospitalization) frequently or for long periods, may develop chronic separation anxiety manifested by crying, clinging and a generalized fearfulness. When the task of developing trust is not completed the child may have great difficulty in proceeding with the struggle for independence and individuation characteristic of the next phase (Gumaer, 1984:8; Tuma, 1975:30; Cerreto, 1986:27; Schreier, 1980:48; Travis, 1976:25). One of the hallmarks of infancy and toddlerhood is the egocentric inability to distinguish the self from the rest of the world. Concepts of health and illness are primitive; most often expressed in terms of a "place where it hurts" (Cerreto, 1986:26).

The presence of physical illness in the infant or toddler has some potentially disruptive effects on the development of strong attachment between the parents and child. Experiences around feeding are usually satisfying, rewarding and pleasurable; the infants growth confirms the parents sense of adequacy and conversely the child learns to expect the parents to successfully meet his/her needs and to resolve transitory physical discomfort (hunger, cold). Many chronic illnesses however particularly those with gastrointestinal features interfere with feeding, growth and energy and thus disrupt these usually pleasurable (bonding) experiences (Perrin & Gerrity, 1984:21).

The pre-school age child continues to develop skills of independence and exploration. The sense of "I can do it" is central and is accomplished mainly through physical manipulation and exploration. Stage related tasks such as the development of a sense of social reality, learning sex differences and the development of a body concept are also paramount (Cerreto, 1986:28; Erikson, 1950:255-257; Havighurst, 1972 from Perrin & Gerrity, 1984:24).

Early school age children must develop a sense of initiative and curiosity simultaneous to increased impulse control. As the child passes through the school age years he/she becomes increasingly focused on learning, skill acquisition and peer relationships (Cerreto, 1986:30; Erikson, 1950:258; Travis, 1976:27). The childs understanding of health and illness gradually evolves from phenomenonism (defining illness in terms of a single symptom) and contagion (illness caused by an event, person or activity) to a stage called internalization in middle childhood. This last conceptualization involves the recognition that illness occurs globally within the body system (Cerreto, 1986:31; Altman & Reverson, 1985:61). The school age child has also developed an awareness of and pride in his/her body and as a whole and experiences fear of mutilation, loss or impairment of body parts. Thus medical procedures such as blood tests or tissue biopsies may create great anxiety for the child (Schreier, 1980:49).

These tasks point to the need for extra efforts to allow the child to maintain control and responsibility when possible. Childhood chronic illness often occurs before independence is firmly established thus pulling the child back into dependent patterns which he/she is striving to leave behind (Moos, 1979:180; Travis, 1976:59; Cerreto, 1986:31; Perrin, 1986:10). The sense of mastery and competence or "I can do..." must be fostered within the framework of the limitations but also the maximal potential control of the illness (Perrin & Gerrity, 1984:26). It has been hypothesized for example that children challenged with the positive achievement in attaining control, will do better than children who are confronted continually with the "I can't" dimensions of their illness (Cerreto, 1986:31; Stein, 1986:73; Rose, 1984). In addition, at a time when peer relationships are becoming increasingly important, the chronically ill child may experience isolation, restricted activity and body image distortions. This accentuates the necessity of ensuring peer group involvement and the promotion of self esteem (Travis, 1976:61).

(e) The Chronically Ill Adolescent

Many theorists, clinicians and investigators suggest that the strains of chronic illness peak at adolescence (Frey, 1984:252; Mattsson, 1972:806; Travis, 1976:61; Weller et al., 1984:152). On the optimistic side however, Mattsson also states that each progressive step in the childs emotional, intellectual and social development changes the impact of the illness often equipping him/her with better means to cope (Mattsson, 1972:805). The achievement of identity and autonomy are the central developmental tasks associated with this phase. The acceptance by peers, a definition of sexual identity, the development of a value system and the beginning of career or occupational direction are important aspects of adolescent development (Carter & McGoldrick, 1980:148; Eshleman, 1978:568; Schaefer & O'Connor, 1983:112).

Inability to form a sense of identity or separate selfhood results in what has been coined as "role confusion", a bewilderment about what others expect and what one should expect from oneself (Travis, 1976:61). Adolescence is a period of rapid physical and psychosocial change and has long been acknowledged as potentially tumultuous and painful for even the most normal, well adapted child. Thus the appearance or existence of chronic illness in this life phase has some dramatic implications. The emergence of a positive self image involves an incorporation of experience of the self in relation to others. Physical limitations, isolation and altered appearance contribute to a feeling of being different or even inferior in comparison to peers. Travis suggests that the "violation of the compelling urge to be like his/her peers is a torment with varying manifestations" for the chronically ill adolescent (Travis, 1976:61).

Characteristics such as a chronic cough, hair loss from radiation, obesity and hair growth from kidney disease create a context of potential social stigmatization which has the potential for erosion of self-esteem. Goffman describes the social context of the stigmatized as following:

> The stigmatized individual tends to hold the same beliefs about identity as we do...shame becomes a central possibility, arising from the individuals perceptions of one of his own attributes as being a defiling thing to possess...[the physically normal person] feels on shakey ground...showing familiar signs of discomfort and stickiness: guarded references, fixed stare elsewhere, artificial joviality, compulsive loquaciousness, and awkward solemnity"(Goffman, 1963:17).

While the peer group is an essential source of support and social identity for all adolesents this need is exemplified in chronically ill teenagers. The adolescent may for example experience deep and intense feelings of rage, sorrow and fear that may be difficult to communicate to parents, even those who are caring and supportive (Tuma, 1982:34). Many parents have trouble discussing death which is bound to be an issue for teenagers continually faced with their own physical vulnerability. The adolescent who has necessarily become overly involved with family members may experience a magnified need to develop an adult identity outside of the family (Wolraich & Routh, 1982:73). Those investigators particularly concerned with the educational implications of chronic illness for the child point out the importance of the school environment for the psychosocial health of the ill child. A double pronged approach which incorporates:

1. social skill training;

2. education of healthy children about chronic illnesses is advocated in order to reduce stigmatization and promote social integration (Cerreto, 1986:33; Hagen et al., 1986:55; Stein, 1986:33; Walker, 1984:226).

Coupey & Cohen point out that the chronically ill adolescent faces issues of emerging sexuality just as the healthy teenager does. There is some evidence that chronically ill girls are at even greater risk of pregnancy than their healthy peers. This has been interpreted as a subconscious effort to prove normality or as a compensation for other limitations. Appropriate timely offering of information and discussion regarding sexuality and pregnancy are especially important for adolescents for whom pregnancy and childbirth present serious physical risks. In addition many teenagers with chronic illnesses especially those with visible deformities and symptoms (such as ostomies and amputations) are at risk of developing distorted body image that could potentially interfere with sexual expression (Coupey & Cohen, 1984:214-215). Travis notes that Erickson emphasizes the need for the adolescent to emulate the same sex parent. Thus the physically limited boy with small stature may feel frustration and dispair about not being able to model this father through participation in male oriented activities (Travis, 1976:63).

Orr et el document the psychosocial implications of serious chronic illness for the adolescent. This involved a follow-up investigation (to a study completed eight years earlier) of a sample of one hundred and forty-four children. Those children who experienced moderate to severe disability into adolescence seemed to suffer negative psychosocial effects compared to the emergent well segment of the sample.

The authors report that predictably, adolescents with chronic disorders rate their own health less well than do those without illness. They suggest that while this is intuitively obvious, recent findings on the meanings of health and wellness suggest a more elaborate interpretation; Tessler & Mechanic have apparently demonstrated that "self-perceived health status is a useful global assessment of well-being" (Orr, Weller, Satterwhite, Fless, 1984:155-156). It is argued that this is related to several psychologic factors including the degree of anxiety, depression and unhappiness. The conclusion inferred is that self-assessed health may be a valid measure of psychosocial functioning. It is reported that the significant indicators of poor psychosocial adjustment were: not having obtained a drivers license, dating less frequently (than the physically healthy subgroup) and not making career plans for the future. Family relationships were also found to be impaired with the ill adolescents. However the evidence for this conclusion does not appear to be clear-cut. For example with regard to the finding that chronically ill teenagers were twice as likely to report sharing problems with siblings; the authors speculate that this is an "indirect reflection of peer difficulties" (Orr et al, 1984:156). This finding could as easily be interpreted as an indicator of positive family adjustment. There are other serious problems with this study; psychosocial adjustment seems to be very narrowly defined and is based on indicators which may not be significant for many adolescents. This investigation also did not allow for individual elaboration of feelings about self since it contained only a structured interview and psychological inventory. As is the case with many of the available studies in this area, this investigation focused on the identification of negative effects thus providing little illumination of the features associated with positive coping and adaptation. Further empirical research which explores the impact of chronic illness on the child and adolescent within a more interactional framework is essential.

Chapter iii - The Impact of Inflammatory Bowel Disease on the Child and Family: Current Understanding

The emerging view regarding how to approach the understanding and treatment of the psychosocial impacts of chronic childhood illness reflects a non-categorical framework. This involves assessing the implications of a particular illness according to certain key dimensions (i.e.: fatality, degree of disruption of daily activities) rather than focusing on the specific manifestations of a disease entity. This evolving perspective contains two apparent benefits:

1. It reduces the use of diagnostic labels which detract from consideration of the child as a whole person (Travis, 1976:12).

2. By focusing on commonalities across disease categories, it provides a more complete understanding of the impacts of childhood chronic illness (Stein & Jessop, 1984:192-193).

Given the acceptance of this orientation the parameters of the population of interest have intentionally been introduced and defined according to selected important dimensions rather than particular diagnostic labels. Nonetheless the client population selected does represent certain medically distinct categories of illnesses. The selection of children with inflammatory bowel disease reflects organizational and pragmatic considerations: it is assumed however, that to some degree the psychosocial features of these disorders resemble a range of illnesses which match the criteria outlined in the introduction. Within this conceptual framework then the student's experiences and findings can be tentatively generalized to a wider population of chronically ill children and their families.

There has been some investigation of the specific impacts of inflammatory bowel disease on the child and his or her family. Attention has been paid to both ulcerative colitis and Crohn's disease which represent the two distinct illness categories included within this diagnostic title (Steinhausen & Kies, 1982:33). Many of the existent studies are problematic as the result of weak experimental designs, poor or absent control groups and conclusions extrapolated from indirect evidence. However given their direct relevance in the present context, these findings will be reviewed and summarized.

While many gastroenterologists suggest that both diseases represent the final path of two rather similar pathophysiological events, there has never been an emphasis on psychogenesis in Crohn's disease. In contrast ulcerative colitis has been listed among the seven classical psychosomatic disorders (Steinhausen & Kies, 1982:33). Although there has been very little documented in this area it has been noted recently however that emotional stress may aggravate symptoms, precede exacerbations and influence the clinical course of Crohn's disease. Early investigators described a certain personality pattern in children with ulcerative colitis. Patients were found to be obsessive, rigid, depressive, withdrawn and dependent. Problems in the areas of aggressive and emotional expression, gender identity and interpersonal relationships were identified. Family constellations are typified as including an aggressive dominating mother with a perfectionistic attitude and a withdrawn uninvolved father (Finch & Hess, 1962:819-820; Steinhausen & Kies, 1982:33-34; Minuchin et al., 1975:1031). Prugh & Jordon and other early theorists have linked the onset of the disease with psychoanalytic thinking; an early disturbed mother-child relationship results in conflicted experience during the oral and anal stages of psychosexual development (Finch & Hess, 1962:820). Engels who has written fairly extensively in this area observed that a "state of anxious hopelessness and despair based on disturbance of a key relationship may be accompanied by altered physiological phenomenona in the gastrointestinal tract characteristic of ulcerative colitis" (Engels, 1952 from Finch & Hess, 1962:819).

A 1983 Dutch study concluded that an incomplete separation-individuation phase may be partially responsible for ulcerative colitis in children. Each step in the separation-individuation process causes a crisis in the child's developing independence. Van Noort reported that the illness was often diagnosed following such a crisis of individuation (Van Noort, 1983:6). Reinhart advocates routine psychiatric and psychosocial assessment based on observation of similar features in the treatment and management of gastrointestinal disease in children (Reinhart, 1982:Abstract).

These early studies seem to reflect a fixation on pathological psychiatric labelling with very little documentation or elaboration of environmental factors and treatment methodology. These investigators tended to take the view that these children were permanently damaged and impaired by inadequate parenting. Finch & Hess for example propose that those involved in the treatment of these children "recognize them as suffering from severe psychopathology often close to psychosis" and that "these youngsters must be considered as long-term therapeutic cases in much the same way as a youngster who has suffered a schizophenic psychosis" (Finch & Hess, 1962:819). One wonders about the negative impact of this viewpoint which seems to both stigmatize the child and blame the parents. Although long term family treatment is suggested, the effectiveness of extensive psychiatric therapy is not described.

Steinhausen recently undertook a study comparing children and adolescents with ulcerative colitis and Crohn's disease. This investigation is progressive in that it sampled patients who were functioning well in addition to those experiencing difficulty. Thus the common bias distorting many previous studies (which examined only those suffering psychosocial impairment) was avoided. It was found that children in the clinical groups did experience more psychiatric disturbance than the physically healthy control groups. In addition similar effects were identified in both diseases. These included such features as fearfulness, anxiety, shyness and relationship problems (Steinhausen & Kies, 1983:37). A comparison of indices of family and social functions revealed only minor differences between the environments of clinical vs. the control groups. Growth retardation, a common consequence of Crohn's disease, was significantly correlated with psychiatric problems. The researchers concluded that psychopathology in most patients was secondary to the chronic illness. They speculate that psychosocial events may provoke or exacerbate illness in an organ which is already vulnerable (Steinhausen & Kies, 1983: 40).

In 1982, Steinhausen investigated the locus of control among children and adolescents with psychosomatic and chronic illnesses. One of the problems with this study is the unsubtantiated arbitrary assignment of subjects to the psychosomatic and chronic illness groups. For example colitis was assumed to be a psychosomatic illness while Crohns was assumed to have no psychogenic components. It was found that the more severely ill children had an internal (rather than external) locus of control. It was hypothesized that the sicker children may have acquired a generalized expectancy to perceive what happens to him/her as a consequence of his/her own actions due to experience with the disease. An additional potential explanation is that for the more serious diseases (including those from the chronic and psychosomatic categories), the extreme limitations placed on everyday behavior, the intensity of the medical treatment and general demands for patient compliance fostered a high degree of behavioral control (Steinhausen, 1982:614).

In summary, the available research and literature on the psychosocial implications of inflammatory bowel disease is spotty and problematic. The psychiatric orientation which provides the framework for these investigations provides a limited and often dysfunction focused understanding of these illnesses. Future research needs to be directed towards elucidating factors which enhance successful management of the disease process. Also very little has been elucidated regarding the effects of this illness on the family system. Finally review of this area reveals an almost complete absence of documentation regarding the effects of different treatment approaches.

PART III: INTERVENTION MODELS

Chapter i - Assessment

The assessment phase is essentially viewed as a dynamic and ongoing component of the helping process. This perspective is consistent with the ecological premise that individuals (and families) and their environments are in a continual state of adaptation in response to one another. Germain notes that assessment may point to the need for further exploration which may in turn modify the assessment (Germain, 1984:113). However, the assessment may be viewed as a conceptually distinct phase which sets the stage for further exploration and the direction and activities of the helping process.

The assessment process utilized represents an integration of the ecological model (particularly as articulated by Germain) and the problem centered family therapy model which are the chosen intervention approaches. Assessment was supplemented by the selected standardized measures (see section Measurement and Evaluation). The content of the assessment will include the following:

1. Illness factors, including diagnosis, prognosis and likely sequelae.

2. Personal factors, including patient's developmental stage and associated tasks connected to age and gender; statuses and roles, emotional and psychological features, social and cultural features.

3. Interpersonal factors including the family's developmental stage and associated tasks, communication and relationship processes, structural aspects.

4. Environmental factors, including obstacles and resources in both the physical and social environments.

5. Cultural factors: norms, values, goals and attitudes towards illness, all as derived from race, ethnicity, social class, religion and occupation.

6. Interplay of the five preceding sets of factors in the creation or maintenance of stress and the absence or presence of coping resources (internal and external) (Germain, 1984:113).

7. Systematic exploration of the seven dimensions of family functioning described within the problem centered family therapy model: problem-solving, affective expression, affective involvement, communication, values and norms, roles, behavior control (Epstein & Bishop, 1981:454-467) (see Appendix 3).

The Family Assessment Measure (FAM) scale will also be utilized in assessing family functioning. This standardized instrument provides an objective evaluation of functioning according to the seven dimension contained within the McMaster model (see Appendix 4, pg. 207). The Chronicity Impact and Coping Instrument: Parent Questionnaire will also be utilized for assessment purposes. This instrument should provide information about the impact of the illness on the family and their characteristic coping style (Appendix 5, pg. 209). For further information on these standardized instruments see section entitled Measurement and Evaluation.

Assessment of the child will be partly accomplished through the family assessment process. The child may also be interviewed individually where indicated. Projective drawings and sentence completion exercises may be utilized, especially with pre-school and school age children (see Appendices 6 & 7). These techniques have been found to uncover feelings, needs, motivation and inner conflicts which are not revealed through verbal questioning (Tuma, 1982:85; Schaeffer & O'Connor, 1983:6). Leventhal's model for psychosocial assessment of the child will be used as a general guide. This includes four broad categories of functioning: personal growth and development, relationship with family members, activities outside the home and responses to the illness. Leventhal denotes key variables to explore under each heading (Leventhal, 1984:73) (see Appendicies 8 & 9: p. 220 - 221). The self-appraisal inventory of children and adolescents will be utilized as an assessment (as well as an evaluation) instrument (see Appendix 10). This is described in section entitled Measurement and Evaluation.

Chapter ii - The Ecological Approach

(a) Introduction

As discussed earlier in the literature review there is an increasing recognition among health professionals that the processes of health and illness are much more complex than was previously assumed by the traditional medical definition of health as the absence of illness. Rene Dubos, an internationally respected microbiologist described health and disease as "the outcomes of a complex interaction involving an assault (microbiological, chemical, physiological or psychic), the state of the human organism and its response and the past and present environment of the individual" (Dubos, from Germain, 1984:58).

The ecological approach is essentially a variation of the systems perspective in that it views the individual in the context of his/her social environment. It has been suggested that the ecological model differs from general systems theory in that it does not focus on the ability to change, rather it is concerned with the individuals ability to negotiate and compromise with the social environment in the ongoing effort to adjust and survive (Dehoyos and Jensen, 1985:492). The central concept in this orientation is the idea that human functioning and development, including health and illness are the outcomes of continual and dynamic interchanges between the individual and social environment, the physical setting and the cultural context. Carol Germain who is one of the primary proponents of this approach describes the interchanges as having the properties of circular feedback loops rather than linear chains of cause and effect (Germain, 1984:58).

Ecological theory has broad relevance and applicability to social work practice in a range of settings, target populations and problem areas. The selection of this framework as a map for working with chronically ill children and their family's was based on two primary factors. First, it focuses on adaptation, growth and assumed strengths rather than dysfunctions and pathology. This is consistent with the recent research findings which emphasize the need for a health oriented approach. Secondly its holistic view suggests and guides intervention of different levels: the individual, the family and the social environment. Furthermore, it focuses on the family as a micro ecosystem which mediates the transactions between the individual and the social systems he/she is in contact with. It seems clear to the writer that the practitioner often needs to intervene at multiple levels simultaneously in order to facilitate enhanced coping. For example assessment of the Jones family may reveal a need for: 1. Individual play therapy to assist their 6 year old son with kidney disease to work through unexpressed emotions around illness such as the restrictions imposed by dialysis. 2. Family therapy aimed at reorganization of household and parenting responsibilities. 3. Help in locating a parent support group and practical home help.

The ecological perspective thus offers an integrated approach which provides a unifying orientation to practice with these families: the literature points to the fact that the absence of a linking theory leads to interventions which are piecemeal, disconnected and therefore ineffective.

(b) Adaptational Paradigm

In her book Social Work Practice in Health Care, Carol Germain has applied the ecological approach to practice in health care settings such as hospitals and community health clinics. She talks about the need to focus the process of problem-solving on the social, emotional consequences of the illness on the patient and family (Germain, 1984:73). To achieve this broad goal, Germain has developed an adaptational paradigm which incorporates three main notions: stress, coping and adaptedness. These concepts provide a framework for identifying and formulating specific treatment methodologies. This may be summarized as "the overall process within which the needs and problems (identified by the worker and client) are viewed and defined as problems in living arising from the stress imposed by the discrepancy between demands and the capabilities for dealing with them (see Appendix ll p. 225).

The ideas of stress, coping and adaptation represent the skeletal foundation of the ecological model. This transactional perspective is consistent with a psychosomatic approach in medicine which incorporates the notion that illness results from interactions among systems: somatic, psychic, social and cultural (Grinker, from Travis, 1984:13). These concepts are helpful in translating systems thinking into practice with families with chronically ill children.

Adaptedness (or person-environment fit) is said to exist when the individuals rights, needs, goals, are met by the capacities and the qualities of the environment. People use an almost limitless variety of physiological, cognitive, emotional, social and cultural processes. Adaptation is continuous and reciprocal because environments change and peoples needs and goals also change. An example is the modification of the family residence to assist in the care and adaptation of the severely asthmatic child, such as removal of carpets, plants and pets.

In contrast to adaptedness, stress represents a poor person-environment fit. Stress arises when the individual makes a conscious or unconscious appraisal of discrepancy between a demand (stressor) and his/her personal and environmental resources for meeting this demand. Lazarus and colleagues make a distinction between harms losses, threats and challenge. The difference between stress and challenge lies in the stress related feelings such as anxiety, depression, guilt, despair as compared to the positive feelings of zest and anticipated growth and mastery associated with challenge (Germain, 1984:60-61). Any given situation (i.e. the need to learn at home treatment techniques) may be experienced by different families in very different ways. The critical element has to do with the appraisal of an imbalance between a painful demand and the personal and environmental resources for dealing with it. The practice implication which follows from this is the need for the worker to assess the family's subjective definition of events and problems. Once meaning is established it is be possible to devise helpful coping strategies. Coping then, is also an expression of the person-environment fit. Coping responses are the special adaptations called upon to deal with stressful demands. Ineffective coping (such as denial of the seriousness of the child's illness) result in unrelieved or intensified stress. Travis suggests that depression, regression and denial are three important indicators of a downward struggle to cope (Travis, 1976:66-67). Effective coping increases the family's ability to manage stress. For example, asking for network support might increase capability; resorting to alcohol would likely decrease it (Germain, 1984:67). A primary goal in short and long term intervention is to help children and families to work towards developing more effective coping mechanisms. This may involve a range of methods from providing information to exploration of intergenerational patterns of grieving and loss.

Like other conceptualizations of social work practice, this model recognizes three distinct phases which are necessary in carrying out the activities involved in the accomplishment of client/worker goals. These are: 1. The initial phase which includes the processes of engagement, exploration, problem definition, assessment, contracting, goal setting and planned needed action steps. 2. The ongoing phase which refers to the activities undertaken by the client and worker in order to achieve agreed upon goals. 3. The ending phase which refers to the processes of termination, referral and transfer as well as evaluation of outcomes (Germain, 1984:70-72) (see Appendix 12: p. 226).

Germain stresses that within an active treatment setting these work phases tend to be telescoped. One of the implications of this is that the practitioner must have strong skills in carrying out the tasks of the initial phase. For example, at a time when a family (at the point of diagnosis) is highly stressed, fearful, overwhelmed regarding the uncertainty of the future and the child is experiencing pain and discomfort the practitioner must be adept at explaining roles and functions to the family in terms of their felt or anticipated needs (Germain, 1984:70-71). Thus the adaptational paradigm incorporates the basic notions of crisis theory as appropriate in certain situations and phases of helping.

(c) Crisis Theory and Long Term Adaptation

When parents are first informed of their child's illness there is frequently a profound sense of grief and loss. This represents a period of extreme stress or crisis (Soricelli and Utech, 1985:429). Families at this time are extremely susceptible and require assistance and emotional support. In outlining the necessity for social work services in a regional pediatric center, Ross emphasizes the need to intervene in the early stage of the illness if possible in order to help families to cope with the meaning and impact of the child's serious condition thereby encouraging positive coping and preventing the development of maladaptive patterns. As the family works through the tasks of;

telling other family members, deciding how and what to tell the patient, arranging for care of the other children, evaluating financial resources, dealing with feelings such as grief and fear, during the initial phase, they are developing the psychosocial tools needed to cope with successive phases (Ross, 1982:256-267; Golan, 1978:199-202).

This concept is exemplified in the following scenario of a young couple who have just given birth to an infant with cerebral palsy.

> The social worker encouraged Mr. and Mrs. R. to recognize their grief and to mourn the perfect child they had expected. Together they discussed the parents pre-birth fantasies and how these related to their current feelings. The social worker helped the parents identify strengths they could use in coping with the situation (Parks, 1977:52).

Without effective intervention this couple might have repressed their feelings of grief and anger such that these emotions become manifested in chronic sorrow or an absence of bonding with the sick infant.

Caplan argues that from a crisis intervention viewpoint that "by deploying helping services to deal with individuals and families in crisis, a small amount of effort leads to a maximum amount of lasting response" (Caplan, from Soricelli and Utech, 1985:430). If the practitioner can engage the family at this point, the potential for working together around a range of social and emotional adjustment issues is increased.

Germain suggests the integration of crisis theory into the ecological model because it clarifies what occurs psychically during the actual crisis (including heightened anxiety, lowered defenses) when the family is most accessible to the worker and secondly that it therefore emphasizes the importance of envrionmental supports for successful crisis resolution (Germain, 1984:66).

Recent studies have revealed that many families have greater difficulty and feel more stressed with regard to the tasks inherent in long term adaptation than the shock of the initial diagnosis phase. One might speculate that this experience is quite different from that of the family of the acutely fatally ill child whose disease has a different anticipated course and long range prognosis. The family with a chronically ill child must often face a series of intermittent crises as the child alternates between phases of effective management of symptoms and phases of acute illness which may or may not require hospitalization, but always demands extra physical and emotional energy and often disrupts family life. The crisis therefore may occur long after the diagnosis at a time when other variables (i.e.: normative developmental transitions or other life events) render the family system more vulnerable to the strains of the illness.

Germain not only does not make a sharp distinction between crisis intervention and long term treatment strategies but in fact suggests that so called crisis states often present or represent long term demands or difficulties. Families with a chronically ill child must not only deal with the anxiety and sometimes overwhelming demands of the crisis phases (such as acute illness periods) but they must also devise ongoing plans in anticipation of adaptive tasks to be faced at a future time. For example, many families experience a need to reorganize with regard to parental roles and division of household responsibilities. In addition, ongoing social work involvement may be indicated with regard to the mobilization and maintenance of an adequate social support system.

This involves interventions which integrate the roles of mobilizer, facilitator, innovator and advocate to assist family members to access and make use of resources such as parent support groups, respite care, volunteer services (Germain, 1984:78; Compton and Galloway, 1979:256).

(d) Mobilizing the Social Support Network

The available literature regarding this contextual problem and the ecological perspective with it's emphasis on person-environment exchanges, strongly suggest intervention strategies that attend to these families commonly felt need for increased social supports and instrumental services (Saulnier, 1982). While family therapy is often indicated in order to resolve internal organizational, structural and affective difficulties, it does not diminish the need for nourishing contact with a supportive social network. Many families report feelings of loneliness and isolation following the onset of the disease (Kazak and Marvin, 1984:69). While many families with sick children make greater use of available medical services and other formalized helping resources; recent evidence points to the necessity for and even greater benefits associated with informal natural support networks. Caplan and Killilea have defined social support as "attachments among individuals or between individuals and groups that serve to improve adaptive competence in dealing with short term crises and life transitions as well as long term challenges, stresses and privations" (Caplan and Killilea, 1976:41). They document three major ways in which social support accomplishes this: providing emotional mastery, guidance regarding anticipated problems (i.e. educational lectures for parents of child with cystic fibrosis) and thirdly, providing feedback on behavior that fosters improved performance.

It has been suggested that social workers working with families with a sick or handicapped child make use of a normalized family resource framework. This involves encouraging families to develop extended family resources such as friends, relatives, neighbors and volunteers. The practitioner can be of aid in facilitating this through encouragement and promoting skill development related to negotiating, contracting and sharing of information between the family and it's support network members. Slater and Wikler suggest the formulation of an individualized family plan for the family and (for example) the extended family network. The social worker (amongst other roles) thus acts as an activator of informal social supports; this allows the worker to serve as a resource to the family's internal and external support structures (Slater & Wikler, 1986:388). In this way natural helpers are mobilized to ease the stress of this life crisis through the provision of instrumental help and affective involvement.

The practitioner may also take on the related role of systems convener in assisting families in identifying external informal sources of support. Eco-maps may be employed to visually represent the family unit within it's social context. The eco-map provides a helpful tool in assessing the extent to which the family is embedded in a community network (Hartman and Laird, 1983:157-159). Relationships that could be activated or new relationships that could be developed are pinpointed (Slater and Wikler, 1986:388).

Much can be learned from those families who have experienced positive adjustment over time to having an ill child. Trute and Hauch for example, note that the well-adjusted families separated their ongoing resource needs from purely social support and escape needs: these couples did not attempt to pull their friends into their requirement for concrete help (Trute and Hauch, 1986:19).

In reality, the degree to which a natural support network can be activated to provide substantial, reliable, ongoing assistance varies depending on several factors. These include such considerations as physical proximity to and quality of the previous relationship and closeness with extended family members (Kazak & Marvin, 1984:7 -75). In working with families with a sparse ecosystem, the practitioner must exert greater and more innovative efforts towards establishing connections with other sources of support such as agencies, volunteers, support groups. In addition information should routinely be provided about the range of resources available as families are frequently unaware of what is available. Volunteer child care, special recreational programs, group programs may considerably ease the strains and potential isolation associated with having an ill child. The practitioner thus intervenes to develop and enhance the links between the family system and their potential informal and formal social support networks. This serves the overall goal of reducing stresses, enhancing coping strategies and normalizing family life.

(e) Contribution of Ecological Thinking to the Multidisciplinary Team

One of the realities of working with this population in a health care setting such as an active treatment hospital is that the practitioner usually offers services as a member of a multidisciplinary team. The social worker must often have to rely on physicians and nurses for referrals. The team of helping professionals is often necessary for the child and family to meet the range of psychosocial, medical, developmental and rehabilitative needs. One of the potential difficulties with this approach is that the individual professionals involved predictably become highly focused on a specialized area of need, such as nutrition, physical therapy, speech, medical specialties: this sometimes leads to a loss of recognition of the interrelationship of the child's various needs and between the child and family. The ecological clinician can make a significant and valuable contribution to these efforts by taking responsibility for connecting these compartmentalized concerns or specialized interests, thus providing a broader "wide angle" view (Stein, 1986:77). For example the child with Crohn's disease must often adhere to certain dietary restrictions. Failure to comply to special needs can lead to exacerbations or flare-ups in the disease process. In this scenario the medical evaluation may reveal a lack of appropriate meal planning as the cause of heightened symptoms. As the team works towards rectifying this situation it would be important to know that this problem (for example) reflects mother's general level of exhaustion as the result of the many demands on her. The team social worker in this example can help to ensure that such information is brought to the attention of team members so that effective helping strategies can be developed. The worker can therefore promote appreciation of systems issues and the notion that the child functions as a total dynamic biopsychosocial entity (Travis, 1976:12).

(f) Summary

The adaptational paradigm which is the operational and conceptual core of the ecological approach is valuable in its broad systemic scope and flexibility. It incorporates and links interventions at the level of individual, family, and social environment. The ecological perspective also allows for both crisis intervention and long term social work strategies where appropriate. It provides unity and direction for the practitioner working with families with chronically ill children who often have multidimensional needs which also change over time. The ecological perspective is additionally, flexible enough to respond to families who are managing well and require minimal support and information to those who become substantially blocked or dysfunctional as the result of this life event.

Its limitation is that it doesn't offer specific methodologies regarding:

1. Individual therapy (i.e. how to help the ill child or other individual family members work through psychological and emotional conflicts).

2. A prescriptive model for treatment of family systems problems.

It is therefore necessary to supplement or build in compatible practice methodologies. The student proposes the utilization of the problem-centered model as an appropriate framework for intervening with this population. In the following section, this family therapy model will be described and elaborated with regard to its particular appropriateness for the population of interest.

Chapter iii - Problem Centered Psychodynamic Therapy for Families

(a) Introduction

The literature available on characteristics of family functioning in families with chronically ill children is relatively sparse. Recent studies however provide some general direction regarding clinical practice with this population: the consensus regarding the need for a multidimensional, systems oriented approach which addresses the needs of all family members is uniform. As discussed, interventions aimed at building or enhancing social support networks are also universally recommended in the literature. The need for a health oriented perspective which focuses attention on strengths and skill building rather than dysfunction is also a repetitive theme in the recent literature. This is essential in working with these families who come into contact with helping professionals as the result of an unanticipated live event (the occurence of which they have no control) and are therefore by no means inherently problematic. All families with chronically ill children experience stress and many require some form of family intervention; this may range from a need for occasional supportive telephone contacts to ongoing family therapy aimed at resolving longstanding relationship issues which are triggered or aggravated by the onset or ongoing stresses of the illness.

What is missing in the literature is more specific clinical direction regarding how to work with internal family system problems which arise for many families with chronically ill children. While several key typical dynamics are referred to (such as a shift of parental attention onto the ill child and away from healthy siblings) very little has been documented with regard to treatment of these difficulties. Tritt and Esses note that, as is often the case when new ways of thinking are brought to bear on old problems (in this context, the growing systemic understanding of the impact of childhood chronic illness), theoretical understanding precedes empirical documentation of these dynamics. Predictably then, it will take some time before hospital based programs with their previously unwavering adherence to the medical model incorporate intervention strategies which are consistent with a family centered approach (Tritt and Esses, 1986:2). Most clinical and research oriented writers allude to an approach which incorporates skill building, problem-solving, normalizing and restructuring. Slater and Wikler in Normalized Family Resources for Families with a Developmentally Disabled Child suggest sessions that emphasize the importance of shared responsibility for child care, flexible role relationships and the development of a family atmosphere which promotes personal growth and family adaptability. They further recommend that the worker begin to "observe family interactions and structures ... to formulate tentative hypotheses as to the needs of the family ... and if appropriate, restructure the family system" (Slater & Wikler, 1986:389).

Given the information and experience available, the writer is proposing the Problem-Centered Psychodynamic approach as articulated by Will and Wrate (1985). This is a model of family therapy which is founded on the problem-centered and McMaster frameworks originated by Epstein, Bishop (1981) and which also incorporates concepts and techniques from the structural school. It further attempts to integrate some basic psychoanalytic thinking into the therapists conceptualization of and response to the family system.

This third component of this integrated model involves consideration of the impact of past experience in shaping a family's current understanding of and response to given life situations. Within the context of chronic childhood illness this would suggest attention to the families previous illness experiences and assessment of how these experiences impact upon the subjective meaning of the child's illness for the family system.

The proponents of the problem centered psychodynamic family therapy model (PCPFT), describe it as a comprehensive form of an open, directive family therapy approach. In directive family therapy the therapist attempts to work collaboratively with the family in order to openly explore, understand and work with the homeostasis of the family system. Directives such as those involving tasks are negotiated: these are intended to be carried out (as opposed to strategic tasks which are often expected to fail) so that the family system becomes a more adaptive one in which problem-solving capacity is enhanced (Will and Wrate, 1985:31). These features are highly compatible with the population of concern which (although diverse in many ways) may be assumed to be healthy and readily able to make use of collaborative problem-solving opportunities.

(b) Relationship of PCPFT to the Ecological Approach

The integrated model of family therapy being presented is consistent with the overall ecological orientation in the following ways:

1. It is systems based--it assumes that what occurs in or to an individual effects the family and that what occurs in a family effects the individual (Epstein and Bishop from Gurman & Kniskern, 1981:446).

2. (a) The family is viewed as an open system consisting of systems within systems (individual, marital, dyads) and relating to other systems (extended family, schools, industry, religions) (Epstein and Bishop, from Gurman & Kniskern, 1981:447).

(b) The family is seen as the mediating force which buffers interaction between the individual and broader social environment.

3. It includes a broad range of family functioning dimensions: the McMaster model provides a wide view which is based on research with clinical as well as non-clinical families (Walsh, 1982:115).

4. It attends to issues of value differences among families and emphasizes the need for the therapist to respect the family's world view: this is essential in a pluralistic society.

5. There is a focus on strengths and the family's ability to resolve their own problems; therapy is fundamentally health oriented rather than seeking out and focusing on dysfunction. The main therapeutic question is: what can you do? rather than: what is wrong with you? or: what needs to be fixed?

6. Change is viewed as taking place mainly through the process of taking on tasks agreed upon by all family members. This is parallel to the notion of problems in living and adaptational tasks within the ecological framework.

7. Lastly, the central goal of this therapy process is to help the family develop new or more effective problem-solving; the family is

assisted to become their own therapists (Epstein and Bishop, from Gurman and Kniskern, 1981:474). These new skills also help the family to negotiate more effectively with other social systems.

(c) Problem Centered Model: Integration of the McMaster Model and Structural Concepts

The McMaster model of family functioning and the associated problem-centered therapy provide the core of PCPFT. These building blocks are valuable in the provision of a clear, integrated understanding of family functioning and a structure for the organization of the therapy process. The treatment method utilizes experiential interventions (such as the assignment of tasks) to promote change and secondly a cognitive component which involves the therapists interpretations about the significance and meaning of the transactions that occur in sessions. The practitioner comments on what is being observed regarding verbal and non-verbal exchanges in a "here and now" way. The six dimensions associated with the McMaster model are: problem-solving, communication, affective responsiveness, affective involvement, control, roles (see Appendix 4: p. 215). While this schema does not cover all possible aspects of family functioning, it is broad (compared to other models) and includes many of the areas typically affected in families with a chronically ill child. For example, parents frequently shift attention and energy onto the sick child thus neglecting the well siblings (magnified) need for nurturance and support. Parents may indulge the child due to feelings of guilt, anxiety and concern thus diminishing expectations regarding behavior. Disparate disciplining and attention giving frequently leads to resentment and acting out of the well children. This typical scenario reflects difficulties in the dimensions of; control (discipline of the children), roles (system maintenance and support), affective involvement (overinvolvement with the afflicted child and lack of involvement with other siblings).

The McMaster model of family functioning suggests that the family is the laboratory for the social, psychological, biological development and maintenance of family members. As such, it is designed to accomplish certain tasks and functions which are categorized in three task areas. These include basic tasks (provision of food, shelter, clothing), developmental tasks (those issues which are associated with individual development and family life cycle phase) and hazardous events (crises that occur in association with illness, accidents, unemployment, etc.) (Epstein and Bishop, 1981:447). This schema helps to normalize and provide some theoretical understanding of the impact of serious childhood illness. Will and Wrate note for example that even where hazardous events are considered to be the primary source of a families difficulties, in many instances pre-existing vulnerability determines how the family responds to the event. For example, diagnosis of a serious illness in a child may lead to heightened conflict and tension in an already unstable marital relationship. The therapist may in this case need to help strengthen the marital relationship as a first step in establishing long term coping strategies.

Utilization of the PCPFT model guides the therapist in assisting the family to deal with those stresses and demands which arise as the direct result of the illness and secondly to facilitate insight and awareness about how this event triggers past unresolved conflicts.

Action steps such as the implementation of tasks are usually incorporated into both of these types of issues. This double pronged approach is helpful in reducing the sense of being overwhelmed which many families experience (Moos, 1979:82). Because this approach relies on collaborative problem-solving the family is guided in partializing what may be a long list of concerns. These problems are then priorized and addressed in a sequential systematic manner (Will and Wrate, 1985:65).

The contribution of structural family therapy concepts and techniques to this integrated model is substantial. The incorporation of structural theory into the assessment and treatment phases of the original problem-centered model provides added richness and depth of the conceptualizaton of family functioning and flexibility with regard to interventive choices. The description of basic dysfunctional transactional processes such as triangulation, enmeshment/disengagement are helpful in assessing structural difficulties and in designing interventions which effectively address these problems. Will and Wrate summarize the contribution of structural theory to the McMaster model as: 1. The assessment of family roles, particularly the executive subsystem. 2. The assessment of affective involvement (i.e. through enactment). 3. Offering an understanding of how symptomic behavior may be homeostatic. 4. Provides an appreciation of the important repetitive characteristics of the family system (Will and Wrate, 1985:28).

The application of this aspect of the PCPFT approach is generally helpful in making sense of, and intervening in the organization of the family; it is particularly useful in working with dysfunctional families for whom the straight forward problem-solving approach is insufficient. Families with chronically ill children who experience dysfunction often exhibit certain typical patterns. For example, the mother often almost unavoidably becomes overly involved with the ill child. This is usually the result of medical regimens, the child's activity restrictions and the parents heightened concern, feelings of anxiety and sometimes guilt. To some extent this increased intensity and contact is beneficial and necessary. As in other types of triangulated families however, this becomes a problem to the extent that other family relationships (i.e. the marital subsystem) are disrupted or impaired. In a case of triangulation of the child (into the marital conflicts), the family needs to strengthen boundaries around the parental subsystem and to solidify the boundary between the executive and sibling subsystem. This would be important in: 1. Strengthening the marital relationship in order to ensure the mutual support needed to cope with the added stresses and demands that the child's illness imposes. 2. To free the child up to pursue already conflicted developmental tasks such as the achievement of a maximum level of independence.

One of the major differences between the MccMaster model and the structural approach is the assumptions about how change occurs in families. Within the McMaster school, change is viewed as taking place through collaborative efforts within the therapist; the therapists efforts to influence are primarily overt, direct and straightforward (Epstein and Bishop, from Gurman and Kniskern, 1981:450). In structural family therapy the therapist is regarded as the "sole agent of change within the therapeutic system, creating new realities in successful opposition to the familys own homeostasis" (Will and Wrate, 1985:61). The integration of some basic structural notions in the McMaster model has two main benefits: 1. They provide depth and meaning to a conceptualization of family functioning which may be criticized as simplistic and overly economical. 2. They offer more powerful intervention strategies for working resistant and dysfunctional families.

The basic structural concepts can easily be applied in discussion and intervention in relation to several of the dimensions specified in the McMaster model. Issues connected to roles, control, communication patterns and problem-solving may be better understood and worked with using such concepts as boundaries, subsystems, disengagement/enmeshment. The integration of these two models thus provides a flexible framework which is appropriate and potentially effective in treatment of families within the target population which contains the continuum of family health and a range of psychosocial responses.

Will and Wrate pay particular attention to the integration of four structural concepts in the PCPFT model. The first involves the therapist as the actual change agent and leader: this role enables him/her to challenge the family organization and to retain the freedom to manipulate himself as well as the family, forcing it's members to accommodate him/her in ways that will facilitate movement towards the therapeutic goals (Minuchin and Fishman, 1981, from Will and Wrate, 1985:62). The manipulativeness and omnipotent attitudes inherent in this viewpoint leaves the student uncomfortable. The position of "expert" would therefore be avoided except with regard to those families who are extremely stuck and who seem otherwise destined to spin their wheels. However the writer would also argue that structural theory can be of general value in conceptualizing a family's organization and thus provide direction for interventions which are consistent with the McMaster model.

The second major structural concept is joining. While it is said that this is necessary in order to be acceptable to the family as a central change agent, the development of rapport and trust is a first step in almost all current schools of family therapy. The idea of establishing an early affinity with the family using their own presenting dramas and patterns of complementarity is very helpful. For example, the therapist may utilize the strong mother-child dyad as a beginning point to develop proximity and a willingness to proceed in therapy.

The third structural notion which is specifically addressed in the PCPFT model is that of working with disequilibrium. This basic therapeutic process involves application of the concept of the dual nature of family systems: the continual balance between homeostasis and change (Nichols, 1984:512). Change comes about when the energy for movement and growth associated with periods of disequilibrium is successfully harnessed and directed. At times the therapist may work towards destabilization in order to help families address hitherto avoided patterns and difficulties (Will and Wrate, 1985:64). The concept of disequilibrium is highly relevant to families with seriously ill children who commonly experience crises and upheaval at various points in time. These crises as discussed earlier, create intense emotions and often render the family system more amenable to exploring alternative ways of operating. It would rarely be necessary to manipulate instability in this context. Furthermore destabilizing manoeuvers present serious ethical questions regarding the appropriateness and helpfulness of further stressing an overwhelmed family system. The motivation and openness characteristic of existent states of disequilibrium are utilized to enhance the effects of the problem-solving strategies which form the core of the integrated approach.

The fourth main structural element which is addressed in the Will and Wrate model is the notion of sequential change. This essentially involves the assumption that change follows a developmental path in which "successful restructuring of the family arises not from a single intervention but from the therapists continuous involvement in the direction of the therapeutic goal" (Will and Wrate, 1985:64-65). This structural concept is parallel to and congruent with the use of graduated task setting in the McMaster/problem-centered model.

The process of negotiating, implementing and evaluating tasks represents the backbone of the integrated model. The main goals of this approach are to: 1. Help members of the family system to experience each other in a different way. 2. Out of this ongoing process to begin to see alternative ways of understanding (cognitive restructuring) and relating (experiential). 3. To develop long term coping strategies and problem-solving skills which can be applied to future difficulties.

Tasks may be direct solutions to problems or they may be indirect attempts to induce movement in the family system. Families with ill children both at the time of diagnosis and at later stages frequently become overwhelmed by the intensity and array of affective and instrumental demands which confront them.

This model focuses on the family's need to brainstorm and to priorize their problems/concerns such that they can be addressed in a systematic, sequential manner. The process of partializing problems may in many cases, in itself help to reduce stress. Having gained a new outlook or perspective on the situation; what was previously experienced as overwhelming may then seem manageable. In addition the successful completion of tasks (which the family maintains responsibility for accomplishing) provides a sense of mastery and control at a time when family members feel helpless and vulnerable. The therapist has an important leadership function in assisting the family to select tasks which are constructive, realistic, appropriate and which contain the maximum potential for success (Will and Wrate, 1985:57). Epstein and Bishop offer several helpful guidelines for task setting (Epstein and Bishop, 1981:470-471).

In their description of problem-centered therapy, Epstein and Bishop emphasize that "from the moment family members come in, we repeatedly orient them to what we are doing and seek their permission and agreement before proceeding from one step to the other" (Epstein and Bishop, 1918:451). This is especially valuable for the families of concern who may feel anger, powerlessness and resentment towards medical staff who the family views as having imposed treatment regimens.

Relationships between parents and medical treatment providers may be strained, leaving the family feeling alienated towards those people they must depend on. As noted earlier the social worker practitioner also has an important role in intervening with the team in such cases.

The implicit message to the family in this task centered model is that they have the strengths and potential to resolve their own problems. The therapists role is to support, guide, offer feedback (i.e. reframe) and provide stability and objectivity in moments of emotional intensity. One of the overall goals of the therapy (which links together various tasks) is to promote problem-solving skills (Epstein and Bishop, from Gurman and Kristern, 1981:450). This is essential for many families with sick children who find that their previous style of relating has become insufficient or ineffective in light of new demands.

There are two central components involved in the integration of psychoanalytic thinking into this model of family therapy.

The first major component of psychoanalytic thinking involves the assertion that the therapist meeds to make formulations about family function and dysfunction not just describe them. Will and Wrate summarize eight typical dysfunctional patterns which occur in families; these processes (such as scapegoating triangulation and family beliefs and myths) allow conceptual understanding of family problems.

The second related concept involves interpretation as a method of effecting change through insight. They suggest that this aspect of therapy compliments the behaviorally oriented structural problem centered approach which represents the core of the integrated model.

Interpretation occurs through the "here and now" labelling of feelings and transactional processes as they occur in the therapeutic context. The application of this psychoanalytic principle differs drastically from its application in individual psychotherapy. In PCPFT the fundamental criteria for accessibility to treatment is the degree of emotional involvement of family members with one another; this contrasts with the pre condition of treatment in individual psychotherapy which requires the patient's ability to develop a transferrence relationship. In the PCPFT model the family remains preoccupied with each other rather than the therapist. (Will and Wrate, 1985:106-107).

The psychoanalytic component of the integrated model adds depth and conceptual clarity to this framework. It also allows (but does not rely on) the utlization of awareness in promoting the change process. With regard to the population of interest these concepts are particularly helpful in illuminating the nature and impact of past experience, and cross generational issues in the families ability to cope effectively. The labelling and interpretation of dysfunctional processes provides the family with the means and opportunity to evaluate their relationship patterns and responses to the illness experience. Of particular relevance is the explanation of idiosyncratic myths and beliefs about the illness which tend to greatly influence both the definition of this and long term coping strategies.

(d) Summary and Conclusions

The preceding discussion has attempted to provide an overview of the relevancy and appropriateness of the integrated model (PCPFT) as a framework for intervening with families with chronically ill children.

Particular attention has been paid to the writer's personal understanding of and recommendations regarding integration of the structural approach and the McMaster/problem centered model. Clearly the expressed bias is in the direction of upholding the straightforward, open, task-focused style which forms the basis of the McMaster framework. Structural concepts are accepted as invaluable in conceptualizing family organization; thus elaborating on the rather simply described family functioning dimensions associated with the McMaster model. In addition structural theory provides interventive tools needed to challenge those families who are resistant to a more direct approach. While relatively brief it was intended that this discussion would provide a basic understanding of how this practice model is applied to the target population. The integrated approach described by Will and Wrate is appealing because it is flexible enough to respond to families at times of crisis (diagnosis, acute illness phases) as well as for working on long term adjustment needs such as the requirement for reorganization of family roles. Furthermore it makes use of both behavioral and insight oriented techniques thus accommodating stylistic variation between families.

A point which should be reemphasized is that family therapy aimed at resolving internal systems problems is one aspect of the ecological approach which represents the writers overall orientation in working with this population. The interventions (discussed earlier) directed towards building social support networks, resolving team issues and helping the individual sick child to work through painful psychosocial conflicts are important adjuncts to family therapy.

Chapter iv - Individual Intervention with the Chronically Ill Child

(a) Introduction

The ecological approach builds on the notion of the "child as a whole". This incorporates the belief that "the child does not and cannot function in separate pieces, but only as a total dynamic biopsychosocial entity" (Travis, 1976:12). This holistic systems perspective provides a foundation for the selection of appropriate social work interventions. It has been emphasized that treatment should always include the family system which represents the mediating ecosystem which buffers the child's interactions with the external social environment.

Social work interventions aimed at the individual child are also indicated in some cases. One to one (or peer group) therapy particularly helpful for those children who are:

1. struggling with overwhelming and intense unexpressed emotions (for example, the child who is fearful of death but is reluctant to burden her already anxious parents);
2. experiencing conflict around identity issues and the need to become more independent.

In addition, there are many developmental issues particularly in the context of adolescence which are most sensitively and effectively addressed outside of the family interview (see section Literature Review - Impact of Chronic Illness on the Child, for further discussion regarding these issues). The need for individual therapy was assessed on a case by case basis.

(b) Principles of Selected Treatment Approach

In recent years, a plethora of therapy techniques has emerged. Most of the literature on interventions with chronically ill children has focused on individual verbal therapies (Schaeffer & O'Connor, 1983:1-3). Based on a review of literature in this field, it seems that many of the forms of intervention are viewed as falling within the broad category of "child psychotherapy". Dodd's describes this as:

> the process whereby a child is helped in a relationship with a psychotherapist to resolve emotional, behavioral or interpersonal problems. This process is designed to change the child in some way, either to ease internal pain, change undesirable behavior or improve relationships between the child and other people in the child's life (Dodds, 1987:15).

The child-therapist relationship in child psychotherapy is different from and yet shares some of the features of the child's other relationships. Some of the elements of the parent-child, sibling, and peer relationships are incorporated into this relationship, such as the degree to which the therapist imposes limits, plays, challenges, supports, and conveys positive regard (Dodds, 1987:16). Those elements which make the therapeutic alliance unique involve the attention to and intensive focus on the child's behavior, perceptions, fantasies, worries, and feelings rather than on the therapist. The therapeutic relationship may therefore involve a strong reciprocal emotional attachment. Because this is time limited, it is important to address termination issues with the child early on in the process so that he/she does not feel deserted, rejected, or confused by the ending of the therapy. The ultimate goal of this relationship is to help the child achieve more adaptive (and less painful) ways of adjusting to stresses

(Boston & Daws, 1977:206-207). Underlying the child-therapist relationship is a professional contract between a helper and a child which essentially involves a commitment of the therapists energies to the well-being, healing and growth of the child (Dodds: 1987:17).

The term psychotherapy often evokes certain negative connotations. These associations include: a narrow, inward looking focus, a fixation on identifying static personality traits, a tendency to attach stigmatizing diagnostic labels and a disregard for environmental influences. While these characteristics may accurately describe psychotherapy in its original form and it is carried in other current contexts, they, in no way reflect the students application of these concepts. This term is therefore used here to represent the basic therapeutic relationship outlined in the preceding description.

Within this relationship a range of specific techniques and activities may be selected depending upon the identified goals of the therapy and other relevant variables (such as age, sex, cultural identity, developmental stage). Play therapy represents a category of techniques which may be utilized in helping a child to resolve problems, communicate feelings about self and others and to promote developmental growth. It may also be effective in addressing conflicted emotions which underlie behavioral difficulties. For example many of the psychosocial problems encountered by chronically ill children and adolescents become manifested through acting out or self-destructive behaviors. Play therapy or other expressive activity may help the therapist in understanding the meaning and function of the (apparently dysfunctional) behavior for the child and secondly allows the opportunity for catharsis for the child. Play therapy and other expressive techniques are being proposed as particularly appropriate for chronically ill children for the following reasons:

1. Many children particular younger ones have limited verbal skills.

2. Lack of verbal skills in combination with the potentially limited ability to identify and express emotions imposes limitation on the effectiveness of verbal therapies.

3. Emotions related to the illness may be overwhelming, intense and highly negative; such feelings and their expression may have been discouraged by family members who tend to minimize or deny certain realities of the illness (Segal, 1984:593).

4. Consequently opportunities for release, catharsis and expression may be indicated but not in a manner that requires direct verbal acknowledgement. Games and play are an integral part of the child's world; such activity is familiar, non-threatening and associated with "fun" (Segal, 1984:593). As such playtherapy makes use of the child's comfortable way of being which relies on spontaneity and creativity. This allows for expression without "talking about" feelings.

5. Many treatment modalities construct a worker (expert) - client (recipient) structure in which the practitioner takes primary responsibility for analyzing and providing solutions to problems. Sick children are often already traumatized by the imposed need for dependence and obediance to activity and medical regimens. Expressive modalities create a context for self control and mastery over the

process of being helped (Fine, 1979:733).

In many ways play therapy represents more of an orientation to work with children rather than a cohesive theory. Play is an elusive concept to define; Bronfenbrenner describes three themes inherent in all play activity. The first is that play is an intrinsically motivated activity which is undertaken for it's own sake rather than being primarily a means to an end. Secondly play is essentially spontaneous and voluntary; thus it is engaged in by choice rather than compulsion. Thirdly, play includes an element of enjoyment or something that is done for fun (Musselwhite, 1986:3-4). Techniques within play therapy vary primarily in terms of the type of medium selected, such as use of toys, puppets, paints, dramatics, music or dancing; all share a commitment to the utilization of play (rather than only verbal exchange) in furthering therapeutic goals.

The student accepts the prescriptive approach to selection of specific methods and activities advocated by Schaeffer & O'Connor (1983:1). This involves selection of the most appropriate method based on the childs needs. For example the use of puppets might be helpful in work with a five year old, however such an activity would not be well received by a fourteen year old. One of the major conceptual divisions within play therapy is the distinction between classical structured and unstructured client-centered therapy. Given that the population of chronically ill children is not homogeneous both variations might be utilized. Thus while, a child from a highly disorganized family might benefit from the structure and security of the theraplay approach (Jernberg, 1983:6-9), another child may require the freedom and unconditional acceptance of Axline's Client-Centered Model (Mishne, 1983:279; Gumaer, 1984:38). With regard to adolescents, the use of play techniques will be much more limited. However, expressive activities will be used to enhance and supplement verbally oriented sessions.

One of the recommendations within this approach is that the therapist should seek to expand her influence thereby broadening the focus on therapy from the traditional emphasis on the unconscious self to include the child's cognitions, observable behavior, family system and other social relationships (Schaeffer & O'Connor, 1983:2). This framework is therefore compatible with the ecological approach which is being proposed an overall interventive guide.

PART IV - THE PRACTICUM EXPERIENCE: INTEGRATING THEORY AND PRACTICE

Chapter i - Implementation of the Practicum Design

(a) Introduction

This practicum involved contact with twelve families over the course of six and a half months in the pediatric gastroenterology clinic. Implementation of the practicum design did not differ substantially from the original plan although some relatively minor changes were made. The opportunity for the student to spend time in the practicum setting (the pediatric gastroenterology clinic) prior to the actual practicum phase facilitated the development of a workable realistic design. There were two features associated with this practicum plan which proved to be particularly challenging.

Firstly, the selected clinic area had not previously been covered by the social work department or had any significant experience with social work services. Thus in addition to the specified objectives there was a need to exert a substantial amount of time and energy particularly in the initial stages towards establishing a social work role in this setting. This challenged me to clarify my own thinking regarding the potential roles for social work in this setting.

This task was made more difficult at times by the added complexity of the dual researcher/clinician roles. Although the successful integration of these roles was possible there were inevitably at moments, some uncertainty regarding the nature and parameters of my involvement. These issues will be elaborated later on in this chapter.

It was agreed during the planning of this practicum that the placement period would involve six months rather than the usual three and a half. It was decided that an extended time period was needed both to address the students goals and to accommodate the needs and interests of the client group being served in this setting. This second consideration reflects the family focus of the practicum work and the particular long term needs of this population. The extended length of this practicum was extremely helpful in permitting the amount of time and energy needed to address the roles issues referred to above.

The practicum committee is composed of three members: Ruth Rachlis (primary advisor) associate professor, Faculty of Social Work; Dick Marinelli, director of the social work department, Children's Hospital; and Shirley Grosser, associate professor, Faculty of Social Work. Clinical supervision was provided mainly by Ruth Rachlis; consultation and support within the setting were received from Dr. Stanley Moroz, the physician in charge of pediatric gastroenterology and Dick Marinelli.

(b) The Setting and Client Population

The setting for this practicum was the pediatric gastroenterology clinic at the Children's Hospital, Health Sciences Center in Winnipeg. This is primarily an outpatient clinic however patients are sometimes treated on an in-patient basis. Medical care for these children is essentially provided by the primary physician, Dr. Stanley Moroz and the clinic nurse, Lynn Hilliard-Thorson. Other medical specialists and disciplines (such as dietetics, psychiatry and education) are consulted as necessary. There has never been systematic coverage of this clinic by social work; consults may be requested on an as needed basis.

This is the only pediatric gastroenterology in Manitoba. This clinic serves all children and their families in Manitoba who require this specialized medical care as well as some parts of Saskatchewan and Ontario.

The selected client group was drawn from the population of patients and their families under the care of Dr. Stan Moroz. The target population was defined as those children with inflammatory bowel disease; this includes Crohn's disease and Ulcerative Colitis. This specific disease category was selected as it matched the criteria of serious chronic illness established by the student (see Part I Introduction, Chapter iii - Parameters of target population and rationale). Other types of illnesses which are treated in the gastroenterology clinic such as liver disease were excluded as the result of obvious major qualitative differences in the experience of child and family.

Clinical features common to both disorders include diarrhea, gastrointestinal blood and protein loss, abdominal pain, weight loss, fever, poor energy level, and growth failure when the disease is severe. Crohn's disease differs from colitis in that it is not limited to a particular area of the gastrointestinal tract and may manifest itself from the mouth to anus. Both diseases may ivolve extraintestinal manifestations involving the eyes, joints, skin and liver (Grand and Homer, 1975:835).

(c) Selection Criteria and Referral Process

A total of twelve families was selected from this population over the six month practicum period. All families had a child with inflammatory bowel disease; either Crohn's disease or ulcerative colitis.

The main criteria for selection of families from this population involved age of the child. It was originally intended that if possible an equal number of children from each of three designated age groups (preschool; primary school age - grades 1-6; adolescents - grades 7-12) would be selected in the sample. Unfortunately there was a highly disproportionate number of late primary school age and adolescent patients in the broader population of patients: the sample drawn thus reflects this characteristic (Moroz, 1988). The client group included: one preschool age child, three primary school age children and eight adolescent age children; it should be acknowledged that there was a wide range of variation (age twelve-eighteen years) between the ages included within the adolescent category. This characteristic of the sample group reflects the nature of the broader population which typically involves onset of inflammatory disease in late childhood and early adolescence (Wood, Watkins, Boyle, Nogueira, Zimond, Carroll, 1987:778).

In addition to the age criteria, it was decided that Dr. Moroz (the referring physician) would refer approximately equal numbers of families who he perceived as coping well and families who seemed to be experiencing difficulties. The purpose of this additional criterion was to ensure a range of variation with regard to psychosocial functioning. This criterion had the effect of preventing the selection of a sample group characterized by extremes; either an overrepresentation of pathology or exceptional coping patterns. This was in no way conceptualized as an assessment tool or method of classifying families according to coping abilities. In fact it was agreed that the physician would not inform the student of these impressions until after the initial assessment had taken place.

It should be noted that it was assumed that selection according to these criteria would allow some variation with regard to stage of illness which is an important variable in determining illness experience.

It is worthy of mention that this selection process was made intentionally simple. While a more elaborate selection criteria might have been developed there was a concern that preoccupation with sample variables would potentially detract from the central goals of this practicum experience which involved developing a greater understanding of the experiences of chronically ill children and their families and to develop an ability to intervene effectively. Since rigorous empirical study of variables and causal explanation were not the aim of this practicum, it was decided that sampling accuracy was less crucial than the above considerations.

Initial contacts with all families were made by Dr. Moroz either by telephone or during clinic visits. The purpose of these contacts was to explain the purpose of the students involvement and to obtain permission for the former to contact the family for an appointment. Normally I contacted the family (parents) by telephone to set up the first family meeting. Occasionally this first contact involved a brief interview in the clinic setting. The student initially requested two family interviews; a family meeting and a second meeting to discuss the results of the paper and pencil measures which the family were asked to complete. Additional interviews with the children either individually or as a sibling group were often requested. The decision to request meetings with the children was based on assessment considerations such as a child's apparent ability to express herself in the context of the family interview and the identification of clinical concerns. My role was twofold; firstly that I was a graduate student learning about the impact of chronic illness on children and their families and secondly that I was also available to provide service in the form of information giving, counselling, sharing experiences of other families should such a need be identified.

This referral process worked very well. The initial contact by the physician had the effect of validating the student's role as an accepted member of the team providing care for their child. It also provided an opportunity to reassure families that involvement in this study was purely voluntary and that non-participation would in no way affect the medical care provided to the child.

(d) Researcher and Clinician: The Challenge of Dual Roles

As stated earlier, the task of simultaneously carrying out the roles of clinician and researcher represented a major challenge within this practicum experience. While at times this duality was frustrating, much of my personal learning was based on the process of wrestling with these issues. Although in some ways this role integration was problematic (particularly with regard to limiting clinical involvement) there were also unexpected gains.

One of the issues resulting from this design was a tendency for families to focus on the research aspect of the student's involvement in the gastroenterology clinic. Even though it was explained during the initial contact that I was available to provide social work services, families tended to adhere to the researcher component of my role. This pattern was problematic in that it was difficult to engage families in working on concerns and problems identified in the assessment process.

One plausible explanation for this development is the level of comfort experienced by families in participating by offering information in contrast to asking for help. This researcher/educator relationship permitted a degree of personal distance (and thereby safety); the helper client relationship in comparison necessitates a level of openness and vulnerability which is generally much more threatening.

One of the positive outcomes of the research role was the opportunity it created for the acknowledgement of the family's struggles and experiences and for an affirmation of their strengths and competence in coping with this life experience. The initial family interview thus provided a forum within which families could air their concerns and ventilate emotions. In verbally conceptualizing and reframing families' stated responses about how they managed their child's illness as (for example) "ways of coping" or "the difficult aspects of this experience" the families were offered a new framework for making sense of their experiences. The assessment interview thus provided the opportunity for family members to reflect on and reevaluate their own issues and needs without having to request or even accept professional help. For a small number of families this contract led to identification of needs or problems for which they wished assistance from the social worker or other community resources.

A less primary but influential factor was that some families viewed the researcher/practitioner role as mutually exclusive. This became evident as the result of discussions with families about these issues. One parent commented that "I didn't know social workers did studies like this . . .". This situation is connected with commonly held assumptions and perceptions with regard to the potential scope of the social work role and the purposes of social research. The notion that research may be a step in the process of discovering "how to be helpful to families with an ill child" was quite novel for many clients. In reflection, the predominant view that research/practice are disassociated activities is completely understandable, particularly given that even within the social work profession there is currently much controversy about the compatibility of and potential for integration of these functions. Thus the multidimensional aspect of my involvement in this setting was bound to lead to some confusion in relating to families, particularly in the initial phases.

Of note is the fact that this role duality was not an issue within the medical team. The integration of direct patient care and medical research have historically been accepted as important components of the physician's role, particularly medical specialists. The physician's familiarity with and acceptance of this orientation to medical care therefore served to promote and encourage the incorporation of research and clinical social work objectives.

One of the unexpected benefits of the researcher role was that it provided me with the opportunity to share findings with families regarding how other children and their families have coped with the experience. Almost all families interviewed specifically asked how other families had managed particular aspects of the illness experience. Some of the common refrains included "is my child like other kids you've met?", "do other parents worry about their child's diet?", "are we managing O.K. compared to other families?" The offering of information about the experiences of other families helped to normalize families (particularly parents) experiences; this represented a small but significant therapeutic intervention even with those families who were seen only for assessment. Furthermore this was found to be a powerful vehicle for change in the small group of families who received more intensive service. For example one family struggling with a non-compliant teenage boy with Crohn's disease found it very helpful to know that other adolescents went through similar phases of response to their illness; this offering of information provided the opportunity to reframe this boy's behavior in a positive way (see Chapter ii (b) Case Illustration - Family B).

An associated positive aspect of the dual role involved the opportunity to share a broad base of information regarding families subjective experiences within the medical team. In addition to specific case discussions, weekly meetings with the primary physician and nurse (and informal contacts with the hospital, school teacher and other service providers) provided these other care providers with new awareness and deeper understanding of the range of psychosocial and pragmatic issues experienced by this populations. The physician reported that this information about psychosocial functioned helped him to respond more sensitively to families' specific needs and therefore to more effectively promote the care of the child.

(e) Creating a Niche: The Social Worker as a Member of the Multidisciplinary Family

It has been previously stated that this clinic setting had not had regular or systematic social work coverage prior to the practicum arrangement. Consequently there was no pre-determined role assigned to social work. The process of carving out a role for social work within the team, establishing credibility and clear parameters regarding social work activities and goals, represents an important aspect of the work involved in my practicum experience. This was made even more personally challenging in that I was relatively new to the multidisciplinary health care setting.

It should be noted here that while there were often multiple disciplines involved in the care of the patient over time, there was no formalized team structure. Thus team is used in this context mainly to refer to myself, the physician, clinic nurse and other specialists and disciplines who were consulted on a case by case basis.

In certain ways, integration of social work into the gastroenterology clinic was facilitated by the physician's sensitivity to psychosocial issues and an identified need for social support services. The need to develop a better understanding of the psychosocial impact of chronic childhood illness and to extend efforts to promote positive coping (i.e. towards optimal management of symptoms) were goals shared by the physician, nurse, and social worker. The articulation of these commonly held objectives provided the basis for the development of ongoing working relationships.

Weekly meetings which included myself, the physician and clinic nurse provided the opportunity for exchange of information, planning and problem-solving. These sessions allowed me to define and clarify my professional orientation, to offer perceptions of family issues and to suggest intervention strategies. Conversely these meetings enabled me to learn about the teams' long term and immediate experiences and problems with regard to provision of care to patients and their families.

This was a reciprocal process which involved mutual benefits for the three primary disciplines represented. As social worker, I needed to learn about the medical aspects of inflammatory bowel disease, principles of medical management and the physician's perceptions of families strengths and difficulties in order to understand and respond to clients' social, emotional needs. The physician on the other hand needed to better understand the family's subjective experience of their child's condition in order to provide more effective physical management of the disease. For example, knowing that a particular family believes that their teenage son's high chocolate intake brings on symptoms provides the opportunity to clarify dietary issues and promote understanding of lifestyle factors in the management of Crohn's disease.

The clinic nurse contributed an additional dimension of understanding as she maintained regular contact with children and their parents during clinic visits. She therefore had a long term perspective of individual children's coping and management concerns as well as knowledge of anxiety surrounding clinic visits and diagnostic procedures. Her community health background facilitated an integration of medical knowledge with a basic comprehension of the psychosocial aspects of pediatric illness.

At times I was aware of a potential overlap between the nursing and social work roles. This is increasingly an issue within the context of the multi-disciplinary team approach in general, particularly given the recent broadening of the nursing role to include greater attention to the psychosocial aspects of illness. Within this clinic setting for example, there was potential for expansion of the nursing role to providing community health education, follow-up of medical management (such as home treatment regimens) and social support activities.

As a member of this team I supported the idea of expanded nursing involvement in these directions. For example, one possibility discussed was the development of education/support groups for parents, ill children, and siblings to be co-led by nursing and social work. This would provide an opportunity to combine and optimize the related, complimentary skills and knowledge of the two disciplines. In this and other clinic settings the nurses knowledge of medical management issues, the stresses associated with diagnostic and treatment procedures and skills in providing social support are extremely helpful to families.

While also oriented towards providing social support the unique contribution of social work involves the skills and ability to assess and intervene in the psychosocial functioning of the child and family. In addition, the social worker offers skills in understanding the child and family within their broader ecosystem and in identifying the need for and accessing resources and supports. In addition, the social worker's attention to the interplay between systems with which the family is in contact, suggests a role in coordinating and integrating multi-disciplinary services provided by the team. It is these features which in my perceptions and experience, differentiate the social work from the nursing role.

The explicit distinction of professional roles would be especially important in those settings in which the nursing role was expanded (beyond traditional confines) in order to maintain some clarity of function and to minimize duplication of service. Based on my experience in this clinic however I found that the overlap or degree of shared attention was beneficial and promoted strong team relationships and optimized the consistency of care provided to the child and family.

One of the important organizational features of this setting was that economic resources were very limited. One of the reverberations of this situation was that the clinic nurse maintained responsibility in several areas; her opportunity to become involved with children and their families was essentially confined to brief contact at the time of clinic appointments. In contrast, I had the opportunity to become intensively involved with families; this included home visits and discussion about medical management concerns. While the nurse clearly recognized and supported the need for social work involvement, my activities and presence seemed to serve as constant reminders of the limitations of the nursing functions as imposed by this setting. This tension was not, in my mind, an evitable outcome of the recent blurring of professional (social work and nursing) roles described above but rather reflected the particular rigidity (apparently based on limited resources) of this health care system.

This situation in fact suggests that the flexibility of the organizational structure and its responsiveness to the needs of its care providers (ie. making optimal use of capabilities and skills) has a dramatic impact on the success of the multi-disciplinary team approach. From an ecological perspective then, issues such as professional "territoriality" referred to so extensively in the literature are as much a product of organizational features as they are an outcome of unclear professional boundaries and personality conflicts.

Ongoing attention to these role issues and efforts to support the nursing role was found to be important in the process of establishing a mutually respectful working relationship.

Implicit within the medical model which represents the foundation of health care delivery in this setting is the notion that problems can be diagnosed and resolved through specific prescriptive measures. To some degree organic medical problems are amenable to this approach; in comparison, the psychosocial issues which may arise out of or separately from illness experiences, are usually much more complex and difficult to resolve. One of the most challenging issues confronted in this practicum experience was the need to develop effective team relationships in the face of different and sometimes opposing views about problems and more importantly the nature of the change process.

The physician typically (and appropriately) identifies a problem and instructs the child and family about how to go about alleviating it. For example a reactivation or increase in symptoms (ie. stomach cramps) may be responded to with a specific change in medication or recommendations with regard to diet. It should be acknowledged that while this is an oversimplification of the complexity of diagnosis and treatment it explicates the linear problem solving process on which the medical model is based.

This model is limited in that it does not account for, or prescribe alternative strategies in dealing with factors such as non-compliance which complicate straightforward medical treatment. Cultural values, cross generational illness experiences, family dynamics, developmental features (ie. child's age) and the presence of other major stressors represent some of the primary variables associated with acceptance of and compliance with medical regimens (Pravder, Mirkin, Koman, 1985:92).

It is with regard to these and other coping issues that social work referrals were often initiated. The ecological model provides a useful supplement to the medical model in that it provides a more complex understanding of (for example) compliance by comprehending and responding to it within the longer psychosocial context of the child/family's illness experience. Thus compliance becomes a question of: "how does this family make sense of and respond to this illness in ways which interfere with medical treatment" rather than "why won't this family help the child to get well?"

Change in the social work framework thus involves an ongoing process of reevaluating meaning and depends on family members' ability and motivation to take charge and help themselves rather than advice giving.

This incongruency in perception of how problems are resolved manifested itself, especially in the first few months of the practicum experience, in several ways. Firstly as I began assessing families and identifying problems in coping (ie: denial of permanence of illness, excessive focus on the needs of the ill child) it was expected that these families would in most cases (1) agree that there was a problem; (2) accept my view of the problem; and (3) welcome the opportunity to receive help in resolving it. Predictably some families who were assessed as having some degree of trouble coping, viewed themselves as managing well and did not desire support or services from the worker or other helping professionals. (It should be noted here that many families who were assessed to be extremely skilled at managing the ongoing stress of their child's illness were much more critical of their shortcomings than was the interviewer.) This situation was not surprising to the social worker who found this characteristic based on several years of clinical experience in working with families.

One of the tasks in addressing this difference in professional perspectives was to present a more realistic picture of social work involvement and to establish appropriate expectations through ongoing dialogue with the physician and nursing, ie. that not all families think they need help and even when they do, the social worker cannot ensure that problems will be solved.

Over the course of these six months, the worker was able to clarify these issues and to establish more realistic parameters. This issue was recognized as typical of the multi-disciplinary team context which necessitates the integration of multiple perspectives and requires ongoing attention and clarification. The challenge for the worker was to retain a clear vision about the parameters of her potential and actual contributions to the overall care provided to the child and family and at the same time not accepting or internalizing inappropriate expectations about what could be accomplished.

Over the first few months of this placement the social worker overcame an initial reaction of vague discomfort and anxiety (about the degree to which she could prove her value as a team member) to a clearer conceptualization of this issue as the natural struggles involved in the integration of a new discipline into a pre-established medical team. The challenge then became one of educating others about the social work role and perspective and secondly to find ways to work together given differences in perspective rather than continually trying to minimize or avoid them.

Recent literature on the subject of the integration of social work into the multi-disciplinary health team stresses the role of informal educator as an essential component of social work involvement in this setting (Abramson and Mizrahi, 1986:8). This is described as one aspect of an overall strategy towards collaboration with physicians and other team members. Many of the tenets of this model were found to be very helpful to the social worker in conceptualizing and carrying out her role within the team.

Abramson and Mizrahi (1986) suggest the utilization of the concepts of negotiation and exchange in establishing social work roles; they argue that social workers will have greater success in influencing physicians if they focus their efforts on strategies which take into account the power and socialization differences between the professions. These theorists assert that social workers can have the greatest influence by the identification of social work as a resource for the physician rather than always striving for equality in status and power. Activities directed towards this end include informal education regarding psychosocial and environmental issues, integration of counselling and concrete services (ie. community resource liaison) and providing support and acknowledgment of physician's stresses. This last strategy involves recognition that "many unsetting feelings remain unaddressed in a medical culture that does not permit their expression" but which promotes detachment from emotional issues and autonomy and self reliance as basic values (Abramson and Mizrahi, 1986:2). Thus the social worker who has been socialized and educated to be sensitive to psychosocial realms, to work collaboratively with others and to offer support can make optimal use of skills in building team relationships rather than being hindered by the differences in values and perspectives.

(f) The Client Population: Overview of Demographic Features

I became involved with a total of twelve children and their families. While the selection process was designed to maximize sample balance with regard to key identified variables, such as age and stage of diagnosis there were certain characteristics of this group which should be noted. The distortions in the features of this sample reflect two major factors; firstly the inherent problem of representativeness associated with small sample size and secondly the particular characteristics of the broader population of children with Crohn's disease and ulcerative colitis. Based on discussion with Dr. Moroz it was learned that the majority of children with inflammatory bowel disease are diagnosed between late elementary to adolescent age categories.

The particular features and characteristics of this client group are worthy of description since they influenced both the type of social work involvement and the observations made about family functioning and coping styles (see Table 1: p. 111).

Because one of the stated objectives was to learn more about how illness experiences interact with developmental tasks the social worker attempted to select children from a range of ages. To a great extent the variation within the sample was limited. This reflects the typical onset of inflammatory bowel disease in late childhood and the early teenage years; there are very few patients in this category under age seven or eight years. Within the adolescent category there was a concentration of older children with an average age of 15.5.

Another feature of this group of families is that only two had experienced diagnosis within the past four months or less. All other families had children who had been diagnosed from two to five years previous to the social work contact. This is due in part to a greater actual number of long term patients than new ones but perhaps also a tendency for the physician to refer families with whom he was better acquainted and therefore more comfortable. This feature of the client group meant that most families interviewed were experiencing later phases of adjustment to chronic illness; there were few opportunities to directly observe the experiences of families in the initial phases. In fact the majority of familes had lived with the diagnosis for at least two years. This pattern had a significant impact on the process of engagement and nature of social work involvement with this client group (see Chapter ii - Summary of Social Work Involvement for further discussion).

Another notable aspect of this sample group is the over-representation of girls. There was a total of eight female children compared with four males. This imbalance is partially explained by the fact that two of the referred families (whose ill child was male) did not follow through with participation in interviews and are therefore not included in the sample group. In addition to the under-representation of boys the ages of male children were clustered between fifteen to eighteen years while the ages of female children ranged from four and a half to eighteen. This pattern is not representative of the larger population of children with inflammatory bowel disease and is a product of the small sample size. In other words there is a relatively equal number of boys and girls with IBD and relatively parallel age distribution across gender (Moroz, 1988).

Interestingly, there was a surprisingly high number of traditional two parent households in this group; only two families were headed by a single parent (mother). In fact one of the two single parent households became a two parent household over the course of the social work contact. This high percentage of two parent households (which is certainly disproportionate to the general population) is representative of the broader population of patients with inflammatory bowel disease seen in this clinic. An additional associated observation is the relatively high socioeconomic status of this group of families. General information regarding this feature was obtained through the Chronicity Impact and Coping Instrument: Parent Questionnaire.

Table 1

Client Population Demographic Information

Racial Origin Caucasian - 12	Area of Residence Winnipeg - 10 Center outside of Winnipeg - 2	Socio-Economic Status Upper - 0 Upper-middle - 4 Middle - 6 Working - 2
Family Structure /Form Reconstituted - 2 Single Parent - 1 Two Parent - 9	Number of Children in the Family One child - 1 Two children - 8 Three children - 3	Sex of Siblings male - 7 female - 5
Sex of Patients Female - 8 Male - 4	Birth Order of Patient First born - 6 Second - 5 Third - 1	Age of Patient at Diagnosis Birth-Two - 1 Two-Six - 0 Seven-Ten - 4 Eleven-Thirteen-7 Thirteen + - 0
Diagnosis Crohn's disease - 10 Ulcerative colitis - 1 Ulcerative colitis with unusual liver involvement - 1		Length of Time Since Diagnosis (at time of Initial Contact less than two months - 1 less than six months - 1 six months - one year - 0 one to two years - 0 two to three years - 7 three to five years - 3

Chapter ii - Summary of Social Work Involvement

(a) The Nature of Contact with Children and Families

One of the primary objectives of this practicum was to develop a better understanding of the coping strategies utilized by chronically ill children and their families. Of particular interest was the elucidation of helpful coping mechanisms and the factors which moderate these strategies. A second objective was to develop an understanding and ability to intervene effectively with families who were experiencing difficulty in adaptation to this life situation. This combination of objectives necessitated the development of dual researcher/clinician roles in the gastroenterology clinic. As a result of this integration of roles, the social worker contact with the client group involved only assessment interviews with some families and more intensive involvement with others. The type and extent of social work involvement was based on identification of need by the worker and family.

One of the limiting aspects of the research component of the practicum work was that it restricted the opportunity for clinical intervention based activities. This occurred given that many of the families seen by the social worker were managing well and did not require social work services. In addition (as is predictable in any clinical helping context), within the sub-group of children and families who were assessed as experiencing problems (or who themselves voiced concerns) there were some who did not wish external support services. A third important factor which greatly impacted the social workers ability to engage families to work on various issues was the fact that the vast majority of families in the sample had lived with the diagnosis for at least two years. Consequently many of these families felt that they had "been through" the experience and had to a greater or lesser extent mastered the demands and stresses associated with it. One of the themes in my contact with this group over the six months was that families repeatedly stated that they wished I had been available at the time of diagnosis.

While this practicum could have been designed to maximize the social worker's opportunity to intervene with families around illness issues (ie. such as referral only of families with identified problems or at the initial stage of diagnosis) this would have eliminated the opportunity to learn from positively coping families. Thus the limitations described above are not viewed as problems with the practicum design but rather as an outcome of my conscious effort to balance personal objectives.

Of the twelve families, the social worker became involved in intensive intervention efforts with three and limited short term services to two others. The remaining seven families were seen for two or three assessment interviews although it has been suggested earlier that these contacts were in themselves therapeutic in nature (see previous Chapter i (d) Research and clinician . . .). The second meeting with families was set up to share information and obtain observations made as the result of scales which family members were asked to complete. Discussion and feedback about coping patterns and family relationships tended to elicit dialogue between family members themselves and between myself and the families. In my mind this contributed to the depth and richness of these contacts.

None of these seven families had ever had the opportunity to discuss their experiences with a professional helping person. Almost all families interviewed reported some gain from this process; these included (for example) a better understanding of the illness, getting the chance to learn about other family members' thoughts, feelings, feeling like "we're doing O.K.", hearing about other families' experiences, leanring about other resources in the community. Several families also said that they appreciated the fact that someone was interested in "what we have gone through . . .". I also maintained occasional contact with some of these families with regard to an identified and for medical information or clarification of medical management questions (ie. concern regarding number of pills prescribed and queries about diet).

(b) Case Ilustrations

Introduction

Given the number of families interviewed over the course of this practicum it is not possible to describe each one in detail. Chapter iv [(b) Themes, patterns, issues . . .] will incorporate a summary of the patterns and variations in the coping experiences of this client group as a whole. The purpose of this section is to present three case illustrations intended to elaborate the experiences of three families in adapting to inflammatory bowel disease. An attempt has been made to include families with whom the social worker became the most involved and to include a range of variation with regard to the ill child's age and family form.

Within the context of these case illustrations I have incorporated discussion of the selected practice models. The ways in which the described integrated approach was found to be helpful in conceptualizing illness experiences and assessing and intervening in family systems will be explored. The following discussion will additionally incorporate the perceived limitations of the practice models as they were utilized in this practicum experience.

Family A: A Family with Multiple Problems

Identifying Information

Patient: Nicky (age fifteen)

Diagnosis: Crohn's disease, approximately 2.5 years ago

Treatment:
- has had major surgery in initial phase
- in initial phase home tube feedings
- currently not on any medication

State of Health over period of Social Work Involvement:

excellent, no symptoms

Family:
Mother: Louise
Mother's fiancee: Dave (currently living in the house)
Nicky: age fifteen
Lorne: age eight
Aaron: age seven

(see Figures 1-3 for: Summary of Chronicity Impact and Coping Instrument, Self-Appraisal Inventory and Family Assessment Measure)

Social Work Involvement

This family was referred in the second month of the practicum. Louise communicated some reluctance to set up a family meeting on the telephone; it was finally agreed that I would meet with the family in their home on a Saturday morning. All members of the household (at that time) were present; Louise (Mother), age approximately thirty-eight years; Nicky, age fifteen; Lorne, age eight; and Aaron, age seven. Dave and Louise were dating t this time but he was not yet living in the home.

The focus on the first two assessment interviews was on the family's experiences, perceptions, feelings around Nicky's illness. All members were asked about their understanding of the disease and how they would describe its impact on them individually and the family. A theme which quickly emerged was this family's predominant experience of the early acute phase of Nicky's illness and the frightening and somewhat overwhelming nature of the treatment process.

Lorne, Nicky's eight year old brother indicated that he was afraid that his sister would die when she was in the hospital. Aaron did not seem to have much memory of this experience. Although Louise communciated confidence in the medical care provided to her daughter, she did indicate anxiety about the necessity of surgery. Louise in fact consulted a woman involved in "healing through magnetic fields" who claimed an ability to alleviate Nicky's medical problem. Louise was dissuaded from this alternative treatment by the physician.

Nicky and Louise conveyed a great deal of pride about their successful home management of Nicky's TPN (total parenteral nutrition) system which required hooking an intravenous tube to the central line surgically implanted in her chest. They seemed to view this home treatment as a challenge and not as negative intrusion.

Through the first two interviews it became clear that Family A had thus far experienced Nicky's illness as a short term crisis and that her Crohn's disease was not an immediate (or particularly primary) concern for any family members. My assessment of this was confirmed by the results of the Chronicity Impact and Coping Instrument: Parent

Questionnaire (CICI:PQ) which revealed no concerns regarding coping with the illness. This subjective appraisal may be partly explainable by the fact that Nicky had been in excellent health for an extended time period so that the family had not experienced the chronicity element to the same extent as many other families.

They seemed to understand that the illness was incurable and likely to reappear, but didn't express chronic anxiety about the future in this regard.

Family A generally viewed Nicky as a healthy, normal person. This was confirmed in the finding of the CICI:PQ which indicated high physical health ratings for all members (see Figure 1, p. 194). In my assessment there were additional factors related to this family's social milieu which also influenced their particular appraisal of Nicky's illness; this will be discussed later on.

Family Background and History

The integrated model of family therapy described earlier emphasizes the importance of focusing on here and now functioning in family systems in assessment and intervention. While I accept this basic premise I also believe that, particularly with regard to long standing family functioning problems, an understanding of the historical social context is extremely helpful in making sense of current problems. This is consistent with the ecological approach which stresses the concept of long term adaptation or person/environment fit in influencing how families respond to the crisis of serious chronic illness (Germain, 1984:58-59).

This particular case illustration represents my experience in working with a family with multiple serious long term social problems which precede the onset of illness. Some of the primary historical features will be briefly sketched in order to provide background to the family's response to Nicky's Crohn's disease and my involvement with this family.

Louise has been divorced from the children's father Jacque for two years, however the last separation from him occurred six months ago. The couple were separated intermittently through fifteen years of marriage; usually precipitated by Jacque's violent tempers in association with his severe alcohol problem. Although present in the home at the onset of Nicky's illness Jacque is described as uninvolved. Louise is now engaged to an ex-friend of her ex-husband. While Nicky was spared direct violence from her father she developed a parental role in the family; protecting her mother and calming her father during his frequent violent outbursts. She stated that "I'm the only one he would listen to ...".

As a young mother with three small children, Louise (with no job skills and a low confidence level) found it impossible to permanently extricate herself and the children from this marital relationship. She had few supports and describes her extended family as being more troublesome than helpful. Louise describes a history of sexual abuse in her family of origin involving abuse perpetrated by her brothers against her younger sisters. In addition Jacque maintained a long term sexual relationship with her sister over the course of their marriage and with whom he has had a child.

In summary, Louise has experienced chronic lack of stability in relationships, violence, social isolation, alcoholism and poverty. It seemed to me that Louise had experienced betrayal by many if not most of the significant people in her life. At the time of the first interview Louise was receiving social assistance but had just received employment involving on the job training. She indicated that she was looking forward to being independent and at the same time anxious about her ability to succeed. She also described a history of negative, conflictual contact with social workers and other helping professionals.

Family A's particular response to Nicky's illness must be comprehended within their social milieu. The lack of social stability and patterns of alcoholism and poverty are clearly integenerational in nature and involve deeply ingrained values and beliefs about the world. This event (which is perceived as unpleasant and uncontrollable) represents one more life experience which confirms the family's view of the world as an antagonistic place in which negative things regularly occur, over which one has little control. Furthermore it is perceived that although often one can expect to be betrayed and injured by family members, individuals and (for example) child welfare, social assistance systems outside the family are even more threatening to the family's integrity and survival. This is reflected in the CICI:PQ which reveals concern about child management and behavior but no identified wish for help from external resource systems. These beliefs have in this case led to a coping style characterized by a reactive, passive stance, rigid boundaries around the family system with few efforts exerted towards anticipating or planning long term needs. This has created a reciprocal pattern in which the family's coping style (or way of responding to the world) in itself perpetuates and precipitates events and processes which serve to continually reaffirm their reactive, insular response style.

Family A therefore does not focus or reflect much on the illness not only because it is inactive but also because they are understandably attending to ongoing survival concerns (money, avoiding violence, keeping the family together) and don't perceive that they have any ability to control the illness experience anyway. Secondly this family operates in an intermittent state of crisis and will respond to a flare-up when it happens. Their familiarity with crisis response in fact enabled them to cope very well with the dramatic emotional and instrumental disruption of the initial acute phase of Nicky's illness.

Louise describes a scenario in which she "rocked (her twelve year old daughter) to sleep" when Nicky had severe abdominal pain at night prior to the diagnosis. From a psychosomatic perspective the onset of Nicky's Crohn's disease had the effect of forcing the family (particularly her parents) to recognize and respond to her childlike need to be physically and emotionally comforted and nurtured, thereby allowing her (at least temporary) respite from her undesirable parental role in the family. Within this perspective it may be speculated that Nicky's physical symptoms represent a reverberation of dysfunctional family processes (Dillon, 1985:36).

Even if the etiology of her illness is accepted as organic in nature, one might at least expect a pattern of continued activity of the disease due to the ongoing stresses and conflicts experienced within this family. However in this case there has been no reappearance of symptoms since the resolution of the first illness episode. This seems to provide evidence which challenges the psychsomatic model of pediatric illness.

Engagement and Contracting

At the end of the first interview Louise and I identified two central immediate concerns; first Louise's concern that the children had been negatively impacted by their experiences with their father (and that this was expressed primarily as "acting out" behavior) and secondly that Louise herself was in the initial phase of recovery and was struggling with instrumental and self esteem issues. While Nicky's health was not an identified problem at this point I emphasized that what was happening in the family was likely to influence the appearance of symptoms and reciprocally, that when Nicky was sick this had an effect on all family members. This made sense to the family. I was careful not to leave the impression that family problems had caused the disease but rather that stress and unresolved conflict tended to activate as opposed to calming symptoms.

At this point I offered to meet with the family for two or three additional sessions to further explore and discuss these concerns. Particular efforts were made to acknowledge Louise's strengths as a "survivor" of a long history of abuse and her ability to "make it on her own". The offer of service was framed as a resource for Louise in her personal efforts to get on with her life and in helping the children to express themselves and make sense of their experiences. It was also agreed that the worker would meet individually with Nicky to further discuss her illness and feelings about her father.

Intervention

The social worker's involvement with this family over the following four months was focused on their immediate social, emotional problems. While Nicky's diagnosis of Crohn's disease was the entry point for social work contact it was not the focus of the work. In the initial stage of contact the family accepted the offer for help and support particularly with regard to adjustment to the loss of their husband/ father. The availability of the social worker to assist the family in resolving problems separate from those related to the illness was clearly stated. This is seen to be consistent with the ecological orientation involves attention to the context within which illness occurs particularly those features likely to impact upon (1) the progress of the disease process and (2) long term adaptation to this illness. In this case scenario while the illness had not in itself had dramatic reverberations for the family, their overall level of functioning was likely to promote reactivation of the disease and impair successful long-term coping. Data from the Family Assessment Measure (FAM) provided additional confirmation about the nature and degree of unresolved conflict; particularly between Nicky and her mother around rules, responsibilities (see Figure 3, p. 196).

The social worker met with family A for three additional sessions. The first two sessions included Louise, Nicky and the two boys. Louise talked about the difficulties of parenting alone but expressed relief about finally having Jacque out of their lives. She also expressed concern about being able to provide financially for the children. Louise indicated that she knew the kids had been hurt by their dad's drinking, temper and his irregular presence in the family over the years. She felt that the main indicator of this was their "wild" behavior. Louise was encouraged to express her feelings and concerns to the children during these sesions. The boys (particularly Lorne) were quite verbal and expressed feelings of anger towards their father and also gladness that he was gone.

Information collected from the Self Appraisal Inventories provided important supplemental assessment information. For example while the children expressed little concern about the current family situation, all three had low scores on the family subscore, particularly the boys. One of the goals in this initial stage of work was to help family members identify and discuss their feelings directly to each other and to help connect past experiences with current family functioning.

One of the structural features which became evident was the lack of clear generational boundaries characterized by mother vacillating between authoritarian and laissez-faire parenting styles; this was exemplified in Louise's relationship with Nicky. While in some circumstances Louise treated her daughter as confidante the next moment she was extremely controlling and demanded absolute obedience. Nicky stated that she thought her mother was overly strict and made too many demands. I commented often on the developmental aspect of this ongoing conflict; that Nicky was a teenager and wanted to be treated as an adult (ie. freedom to go out) and that Mom often responded to her daughter inconsistently. I suggested that this was hard for parents when their child has one foot in childhood and the other in adulthood. This led to discussion about "finding a balance" and reasonable limit setting. I drew on the concepts of control and roles and the structural notion of boundaries from the problem-centered model in conceptualizing and clarifying this problem area (Will and Wrate, 1985:28).

I met with Nicky individually initially for assessment purposes. This was perceived as valuable particularly given the current family conflicts identified in family sessions. Nicky presented in this context as a very vivacious bright fifteen year old who had been through some very difficult and painful experiences. She had developed in response, a sort of "tough girl" persona characterized by wild hairstyles and clothing and wild behavior with her peer group. Clearly Nicky had learned to get her emotional needs met by boyfriends and her peer group in general rather than her family.

Based on Nicky's identified need to have someone to help her sort through her experiences, a contract was developed. It was agreed that I would see Nicky once every two weeks for an hour; we agreed to hold these sessions at the neighborhood donut shop. Louise gave her approval for this contact. The arrangement that I would pick Nicky up provided the opportunity for brief contact with the rest of the family.

The decision to work with this teenager individually was based on (1) her identified need to talk about her history and current concerns, (2) that although mom had indicated a desire for support she did not wish to continue family counselling.

At the time of the fourth family session it was decided that family counselling would be terminated. Dave, who I had not met previously was present at this interview; it was announced that he would be moving into the apartment. This session represented a major shift in the relationship between myself and Louise; her previous presentation of guarded vulnerability changed to more overt antagonism and suspicion. When I attempted to frame this change in the family situation (Dave moving in) as a blended family issue; "it takes some time and work for people from two families to learn to live together . . .". Louise interpreted this as criticism of her adequacy as a parent. She also reemphasized her past negative contacts with intrusive social workers. Louise also stated that the children were going to have to "tow the line' from now on. Dave refused eye contact and responded in one word answers. The children clearly took their cue for passive participation from Louise and Dave. It was agreed that for the time being it would be alright for me to continue meeting with Nicky individually. I acknowledged Louise's feelings of being intruded upon and her right to discontinue family meetings. I also attempted to reframe our family work as my offering support to Louise and the children in their efforts to solve their own problems rather than as imposing solutions.

I assessed this development in my contact with Family A as a result of Louise's growing discomfort with allowing a helping person into the family but even more importantly the now solid presence of Dave as the head of the household. Dave not only wanted complete control of this family but had also apparently had conflictual contact with Child and Family Services around the apprehension of a young child from a previous relationship. I was able to maintain some contact with Louise by telephone over the course of her involvement with the fifteen year old and took the opportunity to mail her information (about out of school care programs subsidies) however there was limited involvement after this point in time.

Germain and other theorists talk about offering services to families in the early stage of crises (ie. diagnosis of serious illness) when families are most amenable to intervention efforts (Germain, 1984:66). This change in my relationship with this family may be understood within this theoretical framework. Initial contact took place at a time when Mother was feeling vulnerable and alone; receptiveness to external involvement thus reflected this state. The solidifying of Louise's relationship with Dave who served as rescuer/ protector/provider altered her receptivity to outside help.

I continued to meet with Nicky over a two and a half month period. An offer was made to continue for an additional two months however Louise was firm in her wish to terminate completely. Her reasons for discontinuing were clear. Firstly she became increasingly uncomfortable with the extremely positive relationship which I had developed with Nicky. Louise seemed to feel that her role as mother had been usurped and she therefore experienced my relationship with her daughter as a reminder of her doubts about her parenting ability. Secondly as Nicky developed better communication skills and an ability to be more assertive with her mother, this intensified the longstanding conflict between them. Thus from Louise's point of view I was making things worse rather than better. It should be noted that throughout my individual work with Nicky I attempted to recruit Louise's involvement by making telephone contact and inviting her participation in sessions, however she did not wish to make use of this opportunity.

The goals of this work with Nicky were to (1) provide an opportunity for ventilation of long standing feelings about herself and family experiences, (2) to give Nicky the experience of a relationship with an adult in which she was respected and valued.

I also made efforts to work systemically with Nicky in assisting her to make sense of her role in the family and providing feedback in the form of alternative strategies to resolving conflicts with her mother such as "how about asking your mom for a twenty minute appointment to talk rather than just yelling and slamming doors . . .". One of the basic objectives of this work became helping to equip Nicky to survive in a family which was often chaotic, unpredictable and unresponsive to her needs. It was decided that efforts directed towards promoting self esteem and development of skills in meeting needs (particularly within the family) would be most helpful in furthering this objective.

I made a referral to a community based group program for adolescent girls; Nicky agreed to attend with a friend. This program represented an ongoing support for Nicky in anticipation of termination and also provided an opportunity for positive peer contact, recreation (outside the home) and positive adult involvement.

Feedback from Nicky indicated that our meetings had been very helpful to her in several ways. She stated that "I feel relieved just to have told the whole story about my life . . ." and "you weren't even shocked!" Nicky also verbalized feeling better about herself and an increased understanding of her family. She also said that she felt as though she had had a "big sister" for a while and that she was "sad" that this had to end. I also shared my sadness in ending the relationship and that I had also learned a lot especially about surviving and staying positive. Nicky was given my telephone number and asked to call if things at home became intolerable so that an appropriate referral could be made.

Family B: A Reconstituted Family with Severe Illness in an Adolescent

Identifying Information

Patient: Joseph (age sixteen years)

Diagnosis: Crohn's disease - three years ago

- has experienced two major acute illness phases: at time of diagnosis and currently

Treatment:

- has experienced extensive medical treatment: medication, surgery, Total Parenteral Nutrition (home tube feeding)
- has experienced severe symptoms, dramatic weight loss, depression

Family:

Mother: Sally (late thirties)

Stepfather: Bob (late thirties) (commonlaw relationship)

Joseph: age sixteen years

Christopher: age eleven years

(see Chronicity Impact and Coping Instrument: Parent Questionnaire:
Summary - Figure 4
Self Appraisal Inventories - Figure 5
Family Assessment Measure - Figure 6

Social Work Involvement

Initial Contact

This family was referred to the social worker in the third month of the practicum period. The referral was initiated partly as a result of the hospital school teacher's ongoing concerns regarding her perceptions of the family's difficulty in coping with Joseph's illness. This teacher had been involved with Joseph for three years around school issues (ie: extended periods of absence) since the onset of his illness.

At the time of referral Joseph was physically well and had just completed playing football for the season at school. The initial social work contact involved a brief interview with Joseph and Sally following a regular follow-up appointment in the outpatient clinic. At this point Sally indicated a concern regarding her younger son Chris who was "acting out" in school and behaving very aggressively towards the other children in the schoolroom and playground. Sally also noted that Chris was frequently moody and sullen at home and that he and Joseph fought constantly. Sally stated that Joseph's illness had been very difficult for the family especially for Chris who had increasingly resented the attention and special treatment his older brother had received as the result of being sick. She further indicated that she would like help in resolving these problems. Joseph was attentive and outgoing in this initial meeting and appeared very comfortable in discussing family concerns.

The social worker acknowledged these concerns and emphasized that having a chronically ill child was very stressful for families and that Chris's reactions were understandable. It was suggested that the social worker arrange to meet with the family as a whole in order to get a better understanding of their views and concerns. The worker also stated that this meeting would enable the family to more clearly identify their needs and to develop a plan about how to address them. This was agreeable to Sally and Joseph and a meeting time was arranged. It was decided that this appointment would take place in the family residence.

Engagement and Contracting

The first family interview included the social worker, Sally, Bob (stepfather), Joseph and Chris. The purpose of the session was restated and clarified; to provide an opportunity for family members to share their perceptions and feelings of the impact of Joe's illness and secondly to identify their current needs and problems. Given time constraints the assessment process was extended into a second family interview.

This family exhibited a high degree of openess and ability to express feelings and concerns even in the initial stage of social work involvement. Family B clearly had experienced a great deal of stress and disruption as a result of Joseph's illness and wanted the opportunity to talk about their experiences. They also stated that they wished there had been social work and other support services available to them over the three years that they had lived with Joseph's illness. Although Sally was the most verbal, all family members contributed to these discussions. Chris was somewhat shy although very attentive during these first family meetings; he seemed interested in relaying factual data but reticent in talking about his personal reactions. Although this family identified some major problem areas with regard to family relationships, they were able to present their conflicts and views quite openly and directly. I was struck by this family's overall lack of concern about presenting a socially desirable picture or censoring feelings and information.

In essence, Family B's concerns (mainly expressed by Sally and Bob) revolved around residual tensions and conflicts dated to Joseph's initial diagnosis and the first prolonged active phase (over several months) of his illness.

Over the two assessment interviews the social worker helped the family to clarify their perceptions about the aspects of Joe's illness which had created the most concern for them. This was viewed as important assessment information with regard to understanding the family's subjective definition of their illness experiences and in providing a context for understanding their current issues. Emphasis on this angle was confirmed by the assertion within ecological theory that family responses in the initial phase of illness (ie. meaning of diagnosis, management of symptoms) set the stage for ongoing psychosocial adaptation (Ross, 1982:256-267; Germain, 1984:66). This conceptualization was extremely helpful to me in understanding how three years after the initial illness phase this family continued to have such great difficulty in coping.

Through this process of personal sharing and discussion it was identified by the famly with my help that their difficulties stemmed from two sources; (1) the stress and disruption of adjusting to and managing Joseph's extensive medical care (including at home treatments such as TPN system, medication and intermittent hospitalizations) and (2) Joseph's negative attitude towards the treatment process and his resistance in complying with them. Joe readily accepted his mother's description and admitted that he hated "being on TPN and was never going to do it again".

Christopher indicated that he was sick of hearing about Joseph's illness and that his brother was "lucky" to be able to miss school. He did not seem to have a good understanding of the seriousness of Joseph's Crohn's disease and expressed little sympathy for his brother. Christopher openly acknowledged that he and Joseph "couldn't stand each other".

Based on these initial interviews the following contract was developed; that I would meet with the family on a regular basis (once every two weeks) for an initial period of two months to address their ongoing family concerns and to help them develop some strategies for resolving them and secondly that I would meet with Christopher individually to assess his functioning and needs. As the result of this couple's shift work schedules at that point, it was agreed that formal family sessions would begin in one month following the time of assessment.

The need for family system intervention in this case was obvious. Family B had clearly identified ongoing relationship issues and had communicated a desire for my help in resolving these problems. My initial interpretation of Christopher's emotional, behavioural problems (at home and school) as presented by his mother, was that they were primarily an outcome of this family's ongoing coping difficulties. Given Chris's shyness in the context of family sessions and his developmental stage, I felt that it would be helpful to work with him on a one to one basis in order to better understand his perceptions and experiences related to his family and his brother's illness. This was viewed as a helpful intervention strategy in allowing Chris to work through his intense feelings.

Family Background and History

As in Family A, there were historical features in this family which had a significant impact on their response to this illness. My experience in working with these twelve families dramatically confirmed the importance of cross generational and historical background in order to assess and intervene effectively in the "here and now" with this population.

My personal experience thus highlighted the relevance of the psychodynamic component of the problem centered family therapy model which emphasizes the exploration, interpretation and labelling of historical issues as they relate to current functioning (Will and Wrate, 1985:107).

An important aspect of Family B's background was that Sally was previously married to Randy which whom she had had the two boys. He was an alcoholic and emotionally abusive to both Sally and Joseph. There had not been any contact with him for several years. Bob, who had been in this Family for ten years as Sally's common law spouse had never been perceived as the boy's father. This is particularly noteworthy given that the boys were only five and two years of age when he entered the family. On several occasions Sally referred to Bob having to deal with "my kids".

Consequently Bob had maintained a somewhat ill-defined and tenuous role with the children. When the children were young his adult status allowed some automatic parental control, however as they got older and Joe entered adolescence this lack of clarity in his role within the family became increasingly problematic. It was precisely at this transitional phase in this reconstituted family's development that Joseph became ill. While the onset of chronic illness in adolescence tends to intensify parent/child struggles anyway (ie. around control, autonomy, responsibility), this process was further magnified by Bob's lack of clear parental authority in the family. What resulted was an extremely stressful period for this family reflected in the simultaneous convergence of: predicatble normal family life cycle changes, a heightening of prexistant conflicts particularly related to their reconstituted structure and the occurence of serious chronic illness. This scenario may be conceptualized as the "pile up" factor described by McCubbins and Figley. This involves an accumulation of demands and stresses which exceed the family's resources for dealing with them. They suggest that the family system has become overwhelmed and vulnerable to developing maladaptive patterns (McCubbin and Figley, 1983:12-13) (see Appendix 3: p. 214). In my assessment this family had not satisfactorily resolved any of these three major issues and they attributed all of their ongoing difficulties to the illness. The level of conflict here is dramatically confirmed in the results of the Family Assessment Measure which demonstrates problem areas particularly in communication, affective expression, and task accomplishment (see Figure 6, p. 199).

An additional key aspect of this family's background involves the fact that Sally has a disabled younger brother with multiple physical problems including deafness and some mental impairment. Sally stated that her parents were often focused on his needs and though she understood this as a child, she sometimes found it difficult. These experiences influenced Sally's definition of and response to Joe's illness in two main ways. Firstly she experienced ongoing anxiety about his future particularly his ability to be economically self sufficient, and to make career choices. Secondly she felt that she should be able to cope with this experience although in reality she found this exceedingly difficult.

Although both Sally and Bob had extended family with whom they maintained fairly regular social contact, they were reluctant to ask for practical help or emotional support given the extended family norms of self-sufficiency.

Intervention

An important development in family B was the steady deterioration in Joseph's state of health during the time of my involvement. Approximately two weeks following my initial contact, Joe began to develop characteristic symptoms of Crohn's disease: low energy, abdominal pain and diarrhea. At first family members stated that they thought Joseph had a stomach flu, however medical examination in the clinic soon confirmed that this was in fact a "flare up" of Joe's Crohn's disease. Over a two month period this child became increasingly ill; he changed from a cheery robust looking, rosy-cheeked adolescent to an extremely pale, fragile looking child. Joe's weight dropped almost thirty pounds over about seven weeks, at which time he was finally admitted to hospital. Once in hospital Joseph was treated with an intravenous tube (TPN system) and then underwent surgicalimplantation of a gastric tube. This enabled Joseph to continue tube feeding at home. This supplemental feeding system is typically used with Crohn's patients with active disease (particularly involving chronic poor energy levels, weight loss) who require nutritional supplementation. At the time of termination, Joseph had been in the hospital close to a month and had gained over twenty pounds and was to be released within that week.

I maintained regular contact with this family over four months until the end of my time at Children's Hospital. As we initially contracted, I worked with Christopher individually and with the family as a whole. I also became involved in some individual work with Joseph while he was in hospital. Another important dimension of my work with this family involved the ongoing consultation with the team (mainly the physician, nurse, hospital school teacher) regarding Joseph's unstable health and the family's response to the onset of this acute illness phase.

Family B experienced this development as a crisis; it seemed to them that Joseph's flare-up was a painful replay of the same situation which they had experienced three years ago. Given the lack of resolution of the issues they faced at that time (as summarized in Family Background and History) and their ongoing difficulty in coping with this illness this general response was not at all surprising. Family B once again were faced with heightened conflict in the family especially between Joseph and Bob and general feeling of powerlessness regarding not being able to control the course of the illness or its negative impact on the family system.

As Joe became increasingly symptomatic he began to refuse to take his pills, reporting that the medication made him "feel sick to my stomach". Joseph also became somewhat depressed, pessimistic and withdrawn, spending most of his days in his bedroom sleeping or watching television. After about the third week of his flare-up, Joseph also stopped attending school. The conflict or power struggle with Sally and Bob essentially centered around Joe's refusal to take his pills consistently or to do anything (in Sally's and Bob's perceptions) to promote his own recovery. In addition Joseph became short-tempered, and less and less communicative with his family.

My intervention with this family mainly focused on these immediate concerns. Family sessions were held in Family B's home; this was essential in ensuring Joe's participation given that much of the time he felt too ill to leave the house. Data from the Family Assessment Measure was found to be extremely helpful in identifying problem areas with this family. The simple graph allowed members to visualize their conflicts and confirmed consensus and discrepancies between members perceptions of family issues. This is a particularly valuable clinical tool in working with families like this one with a rather concrete problem-solving style who have difficulty with abstract thinking. It was even found to be useful to compare family members responses to specific questions (within identified problematic dimensions) to provide further illumination of conflicts (see Figure 6, p. 199).

These sessions provided ongoing opportunity for family members to ventilate their frustrations and concerns. Sally and Bob frequently commented at the end of a session that "this is the only time we all really talk . . . especially Joseph". One of the goals of the family work was to help members to communicate more effectively with each other. For example, there was a tendency to cloud messages intended to convey concern or anxiety in the form of angry criticism. Family members were assisted in developing awareness of their emotions (and to differentiate them) and to express them more clearly.

A second goal was to reframe Joseph's negative attitude and non-compliance as (1) reflective of normal adolescent/parent struggle, (2) a way for Joe to retain some sense of mastery over his own body and exercise some choice in a life situation which continually threatened his autonomy and emerging adult identity. Thus while other teenagers (Joseph's peers) were learning to drive cars, getting jobs and dating, Joseph was forced to regress to a state of at times almost infantile dependency. As the result of his specific disease, Joe was for example constantly questioned about the number, nature of bowel movements, as well as other aspects of bodily functioning. Compliance with medical regimens was necessary to provide recovery. Thus Joseph was in a double bind; torn between independence and self control on one hand and regression on the other.

This view of the situation was very helpful to the family particularly Bob, who stated that he felt "relief" in "finding a way to sort out the confusing pieces of this situation". In addition Sally and Bob reported that this made them realize that Joe wasn't behaving in this manner "just to make us miserable". Joseph indicated that he felt better not always being "the rotten kid". Christopher had some trouble viewing his brother in any manner other than as "a real pain" in the context of family interviews, although individually he was able to express some complex and intense feelings about his brother.

We also identified that there was a difference between understanding a problem and being able to respond more effectively. I used several concrete tasks with this family in order to assist them in this regard. These assignments involved for example, asking Sally and Bob to stop nagging about pill taking for one week and asking Joseph to (on his own) get up and take his pills by 11:00 a.m. each morning. Paradoxically it was later decided that Sally and Bob should keep nagging after all because (although he protested) Joseph needed help to take his pills. The important element in this strategy was it provided Joe with a choice; this promoted his sense of self control and at the same time allowed him to ask for help and support. The utilization of tasks as a way of promoting change and teaching problem-solving skills was very effective. This substantiates the value of the problem-centered model (which relies on the use of tasks in advancing therapeutic goals) particularly with those families who are highly motivated and committed to the change process.

I also attempted to relate the family's immediate conflicts to the uncertain role of Bob in the family. In essence he seemed to be making sincere efforts to maintain a father role but was constantly reminded that "you're not my father". I encouraged Sally and Bob to view themselves as the parents and to discourage efforts by the boys to undermine Bob's parental role and authority within the family. I also reinforced the notion of stepfather role as appropriately involving the responsibilities of caring for, guiding and disciplining. Unfortunately the limited period of involvement in combination with the presence of other pressing concerns did not permit extensive attention to this issue.

Work with the team in regard to this family involved (1) providing updated information about their psychosocial functioning, immediate concerns and (2) offering reinterpretations of this family's struggle to cope. The predominant perception of the team was that this family had historically not managed the demands of Joe's illness well and that they tended to get distracted by other less important everyday pragmatic demands. I offered the view that this family's focus on household organization represented their way of maintaining a sense of mastery over their lives in a situation in which they had very little control. I also emphasized that this family was under a high degree of stress and that this situation was very disruptive (ie. frequent clinic appointments, visiting Joseph everyday especially given that the family lived out of Winnipeg).

I also attempted to offer support especially to the physician who was in the frustrating position of trying to provide medical care to a teenager who, from one vantage point, refused to take care of himself. I encouraged the physician to offer Joseph straight information about the possible implications of choosing not to accept medical treatment.

I quickly developed a warm, positive relationship with Christopher during our individual sessions. I experienced this child as a very bright, amiable, humorous boy who sometimes had emotions and behavioral reactions which sometimes surprised and overwhelmed him. Christopher was much more expressive and responsive on a one to one basis than in the family session context but did have some difficulty in identifying his own feelings.

My central goals in working with this child were to: (1) assist

Chris in learning to recognize and accept his intense emotions particularly with regard to his brother Joseph and (2) to promote his self-esteem. My involvement with Christopher incorporated the use of many projective techniques and play therapy modalities. In addition I initiated contact with the school system (where many of this child's difficulties were being expressed) and met with his home room teacher and principal. This school contact represented one element of the broader ecological approach which was utilized in my work with this family. This was helpful in providing a better understanding of how Chris functioned in the school context and with regard to peer relationships.

Christopher's poor self-esteem level was assessed through various expressive exercises, discussion with school staff and the self appraisal inventory. The Self Appraisal Inventory was valuable as a supplement to the assessment process. Christopher's low scores on all subscales confirmed his poor self concept; particularly within those dimensions related to school and peers. Review of specific questions also facilitated dialogue about problem areas and also strengths (see Figure 5, p. 198).

The substance of my work with Christopher involved non-verbal play therapy activities. I made extensive use of drawing and coloring games given Christopher's natural inclination to draw. I supplied colored paper and crayons and frequently requested that Chris do "picture stories" from session to session, for example, "draw a story about you in school with a picture for each day, then we will read it together when I come back . . .". I also asked Christopher to sketch himself in his family on several occasions.

One of the highlights of my individual contact with Christopher was the use of Gardiner's story-telling technique. This involved bringing a tape recorder and tape to our session and conducting a radio show in which I played the interviewer and Chris was the special guest introduced as "storyteller of the week". He was then interviewed and asked to tell a story for "all the boys and girls at home listening". The central assumption in this technique is that the child automatically projects his/her own inner struggles into the context of the story (Schaefer and O'Connor, 1983:313).

Based on Christopher's highly imaginative saga about "the dragon who couldn't breath flames" I then developed a story using this child's metaphors which incorporated a therapeutic message acknowledging Christopher's obvious love/hate relationship with the dragon (his brother) with whom we wanted to both "fight" and "help get his flames back". While it is not within the scope of this case illustration to provide specific elaboration of this intervention experience, it is being presented here as one example of a range of activities used within the play therapy medium.

This and other expressive techniques were found to be extremely effective in working with this child (and other children) for whom direct expression of psychic struggles and painful emotions is extremely difficult. From a developmental perspective children have difficulty firstly in recognizing and classifying emotions and secondly in expressing them in words given limited verbal skills (Schaefer and O'Connor, 1983:5-7).

The sibling of a chronically ill child (especially when the latter has such severe, usually dramatic symptoms) such as Christopher is confronted with a central ongoing inner struggle. On one hand Christopher deeply resents the amount of attention his brother is able to command as the result of his illness and thus experiences intense antagonism and hostility towards Joseph. Conversely, Christopher also experiences a degree of anxiety about his brother's health, particularly when he becomes very ill and fragile.

Christopher experienced a high degree of dissonance in these simultaneous contradictory reactions although both are normal. This is confirmed by recent theroists who contend that the ability to "acknowledge both positive and negative feelings directed towards the same target at the same time" is one of the most complex and challenging tasks faced by the child in his/her psychosocial, cognitive development (Schaefer and O'Connor, 1983:102). In case situations involving younger children, this dilemma is further complicated by anxiety about the ability of these powerful feelings to cause the onset of symptoms (Schaefer and O'Connor, 1983:216; Moos, 1979:186).

The primary objective in using the story-telling and other play therapy techniques in this case, was to provide Christopher with the opportunity to develop an awareness and acceptance of these apparently opposing feelings within himself. The therapeutic relationship which represents the context of this personal growth process, permitted affirmation for Chris that (even given his sometimes intense negative feelings and behaviors) he is respected and lovable.

Considerable gains were made in working with this eleven year old.

Chris seemed to develop a greater sense of comfort with himself and ability to focus on his strengths rather than his failures. His mother reported that Christopher became more cheerful and less moody at home although he continued to have some negative feelings about school. Unfortunately the time constraints of this practicum necessitated termination after three months of therapy; longer term involvement would have been helpful in consolidating these changes and addressing additional issues. I would also have liked to involve other family members in selected play sessions in order to promote a better appreciation of Christopher's needs and family relationships in general.

In conclusion, the social work approach which incorporated interventions based on the ecological orientation, problem centered family therapy model and play therapy techniques, was found to be extremely helpful. Although the range of problems experienced by this family were by no means completely resolved, very significant gains were made. Family B offered a great deal of positive feedback about the helpfulness of my involvement over the four months. They specifically reported having learned a lot about themselves and had found some new ways of relating to one another. Of particular note was the family's comment that the most helpful aspect of my involvement was that I understood Crohn's disease and was part of the team providing Joe's medical care and secondly that I also "knew about family problems". They expressed frustration and disappointment about my leaving as they would have liked to continue our work. Although a referral to another family counselling agency was discussed, Family B felt that this service would not be helpful if it was disassociated from Joseph's medial care.

Family C: A Family with a Preschool Age Child with Severe Chronic Illness

Identifying Information

Patient: Beverley (age five years)

Diagnosis: Ulcerative Colitis - three years ago

- has experienced continual symptoms since age two
- abdominal pain, extreme diarrhea associated with lack of bowel control
- rare liver involvement involving progressive deterioration likely to lead to need for liver transplant

Treatment:

- has had extensive diagnostic work up
- on medication which does not seem to have a significant impact on symptoms
- some delayed growth associated with illness and prednisone (anti-inflammatory medication)

Family:

Mother: Sheri (age twenty-eight)

Father: Pat (age twenty-eight)

Beverley: daughter (age five years)

Social Work Involvement

Introduction

Family C was referred to me in the second month of the practicum period. They were essentially seen for assessment purposes although there were some limited social work services provided including information and referral. Contact was limited to four interviews and several telephone contacts.

This family was selected for discussion in this context for several reasons. Firstly Family C is somewhat unusual in that their child with inflammatory bowel disease is considerably younger than most of the patients in this population (Moroz, 1988) and also has a relatively rare liver involvement associated with her disease. Beverley's age is a feature of particular interest given my specified objective of developing a clearer understanding of the impact of chronic illness at different developmental stages.

The existence of Bev's liver disease also adds a complicating dimension to this family's experience given the potential fatality associated with it. While Beverly may well be a good candidate for liver transplant and may survive this surgery and live out a normal lifespan, this is still a relatively new and risky medical procedure. In addition, Beverly's ulcerative colitis may prohibit or complicate the success of liver transplant.

The third important feature related to the particular selection of this family for the purpose of illustration is their ability to rally together and manage their experiences, given both chronic disruption of their daily lives and the necessity of living with intense uncertainty about the future of their only child. Description and analysis of this family's experience will allow elaboration of a positive coping style; this provides a balance with the first two case studies which explicate problematic adaptive patterns. It should be acknowledged that while this family was assessed as having substantial strengths there are also certain problem areas. My overall experience with these twelve families in fact confirms that while some families are able to cope better than others, there is no one ideal coping style or perfectly adapted family.

Summary of Social Work Involvement

Family C was seen for three assessment interviews; the first two included Sheri and Pat and the third included Sheri and Beverley. This family expressed no hesitation about agreeing to meet with me and in fact seemed pleased to have the opportunity to share their experiences. Although they identified some ongoing family issues through this process, Sheri and Pat viewed these basically as inherent in their situation and did not wish professional help (this will be discussed later). They did however identify a need for information with regard to (1) the current state of Beverley's illness and the anticipated trajectory of her disease and (2) financial and social support resources regarding the (potential) transplant experience.

Two short term interventions resulted from these information based needs. The first involved consultation with the physician about Family C's desire to have more in-depth information about Bev's illness and conversely to encourage Sheri and Pat to be more assertive with the medical team in asking questions and obtaining as much information as possible. This led to a meeting between Family C and the physician which allowed clarification of Beverley's current condition and long term medical concerns.

The second intervention involved arranging and facilitating a meeting with Sheri and the social work assistant responsible for out of town arrangements for families who need to travel to other cities. This had two central purposes: to connect the family with the individual who would be an important resource to them if and when Beverley was to undergo transplant, and secondly to provide some information (and reassurance) about financial aid as this was a primary concern for them. In addition the arrangement of the meeting itself represented an acknowledgement of the validity of their anxiety about the future.

Family C was also given information about the local chapter of the Society for Ileitis and Colitis and a parents' manual for coping with illness experiences. Support was provided to Beverley and the family during a brief hospital stay for a liver biopsy. This family indicated that my involvement was helpful in providing the opportunity to talk about Bev's illness and secondly that they felt good that other families might benefit from their experiences.

Family Background and History

Beverley was diagnosed as having ulcerative colitis three years ago at age two years. Sheri and Pat had been married for two years and were both twenty-three years of age at that time. Both Sheri and Pat's extended families live outside of Canada. Pat has a married sister in Winnipeg with whom this family maintains regular contact. Family C have a small group of friends who also have young children with whom they socialize and exchange instrumental support, but describe themselves as "self-sufficient".

Sheri and Pat state they experienced a great deal of anguish when their daughter first became ill but gradually became accustomed to the idea that Beverley had a chronic illness. The presence of liver disease has always been of the most concern for Sheri and Pat; although they are optimistic about the potential success of a liver transplant they also worry about whether Bev will survive into adulthood. This aspect of Beverley's illness has had a major impact on Family C's lifestyle in that they do not feel that they can plan extended trips away from Winnipeg given the uncertain course of their daughter's illness and secondly, they don't feel that they could handle the financial, instrumental and emotional strains of having another child. This decision reflects the current demands which Bev's illness imposes and also the anticipated disruption of the transplant experience.

Beverley presented as a happy likable child. Her somewhat babyish manner and small stature give the impression of a child somewhat younger than five years. Sheri attributes her daughter's shyness especially around other children to repeated hospitalizations and medical tests. Beverley was able and willing to talk about her illness; she stated "my tummy hurts a lot and lots of times I have accidents . . .". She had begun Kindergarten two months before my initial contact and seemed to be enjoying herself and doing well. A special teacher's aide had been arranged to assist Beverley to go to the washroom in order to manage her incontinence resulting from severe chronic diarrhea. Although accidents had occurred, this had not been experienced as traumatic by Beverley.

Beverley's continual symptoms which have not to date responded to medical treatment represent a major ongoing source of stress for this family. Beverley is often ill and usually has at least one accident at night. This requires one of her parents to get up with her and change her bed. Sheri and Pat consequently report continual fatigue. Sheri also reported that Beverley was often whiney and demanding usually in association with active bouts of her illness.

In response to Beverley's illness, Sheri and Pat now run a group home for mentally handicapped adults. They reported that they found this work rewarding but more importantly find it particularly well suited to the uncertainty and constant demands of their daughter's condition. Because of frequent periods of illness requiring intense caretaking, this couple felt that only one of them could work outside of the home. This arrangement allows them to have two incomes and yet be available to their child. Both Sheri and Pat take evening courses towards a diploma in their field; neither partner has finished high school.

Assessment

Family C is a family who must cope with multiple, potentially overwhelming stressors in their lives. Like the other eleven families interviewed, this family must adapt to all of the demands imposed by chronic pediatric illness such as symptoms, treatment, hospitalizations and unpredictability of the child's health. In addition however, this family faces the added anxiety associated with potentially fatal illnesses. Thus Sheri and Pat, in order to adapt, have had to develop a way to both cope with the daily demands of Bev's condition and to address the psychosocial issues involved in parenting a child with a highly uncertain future. This couple are faced with the challenge of, to the extent possible, treating their child as normally as possible (like any other five year old) and at the same time finding ways of dealing with their recurrent anxiety about whether she will survive her disease and for how long. They are aware of their own tendency to "overprotect" Bev as the result of these intense emotions, and try to maintain appropriate expectations for her behavior and at the same time remain flexible and responsive to her needs.

They have essentially responded to this complex set of demands by making Beverley the central organizing force within the family. Family C's lifestyle, major life decisions (related to number of children in the family, career choices) largely reflect Beverley's current medical condition and anticipated long term needs. Sheri and Pat are stoical in their acceptance of daily demands (such as getting up every night, clinginess, tummy aches). Although they express a chronic weariness and some frustration that their daughter has these medical conditions, they generally demonstrate acceptance of the permanence of Bev's illness and a desire to "do the best we can . . .".

Sheri and Pat appear to find strength in their positive, mutually supportive marital relationship. To a great extent they are able to lean on one another for support although they admit that sometimes it is a strain when "we are both worried and sad". The problem-centered family therapy model was helpful in conceptualizing this couple's strengths and in highlighting the importance of this structural component (the executive and parental subsystems) in promoting successful family coping in response to this stressful life event (Will and Wrate, 1985:30-31). My assessment was also confirmed by the Family Assessment Measure results which demonstrated very positive ratings on almost all subscales (see Figure 9, p. 202).

This couple are also fueled by the deep sense of satisfaction and pride they exprience in taking care of their child in the best way that they can. They share a philosophical orientation to this experience characterized by a belief that one should "accept things that can't be changed" and "make do with what is" (see Figure 7, CICI:PQ, p. 200).

Although Family C tends to be future focused (events are often referred to in context of the anticipated transplant) they also exert conscious efforts to live for today. For example, they have purchased a horse and take great pleasure in taking Beverley riding even though "we really can't afford it".

This family, in their ongoing quest to learn more about Beverley's condition, clearly used information and factual understanding both as a way of relieving stress and in maintaining a degree of mastery and control over their lives. In my consulation with the team in regard to this family I attempted to define and reframe their need for detailed explanation as a coping mechanism rather than as demandingness or lack of faith in medical care provided. This helped Dr. Moroz gear his approach to this family's particular style and to recognize and support their ongoing efforts to cope.

Again the ecological model provided a useful perspective for understanding and intervening in this context in which this family must continually strive to adapt. Without adequate affirmation and support from care providers, this family would be at risk of abandoning one of their most central coping strategies. This piece of team work is extremely worthy of mention gien that this particular coping mechanism is in fact typical of many well-adapted families and is frequently not clearly understood by medical care providers.

Another important and related aspect of Family C's coping style involved their initiative and involvement in establishing a local chapter of the liver foundation in order to promote public awareness (of liver disease) and to provide a mechanism for connecting families of patients in the community for mutual support and education. This activity may be viewed as representing an effort to master a life situation largely out of their control and also to develop a supportive network given the obvious lack of existent appropriate resources. this second aspect of this activity is especially important for this family given the absence of extended family support.

Beverley seemed to be a fairly well adjusted happy child. On the whole she seemed to cope remarkably well with her illness. Given her developmental stage and cognitive capacities. Beverley did not yet have a grasp of the meaning of her liver disease, although she did verbally indicate awareness that she might have to "go somewhere to have an operation . . .". This seemed to represent for her, one more medical procedure in a long history of medical intervention. Beverley's main psychosocial challenge was to adapt to the immediate symptoms of her colitis.

In my assessment, Beverley's lack of embarassment and anxiety regarding frequent accidents (even apparently in public places) and ability to talk openly about symptoms reflects a deep sense of security gained from her parents acceptance of the condition. She essentially views herself as like other children and demonstrates an interest in many age appropriate activities; Bev loves school, rides a bicycle, takes figure skating lessons and plays with neighborhood children.

Beverley's tendency to be babyish and whiney seems to be a predictable consequence of her experience with medical intervention, chronic symptoms, and frequent lack of bodily control. In fact successful adjustment to this state of affairs may be viewed as requiring her to regress to an earlier developmental stage in order to accept medical treatment and a high degree of parental involvement (Schaefer and O'Connor, 1983:214-215). In order to avoid becoming overwhelmed by the potential anxiety particularly regarding urgent bowel movements, Beverley must allow herself to relinquish some control and be taken care of.

This child's somewhat delayed language ability may be a reflection of these life experiences. Beverley was receiving speech therapy over the course of my involvement with this family; this was intended to assist her with articulation and vocabulary development. Her frequent bouts of active disease have prevented her from having the amount of peer contact experienced by most children of her age; this has had the effect of delaying Beverley's social skills. Despite these setbacks however she seems to enjoy Kindergarten and is making good progress.

In my assessment of this child I utilized the Self Appraisal Inventory (form: Kindergarten - grade 3) and projective drawing technique (see Appendix 7: p. 219). The SAI was applied orally given Beverley's inability to read: this was somewhat valuable although certain questions were too advanced for a child of this age. For example: "Do most children have fewer friends than you?", "Does your family want too much of you?". The projective drawing seemed much more appropriate and elicited more information. Beverley drew a picture of her house with a happy face on the outside and herself playing in the yard with her dog. Discussion about these pictures provided me with a clear understanding of Bev's overall feelings about herself and family at that time. A theme throughout my work with these children was the obvious value and effectiveness of utilizing creative play techniques in assessment and treatment.

My overall assessment of this family is that they have many strengths and cope remarkably well with a highly stressful life situation. One of my concerns with their coping style however, was that this pattern of sacrifice and absolute devotion to Beverley's short and long term needs seemed to, at times, increase their anxiety level by continualy refocusing their attention and energy onto their daughter's health and future. Furthermore, I experienced some concern about the devastation that Sheri and Pat would experience in possibly losing this child after such enormous investment. The death of a child is of course deeply painful and tragic for any family; but perhaps even more catastrophic for a couple like Sheri and Pat whose whole lives have been dedicated to her care.

In the second and third assessment interviews I asked Sheri and Pat about their perceptions of the long term implications of their decisions, for example, regarding not having any more children. Family C expressed awareness that they would be devastated if Bev died but say that "We have to deal with things as they are not as they might be . . ."

Although Family C did not identify a need for social work services, I made use of my contact with them in to reaffirm their many strengths and to support their obvious efforts to cope. I also encouraged Sheri and Pat to take time for themselves in order to meet their own needs as individuals and as a couple.

Chapter iii - The Impact of Chronic Illness on the Child and Family: Summary of the Data

(a) Review of the Standardized Measures

The purpose of this section is to discuss my experiences in using three selected standardized measures and to review the benefits and problems associated with them. References to these instruments and the data derived from them have also been made, in the previous chapter within the context of case illustrations. Increasingly, standardized scales, questionnaires and other paper and pencil tools are being incorporated not only into clinical practicums but also as a part of everyday clinical practice. These measures are generally used to supplement and to some degree objectify, the social work assessment and also to evaluate the impact of interventions (Bloom and Fischer, 1982:134-135).

The utilization of the selected measures was essentially for assessment purposes. Although two of these scales (the Family Assessment Measure and the Self Appraisal Inventories) have potential for application as pre and post measures in relation to intensive social work interventions, I did not expect them to be sensitive enough to reflect the subtle changes and gains made as the result of the limited short term social work services provided. With regard to the small number of families with whom I did become very involved there were dramatic developments in the life situations of all three families over the course of my contact with them; it would therefore have been very difficult to know whether changes were attributable to social work intervention or other factors. For example in one famly, the ill child who had been very sick for several months experienced a remission of his disease; this development in itself altered the family's perceptions of their own functioning.

Over recent years, a plethora of standardized instruments have emerged particularly with regard to family functioning. There were two central considerations in the selection ad application of evaluation tools:

1. That the identified need for in-depth objective information should not outweigh concern for their potentially taxing effects on families;

2. This principle suggested the careful selection of evaluation instruments which would most accurately measure those qualities of concern.

Two measures related to family functioning and overall coping resonse to the child's illness were selected; these include: the Family Assessment Measure (FAM scale) and the Chronicity Impact and Coping Instrument: Parent Questionnaire (CICI:PQ).

The FAM scale is an objective standardized measurement instrument which has been widely used for assessing families experiencing a range of life situations and problems. This scale has strength in terms of its well established validity and reliability. Reliability coefficients range from .86 for children on the self rating scales to .95 (for adults on the dyadic relationship scale) (Skinner, Santa-Barbara, Steinhauer, 1983:96). This measure includes a general scale, self rating scale and dyadic relationship scale; only the general scale was used in this practicum (See Appendix 4: p. 215).

The FAM was viewed as highly relevant to this population because it encompasses seven major dimensions of family functioning known to be effected by this life event, ie. affective expression, involvement, role performance, behavior control. In their study of families with positive adjustment to having a developmentally disabled child, the FAM scale was found to be accurate in identifying key dynamics or features of interest (Trute and Hauch, 1986). It was therefore theorized that this instrument might prove useful in assessing families with a chronically ill child hwo experience similar strains. Both populations have been described as experiencing a need for increased child care and parental involvement and the maintenance of spousal cohesiveness in managing the demands imposed by the child's illness or developmental disability (Trute and Hauch, 1986; Schilling et al., 1984:48; Trout, 1983:343).

The FAM scale was also viewed as being very appropriate given that it was developed out of the McMaster model of family functioning which provides the conceptual foundation of the intervention model which was used in this practicum. This measure allowed collection of data about family members' individual perceptions about seven dimensions of their family's functioning. These included: affective expression, involvement, control, role performance, values and norms, task accomplishments, communication. One of the valuable features of this scale is that scores for individual members are incorporated into simple graphs; these provide very useful information about both family strengths/problem areas and congruencies and incongruencies in members' perceptions about family functioning.

I found the FAM scale to be an extremely helpful instrument in several ways. Firstly, it is a simple, straight-forward questionnaire which is easy to administer and score and which provides in-depth relevant information that is easy to interpret. Secondly this scale was helpful in supplementing and objectifying my assessments; in most cases the graphed data confirmed my subjective impressions of family functioning. Thirdly, the visual perspective which this measure allows was found to be useful in facilitating discussion with families about their concerns and problems. Many families reported that they learned a great deal about themselves during the sessions in which scores were discussed. Graphed data illustrating three families' FAM scale scores have been included within this report (see Figures 3, 6, 9, pp. 196, 199, 202).

On the whole I found the FAM scale to be an extremely valuable tool in assessing and intervening with families in this population. In my experience, the way in which this measure was presented and utilized was of key importance. Open discussion of scale results and interpretations of patterns helped to demystify all of the standardized measures and reduced anxiety about being evaluated. Explanation of the purpose of this measure and efforts to make this information useful for the family members themselves seemed to be important in the successful incorporation of this measure into my work with families. My only criticism of this scale is that it cannot be applied to children under approximately age eleven. This makes it most useful in working with families with adolescent children in which all members can contribute their perceptions. A separate format designed for younger children would be a helpful adjunct to this measure.

While the FAM scale provided a measurement of internal family functioning, the Chronicity Impact and Coping Instrument (CICI:PQ) provided a broader view of parent perceptions of the impact of their child's chronic illness on the family, and how parents cope with the difficulties encountered as the result of their child's condition.

This instrument was designed as an assessment measure for helping professionals involved with chronically ill children and their families. It was developed by nursing professionals who identified a need to systematically assess the impact of chronic illness on families in order to provide services to them. The CICI:PQ is a structured self-administered questionnaire that can be completed within twenty minutes (Hymovich, 1983:275) (see Appendix 4: p. 215).

The CICI:PQ incorporates Hymovitch's 1979 conceptual framework which includes the following four components:

(1) the developmental tasks of individuals and families;

(2) the impact variables (perceptions of the problem, resources available to or needed by the family;

(3) the coping strategies needed by family members to manage stress imposed by the child's illness;

(4) services needed by families with chronically ill children.

Hoyt's coefficient of reliability for the total instrument is .95 (Hymovich, 1984:218). Content validity has also been established through the use of content experts; both parents and professionals.

My experience in using this questionnaire suggests that it is of limited usefulness. While the concept of a standardized measure which evaluates the impact of childhood chronic illness on the family is certainly valid; this instrument was found to be somewhat confusing for parents and was also difficult to score. I found that frequently parents indicated that they didn't understand the meaning of certain questions such as Section C - question 8, "In what ways does your spouse do things differently when upset with you than when not upset?"

In addition, the results of this questionnaire are very difficult to score. The author seems to intend that groups of scores be analyzed by a computer. As I did not have access to this resource during my practicum, I was not able to collate the data collected in this manner. Given the growing incorporation of computers in social agencies, however, analysis of scores might be possible in some settings. Large scale analysis of CICI:PQ scores might for example reveal patterns of coping or difficulty (ie. martical conflict) within populations.

Although scores can be obtained for the subscales there is no total score. These numbers are difficult to interpret given that score ranges but no norms are provided. The establishment of norms for this instrument would greatly increase its value as an assessment tool and as a pre and post test measure.

The primary strength of the CICI:PQ lies in the depth and relevancy of certain sections which extract important information about families' responses to illness experiences. Of particular note are those dimensions regarding concerns about self and spouse (Section B and C) which extrapolate data about personal coping styles and couple functioning. The questions included in question 6 (Beliefs) also provide very useful information about parents philosophical orientation to managing their experiences which I found to be an important element in successful adaptation (Travis, 1976:398; Anderson, 1981:428-429).

The focus on parents' perceptions of their spouses concerns and coping in this questionnaire provided a catalyst for discussion about couple functioning. Some couples commented for example that they were surprised about their partners perceptions of them; this led to a clarification of concerns and on occasion an identification of problems.

On the strength of these features I think that the CICI:PQ can be helpful as a supplement to the social work assessment, however I found it time consuming to summarize data in a way which made it useful both to me and to families. As a result, I would be unlikely to use this instrument in its entirety in routine clinical assessment. I would utilize particular sections as a conceptual basis for assessment interviews.

The Self Appraisal Inventory represents the third standardized scale utilized in this practicum. This was used as an adjunct to the above described measures in order to assess the psychosocial functioning of children and adolescents. This scale was designed to measure self concept in relation to four subscales; peers, school, family and general. Pravder et al. and Travis indicate that these are dimensions known to be effected by the existence of chronic illness both for the ill child and his/her siblings (Pravder et al., 1985:90; Travis, 1976:60). One of the obvious advantages of this scale is that it includes three separate forms for specific age groups: Kindergarten - grade three, grades four - six; grades seven - twelve. The SAI is a simple paper and pencil test which can be completed in ten - fifteen minutes (see Appendix 9: p. 221).

The SAI has been fairly widely used recently in clinical practice as an assessment tool and to measure the impact of interventions. It has been used for example in measuring the effects of group treatment with children from violent homes (Balicki, 1987). Overall test, re-test reliability has been established at .73 for the primary level, .88 for the intermediate level and .82 for the secondary level (Frith and Narakawa, 1972). In that this scale addresses children's own perceptions and feelings, this scale has face validity. One of the problems with the SAI is that it does not account for social desirability; that is, there is a tendency for respondents to respond accordingly to perceived ideals rather than their true feelings.

I found the SAI to be an extremely valuable instrument in my assessment of children within this population. It provided useful information which, for the most part, tended to confirm my subjective impressions of children's self esteem and problem areas. It was also very easy to score and again, review of the data from this scale was helpful in facilitating interaction between myself and families but also interestingly, between children and their parents. Scores on the SAI were useful in clarifying problem areas; one of the younger children in Family A for example, demonstrated a positive sense of self within the peer and school subscales but had a lower score on the family dimension (see Figure 2).

While the SAI is frequently utilized as pre and post test measure it was used only as an assessment tool in this context. Given the absence of established norms for this scale, the raw scores were found to be somewhat difficult to interpret. Based on applications with the twenty-one children in this client group some very rough norms will be established for the purpose of interpreting the data collected. Only five children completed the primary and intermediate forms combined; this prevented the extraction of only generalizable patterns within this respondent subgroup. Fifteen children patients and siblings completed the secondary form. The following scores represent the lowest score for each subscale found to be associated with healthy self-esteem within these fifteen children. These "norms" were arrived at through (1) review of all scales completed and (2) comparison of my subjective judgement of individuals against SAI scores. (These are not central tendencies: average scores are included in Figure 10, page 203). These are:

Peer subscale - 46
Family subscale - 44
School subscale - 42
General subscale - 44

One of the most helpful features of this scale is that it includes separate forms for three age categories. This makes it easy to use with all children over approximately age five; it can be applied therefore to all school age siblings in a family. Consequently SAI scores can be compared to determine patterns of self concept within families and between ill children and their brothers and sisters. (Specific data on this subject will be discussed later in the chapter.)

While initially I was skeptical of the applicability of these paper and pencil measures in "real life" practice, I found it relatively easy to integrate them into my work with families. From a pragmatic perspective I do believe strongly at this point however that the simpler (easy to score), straightforward scales are most applicable to social work practice. I will continue to utilize both the FAM scale and the SAI given this consideration.

Summary

To a great extent the emerging concern with measurement and evaluation reflects the continuing struggle for social workers to establish professional credibility. In my view one of the underlying assumptions in this movement is that, that which is scientific accrues a great deal more status than that which is artistic and abstract in nature. The direction towards more precise, objectified measurement of human problems is a double-edged sword. On one hand, I believe that it is beneficial in that it challenges us towards clearer thinking about psychosocial issues, and provides the opportunity for evaluation of the impact of our interventions.

At the same time I think that this quest for precise understanding should be balanced with recognition that human problems are exceedingly complex and are not always quantifiable. The standardized instrument by definition represents a particular limited definition or way of thinking (set of criteria) about a given concept (ie. self esteem); this is necessary in order to make the quality of interest measurable. In my personal commitment to the ecological perspective which involves an appreciation of multi-level contextual features of psychosocial problems, I believe that we should however continue to recognize the value and importance of our subjective appraisal of the meaning of life events and experiences. These measurement tools are therefore viewed as supplements to and not replacements for the indepth interviews and other social work contacts which are the fundamental basis for assessment and intervention.

(b) Themes, Patterns, Issues; the Experience of Twelve Families with a Child with Inflammatory Bowel Disease

The review of the literature revealed several key themes in the current understanding of the impact of childhood chronic illness on the family. The most recent literature in this area suggests for example, that while this life experience imposes new demands and stresses it does not necessarily lead to major psychosocial problems or family system dysfunction. Furthermore many theorists have articulated the need to identify ecological and family characteristics which moderate the process of coping and adaptation in order to respond to those families most at risk (Longo and Bond, 1984:61; Tritt and Esses, 1986:118-119). My experience with this group of families provided me with the opportunity to begin to address this apparent gap in the available literature. Over the course of my involvement with this target population, I was able to extrapolate some central features which seemed to be associated with positive family adaptation to the presence of chronic illness in a child.

In addition my contact with this group of twelve children provided new information and insights regarding ill children's individual psychosocial adjustment to having inflammatory bowel disease. Some well known theoretical assertions such as the assumed link between level of family functioning and disease activity were put to question by this practicum experience. New observations were also made: the apparent discrepancy in coping abilities between the sexes represented the most dramatic and unexpected pattern which emerged from the data.

The purpose of this section is to summarize and discuss information collected from the group of twelve families with whom I had contact over the course of my practicum experience. While the case illustrations in the previous chapter explicate the specific coping experiences of three families, the purpose of this discussion is to describe and illuminate the coping mechanisms and patterns of adaptation to chronic illness with regard to the larger sample group. The following analysis incorporates data collected through standardized measures, social work interviews, discussion with other members of the team and additional literature.

One of the striking observations about this group of families was their predominantly positive adaptation to this life experience. Out of the twelve families for example, only five reported having some serious difficulty in managing some aspect of their child's illness. This is particularly noteworthy given that the average family had lived with the diagnosis for two years and thus had experienced both short and long term implications of chronic illness in a child member.

These families general demonstrated an ability to normalize and cope with the disruptions associated with the child's symptoms and medical treatment. Most reported active, often hectic lifestyles and described themselves as "normal" or "regular" families. Only three families indicated for example that their child's illness had led to major alterations in the child's activity level and the family's lifestyle. The vast majority of parents interviewed said that at the time of diagnosis they made a conscious decision to treat their child as normally as possible and not to focus on his/her illness. This seemed to be founded in a concern with promoting self esteem and in helping to maintain a positive self concept in the ill child but also a determination to carry on with a normal active family lifestyle.

Interestingly, most of these parents had known another family with an ill or disabled child; many reported feeling "turned off" by seing this other child "spoiled", "coddled" or "treated with kid gloves". One of the commonly expressed issues was an awareness of the need to balance parental responsiveness to the child's special needs for attention and care (when they were actively sick) with the need for discipline and reasonable expectations regarding behavior. A few mothers indicated concern about the effects of getting angry or yelling at their child on the progress of the illness. One mother expressed anxiety that this might precipitate or exacerbate symptoms in her eleven year old daughter. By and large, however, parents viewed their ill youngsters as being able to handle the stress of occasional famiy conflicts without becoming ill.

Ten of the families reported some concern about the impact of the illness on the siblings of the sick youngster. Although only one family (see Chapter ii - Family B) expressed major difficulty about a sibling's adjustment, most worried to some degree about their other child (children) feeling neglected, deprived or "left out" because of the attention received by the ill child. With the exception of Christopher (Family B) there seemed to be little evidence of maladaptation or even residual negative feelings on the part of siblings. Many expressed sympathy for their brother/sister with inflammatory bowel disease; a few said that they actively encouraged their siblings to "take care of themselves . . ."

Self Appraisal Inventory scores reflected generally positive self concepts. For example on the general subscale (Secondary form: grade 7-12), the average sibling score was 46; this was exactly the same as the average score for the ill children themselves. (See previous section for further explanation of scores.) Thus while parents expressed anxiety about the impact of the illness on the other children in the family, there were no obvious trends towards dysfunction within siblings. It may be theorized that the apparently positive adjustment of many of these children is associated with their parents concern with normalizing family life. The fact that most parents verbalized on awareness of this issue in fact suggests that they do not make efforts to attend to the well siblings' needs.

On the whole most of the chronically ill children themselves demonstrated a high degree of resilience to the disruption and unpleasantness of symptoms and treatment and were assessed as both emotionally healthy and developmentally normally. My experience in this practicum confirmed the view that while chronic illness is certainly a stressful life event it does not necessarily lead to psychosocial problems. Despite the sampling problems, I did observe some rather striking patterns which are worthy of examination here.

One of the primary themes which emerged regarding the individual ill child's adjustment to the illness was the differences in response associated with gender. Generally the girls in this group seemed very well adjusted and relatively unimpaired by the inflammatory bowel disease. All indicated that they had positive peer relationships and seven of eight were involved in organized sports and/or other community activities. Most spoke freely of their illness and how it had affected them. When questioned about this, these girls typically responded as "I'm the same as other kids . . . only I go to the bathroom more", "I have Crohn's, but it's no big deal", "Mostly I do whatever I want . . ."

This represents a marked contrast to the four boys interviewed who demonstrated a poorer understanding of their illness and a reluctance or difficulty in articulating the impact of the illness on their daily lives. All four male patients exhibited embarassment about having inflammatory bowel disease and tended to minimize the social, emotional impact (ie. ability to participate in activities) but also the immediate physical symptoms associated with their disease.

This was confirmed by both the physician and parents who often indicated that the teenager was (in their perceptions) more symptomatic than he reported. Three of the four male patients' parents were interviewed (one was living on his own and did not want me to contact his family); all three expressed some degree of concern about their child's lack of acceptance of their illness and a tendency towards non-compliance with treatment regimens. In addition, these four males were the most symptomatic of all twelve children interviewed during the course of my involvement. Especially during phases of active illness, they exhibited a tendency towards withdrawal, negativism and depression.

In comparison, the girls in this client group seemed to experience little difficulty in adhering to treatment regimens such as pill-taking. Several in fact demonstrated active efforts to maintain good health and minimize symptoms. Three girls described having to avoid certain foods which tended to precipitate symptoms such as stomach aches and diarrhea. One newly diagnosed twelve year old reported that she was going to do a science project at school about inflammatory bowel disease. None of the parents of female patients described having to "nag" their daughters to take medication regularly.

Both boys and girls reported "hating" or "dreading" medical tests, although again the males in this group seemed to actively avoid or postpone clinic visits and procedures more than the females. Generally all children described much more apprehension and anxiety about the intrusion and discomfort of medical tests (such as barium studies, sigmoidoscopies) than the symptoms of their illness. These procedures are uncomfortable for anyone; they are doubly so for pre-adolescents and adolescents for whom privacy and control over the physical self are developmentally crucial. In addition the need for medical care givers to obtain detailed information regarding bodily functions further seems to contribute to a sense of involuntary regression to an infantile phase of development (Travis, 1976:66-67). In her work on anxiety in chronically ill children, Burton asserts that treatment is also disliked because it represents "a symbol of the child's illness accentuating his/her sense of difference from others" (Burton, 1984:151).

One of the obvious and important questions which arises from these observed patterns is the relationship between disease activity and these individuals psychosocial response to having inflammatory bowel disease. Based on my experience with this small group of male adolescents, it seemed that the pattern of denial of the illness led to long term patterns of poor overall self care and tenuous commitment to medical treatment (ie. taking pills). These behavioral tendencies certainly contributed to the high degree of disease activity.

Recent evidence disconfirms the hypothesis that the level of psychological dysfunction is related to level of disease activity; it has been documented however that style of psychological functioning was associated with disease anxiety. In their 1986 study of psychological functioing of children with Crohn's disease and ulcerative colitis, Wood et al. found a correlation between a tendency to internalize and elevated laboratory values (medical tests indicating an increase in disease activity). They discovered that the more patients with Crohn's disease tended to internalize, the more symptoms they reported. These researchers have identified a predominant psychological style in these children characterized by a negative, explanatory style in which the individual attributes internal global causes for bad events: "I failed the exam because I'm no good at science . . .". At the same time external unstable explanations are offered for positive events: "I made the team because the other players were lousy . . .". This maladaptive explanatory style is associated with a pattern of learned helplessness. It is currently being considered that this may represent an important mediating variable between environmental events and disease activity and between disease chronicity and psycho-emotional adaptation to the illness (Wood et al., 1986:776-779).

These authors did not identify variation of psychosocial response according to gender; rather they suggest that this was a common adaptive style with most children with Crohn's disease. As described, my experience suggested some significant differences in coping styles between the sexes. While the negative internalizing style described by Wood et al. certainly resembles my own assessment of the male component of this group, my observations of female patients (at all developmental stages) suggests a very different kind of response. The girls exhibited much more emotional expressiveness about their illness, generally incorporated their illness into a healthy self-concept and perhaps most importantly, demonstrated efforts towards positive self care. Where the boys seemed to withdraw and become helpless when ill, the girls seemed to exert more active efforts to master their own health or in some cases at least to endure medical treatment.

My hypothesis at this point is that girls are socially conditioned in ways which tend to promote healthy adaptation to chronic illness (Schneider, 1976:212-214). This learning process includes the following components: (1) an emphasis on verbal skills and encouragement towards emotional expressiveness, (2) an acceptance of vulnerabilities and fragile dimensions of themselves, (3) an acceptance of the idea of being taken care of and an associated ability to move from dependence and independence as required by the situation. In contrast, boys continue to be conditioned in ways which promote and reinforce physical strength, self sufficiency, emotional self control. Thus the experience of chronic illness is fundamentally threatening to positive male identity which is bound up in apparently contradictory values. It may be theorized that the girls learned orientation to the self and social world serves to equip girls to accept and adapt to the stress and disruption of chronic illness (such as inflammatory bowel disease) particularly during adolescence.

It may be argued that the observed differences in gender response within this group reflects the sampling distortion described earlier. However I think that this theme is sufficiently dramatic to warrant further investigation both with the broader population of children with inflammatory bowel disease and across illness categories. It may be discovered for example that during very active phases of illness (only one of the girls interviewed had high disease activity over the practicum period) response styles of the girls differ from those observed.

One of the issues frequently described in the literature regarding children's adjustment to their chronic illnesses is the body image distortions which result from disease manifestations and/or treatment procedures. A common outcome of inflammatory bowel disease and its treatment is delayed growth and/or low body weight. The steroids sometimes prescribed to manage chronic inflammation frequently inhibit normal growth and development over the course of the drug therapy and sometimes longer (Moroz, 1988).

Consequently many of these children were underweight and/or shorter in stature than most of their peers. Based on my experiences with this group however it seemed that there were no major psychological problems with body image. Although individuals described themselves as "too skinny . . .", or "the shortest kid in my class", this did not seem to be associated with psychological disturbance or negative self concept. Energy level and freedom from symptoms (and therefore ability to engage in normal activities) seemed to be much more important variables in determining psychosocial health and adaptation. Perhaps this is partially explained by the fact that there is a great range of variation in size and weight amongst the normal population of pre-adolescents and adolescents; thus these features are not necessarily obvious (and therefore not stigmatizing) indicators of illness.

The freedom from disease activity which permitted normal social involvement and activity levels was the primary issue for all children interviewed regardless of developmental level. Minimizing the disruptions of daily life and "feeling good" were especially important for the primary school age patients; these children expressed frustration in having to endure "being sick".

Adolescents, particularly the boys interviewed (as described above) also struggled with identity and autonomy issues related to their illness experiences. For example teenage patients generally indicated that they didn't "want everyone (peers) to know" about their illness whereas the younger children were somewhat less discriminating about who they would tell. Most of these children felt that the particular manifestations of their illnesses (ie. diarrhea) and its location (the bowel) were "gross" and difficult to talk about. The degree to which patients seemed to feel stigmatized by their specific illness appeared to be more associated with pesonality than with developmental stage.

My experience with these twelve families allowed identification of several key variables which seemed to affect both the child and family's ability to cope with their illness experiences. Although there was not one particular ideal coping style there were some ecological features and aspects of family functioning which seemed to be associated with successful adaptation to this illness.

Philosophical orientation to managing the disruptions and unpredictability of the illness was found to be one important task in adjustment. This emerged through interviews and also the CICI:PQ which incorporates a subscale on "beliefs".

The parents' ability to develop a philosophical perspective about this life event appeared to be an essential feature in their ability to cope. For several families (particularly mothers), religious beliefs provided a source of emotional strength in coping with the anxiety regarding the child's future, a sense of hope and optimism, and providing meaning to the situation. Comments such as "I feel that my child's illness is a challenge for me as a parent", "misfortune has helped us to realize how important family is" were common. Many parents who did not report formal religious beliefs found consolation in the thought that "It could have been much worse . . .". For example, in response to the statement "It is lucky that this is the only condition my child has" (CICI:PQ belief subscale) most parents responded "agree".

Of note is the observation that acceptance of the permanence and incurable nature the disease was not necessarily a component of positive adaptation. With regard to the statement, "My child's condition is always going to be there and there isn't much I can do about it" (in the "beliefs" subscale of the CICI:PQ), half of the parents responded that they "disagree". This reflected both a belief that the illness could be controlled (to some degree) by medical intervention, healthy lifestyle, self care and secondly a sense of optimism regarding a future cure. While some theorists would regard the latter belief as representing denial, my observation was that this did not generally impair families' ability to manage the immediate demands of the illness but rather helped them to resist becoming overwhelmed by it.

This ability to find some way of making philosophical sense of this experience seemed to be one of the most important predictors of adjustment. Worthy of note is the observation that it is the ability to develop meaning of this event rather than the specific beliefs themselves that seemed to be the important variable.

In addition, it seemed that the more spouses agreed about how they should respond to and make sense of this life event the better adapted they were. Further, the more explicit this understanding between the couple, the better able they seemed to weather the everyday disruptions and acute phases. This shared perspective also helped the couple to support one another and their children. This was also closely associated with the overall health of the marital relationship including commitment to being a couple (as well as parents) and an ability to communicate and problem solve.

As might be expected those families with generally healthy internal systems functioning adapted well to the presence of chronic illness in their children. This was established through in-depth interviews and the Family Assessment measure. The few families experiencing substantial difficulty in coping with illness experiences tended to have prexisting unresolved relationship issues; the strain of illness seemed to intensify these tensions.

An additional theme related to family organization was the predominant child focus in these families. While couple identity was also important it seemed that the majority of parents (both mothers and fathers) were extremely dedicated to the job of being parents. This was illustrated by the degree of involvement in the children's activities and concern expressed about meeting their needs appropriately.

The presence of a social support network is another feature which seemed to be associated with positive adaptation. The quality of these (ie. extended family) relationships was important in determining the degree to which the family perceived these supports as helpful. Those families with friends and relatives who they perceived as helpful resources reported less problems related to feeling worn out or isolated. Five families reported that colleagues at work or friends were more important sources of ongoing support than extended family. Most families indicated that they felt that it was alright to ask for emotional support (ie. "someone to talk to . . .") but didn't request instrumental help unless absolutely necessary.

Very few families had received services from community agencies or had even considered requesting assistance (for example counselling, group programs) from helping organizations. All families indicated that they viewed the physician (and other relevant medical care providers) as the only available formal support regarding their child's illness. Ten of the twelve families reported that they would have utilized social work (or other sources of psychosocial support) services at the time of diagnosis had they been available.

Approximately half of the twelve families seemed to actively seek out information about inflammatory bowel disease beyond what they had been given by the medical clinic. Several had contacted the local chapter of the Colitis and Ileitis foundation for pamphlets or books; three said that they had gone to the library. Most families asked me about different aspects of inflammatory bowel disease including the role of stress in causing the disease or precipitating symptoms. This pattern predictably seemed to be associated with higher socioeconomic levels. It may be that more educated parents use information as a generalized cope strategy in response to range of life situations and problems.

Summary

In summary, this practicum experience allowed me to develop a more thorough understanding of the particular coping mechanisms employed by families with chronically ill children and to identify several adaptational issues. These observations allowed confirmation of the emerging view that this life event is not necessarily associated with individual or family dysfunction (Longo and Bond, 1984:61; Trute and Hauch, 1986). In essence it seemed that those families with preexisting strengths such as a stable couple relationship, parenting skills, a strong philosophical orientation to life, and a social support network were able to adapt to the occurrence of chronic illness in a child very well. Those few with serious unresolved family conflicts, financial strains, or difficulty in maintaining the lifestyle flexibility needed to cope with unpredictable disruption appeared more vulnerable to becoming overly stressed by the illness.

On the whole, these chronically ill children generally exhibited resilience and an ability to manage their illness experiences effectively. I was struck by the degree to which these children seemed average or normal and the absence of a typical personality profile. My experience certainly disconfirmed the notion that inflammatory bowel disease causes (or is precipitated by) individual or family dysfunction (Finch and Hess, 1962). As the ill child enters adolescence the tasks of adaptation become increasingly complex. This may be conceptualized as the challenge of incorporating the illness into the self concept in such a way as to balance awareness of and attention to one's own special needs and an ability to focus on personal strengths and the normal aspects of the self. As discussed this seems to be somewhat more difficult for males than females; further study is needed to confirm and illuminate this observed gender difference.

Generally families were also assessed as well adapted to their child's illness; evidence for this included cohesive marital relationships, normal active lifestyles and skillful utilization of supports. At the same time this target group seemed to experience a range of psychosocial needs (ie. counselling at the point of diagnosis) which were not being met. Social work services would be extremely helpful in upholding family strengths and in addressing unmet needs and problem areas. This will be discussed in the following chapter.

Chapter iv - Summary and Conclusions

(a) Promoting Change Within the Setting: A Research Proposal as an Outcome of the Ecological Perspective

It is has long been asserted that social workers have a professional responsibility to translate private troubles into public issues (Pincus and Minahah, 1973:13). Germain argues that social advocacy, including efforts to increase the health organizations responsiveness to the rights and needs of patients, is an important component of ecological social work practice (Germain, 1984:238-239).

As previously stated, this pediatric gastroenterology clinic which was the context of my practicum placement had never had systematic social work coverage prior to my involvement. One of the outcomes of my work in the clinic was that the multidisciplinary team clearly identified the need for ongoing social work services in the clinic. While the clinic staff had long been aware of the need to attend to the psychosocial realms of pediatric chronic illness, my involvement over the six months confirmed the particular helpfulness of the social work role in providing complete care to children and families.

The absence of social work involvement in my view represented a serious gap in services. My experience suggested that this population had a range of unmet needs; in some cases the lack of appropriate assistance had contributed to longstanding coping problems, family dysfunction and poor management of the illness itself. My assessment of these needs was based on interviews with twelve families (which incorporated specific questions regarding service needs, ie. if there had been a group program for parents with children with inflammatory bowel disease would you have been interested?) and ongoing discussion with team members. These identified needs may be summarized as including the following basic service components:

(1) Social, emotional support and counselling around short and long term adaptation to the illness

- family system adjustment
- stress management
- children's developmental needs and issues
- sibling concerns

(2) Information and Referral

- providing information
- identifying and linking families with relevant community agencies and resources
- exploration and organization of self-help opportunities (ie. parent support group, children's support group)
- educating relevant systems regarding illness (ie. schools)

(3) Incorporating Social Work into Multidisciplinary Team Approach

- enhancing physician/family relationship
- communication of family concerns
- ongoing sensitization of medical staff to psychosocial ramifications of illness and treatment

Unfortunately one of the current realities of this health care organization is the lack of financial resources available to respond to identified service gaps within the system. Consequently while there was agreement regarding the necessity for a social worker in this clinic area, this apparent resource scarcity prevented the creation of such a position. What continues to be available however is financial support for medical research endeavours from several sources. It was suggested by the clinic physician and Dick Marinelli (social work department supervisor) that these resources might be available for research regarding the psychosocial effects of chronic pediatric disease. In addition it was acknowledged that there existed similar gaps in two other clinic areas which also did not have social work coverage.

What resulted from this discussion was my completion of a research application to the Children's Hospital Research Foundation for financial support in undertaking a comparative study of the psychosocial impact of childhood chronic illness in three clinic areas. The purpose of this research proposal was twofold: (1) to develop a greater understanding of the effects of childhood chronic illness across illness categories; (2) to secure the opportunity to provide at least limited social work services to these clinic areas. This initiative was formally supported by the three clinic physicians and written by myself.

Acknowledgement of this endeavour is important in this context as it represented a direct reverberation of my practicum involvement in the clinic. The time and effort required to prepare this application was substantial. I perceived this as an important social advocacy activity in response to a glaring gap in services within this organization. Given my commitment to an ecological approach in working with this population, it seemed essential to respond not only to casework issues but also to the broader systemic features which had a dramatic impact on these families' ability to adapt effectively to this life situation.

Although this application was not approved I believe that the process of undertaking this initiative was valuable. For those committee members who examined this application it provided some validation and reminder that there continues to be some unmet service needs; this was made more powerful by the formal written support of the three clinic physicians. Secondly the meeting and discussion involved in making this a collaborative project between three clinic areas provided additional opportunity for these physicians to articulate and confirm their shared concerns; that social work was an essential but missing component of care provided to their patient populations. Perhaps this research application process can thus be viewed as one step towards organizational responsiveness to patients' needs.

(b) Evaluation of Personal Objectives

Several personal objectives were identified at the outset of this practicum. These are outlined in the Introduction section of this report (page 3). This practicum experience was generally extremely challenging and personally rewarding. My involvement with the gastroentorology clinic and the social work department at Children's Hospital provided me with the opportunity to strengthen my clinical skills and to develop an understanding of and ability to work within the multidisciplinary health care setting.

As discussed at length in Part IV, Chapter i, one of the major tasks associated with my practicum experience involved the process of carving out a social work role within the multidisciplinary team. The literature on this subject is replete with cautions regarding the everpresent obstacles (namely the traditional, authoritarian, physician dominated model of service) which complicate the integration of social work into the health care setting. While the process of establishing good working relationships with the team did require attention, energy and reflection, my overall experience in this regard was very positive. I found the physician and nurse both eager to consult about families and receptive to my professional assessments. Throughout the six months I was responded to as a respected, valued member of the team. This not only boosted my professional self confidence (given the team's receptivity to my presence) but also validated the view that social workers can make a significant contribution within the health care context. Furthermore, working with other disciplines helped me to clarify my own thinking about the social work role especially those features which distinguish it from other helping professions.

The ecological perspective was most helpful in conceptualizing and articulating these professional parameters. The adaptational paradigm and other related concepts in this model were referred to regularly in presenting assessments of families and children. Notions such as reciprocity and mutual exchange helped me to introduce a new perspective into the weekly team discussions regarding family functioning and illness management issues.

The ecological model also assisted me to clarify my professional capacity to promote change and to verbalize the contextual features associated with families which tended to impede or promote growth and stability. For example one family's ongoing somewhat "irrational" feelings of guilt about their son's illness were based on the child's traumatic loss of a pet which was initiated by the well meaning father. This parental emotional reaction seems odd only when perceived out of the context of significant past experience.

The ecological perspective, in conjunction with the problem-centered model of family therapy were found to be extremely appropriate and useful in working with these chronically ill children and their families. One of the major strengths of the problem-centered model was its flexibility in responding to a range of levels of family functioning; it was as helpful in assessing the most adapted, articulate families as it was in identifying problem areas in deeply troubled families. This practicum thus allowed confirmation of the value of these models for social work practice with this population.

Given the assessment focus of the practicum which resulted from the research component of my role, I did not have the opportunity to intervene with a large number of families. The stated objective of systematically evaluating the effectiveness of the selected approach was therefore not completely satisfied. Feedback from those families who did receive substantial help however indicated that these services were valuable.

This extensive assessment experience did allow me to further strengthen and refine my assessment skills. The opportunity to participate in peer consultation groups with four other social workers at the hospital represented one of the highlights of my practicum experience. Involvement with this group assisted me to strengthen my clinical skills, gain added insight into social work practice in the hospital setting and perhaps most importantly, provided me with collegial support. Given the general tendency towards specialization and identification with the multidisciplinary team in this type of setting, the opportunity for ongoing contact with a peer group helped to promote professional identity and skill development. Although group members represented several different areas within the health sciences centre, shared issues and concerns such as professional role and the effecting change in families continually emerged.

Through an extensive review of the literature and contact with the target group over the six months of my practicum I gained a comprehensive understanding of the impact of inflammatory bowel disease on the child and family. My "hands-on" contact with this population in particular allowed me to develop further insight about this life experience: I was most struck for example, by the general resilience and strengths within these families and the degree to which adaptation seemed to be moderated (in either the positive or negative direction) by preexisting features or unrelated stressor rather than disease severity.

On a personal level I feel that my practicum at Children's Hospital provided me with the opportunity to develop a heightened sense of self confidence and professional competence within a multidisciplinary health setting. In addition to being able to pursue a long standing interest in working with chronically ill children and their families I also had the privilege of working with a range of interesting, skilled individual from whom I learned a great deal.

(c) Recommendations for Social Work Practice

Involvement with the twelve children and families in the gastroenterology clinic suggested some clear directions for social work practice and research in this area. Essentially I believe that the practice models utilized in this practicum were both appropriate and helpful with regard to the feature and needs associated with this population. Although in the planning stages I wondered about the potential cumbersomeness of the integrated approach proposed, I did not find it overly awkward or complex in actual practice. The ecological perspective helped me to maintain a broader understanding of illness experiences and to maintain sensitivity to contextual features which I found to be so relevant to immediate coping issues. The problem centered model of family therapy was particularly helpful in its clear family system assessment component and in responding to a range of levels of functioning and family styles. (My experience with these models is described in greater detail in Part IV, Chapter ii: Case Illustrations and in Chapter iv (b) Evaluation of personal objectives).

Given the perceived importance of family history and intergenerational issues in management of illness experiences, I would also recommend the utilization of genograms as a supplement to the assessment process. Although I did not use these systematically, in retrospect I think that they would have helped to illuminate patterns (ie. subjective meaning attached to chronic illness) which impacted upon families ability to cope with the onset of illness in a child. McColdrick and Gerson argue that the genogram is a potentially helpful tool in medical management; relational patterns may for example suggest the likelihood of compliance with treatment recommendations and indicate what social supports will be available. They also suggest that the genogram may assist in pinpointing life events and critical psychosocial problems likely to effect treatment (McColdrick and Gerson, 1985:139).

Based on my clinical experience with this population I have identified a need for social work services within the clinic. The particular type of service needs are described in the first section of this chapter (p. 183). Eight of the families interviewed indicated that they would have made use of social work services at some point in their experiences had they been available, many of these families specified a need for information ongoing support and counselling particularly at the phase of diagnosis. Generally families reported that by about the end of the first six months of living with the illness they had "learned to deal with it". Approximately four families expressed an ongoing or intermittent need for assistance; they commonly seemed to undergo a crisis or transitional period when the ill child entered adolescence.

I think that full-time social work services are required in this clinic; I would recommend that all families be routinely seen at the time of diagnosis for assessment and offer of service. Thus families could be assisted in developing healthy adaptation at a time when they are struggling with how to cope with this experience. Hopefully this initial guidance would set the stage for long term positive adaptation. I would also suggest that long time social work services be made available to families over the duration of their association with clinic. Casework services (ie. counselling, information and referral) should be accessible on an as needed basis. Routine follow up reviews would also help to consolidate the existence of social work as an important component of the child's overall care and to reinforce awareness of the social worker as an ongoing source of support and aid.

Lastly I think that ideally, the social worker in this clinic setting could initiate programs designed to anticipate, normalize and validate the experiences of these children and families such as educational/social events and groups for ill children, siblings and parents. I believe that the introduction of the social work role and specifically the type of services described above would serve as a concrete acknowledgement of the relevance of the psychosocial dimensions of childhood chronic illness and over time would contribute dramatically to long term healthy adaptation of children and families.

Some important research questions arise out of this practicum experience. One of the obvious areas in need of further investigation is the relationship between gender and coping styles. A larger sample population which included a more even balance of age categories for both sexes would allow further illumination of the observed patterns discussed earlier.

An associated question involves the extent to which children's coping styles reflect the particular nature and demands of inflammatory bowel disease and the extent to which these issues are shared by children with other chronic illnesses. While I suspect that many of these children's experiences are generalizable to other illnesses, comparative study of children representing different disease categories in needed to confirm (or challenge) this assumption.

My experience in working with this population suggested that while there is substantial variation with regard to adaptation to inflammatory bowel disease in a child member; most families demonstrated an ability to cope effectively with this life experience. This finding further disconfirms the long-standing presumed association between chronic childhood illness and family system pathology (Minuchin, 1975:1032).

Rather it validates the emerging view that the family's experience of this life event (and their ability to adapt) is moderated by certain features such as availability of social supports, and philosophical perspective. Although this practicum provided the opportunity for identification of some of these variables, studies which examine larger samples and which include families experiencing different disease categories would further strengthen and expand the understanding of these features.

While the integrated approach utilized was found to be extremely appropriate and helpful in assessing and intervening with this sample group, additional investigation which emphasizes before and after measurement is needed to confirm the impact of the practice models. This type of research could be integrated into the clinical practice of social workers currently working in this field through the incorporation of standardized measures such as those described in this context. As we begin to more clearly comprehend the nature of these families experiences it is necessary to develop social work practice models which both reflect this understanding and allow effective response to the range of psychosocial needs of this population.

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APPENDICES

APPENDIX 1: LIST OF FIGURES

Page

Family A

Family B

Family C

Figure 1

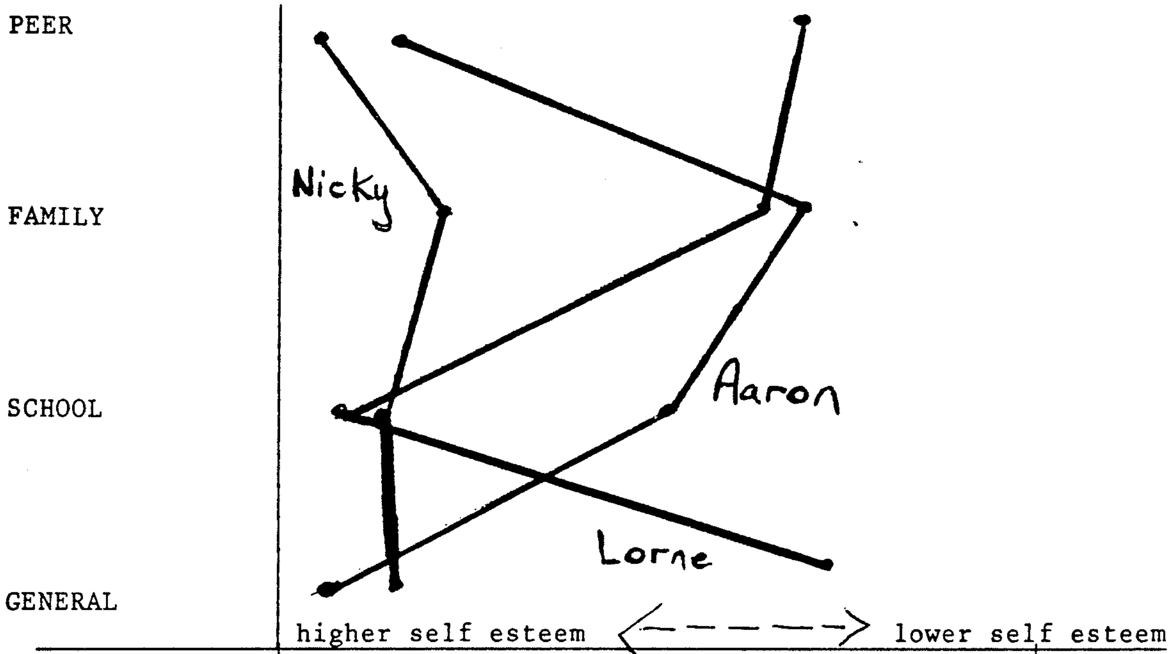
Family A: Chronicity Impact and Coping Instrument:

Parent Questionnaire

Subscale	Response
1. Identified need for help	Would not like help in any any of the areas indicated
2. Self concerns (concerns regarding personal coping, child's coping)	No concerns
3. Self cope (aspects of personal coping style	
(a) sources of information utilized	Nurses, doctors, relatives, friends
(b) coping behavior when problems arise	Cry, talk with someone, pray
4. Sib talk (amount of discussion with children)	A lot of talking regarding subjects indicated especially illness, children's behavior in general
5. Sib help (identified need for help with children)	Identified need for help in behavior management, meeting emotional needs, helping the children to get along
6. Beliefs (philosophical orientation to managing illness experiences)	Acceptance of reality to illness won't go away, belief in the need to get away, to talk of self, good to air feelings to others
7. Family health (perception of overall family health)	Good physical health of all family members

Figure 2

Family A: Summary of Self Appraisal Inventory Scores for Children



# 1	Secondary form (grades 7 to 12)	*64 (56) 54 44 34 24 16	Nicky
# 2	Intermediate form (grades 4 to 6)	*20 (19) 15 10 5 0	Lorne
# 3	Primary form (kindergarten to grade 3)	9 8 7 6 5 4 3 2 1	Aaron

(highest possible subscale score) (lowest possible subscale score)

*Note: #2 - 19 is highest possible score for all subscales except school which is 20 in this form
#1 - 64 is highest possible score for all subscales except school which is 56

L = Louise (mother)
N = Nicky (patient)
age fifteen

Figure 3

Family A

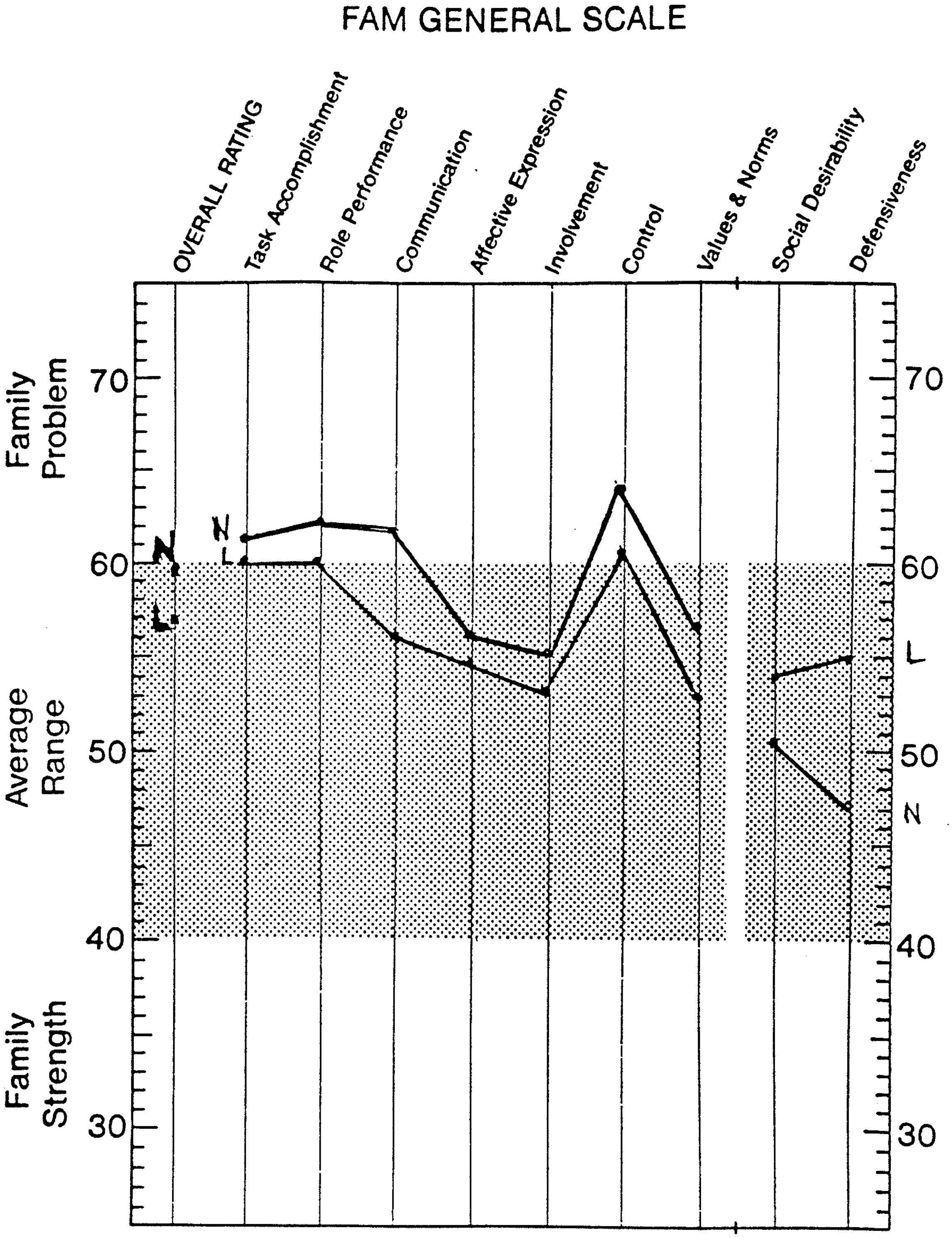


Figure 4

Family B: Chronicity Impact and Coping Instrument: Parent Questionnaire

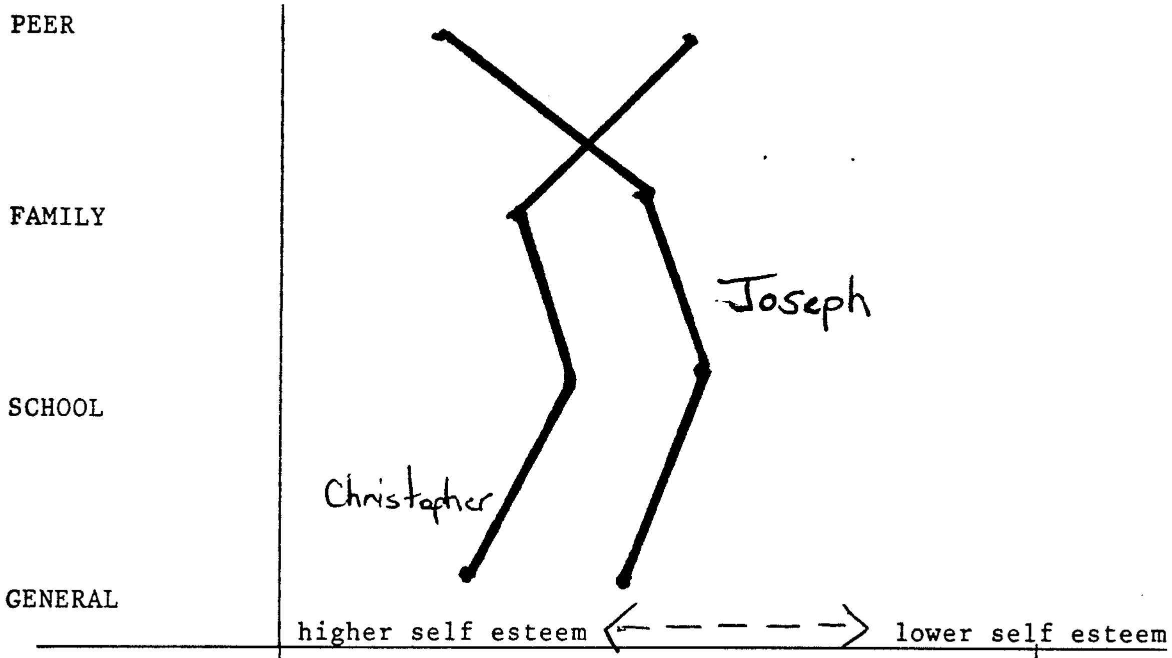
Subscale	Response
1. Identified need for help	Bob: Would like help with; diet, nutrition, managing child's behavior, info about child's social, physical, emotional, intellectual development Sally: Would like help with; managing child's behavior
2. Self concerns (concerns regarding personal coping, child's coping)	Bob: Quite a bit of concern regarding; feeling worn out, wondering about child's future, the responsibilities of caring for my child Sally: Feeling worn out
3. Self cope (aspects of personal coping style)	
(a) sources of information utilized	Bob: Nurse or doctor Sally: Nurse or doctor
(b) coping behavior when problems arise	Bob: Busy self with other things, smoke, get away hide feelings, yell, scream, slam doors, talk with someone Sally: Yell, scream, slam doors, hide feelings, ignore, take alcohol
(c) coping behaviors when upset with spouse	Bob: Ignore, try to forget, hide feelings Sally: Cry, ignore, try to forget
4. Spouse cope (perceptions of spouse's coping behaviors)	Bob: Ignore, try to forget, hide feelings Sally: Smoke, yell, scream, try to forget

Figure 4 (continued)

Subscale	Response
5. Sib talk (amount of discussion with children on given topic areas: i.e. friends, school)	Bob: Moderate amount on most areas listed Sally: Moderate amount about: school, children's behavior in general, growing up
6. Sib help (identified need for help with children)	Bob: Would like help in all areas Sally: Would like help in almost all areas
7. Beliefs (philosophical orientation to managing illness experiences)	General note: High degree of consensus - same response on 6/9 statements: - It is necessary to get out of the house often to relieve the strain of child care (agree), - I usually have control over things that happen in my family (not sure), - it is lucky that this is the only condition my child has (agree), - my child's condition is always going to be there and there isn't much I can do about it (agree), - I sometimes think of my child's condition as a nuisance (agree)
8. Family health (overall rating of family members' health)	Bob: Marginal overall family health rating Sally: Marginal overall health rating

Figure 5

Family B: Summary of Self Appraisal Inventory Scores for Children



# 1	Secondary form (grades 7 to 12)	*64 (56)	54	44	34	24	16	Joseph
# 2	Intermediate form (grades 4 to 6)	*20 (19)		15	10	5	0	Chris-topher

(highest possible subscale score) (lowest possible subscale score)

*Note: #2 - 19 is highest possible score for all subscales except school which is 20 in this form
#1 - 64 is highest possible score for all subscales except school which is 56

Comments: Joseph noted on his form that the following responses apply only "when I'm sick".
- I'm not lonely very often (disagree)
- Often I don't like to be with other kids (agree)
- I'm not as nice looking as most people (strongly agree)
- I'm not a very happy person (strongly agree)

S = Sally
B = Bob
J = Joseph
C = Christopher

Figure 6

Family B

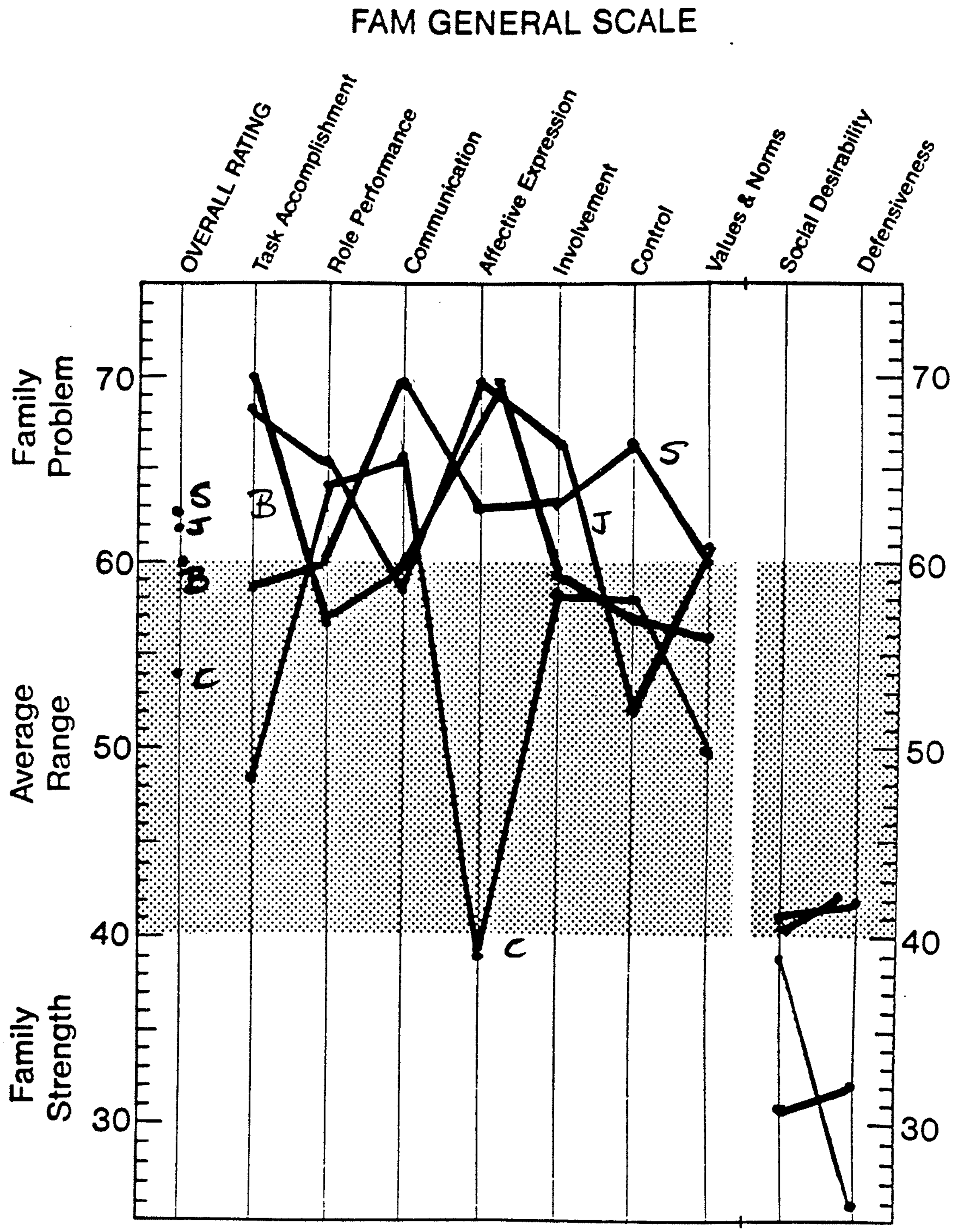


Figure 7

Family C: Chronicity Impact and Coping Instrument: Parent Questionnaire

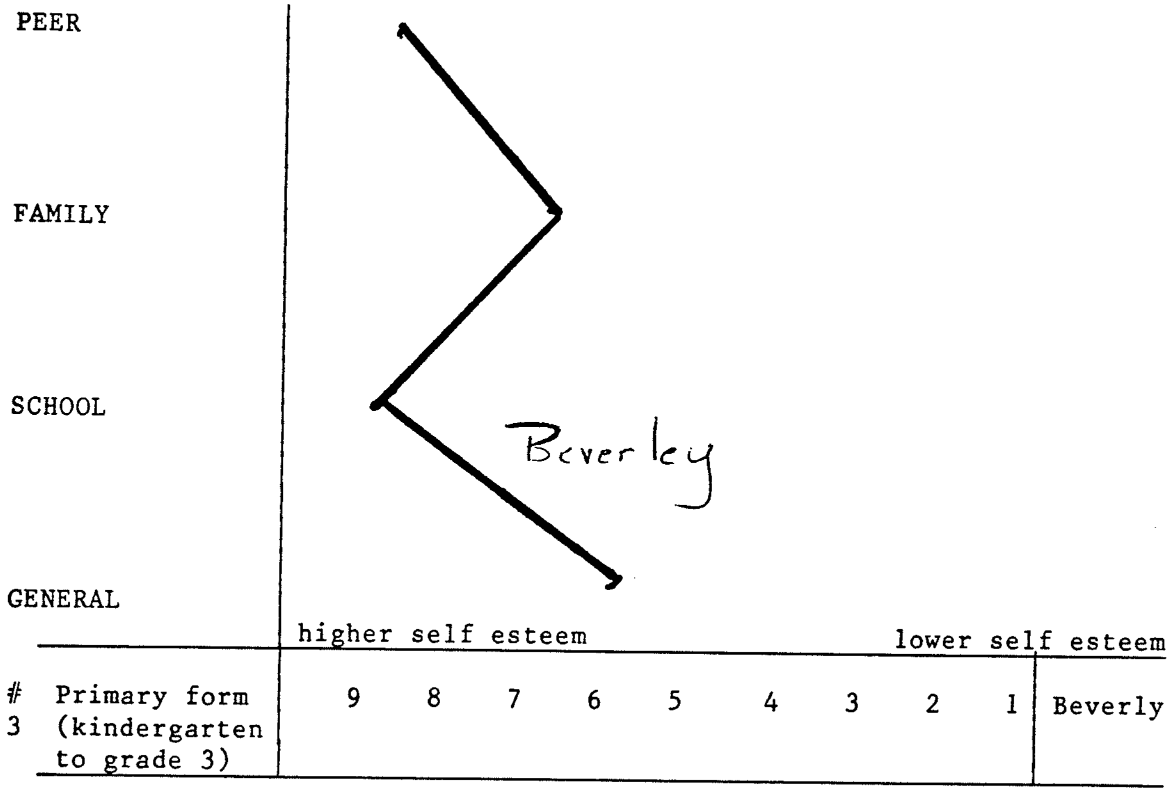
Subscale	Response
1. Identified need for help	Sheri: Would like help with; physical care of the child, diet, genetic counselling, info regarding child's condition Pat: Would like help with all aspects of child development
2. Self concerns (concerns regarding personal coping, child's coping)	Sheri: A great deal of concern regarding what child's future will be like, quite a bit of concern regarding feeling worn out, having to travel too far for medical care, having enough insurance to meet expenses Pat: A great deal of concern what child's future will be like, quite a bit of concern regarding making child comfortable and happy, whether I'm taking care of the child in the best way, not having enough family time
3. Self cope (aspects of personal coping style)	
(a) sources of information utilized	Sheri: Nurse, doctors, friends, relatives, library Pat: Nurse, doctors, friends, relatives
(b) coping behavior when problems arise	Sheri: Do less, get away, talking with someone, do about the same, ask for help, exercise Pat: Do more, smoke, cry, pray, talk with someone

Figure 7 (continued)

Subscale	Response
4. Spouse cope (perceptions of spouse's coping behaviors)	Sheri: Does more, talking with someone, smoking, asking for help, does less, busying self with other things Pat: Does more, busying self with other things, more ignoring, trying to forget, hiding feelings
5. Sib talk (amount of discussion with other children)	Not completed
6. Sib help (identified need for help with children)	Not completed
7. Beliefs (philosophical orientation to managing illness experiences)	General comment: Some consensus on following items: - Parents should take care of own needs before they can help their children (disagree) - It is usually better not to show or talk about feelings to others (not sure) - Sometimes just avoiding or trying to forget something makes it easier to handle (disagree) - My child's condition is always going to be there and there isn't much I can do about it (agree)
8. Family health (overall rating)	Sheri: Very good Pat: Good

Figure 8

Family C: Summary of Self Appraisal Inventory Scores for Children



Average score in this population for form #3 = estimated healthy range = 6 - 9 for each subscale

S = Sheri
P = Pat

Figure 9

Family C

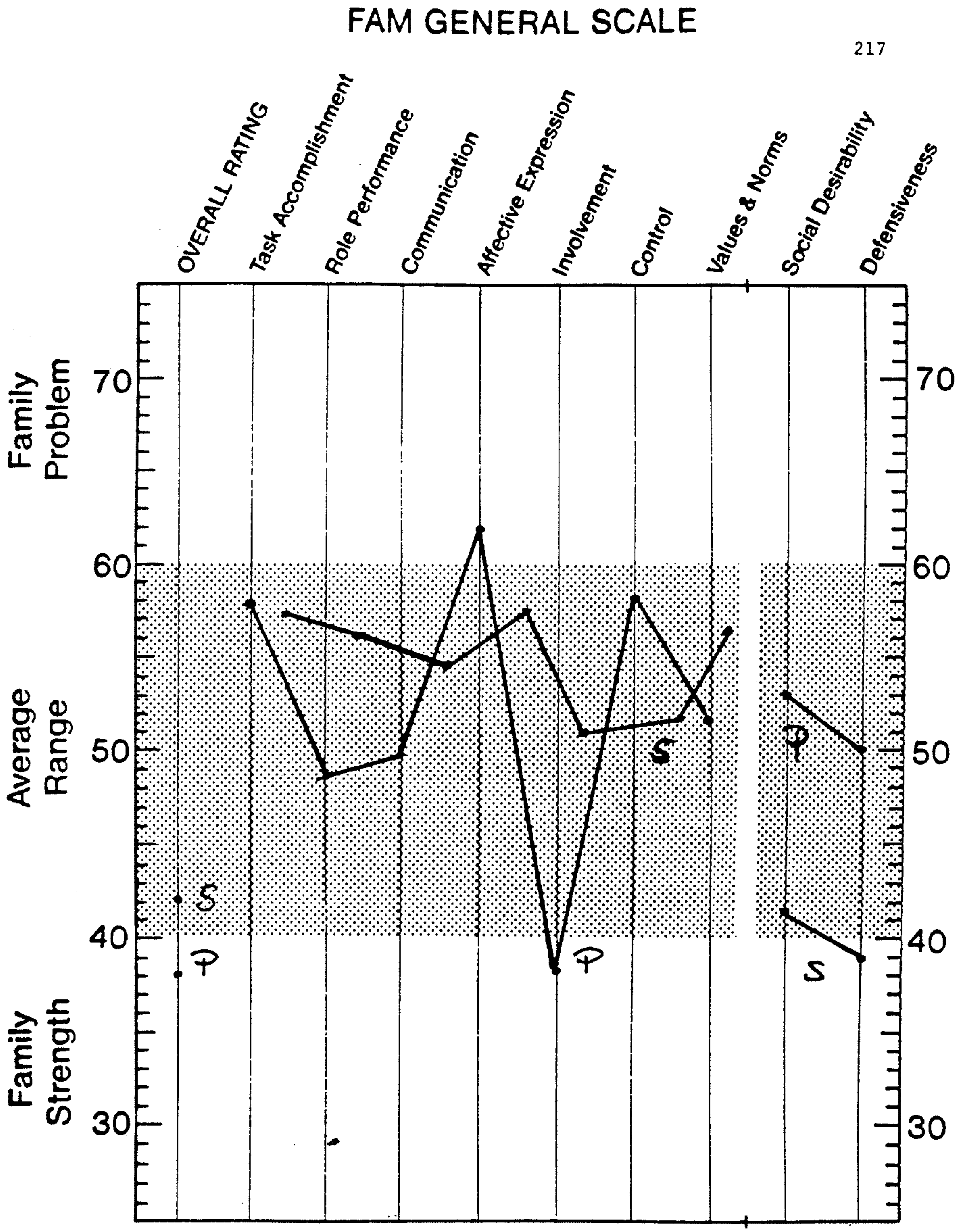


Figure 10

Summary of Self Appraisal Inventory Scores: Ten Families

	Patient: Average Score	Score Range	Sibling: Average Score	Score Range	*Highest Score Possible
Primary Scale (kindergarten to grade 3) Sample includes 1 patient, 1 sibling					
Subscale: Peer	8	-	9	8-9	9
Family	6	-	8	6-8	9
School	8	-	5	5-8	9
General	6	-	4	4-6	9
Intermediate Scale (grades 4 t0 6) Sample includes 1 patient, 3 siblings					
Subscale: Peer	18	-	12	6-13	19
Family	17	-	12	9-18	19
School	18	-	11.6	6-16	20
General	19	-	11.3	10-12	19
Secondary Scale (grades 7 to 12) Sample includes 8 patients, 7 siblings					
Subscale: Peer	48.1	35-57	50.1	46-57	64
Family	46.8	36-59	44	36-50	64
School	44.0	35-54	40	29-49	56
General	46.5	39-54	46	40-52	64

Note: This particular report throughout refers to total of twelve families in population studied. Two families did not complete standardized measures.

Rough norms for secondary scale respondents:
Healthy self esteem levels =

Peer Subscale	46
Family Subscale	44
School Subscale	42
General Subscale	46

*Higher scores associated with higher self esteem

Appendix 2: McCubbin and Figley.. 1983, Volume 2

Responsibilities and Challenges in the Care of a Chronically Ill Child Over Stages of the Family Life Cycle

Infancy (Birth-2 years)
1. Initial Crisis—grieving
    Intensive medical services
    Diagnostic period

Pre-school (3-5 years)
1. Ongoing medical/health monitoring
    Procurement of therapy services
    Prolonged dependency of child requiring added physical care

School Age (6-12 years)
1. School programming
    Ongoing appraisal of child's development
2. Establishment of members' roles in the family
    Dealing with sibling discrepancies re abilities
    Parents' instrumental and maintenance tasks
3. Limited involvement in normal social engagements

Adolescent (13-20 years)
1. Cognitive grasping of "permanence" with disability:
    Parental
    Child
2. Identity, issues of child—"marginality"
3. Increased physical size of child—impact on care
4. More involved adaptive equipment—often necessitated by complications
5. Sexuality issues

Young Adult (21)
1. Discussion about guardianship issues relating to ongoing care of child
2. Placement plans—depending upon feasibility of:
    employment
    self-care
    mobility
    leisure

Appendix 3: McCubbin and Figley. 1983 Volume 2

The Double ABCX Model of Family Adaptation

Adapted from McCubbin, H.I., Nevin, R., Larsen, A., Comeau, J., Patterson, J.M., Cauble, E., & Striker, K. *Families coping with cerebral palsy.* St. Paul: Family Social Science, 1981.

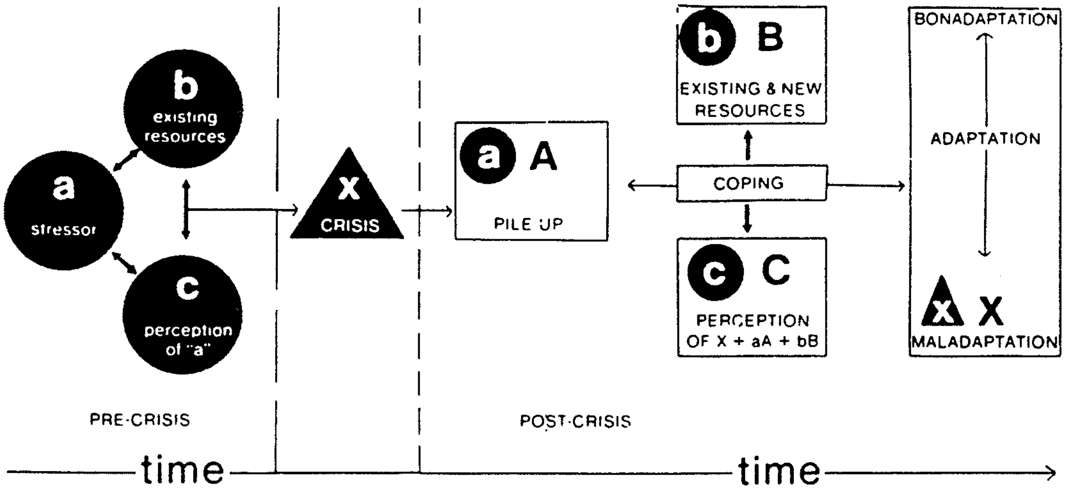


Figure 1. The Double ABCX Model of Family Adaptation

Appendix 4 - Gurman and Kniskern, 1981

Dimensions of Family functioning: McMaster Model

TABLE 2
Summary of Dimension Concepts

Dimensions	*Key Concepts*
PROBLEM-SOLVING	—Two types of problems: Instrumental and Affective —Seven stages to the process: 1. Identification of the problem 2. Communication of the problem to the appropriate person(s) 3. Development of action alternatives 4. Decision of one alternative 5. Action 6. Monitoring the action 7. Evaluation of success *Postulated* —Most effective: When all seven stages are carried out —Least effective: When cannot identify problem (stop before stage 1)
COMMUNICATION	—Instrumental and Affective areas —Two independent dimensions: 1. Clear versus Masked 2. Direct versus Indirect —Above two dimensions yield four patterns of communication: 1. Clear and Direct 2. Clear and Indirect 3. Masked and Direct 4. Masked and Indirect *Postulated* —Most effective: Clear and Direct —Least effective: Masked and Indirect
ROLES	—Two family function types: Necessary and Other —Two areas of family functions: Instrumental and Affective —Necessary family function groupings: A. *Instrumental* 1. Provision of Resources B. *Affective* 1. Nurturance and Support 2. Adult Sexual Gratification C. *Mixed* 1. Life Skills Development 2. Systems Maintenance and Management —Other family functions: Adaptive and Maladaptive —Role functioning is assessed by considering how the family allocates responsibilities and handles accountability for them. *Postulated* —Most effective: When all necessary family functions have clear allocation to reasonable individual(s) and accountability built in —Least effective: When necessary family functions are not addressed and/or allocation and accountability not maintained.
AFFECTIVE RESPONSIVENESS	—Two groupings: Welfare Emotions and Emergency Emotions *Postulated* —Most effective: When full range of responses are appropriate in amount and quality to stimulus —Least effective: When very narrow range (one to two affects only) and/or amount and quality is distorted, given the context.
AFFECTIVE INVOLVEMENT	—A range of involvement with six styles identified: 1. Absence of Involvement 2. Involvement Devoid of Feelings 3. Narcissistic Involvement 4. Empathic Involvement 5. Overinvolvement 6. Symbiotic Involvement *Postulated* —Most effective: Empathic Involvement —Least effective: Symbiotic and Absence of Involvement
BEHAVIOR CONTROL	—Applies to three situations: 1. Dangerous Situations 2. Meeting and Expressing psychobiological needs and drives (eating, drinking, sleeping, eliminating, sex and aggression) 3. Interpersonal socializing behavior inside and outside the family —Standard and latitude of acceptable behavior determined by four styles: 1. Rigid 2. Flexible 3. Laissez-faire 4. Chaotic —To maintain the style, various techniques are used and implemented under role functions (systems maintenance and management) *Postulated* —Most effective: Flexible behavior control —Least effective: Chaotic behavior control

Appendix 5

(a) The Scale

Family Assessment Measure

GENERAL SCALE

Directions

On the following pages you will find 50 statements about your family as a whole. Please read each statement carefully and decide how well the statement describes your family. Then, make your response beside the statement number on the separate answer sheet.

If you STRONGLY AGREE with the statement then circle the letter "a" beside the item number; if you AGREE with the statement then circle the letter "b".

If you DISAGREE with the statement then circle the letter "c"; if you STRONGLY DISAGREE with the statement then circle the letter "d".

Please circle only one letter (response) for each statement. Answer every statement, even if you are not completely sure of your answer.

Appendix 5 - continued

Please do not write on this page.
Circle your response on the answer sheet.

1. We spend too much time arguing about what our problems are.
2. Family duties are fairly shared.
3. When I ask someone to explain what they mean, I get a straight answer.
4. When someone in our family is upset, we don't know if they are angry, sad, scared or what.
5. We are as well adjusted as any family could possibly be.
6. You don't get a chance to be an individual in our family.
7. When I ask why we have certain rules, I don't get a good answer.
8. We have the same views on what is right and wrong.
9. I don't see how any family could get along better than ours.
10. Some days we are more easily annoyed than on others.
11. When problems come up, we try different ways of solving them.
12. My family expects me to do more than my share.
13. We argue about who said what in our family.
14. We tell each other about things that bother us.
15. My family could be happier than it is.
16. We feel loved in our family.
17. When you do something wrong in our family, you don't know what to expect.
18. It's hard to tell what the rules are in our family.
19. I don't think any family could possibly be happier than mine.
20. Sometimes we are unfair to each other.
21. We never let things pile up until they are more than we can handle.
22. We agree about who should do what in our family.
23. I never know what's going on in our family.
24. I can let my family know what is bothering me.
25. We never get angry in our family.

Appendix 5 - continued

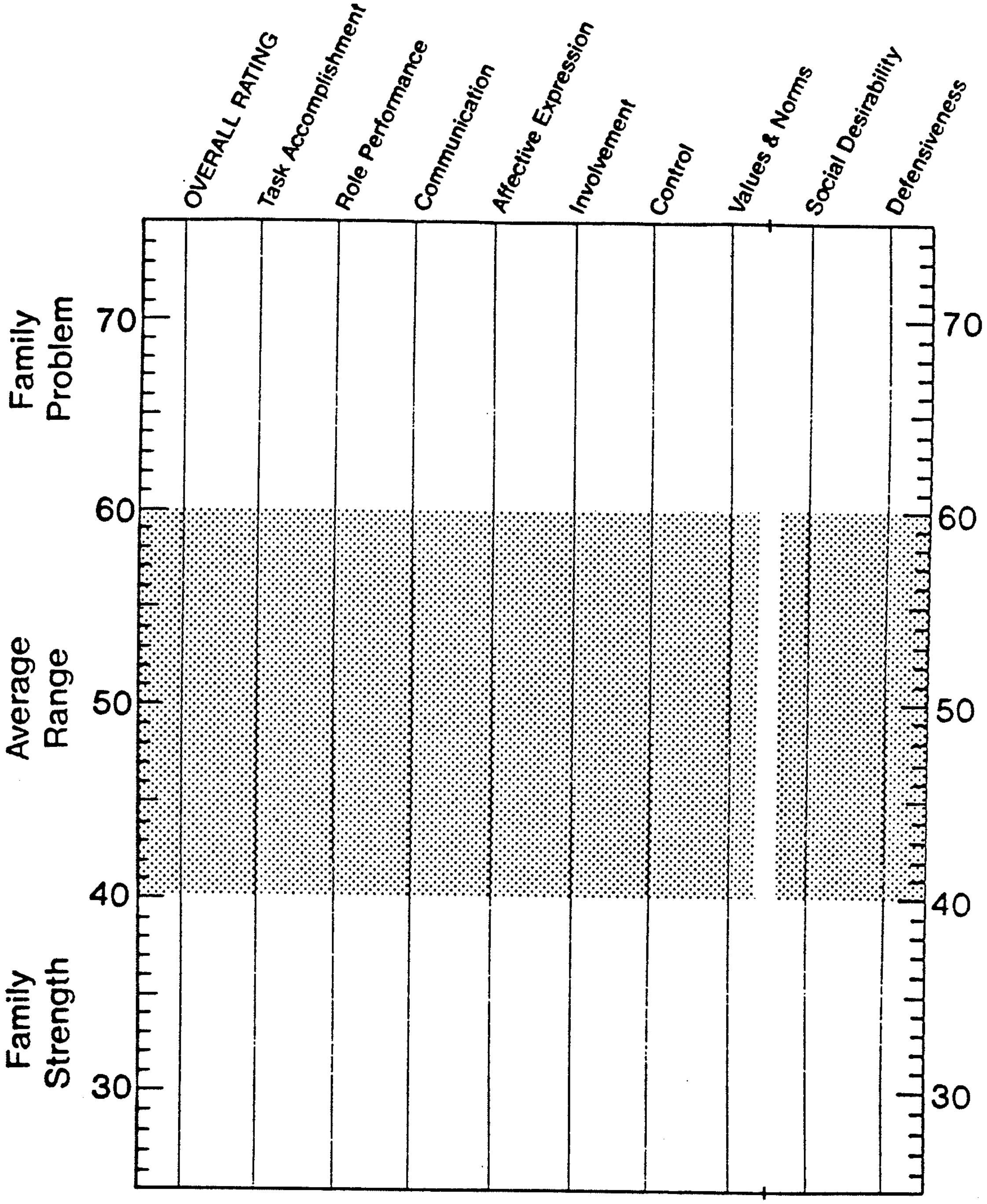
Please do not write on this page.
Circle your response on the answer sheet.

26. My family tries to run my life.
27. If we do something wrong, we don't get a chance to explain.
28. We argue about how much freedom we should have to make our own decisions.
29. My family and I understand each other completely.
30. We sometimes hurt each others feelings.
31. When things aren't going well it takes too long to work them out.
32. We can't rely on family members to do their part.
33. We take the time to listen to each other.
34. When someone is upset, we don't find out until much later.
35. Sometimes we avoid each other.
36. We feel close to each other.
37. Punishments are fair in our family.
38. The rules in our family don't make sense.
39. Some things about my family don't entirely please me.
40. We never get upset with each other.
41. We deal with our problems even when they're serious.
42. One family member always tries to be the centre of attention.
43. My family lets me have my say, even if they disagree.
44. When our family gets upset, we take too long to get over it.
45. We always admit our mistakes without trying to hide anything.
46. We don't really trust each other.
47. We hardly ever do what is expected of us without being told.
48. We are free to say what we think in our family.
49. My family is not a perfect success.
50. We have never let down another family member in any way.

Appendix 5

(b) Graph for FAM Scores

FAM GENERAL SCALE



Appendix 6 (Hymovich, 1981)

CHRONICITY IMPACT AND COPING INSTRUMENT: PARENT QUESTIONNAIRE
(CICI:PQ)

THIS QUESTIONNAIRE IS TO HELP US LEARN MORE ABOUT THE EXPERIENCES YOU HAVE IN CARING FOR YOUR CHILD AND THE THINGS YOU DO TO MANAGE THESE EXPERIENCES.

THE INFORMATION YOU SHARE WILL BE USED TO HELP US PROVIDE APPROPRIATE HEALTH CARE TO YOU AND YOUR FAMILY.

PLEASE FEEL FREE TO ASK THE NURSE ABOUT ANY QUESTIONS THAT ARE NOT CLEAR.

TODAY'S DATE ____________

CHILD'S NAME OR CODE: ________________________________

CHILD'S AGE: ____________________ / ____________________
(YEARS) (MONTHS)

CHILD'S SEX: (1) MALE __________ (2) FEMALE __________

SECTION A: YOUR CHILD

1. What is your child's condition or disability?__________

2. How severe would you say your child's condition is?
   - ____ (1) Not severe (slight)
   - ____ (2) Moderately severe
   - ____ (3) Very severe

3. How long ago was your child's condition first diagnosed?
   - ____ (1) under 3 months ____ (4) 1-2 years
   - ____ (2) 3-6 months ____ (5) 2 years 1 month-4 years
   - ____ (3) 7-11 months ____ (6) over 4 years

4. Does anyone else in your family have the same illness/disability as your child?
   ____ (1) No ____ (2) Yes
   If yes, who?
   - ____ (1) You
   - ____ (2) Spouse
   - ____ (3) Child's brother(s) or sister(s)
   - ____ (4) Grandparent
   - ____ (5) Other: Who? ______________

5. Please indicate your relationship to this child
   - ____ 1) Mother ____ 5) Foster Mother
   - ____ 2) Father ____ 6) Foster Father
   - ____ 3) Stepmother ____ 7) Guardian
   - ____ 4) Stepfather ____ 8) Other: Explain____________

6. Parents have asked for help with many aspects of their child's development and care including those listed below. Please indicate if you would or would not like to have help with or discuss any of the following

	WOULD NOT LIKE (1)	NOT SURE (2)	WOULD LIKE (3)
Physical care of child			
Diet/nutrition			
Sleep habits			
Genetic counseling			
Play or recreation activities			
Managing child's behavior			
Providing the right play and learning experiences			
Care of minor illnesses			
Dental needs of child			
Information about expected child development			
Information about my child's physical development			
Information about my child's social development			

Appendix 6 - continued

SECTION B: YOURSELF

1. All parents have some areas of concern. During the *past 3 months*, how much of a concern have the following areas been for you? (Please put an "X" in the appropriate column.)

CONCERNS	NONE/ DOES NOT APPLY (1)	NOT SURE (2)	A LITTLE BIT (3)	QUITE A BIT (4)	A GREAT DEAL (5)
Extra demands on my time					
Feeling worn out					
Enough fun and relaxation as I would like					
Having enough time alone with spouse/partner					
Talking with or understanding my spouse/partner					
Sexual relationship with my spouse/partner					
Making my child comfortable or happy					
Enough time or attention from spouse/partner					
Getting out of house together with spouse/partner but without children					

CONCERNS (cont'd)	NONE/ DOES NOT APPLY (1)	NOT SURE (2)	A LITTLE BIT (3)	QUITE A BIT (4)	A GREAT DEAL (5)
Getting out of house alone					
Getting to do activities together as a family					
Whether I am taking care of my child in the best way					
Having to travel too far for medical help or child care					
The weather influencing what my child is able to do					
Having enough insurance to meet expenses of child care					
Having adequate agencies in the community providing care related to my child's needs					
Wondering about what my child's future is likely to be					
The responsibility of caring for my child worries me					

2. Parents handle their concerns in many different ways. There are times when you may have more problems and concerns because of your child's condition. In what ways do you do things differently when these problems come up? (Please put an "X" in the appropriate column. *Do not* mark on the lines.)

	Does Not Apply (1)	Do Less (2)	Do About the Same (3)	Do More (4)
Cry				
Busy self with other things				
Talk with someone				
Ignore/try to forget				
Hide feelings				
Get away				
Smoke				
Yell/scream/slam doors, etc.				
Exercise				
Ask for help				
Take alcohol				
Pray				
Take medicine				

3. Are you a member of a parents' association related to your child's illness/disability?
____ (1) No ____ (2) Yes
a. If Yes, how often do you attend meetings?
____ (1) Frequently ____ (3) Rarely
____ (2) Occasionally ____ (4) Never
b. If you go to the parents' meetings, how helpful have they been?
____ (1) Do not go ____ (4) Not very helpful
____ (2) Very helpful ____ (5) Not helpful at all
____ (3) Somewhat helpful

4. Do you have someone who could take care of your child for a day in case of an emergency (such as if you become ill and cannot take care of the child)?
____ (1) No ____ (2) Not sure ____ (3) Yes

5. Do you have someone who could take care of your child for a week or more in case of an emergency?
____ (1) No ____ (2) Not sure ____ (3) Yes

6. Parents have different beliefs about things that influence their life-style. Please indicate whether or not you agree with the beliefs stated below.

Beliefs	Agree (1)	Not Sure (2)	Disagree (3)
Parents should take care of their own needs before they can help their children			
It is necessary to get out of the house often to relieve the strain of child care			
It is usually better not to show or talk about one's feelings to others			
Sometimes just avoiding or trying to forget something makes it easier to handle			
Sometimes getting away from a situation makes it easier to handle			
I usually have control over things that happen to me or my family			
It is lucky that this is the only condition my child has			
My child's condition is always going to be there and there isn't much I can do about it			
I sometimes think of my child's condition as a nuisance			

7. ~~a) What~~ is your marital status?
____ (1) Married ____ (4) Divorced
____ (2) Widowed ____ (5) Single (never married)
____ (3) Separated
b) For how many years have you been widowed, married, separated, or divorced?
____ (1) under 1 year ____ (3) 4–6 years
____ (2) 1–3 years ____ (4) over 6 years
c) How many times have you been married?
____ 1
____ 2
____ 3 or more

IF YOU ARE *MARRIED*, PLEASE GO ON TO SECTION C
IF YOU ARE *NOT MARRIED*, PLEASE GO ON TO SECTION D
IF YOU ARE *WIDOWED, DIVORCED, SEPARATED, OR SINGLE*, PLEASE GO TO SECTION D

SECTION C: YOUR SPOUSE

1. How old is your spouse?
____ (1) under 18 years ____ (5) 35–39 years
____ (2) 19–24 years ____ (6) 40–44 years
____ (3) 25–29 years ____ (7) 45–49 years
____ (4) 30–34 years ____ (8) 50 years or over

2. What is your spouse's occupation? (Please state what your spouse does, not where he/she is employed.)
____

3. How much school has your spouse completed?
____ (1) 9th grade or below
____ (2) 10th grade
____ (3) 11th grade
____ (4) 12th grade
____ (5) Some college
____ (6) College graduate
____ (7) Master's degree
____ (8) Doctoral degree

	Does Not Apply (1)	Do Less (2)	Do About the Same (3)	Do More (4)
Pray				
Take medicine				

9. How has your relationship with your spouse changed since your child's condition was diagnosed?
____ (1) No change
____ (2) Not sure
____ (3) Brought us closer
____ (4) Moved us apart

IF YOUR CHILD HAS SISTERS OR BROTHERS, PLEASE GO TO SECTION D
IF YOUR CHILD DOES NOT HAVE SISTERS OR BROTHERS, PLEASE GO TO SECTION E

SECTION D: BROTHERS & SISTERS

1. During the *past 3 months*, how much have you and your other children talked about the following:

	Not at All/Does Not Apply (1)	A Little Bit (2)	A Moderate Amount (3)	A Great Deal (4)
Information about the child's condition				
How to take care of the condition				
Their friends				
School				
Activities				
Child's behavior in general				
Their futures				
Growing up in general				

2. Please indicate whether you would like to have help with or discuss any of the following in relation to any of your child's brothers or sisters:

	Would Not Like (1)	Not Sure (2)	Would Like (3)
Information about expected child development			
Managing child's behavior			
Physical needs			
Emotional needs			
Social needs			
Intellectual needs			
Helping child understand the other child's condition			
Helping children to get along			

SECTION E: HOSPITALIZATION

1. Has your child ever been admitted to the hospital?
____ (1) No
(If No, please complete *Section F*)
____ (2) Yes
(If Yes, please complete this section)

2. How many times has your child been in the hospital?
____ (1) 1
____ (2) 2-4
____ (3) 5-7
____ (4) 8 or more

3. For how long were the *majority* of hospital stays?
____ (1) under 1 week
____ (2) 1-2 weeks
____ (3) over 2 weeks

4. At what ages was your child admitted to the hospital? (Check as many as apply)
____ (1) under 1 year
____ (2) 1-2 years
____ (3) 3-5 years
____ (4) 6-9 years
____ (5) 10-12 years
____ (6) 13-15 years
____ (7) 16-18 years
____ (8) over 18 years

5. How satisfied were you with the care your child received during the last hospitalization?
____ (1) very satisfied
____ (2) somewhat satisfied
____ (3) somewhat dissatisfied
____ (4) very dissatisfied

Appendix 6 - continued

4. How has your spouse's health been during the *past 3 months*?
___ (1) Excellent ___ (3) Good
___ (2) Very good ___ (4) Fair/poor

5. During the *past 3 months* how much of a problem do you think the following areas have been for your spouse? (Place an "X" in the appropriate column. Please *do not* mark on the lines.)

PROBLEMS FOR SPOUSE	DOES NOT APPLY (1)	NOT SURE (2)	A LITTLE BIT (3)	A MODERATE AMOUNT (4)	A GREAT DEAL (5)
Extra demands on time					
Feeling worn out because of all the family's needs					
Not enough fun and relaxation as spouse would like					
Not enough time or attention from you					
Having enough time alone with you					
Talking with or understanding you					
Sexual relationships with you					
Making your child comfortable or happy					
Getting out of house together with you but without children					
Getting out of house alone					
Getting to do activities together as a family					
Whether you are taking care of your child in the best way					
Having to travel too far for medical help or child care					

6. How satisfied are you with your relationship with your spouse?
___ (1) Not sure
___ (2) Very satisfied
___ (3) Somewhat satisfied
___ (4) Somewhat dissatisfied
___ (5) Very dissatisfied

7. People do many different things when they become upset with their spouse. Please indicate the ways in which *you* do things differently when you are upset with your spouse than when you are not upset. (Please put an "X" in the appropriate box. *Do not* mark on the lines.)

	DOES NOT APPLY (1)	DO LESS (2)	DO ABOUT THE SAME (3)	DO MORE (4)
Cry				
Busy self with other things				
Talk with someone				
Ignore/try to forget				
Hide feelings				
Get away				
Smoke				
Yell/scream/slam doors, etc.				
Exercise				
Ask for help				
Take alcohol				
Pray				
Take medicine				

8. In what ways does *your spouse* do things differently when upset with you than when not upset? (Please put an "X" in the appropriate box. *Do Not* mark on the lines.)

	DOES NOT APPLY (1)	DO LESS (2)	DO ABOUT THE SAME (3)	DO MORE (4)
Cry				
Busy self with other things				
Talk with someone				
Ignore/try to forget				
Hide feelings				
Get away				
Smoke				
Yell/scream/slam doors, etc				
Exercise				
Ask for help				
Take alcohol				

Appendix 6 - continued

SECTION F: OTHER

1. How many children do you have?
   ____ 1 ____ 3 ____ 5 ____ 7
   ____ 2 ____ 4 ____ 6 ____ 8 or more

2. How many of your children are under 5 years of age?
   ____ 0 ____ 1 ____ 2 ____ 3 ____ 4 or more

3. How many of your children are between 6 and 12 years of age?
   ____ 0 ____ 1 ____ 2 ____ 3 ____ 4 or more

4. How many of your children are 13 years old or older?
   ____ 0 ____ 1 ____ 2 ____ 3 ____ 4 or more

5. In general, how has the health of each of your children been during the *past 3 months?*

	EXCEL-LENT/ VERY GOOD (1)	GOOD (2)	FAIR POOR (3)
Child 1 (with disease/disability)			
Child 2			
Child 3			
Child 4			
Child 5			
Child 6			
Child 7			
Child 8			

6. How would you describe yourself?
   ____ (1) Caucasian ____ (5) American Indian/Indian
   ____ (2) Asian ____ (6) Other
   ____ (3) Black Specify____________
   ____ (4) Spanish-American

7. What is your religion?
   ____ (1) Catholic ____ (4) Other
   ____ (2) Jewish What?____________
   ____ (3) Protestant ____ (5) No religion

8. How often have you attended religious services in the *past 3 months?*
   ____ (1) Frequently ____ (3) Rarely
   ____ (2) Occasionally ____ (4) Never

9. Are you employed now?
   ____ 1) No ____ 2) Yes
   If yes, what do you do? ____________
   (Please do not put where you work)
   If yes, do you work? ____ 1) full-time? ____ 2) part-time?

10. Are you satisfied with your current employment status?
    ____ 1) No ____ 2) Not sure ____ 3) Yes

11. What is your age?
    ____ (1) under 18 years ____ (5) 35–39 years
    ____ (2) 19–24 years ____ (6) 40–44 years
    ____ (3) 25–29 years ____ (7) 45–49 years
    ____ (4) 30–34 years ____ (8) 50 years or over

12. How much school have your completed?
    ____ (1) 9th grade ____ (5) Some college
    ____ (2) 10th grade ____ (6) College graduate
    ____ (3) 11th grade ____ (7) Master's degree
    ____ (4) 12th grade ____ (8) Doctoral degree

13. How has your general health been during the *past 3 months?*
    ____ (1) Excellent ____ (3) Good
    ____ (2) Very Good ____ (4) Fair/Poor

14. What is your family's annual income?
    ____ 1) Under $5,000
    ____ 2) $5,000 to $10,000
    ____ 3) $11,000 to $20,000
    ____ 4) $21,000 to $30,000
    ____ 5) Over $30,000

15. Approximately how many of the questions in this questionnaire apply to your child and family?
    ____ (1) All
    ____ (2) Most
    ____ (3) Some
    ____ (4) Few
    ____ (5) None

16. How well do the questions cover the things you believe are important about having your child with this condition?
    ____ (1) Very well
    ____ (2) Somewhat well
    ____ (3) Not too well
    ____ (4) Not very well at all

17. How long did it take you to complete this questionnaire?
    ____ (1) under 10 minutes
    ____ (2) 10–14 minutes
    ____ (3) 15–19 minutes
    ____ (4) 20–24 minutes
    ____ (5) 25 minutes or more

18. Do you have anything else to add that you would like us to know about yourself, your child, or other family members?
    ____ (1) No
    ____ (2) Yes
    If yes, what? ____________

Appendix 7

Instructions for Projective Drawing Exercise

INSTRUCTIONS FOR ADMINISTRATION

Instructions for administering the human figure drawing test come in a number of variations. While they are all very similar, their slight differences may determine the kind of drawing produced. Some researchers have specified the drawing of a man or a woman or a boy or a girl. Others have asked for the drawing of a person in the rain. Still others, like Tait and Ascher (1955) whose major interest is in the inside-of-the-body, have instructed their subject to draw the inside of the body (including all of the organs), to draw a line from each organ to the outside and then to label that organ.

We believe that the less specific the instructions, the richer the drawings will be in terms of projective material. Here is our usual procedure: A child is given a sheet of letter-size paper (8½"x11") and a medium soft pencil, and is simply asked to *"draw a picture of a person."* If the child asks for more specific instructions or some kind of direction, the original instructions are repeated, or a non-directive type of remark is made indicating that he can draw any kind of person he wants. If the child draws only a part of the person, for example, the head, thank him for it and then ask him to draw a *whole* person. (The part of a person drawn may be significant. If a child draws only a head when requested to draw a person, he may be placing too much emphasis on this part of the body or it may be an area of concern. The head represents thinking proceeses, and this child may be concerned about mental adequacy.)

For a child who is very young or who does not understand what the word "person" means, the instructions should be repeated as follows:

"Draw a picture of a person. You can draw any kind of person you want – a man, or a woman, or a boy or a girl."

Never ask a child, "Can you draw a picture of a person?" Some children will refuse or deny that they are able to draw.

If a child draws the examiner, this should be noted. Insecure children often search for models to copy. What they may be saying is that they are not important enough to drawn (we assume most children draw themselves when asked to draw a picture of a person). These insecure children will draw others, such as examiners, teachers, parents, whom they view as more important than themselves.

When asking groups of children to draw, care should be taken to seat the children as far apart as possible to minimize copying. Again, it is the insecure child, lacking confidence in his own production, who is more likely to copy. (source unknown)

Appendix 8

Taken from: Leventhal, 1984:73

Psychosocial Assessment of Children with Chronic Disease

CHILD PROFILE

Table 1 shows an approach to organizing the child's profile of functioning. There are four major headings: (1) the child's personal growth and development, (2) the child's relationships with family members, (3) the child's activities outside the home, and (4) the child's response to the illness. To obtain a complete profile, the pediatrician or team of health-care providers collects data about the variables under each of the major headings.

Table 1. *Child's Profile of Functioning*

- *Personal Growth and Development*
  - Tasks of daily living
  - Cognitive functioning
  - Motor skills
  - Style of performance
  - Emotional and personality development
- *Relationship with Family Members*
  - Parents
  - Siblings
- *Activities Outside the Home*
  - School performance
  - Peer relationships
- *Response to the Illness*
  - Understanding of the illness
  - Participation in care

Appendix 9

(elaboration of Table 8)

Taken from: Leventhal (as referred on Table 5)

Personal Growth and Development

Variables under this heading are concerned with the child's physical, intellectual, motoric, and emotional growth. The variables have been age-appropriate independence? Is the adolescent involved with excessive risk-taking behaviors? The answers to these and similar questions are likely to provide the best picture of how the child has responded to the disability and integrated the problem into his or her personal life. If psychological testing is performed on the child, projective tests such as the Thematic Apperception Test[2] will provide another perspective on this variable.

Relationships with Family Members

The variables under this heading are concerned with how the child gets along with parents and siblings. Variables focusing on how these family members get along with the child are discussed below in the Family Profile. Although separating a relationship into its two sides is somewhat artificial, this distinction helps the clinician remember that there are two important perspectives in a relationship (for example, the child's and the parent's). Obtaining information directly from the child or adolescent can provide an important perspective on the relationships, as well as establish an important alliance with the child.

Parents. Two major issues should be assessed to understand the child's relationship with his parents. The first is concerned with how the child feels that he is viewed by his parents. Instead of feeling accepted, loved, and supported, the child who is chronically ill may feel that his parents are disappointed in him because of his defect. This sense of disappointing one's parents will likely affect the child's self-confidence with friends and teachers and affect how the child views family events. For instance, a boy with diabetes who feels that he is a tremendous burden and disappointment to his parents may feel excessive guilt and responsibility for his parents' divorce. The second area of concern is whether the child is able to communicate with the parents. To whom does the child turn for help? Can the child bring up concerns related to the illness (for example, fear of the pain associated with the treatment or of death)? Is the parent able to help the child manage such problems?

Siblings. In considering the child's relationship with siblings, the physician is interested in both what the child does with the siblings and how the child feels toward them. Jealousy and anger because a brother can run without difficulty or because a sister takes no medications is not an unusual feeling for a child with a chronic illness. In addition, the child may feel guilty that the illness has caused the siblings undue deprivation and suffering.

Activities Outside the Home

Since a major task of growing up is to develop an appropriate independence from one's family, successful adaptation to school and activities outside the home and acceptance by peers are important for any child and even more so for a child with chronic illness. Yet, leaving the security of one's home environment can be particularly difficult and painful because of problems of separation and stigmatization. Therefore, to understand the child's adjustment to the illness, it is particularly important to learn about the child's activities outside the home.

School Performance. Information about the child's performance in school can be divided into four main areas: (1) absenteeism, (2) academic broadly defined, although each can be subdivided into finer details of the child's functioning.

Tasks of Daily Living. These include eating, sleeping, toileting, dressing, and special tasks related to the care of the illness. Information can be collected in each of the areas to determine how the child performs these skills. Since limitations in the child's performance make the child more dependent on the parents, and often on other important adults such as teachers, the pediatrician will be interested in the specific limitations as well as how these limitations affect the child's psychological development and relationship with his or her parents.

The basic information about eating should include the range of the child's diet and what mealtimes are like in the household. Eating and food become even more important in certain diseases. For instance, in diabetes, more details are required about what is eaten (which might be obtained by the dietician), how meals are managed, what the parents do about the child's cheating or stealing of food, and how much of the parent-child relationship is focused on issues of controlling the child's diet.

Information about sleep should include where the child sleeps and whether there are any problems with the child falling asleep or awakening at night. Following hospitalization, children may have difficulties sleeping. The child's illness may also affect the parents' sleep. For instance, parents whose child has a respiratory problem or was a premature infant might be anxious about whether the child will stop breathing. This anxiety might lead to the child's sleeping in the parents' bed, or the parents checking on the child every hour so that neither the parent nor child can sleep well.

For most children with a chronic illness, it is enough to know how the parent is *toilet training* the child, or in older children, whether there are any problems with enuresis or encopresis. In special circumstances—for instance, a child with ulcerative colitis—it would not be unusual for the entire family to know the child's bowel habits. How upsetting is this invasion of privacy for the older child or adolescent? If a child with a chronic physical illness requires assistance getting to the bathroom, the physician should be interested in learning what arrangements have been made for the child at home and at school and how these arrangements are affecting the younger child's mastery of bodily functions or the adolescent's psychosexual development.

Dressing and undressing are tasks that usually are accomplished by five years of age, so that questions concerning these tasks are seldom asked about healthy, school-aged children. For children with muscle diseases or spina bifida, daily help in dressing both at home and at school may be another important reminder of their limitations and their differences from normal children.

Special tasks related to the care of the illness (such as putting on leg braces, taking medications, eating special meals, or catheterizing one's bladder) also may need to be performed on a regular basis. The pediatrician is interested in which tasks are performed, whether they get performed in an appropriate way, and how the child responds to these tasks. For instance, adolescents with a chronic illness often refuse to perform these tasks. Talking to adolescents about this problem and allowing them some control over what they do and how they do it might improve compliance.

Cognitive Functioning (Including Language Development). Pediatricians often fail to assess directly the child's intellectual functioning when the child's illness does not specifically affect this domain of development. For children less than six years of age, the DDST (Denver Developmental Screening Test)[4] can be used as a method of case-finding. A child who has persistent delays on the DDST should be referred for a formal development evaluation using a test such as the Bayley Scales of Infant Development,[1] the McCarthy Scales of Children's Abilities,[7] or the Yale Developmental Schedules.[11] In older children, questions about the child's academic performance in school are an effective and rapid method of screening. If the child is having difficulties in the classroom or is already repeating a grade, office screening instruments such as the Ciba screening cards[10] or parts of the tests of school functioning developed by Levine[6] can be used. Formal psychological testing including intelligence tests such as the Wechsler Intelligence Scale for Children, Revised,[12, 14] might also be appropriate if the child has demonstrated academic difficulties.

Motor Skills. When assessing gross and fine motor skills, the pediatrician is interested in not only what the child can do but also the quality of the child's performance. In younger children, the DDST again can provide age-appropriate norms. In older children, questions about the child's abilities and coordination can provide useful information. In certain chronic illnesses such as asthma or heart disease, children may be limited in their gross motor activities because of severe restrictions by parents, because of their own concerns that they will become sick or have to go to the hospital if they participate, or because of real physical disabilities.

Style of Performance. This includes the child's activity level and how the child approaches tasks. Information about hyper- or hypoactivity, distractibility, and impulsiveness can be obtained. Does the child attack a new task in a methodical manner? How long can a child stick with a task? Children with chronic illness may be anxious and upset about their illness, about being accepted by their parents, and/or about being viewed as different by their peers. This anxiety, which makes it impossible for the child to focus on tasks, may manifest itself as hyperactive, distractible, and impulsive behavior. Quiet, withdrawn, and hypoactive behaviors may also be a concern, since children with chronic illness may be frightened of independence and overly dependent upon their parents. Parents and teachers, however, may not complain of these behaviors because the child is quiet and does not create a problem.

Emotional and Personality Development. This variable, which overlaps with all of the other variables in the profile, is concerned with the child as a person. It includes how the child responds to stresses, new situations, and friends; what the child does for fun; whether the child participates in group activities; how much time is spent watching television; and so on. In learning about the child's characteristics, particular emphasis should be placed on understanding those moods and feelings that occur commonly in children with chronic illnesses. Is the child sad, frustrated, or angry? Does the child have a low self-image? Has the child achieved age-appropriate independence? Is the adolescent involved with excessive risk-taking behaviors? The answers to these and similar questions are likely to provide the best picture of how the child has responded to the disability and integrated the problem into his or her personal life. If psychological testing is performed on the child, projective tests such as the Thematic Apperception Test[2] will provide another perspective on this variable.

Relationships with Family Members

The variables under this heading are concerned with how the child gets along with parents and siblings. Variables focusing on how these family members get along with the child are discussed below in the Family Profile. Although separating a relationship into its two sides is somewhat artificial, this distinction helps the clinician remember that there are two important perspectives in a relationship (for example, the child's and the parent's). Obtaining information directly from the child or adolescent can provide an important perspective on the relationships, as well as establish an important alliance with the child.

Parents. Two major issues should be assessed to understand the child's relationship with his parents. The first is concerned with how the child feels that he is viewed by his parents. Instead of feeling accepted, loved, and supported, the child who is chronically ill may feel that his parents are disappointed in him because of his defect. This sense of disappointing one's parents will likely affect the child's self-confidence with friends and teachers and affect how the child views family events. For instance, a boy with diabetes who feels that he is a tremendous burden and disappointment to his parents may feel excessive guilt and responsibility for his parents' divorce. The second area of concern is whether the child is able to communicate with the parents. To whom does the child turn for help? Can the child bring up concerns related to the illness (for example, fear of the pain associated with the treatment or of death)? Is the parent able to help the child manage such problems?

Siblings. In considering the child's relationship with siblings, the physician is interested in both what the child does with the siblings and how the child feels toward them. Jealousy and anger because a brother can run without difficulty or because a sister takes no medications is not an unusual feeling for a child with a chronic illness. In addition, the child may feel guilty that the illness has caused the siblings undue deprivation and suffering.

Activities Outside the Home

Since a major task of growing up is to develop an appropriate independence from one's family, successful adaptation to school and activities outside the home and acceptance by peers are important for any child and even more so for a child with chronic illness. Yet, leaving the security of one's home environment can be particularly difficult and painful because of problems of separation and stigmatization. Therefore, to understand the child's adjustment to the illness, it is particularly important to learn about the child's activities outside the home.

School Performance. Information about the child's performance in school can be divided into four main areas: (1) absenteeism, (2) academic performance, (3) behavior in the classroom with peers and teachers, and (4) arrangements made by the school to accommodate the special learning, emotional, or physical needs of the child. The questions focusing on each of these areas should provide considerable data about the child's adaptation to school. For instance, if the child is missing school, is it because the child is sick from the illness or because of a related problem such as "feeling different," or separation anxiety and school phobia? Are the child's reading and math skills at the appropriate grade level? Is the child able to pay attention in the classroom? If not, is it because the child is too drowsy from the anticonvulsant medications? What arrangements have been made to include the child with arthritis in recess activities?

Peer Relationships. The child's other major activity outside the home is playing with friends. The physician is interested in whether the child has friends (including a best friend), what they do together, and whether the child participates in organized group activities such as scouting, a swimming program, or baseball. The child with a chronic illness may find it particularly difficult or impossible to participate in certain group activities. How does the child respond to these limitations and what alternatives has the child found? Particular concerns of children with chronic illness include whether to tell their friends about the illness, how to manage special diets and medications outside the home, whether to participate in or how best to manage sleep-overs, and how to respond to being ridiculed by other children.

Response to the Illness

Understanding of the Illness. The pediatrician is interested in what the child knows about the illness (including the etiology), what the child's feelings and fears are about the illness, and most importantly whether the child has achieved a working balance between accepting the limitations and striving toward performing normal activities. Information about these topics can be obtained using straightforward questions such as "Can you tell me why you have to come to the doctor so often? what happens when you can't go out to recess? what do you tell your friends?" Since parents are important sources of information for the child, questions about the communication between the parents and child will provide additional insight. The pediatrician can inquire about whether the parents and child talk about the illness, which aspects are discussed (shots, doctor's visits, problems with children at school, heredity and marriage, and so on), and what kinds of questions are asked by the child.

Participation in Care. As children get older and move toward self-sufficiency, they want to and should take more responsibility for their own care. The pediatrician is interested in several issues: (1) how responsibilities for care (such as giving shots, following a special diet, or performing daily exercises) are divided between the parents and child; (2) how these divisions of responsibility are decided; and (3) what happens when the child forgets a responsibility or does not follow the diet. The gradual transfer of care from the parents to the school-aged child and adolescent can be a difficult transition for both sides. Parents may be reluctant to give up control and supervision, while the child may be reluctant to accept the responsibilities and the increasing independence. Health providers also may have difficulty with this transition; they may become accustomed to talking to the parents about the management of the illness and forget that the child is now old enough to be included in plans for care.

Appendix 10

(a) Kindergarten - grade three

yes/no

1. Are you easy to like?
2. Do you often get in trouble at home?
3. Can you give a good talk in front of your class?
4. Do you wish you were younger?
5. Are you an important person in your family?

6. Do you often feel that you are doing badly in school?
7. Do you like being just what you are?
8. Do you have enough friends?
9. Does your family want too much of you?
10. Do you wish you were someone else?

11. Can you wait your turn easily?
12. Do your friends usually do what you say?
13. Is it easy for you to do good in school?
14. Do you often break your promises?
15. Do most children have fewer friends than you?

16. Are you smart?
17. Are most children better liked than you?
18. Are you one of the last to be chosen for games?
19. Are the things you do at school very easy for you?
20. Do you know a lot?

21. Can you get good grades if you want to?
22. Do you forget most of what you learn?
23. Do you feel lonely very often?
24. If you have something to say, do you usually say it?
25. Do you get upset easily at home?

26. Do you often feel ashamed of yourself?
27. Do you like the teacher to ask you questions in front of the other children?
28. Do the other children in the class think you are a good worker?
29. Are you hard to be friends with?
30. Do you find it hard to talk to your class?

31. Are most children able to finish their school work more quickly than you?
32. Do members of your family pick on you?
33. Are you any trouble to your family?
34. Is your family proud of you?
35. Can you talk to your family when you have a problem?

36. Do your parents like you even if you have done something bad?

Appendix 10

(b) grades four - six

true/untrue

1. Other children are interested in me.
2. School work is fairly easy for me.
3. I am satisfied to be just what I am.
4. I should get along better with other children than I do.
5. I often get in trouble at home.
6. My teachers usually like me.
7. I am a cheerful person.
8. Other children are often mean to me.
9. I do my share of work at home.
10. I often feel upset in school.
11. I'm not very smart.
12. No one pays much attention to me at home.
13. I can get good grades if I want to.
14. I can be trusted.
15. I am popular with kids my own age.
16. My family isn't very proud of me.
17. I forget most of what I learn.
18. I am easy to like.
19. Girls seem to like me.
20. My family is glad when I do things with them.
21. I often volunteer to do things in class.
22. I'm not a very happy person.
23. I am lonely very often.
24. The members of my family don't usually like my ideas.
25. I am a good student.
26. I can't seem to do things right.
27. Older kids like me.

Appendix 10 - continued

true/untrue

28. I behave badly at home.
29. I often get discouraged in school.
30. I wish I were younger.
31. I am friendly toward other people.
32. I usually get along with my family as well as I should.
33. My teacher makes me feel I am not good enough.
34. I like being the way I am.
35. Most people are much better liked than I am.
36. I cause trouble to my family.
37. I am slow in finishing my school work.
38. I am often unhappy.
39. Boys seem to like me.
40. I live up to what is expected of me at home.
41. I can give a good report in front of the class.
42. I am not as nice looking as most people.
43. I have many friends.
44. My parents don't seem to be interested in the things I do.
45. I am proud of my school work.
46. If I have something to say, I usually say it.
47. I am among the last to be chosen for teams.
48. I feel that my family doesn't usually trust me.
49. I am a good reader.
50. I can usually figure out difficult things.
51. It is hard for me to make friends.
52. My family would help me in any kind of trouble.
53. I am not doing as well in school as I would like to.
54. I have a lot of self control.
55. Friends usually follow my ideas.

Appendix 10 - continued

true/untrue

56. My family understands me.
57. I find it hard to talk in front of the class.
58. I often feel ashamed of myself.
59. I wish I had more close friends.
60. My family often expects too much of me.
61. I am good in my school work.
62. I am a good person.
63. Others find me hard to be friendly with.
64. I get upset easily at home.
65. I don't like to be called on in class.
66. I wish I were someone else.
67. Other children think I am fun to be with.
68. I am an important person in my family.
69. My classmates think I am a poor student.
70. I often feel uneasy.
71. Other children often don't like to be with me.
72. My family and I have a lot of fun together.
73. I would like to drop out of school.
74. Not too many people really trust me.
75. My family usually considers my feelings.
76. I can do hard homework assignments.
77. I can't be depended on.

Appendix 10

(c) grades seven - twelve

strongly agree/
agree/
strongly disagree/
disagree

1. School work is fairly easy for me.
2. I am satisfied to be just what I am.
3. I ought to get along better with other people.
4. My family thinks I don't act as I should.

5. People often pick on me.
6. I don't usually do my share of work at home.
7. I sometimes feel upset while I'm at school.
8. I often let other people have their way.

9. I have as many friends as most people.
10. Usually no one pays much attention to me at home.
11. Getting good grades is pretty important to me.
12. I can be trusted as much as anyone.

13. I am well liked by kids my own age.
14. There are times when I would like to leave home.
15. I forget most of what I learn.
16. My family is surprised if I do things with them.

17. I am often not a happy person.
18. I am not lonely very often.
19. My family respects my ideas.
20. I am not a very good student.

21. I often do things that I'm sorry for later.
22. Older kids seem to like me.
23. I sometimes behave badly at home.
24. I often get discouraged in school.

25. I often wish I were younger.
26. I am usually friendly toward other people.
27. I don't usually treat my family as well as I should.
28. My teacher makes me feel I am not good enough.

29. I always like being the way I am.
30. I am just as well liked as most people.
31. I cause trouble to my family.
32. I am slow in finishing my school work.

33. I often am not as happy as I would like to be.
34. I am not as nice looking as most people.
35. I don't have many friends.
36. I feel free to argue with my family.

37. Even if I have something to say, I often don't say it.
38. Sometimes I am among the last to be chosen for teams.
39. I feel that my family always trusts me.
40. I am a good reader.

Appendix 10 - continued

strongly agree/
agree
strongly disagree/
disagree

41. It is hard for me to make friends.
42. My family would help me in any kind of trouble.
43. I am not doing as well in school as I would like to.
44. I find it hard to talk in front of the class.

45. I sometimes feel ashamed of myself.
46. I wish I had more close friends.
47. My family often expects too much of me.
48. I am not very good in my school work.

49. I am not as good a person as I would like to be.
50. Sometimes I am hard to make friends with.
51. I wish I were a different person.
52. People don't usually have much fun when they are with me.

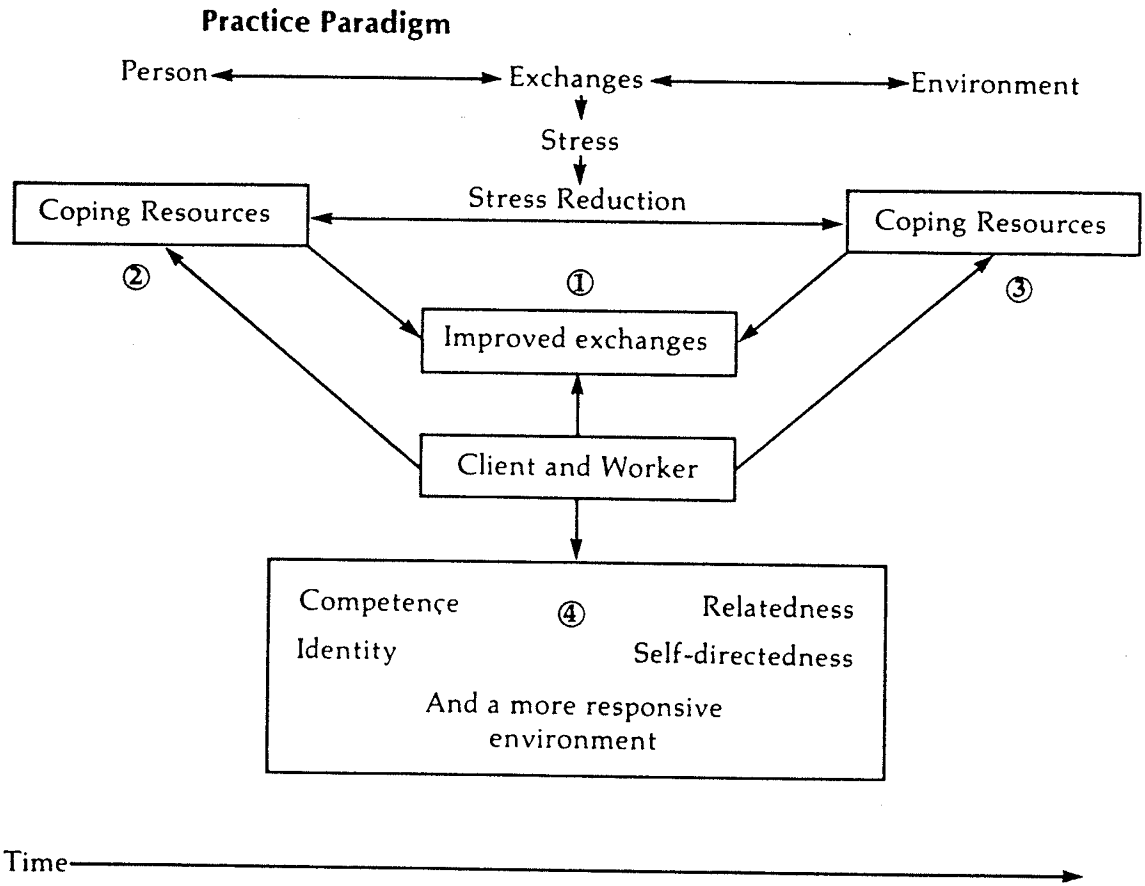
53. I am an important person to my family.
54. People think I am a good student.
55. I am not very sure of myself.
56. Often I don't like to be with other kids.

57. My family and I have a lot of fun together.
58. There are times when I feel like dropping out of school.
59. I can always take care of myself.
60. Many times I would rather be with kids younger than me.

61. My family doesn't usually consider my feelings.
62. I can't be depended on.

Appendix 11 - Germain 1984

Practice Paradigm Ecological Model

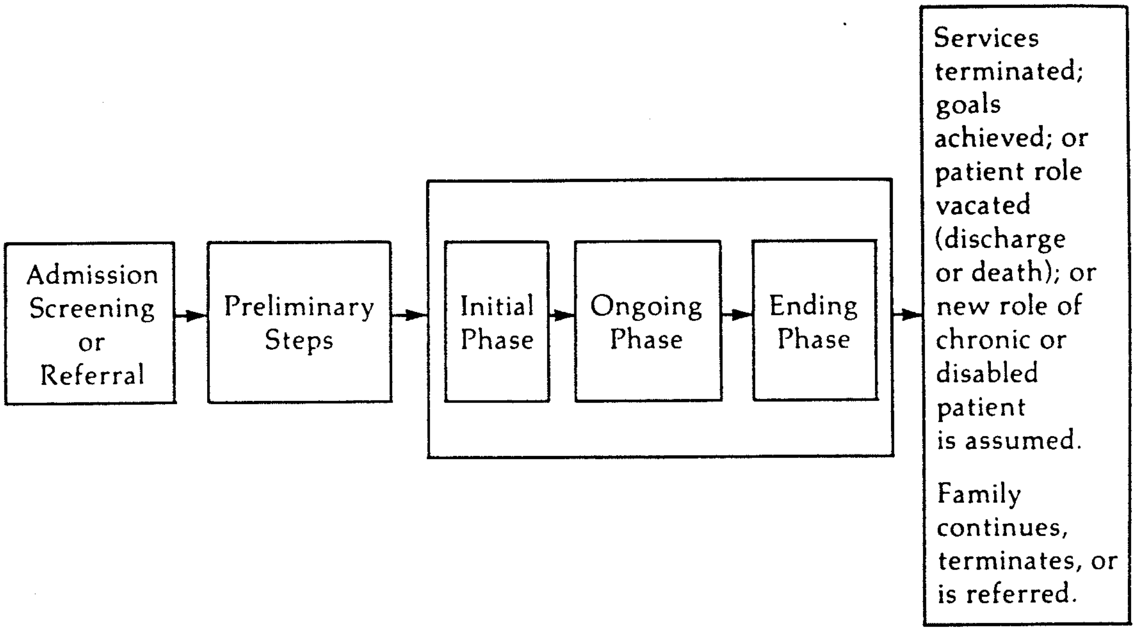


Client and worker seek to bring about ① through work with ② and ③ , in the course of which both gain at ④ .

Appendix 12: Germain, 1984

Phases of the Helping Process Ecological Model

Phases of the Helping Process with Individuals, Families, and Groups in Health Care Settings



PRELIMINARY STEPS: Preparation for initial contact; offer of services; client acceptance of service. For group: securing organizational sanctions, planning group composition, etc.

INITIAL PHASE: Engagement; exploration; definition of need, and assessment; goal-setting; planning the actions. Mutual agreement on next steps.

ONGOING PHASE: Actions by client and worker to achieve desired goals and objectives, including reduction of stress and enhancement of coping. Mutual agreement on next steps.

ENDING PHASE: Planning for discharge, or for transfer, or for referral. Mutual evaluation of the work together. Carrying out the discharge plan, transfer, or referral. Followup. Dealing with another kind of ending: death and bereavement.