National Library of Canada
Bibliothèque nationale du Canada

Canadian Theses Service
Service des thèses canadiennes

Ottawa, Canada
K1A 0N4

NOTICE

The quality of this microform is heavily dependent upon the quality of the original thesis submitted for microfilming. Every effort has been made to ensure the highest quality of reproduction possible.

If pages are missing, contact the university which granted the degree.

Some pages may have indistinct print especially if the original pages were typed with a poor typewriter ribbon or if the university sent us an inferior photocopy.

Reproduction in full or in part of this microform is governed by the Canadian Copyright Act, R.S.C. 1970, c. C-30, and subsequent amendments.

AVIS

La qualité de cette microforme dépend grandement de la qualité de la thèse soumise au microfilmage. Nous avons tout fait pour assurer une qualité supérieure de reproduction.

S'il manque des pages, veuillez communiquer avec l'université qui a conféré le grade.

La qualité d'impression de certaines pages peut laisser à désirer, surtout si les pages originales ont été dactylographiées à l'aide d'un ruban usé ou si l'université nous a fait parvenir une photocopie de qualité inférieure.

La reproduction, même partielle, de cette microforme est soumise à la Loi canadienne sur le droit d'auteur, SRC 1970, c. C-30, et ses amendements subséquents.

NL-339 (r. 88/04) c

Canada

UNIVERSITY OF ALBERTA

ADOLESCENTS WITH CROHN'S DISEASE AND THEIR FAMILIES
CHARACTERISTICS OF FAMILY MEMBERS AND THEIR RESPONSE TO SMALL GROUP WORK

BY

NANCY ROBLIN

A THESIS

SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH
IN PARTIAL FULFILMENT OF THE REQUIREMENTS
FOR THE DEGREE OF MASTER OF EDUCATION.

IN

COUNSELING PSYCHOLOGY
DEPARTMENT OF EDUCATIONAL PSYCHOLOGY

EDMONTON, ALBERTA
FALL 1990.

National Library
of Canada

Bibliothèque nationale
du Canada

Canadian Theses Service

Service des thèses canadiennes

Ottawa, Canada
K1A 0N4

ISBN 0-315-65018-4

UNIVERSITY OF ALBERTA

RELEASE FORM

NAME OF AUTHOR: Nancy Roblin

TITLE OF THESIS: Adolescents with Crohn's Disease and Their Families: Characteristics of Family Members and Response to Small Group Work.

DEGREE: Master of Education in Counseling Psychology

YEAR THIS DEGREE GRANTED: 1990

N.E. Roblin

Nancy Roblin
Hotel Dieu Hospital,
133 Brock Street,
Kingston, Ontario.

Date: Sept 28/90

UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

THE UNDERSIGNED CERTIFY THAT THEY HAVE READ, AND RECOMMEND TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH FOR ACCEPTANCE, A THESIS

ENTITLED: Adolescents with Crohn's Disease and Their Families: Characteristics of Family Members and Their Response To Small Group Work

SUBMITTED BY: Nancy Roblin

IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF:

Master of Education in Counseling Psychology

Dr. John Paterson

Rose Marie Hague
Dr. Rosemarie Hague

Dr. Eugene Romaniuk

Dr. Olive Yonge
Dr. Olive Yonge

Date: Sept. 28/90

DEDICATION

To my husband, Don and to my family
with appreciation of their love, support,
and encouragement.

To Katherine Thompson, with gratitude for the courage
she demonstrated to others and for the support
that she gave to young people and their families.

ABSTRACT

An intervention program was designed to assist young people and their families in dealing with the impact of Crohn's disease. Multidisciplinary teams at a number of health care centers, functioned as group facilitators for the program that was planned to address three parameters: knowledge about Crohn's disease, family coping style, and social well-being. A five session intervention program was provided for parents, siblings, and affected youth.

The research measured aspects of family functioning utilizing two standardized instruments, the Family Assessment Device (FAD) and the Culture-Free Self-Esteem Inventory (CF-SEI) and the Crohn's Disease Psychosocial Inventory (CD-PSI) which is a series of visual analogue scales developed by the investigator. This instrument was designed to measure the three parameters addressed in the intervention program and was compared to FAD and CF-SEI results. Experimental and control groups of Crohn's disease (CD) patients and their families were utilized. Severity of illness as measured by the Crohn's Disease Activity Index (CDAI) and the presence of growth failure were correlated to psychosocial parameters. Demographic data and information related to specifics of Crohn's disease were documented.

Significant findings related to unhealthy family functioning involved communication, roles, affective involvement, and affective responsiveness as demonstrated by the FAD. Differences between the control and the intervention groups, related to improvement in affective responsiveness and knowledge about Crohn's disease.

ACKNOWLEDGEMENTS

Many persons shared their expertise and guidance in the preparation of this thesis. Others, devoted a great deal of energy and committment to the programs for families with a young person with Crohn's disease. Thank-you for your patience and valuable contribution.

University of Alberta
Dr. John Paterson, Dr. Rosemarie Hague, Dr. Eugene Romaniuk,
Dr. Olive Yonge

Hotel Dieu Hospital - Kingston
Dr. Diane Benoit, Mary Bird, Evelyn Cameron, Beverly Carty,
Wayne Greenway, Dr. Aubrey Groll, Jean Hughes, Brian Lutz,
Julie Simpson, and Mary Sullivan.

The Hospital for Sick Children - Toronto
Marilyn Booth, Claire Cox, Dr. Anne Marie Griffiths, Pat Jacques,
Cindy MacDonald, and Judy Savage

Childrens' Hospital of Eastern Ontario
Alice Bruce, Janice McNeil, Colleen Murray,
and Dr. Richard Shipman

The Angada Childrens' Foundation
for their financial support

Queens University - Kingston
Kyler Black, Debbie Brophy, Dr. Hugh Munby, Dr. Kevin Parker,
Dr. Terry Smith, Dr. Robert Wilson,

The Foundation for Ileitis and Colitis
Chapters in Kingston, Toronto, and Ottawa

Dan and Katherine Thompson

TABLE OF CONTENTS

CHAPTER I

RATIONALE AND OVERVIEW OF THESIS

CHAPTER II

LITERATURE REVIEW

CHAPTER III

PROGRAM DEVELOPMENT

CHAPTER IV

METHODOLOGY

CHAPTER V

ANALYSIS OF RESULTS

CHAPTER VI

IMPLICATIONS AND FUTURE DIRECTIONS

LIST OF TABLES

LIST OF FIGURES AND ILLUSTRATIONS

LIST OF ABBREVIATIONS

CHAPTER ONE

RATIONALE AND OVERVIEW OF THESIS

Controversy Regarding the Etiology and Psychological Aspects of Crohn's Disease

The interplay of psychological components and physiological factors in Crohn's Disease has fascinated researchers for over a century (Rustgi, Wise & Boyle, 1985). The debate concerning the psychological aspects of the disease included the possible psychological factors in the etiology of the disease, the emotional implications secondary to the chronic illness for the patient and the family and the relationship of increased emotional stress and bowel symptoms (Bruce, 1986). In view of the diversity of opinion related to the role of psychosocial factors in the etiology of the disease, confusion regarding appropriate psychosocial management for young people with Crohn's disease existed.

Opinions about the psychological characteristics of patients with Crohn's disease range across a broad continuum. Numerous older studies indicated that patients with Crohn's disease were obsessive, rigid, and socially withdrawn. Rustgi et al. (1985) noted that these studies lacked control groups, were imprecise in their definition of the disease and were conducted in a retrospective manner. Steinhausen and Kies (1982) wrote, "there is not a single study reporting on psychosomatic aspects in these children and adolescents" (p.33). Yet Steinhausen and Kies postulated as did Whybrow (Bruce, 1986), that emotional stress may aggravate symptoms, precede exacerbations and influence clinical course (Rustgi et al., 1985). Perhaps, the important factor was the unfortunate reality noted by Binder, Hendricksen, and Kreiner (1986) who noted that, " Crohn's disease remains a life-long incurable condition" and " children are vulnerable to the emotional sequelae of traumas visited upon them" (p.247-248).

Incidence and Impact of Crohn's Disease on Adolescent Lifestyle

Although etiology remained obscure, the diagnosis of Crohn's disease created clarity of concern in terms of its impact on lifestyle and psychosocial well-being of young people. Crohn's disease, a chronic, transmural, inflammatory gastrointestional disease affects three per 100,000 children and youth. Ten to 15 percent of those diagnosed with Crohn's disease are believed to have predisposing genetic factors (Messner, Gardener, & Lewis, 1985). Symptoms include: malabsorption, growth failure, abdominal pain, frequent diarrhea stools with alternating periods of constipation, fistulas, fissures, anemia, weakness, arthritis, and renal and liver complications (Messner et al., 1985; Sanderson and Walker-Smith, 1985; Walker, 1984). Site of disease, specifically the presence of upper gastrointestional disease, is associated with the presence of symptoms that interfere with nutrition, including: dysphagia, vomiting and lesions of the mouth (Leanearts, Roy, Vallincourt, Weber, Morin, & Seidman, 1988). The see-saw of remissions and exacerbations of Crohn's disease interfere with the predictable daily functioning of the child. Binder (1986) believed, that traumatic emotional injury and disequilibrium could also be inflicted on the child by sincere attempts to treat the disease. Physical exams, sigmoidoscopy, and biopsy are often frightening and humiliating procedures for young people. Surgical procedures neither cure nor prevent the reoccurence of complications such as, obstruction, hemorrhage, intrabdominal sepsis, and fistulas. Amelioration of malabsorption and the presence of growth failure may necessitate total parenteral nutrition, elemental diet through feeding tubes or low residue diet during exacerbation of the disease (Messner et al., 1985). Steroid therapy frequently induces remission however it may result in growth suppression. Altered physical appearance including acne, hirsutism, and puffiness of cheeks are common side effects of prednisone, all of which may affect the adolescent's self-concept (Sanderson & Walker-Smith, 1985). Frequent ambulatory care visits or lengthy hospital admissions to implement the above diagnostic procedures and treatments are disruptive to family and to peer relationships. A temporary or permanent colostomy or ileostomy may be surgically created to reduce the impact of the disease process, while creating a major psychological adjustment to body image.

Purpose of the Study

The goal of this study was to determine the effectiveness of an intervention program aimed at reducing the perceived psychological impact of chronicity in adolescents with Crohn's disease. It is hypothesized that psychoeducational information provided in a group format for adolescents and their families will be perceived by families as beneficial to: their knowledge base about Crohn's disease, to their perception of well-being in social settings and to their intra-familial coping style. It is also hypothesized that a psychoeducatioal intervention will increase the well-being of the intervention group, relative to the control group on a number of psychosocial parameters as measured by the Crohn's Disease Psychosocial Inventory (CD-PSI), the Family Assessment Device (FAD), and the Culture Free Self-Esteem Inventory (CF-SEI).

The purposes of the intervention and research study were as follows:

1. To determine the psychoeducational and psychosocial needs of adolescents with Crohn's disease.

2. To provide a five session intervention program for adolescents and their families based on a needs survey, information from health professionals and adult patients with Crohn's disease, as well as, research and descriptive literature.

3. To test the effectiveness of the intervention program by comparing preintervention and postintervention scores related to pertinent chronicity factors.

4. To compare the group which received the intervention, with a control group of adolescents and their families who had not received a similar program, with-in the same two month time-frame.

5. To determine if there was a relationship between severity of disease as measured by the Crohn's Disease Activity Index (CDAI) and growth failure status, with psychological variables as measured by the Crohn's Disease Psychosocial Inventory (CD-PSI).

6. To complete an analysis of the CD-PSI, by comparing the instrument to two standardized tests; the Family Assessment Device (FAD) and Battle's Culture-Free Self- Esteem Inventory (CF-SEI).

The Deficiency of Available Psychological Data Related to Crohn's Disease

Few psychological studies have been completed using youths with Crohn's disease as subjects. Steinhausen and Kies (1982) utilized a structured psychiatric interview and noted that 60% of the children that they studied with Crohn's disease suffered from a psychiatric disorder as compared with 17% of subjects in their control group. Their sample of young people with Crohn's disease was comprised of 10 patients. Messner et al. (1985) stated that Crohn's disease may affect the individual's self-esteem to the extent that the disease actually becomes the patient's identity, however the authors did not offer concrete evidence for this opinion nor suggest an appropriate intervention. Whybrow, cited in Rustgi et al. (1985), found emotional disturbance in 63% of adult patients with Crohn's disease. Pless and Pinkerton (1982) found that 2.5 times as many chronically ill children as the norm had behavioral and social problems as reported by parents to trained interviewers (p.33). However, specific strategies to ameliorate behavioral, social, and emotional problems were not described. Noting strengths versus deficits, Zelter cited in Bruce (1986) stated that young people who had experienced a chronic illness were, "more stoical and less anxious in the face of their illness than normal adolescents" (p.90). Haase (1987) utilized a phenomenological approach, to assess the experience of courage in chronically ill adolescents and found numerous themes related to courage by qualitative analysis. It seemed that the experience of chronic illness produced both psychological strengths and deficits. Yet, there were little data to confirm either perspective and fewer guidelines with which to develop intervention programs.

Overview of the Intervention Program.

A multidisciplinary group of health professionals from diverse backgrounds, began meeting in the fall of 1988 at Hotel Dieu Hospital - Kingston, Ontario, to plan an intervention program for youth with Crohn's disease and their families. Program development was based on the experience of health professionals and an extensive literature search related to: psychological and psychoeducational information regarding Inflammatory Bowel Disease (IBD) in both children and adults, research regarding the psychosocial impact of chronic illness in general, and data regarding the physiological factors of IBD. To determine some of the specific psychoeducational and psychosocial needs of youth with Crohn's disease, a needs survey was conducted. Then a five session program, designed to intervene in three chronicity variables: knowledge about Crohn's disease, social well-being and family coping style was formulated. The program utilized a family system perspective in which all immediate family members were asked to attend the intervention program.

Research Component of the Study

Three outcome measures: knowledge specific to Crohn's disease, social well-being and family coping style were assessed at two different times; prior to the intervention program and at two months following the sessions. A series of visual analogue scales, the CD-PSI, were developed to measure the above components. To control for physical parameters, the CDAI (see Appendix 1) and a standard growth chart (see Appendix 2) which determine the presence of growth failure were utilized in the study.

A disease-specific approach was chosen, although the initial plan had been to incorporate ulcerative colitis patients in the program. However, some theoretical evidence suggested that disease-specific traits existed (Imes, 1984; McAnarney, 1985; Steinhausen, 1982). As well, more detailed information about the condition, treatment, diet, and daily routines can be given in disease-specific groups. Information of this nature has been shown to reduce anxiety in patients and to improve compliance with treatment (Marshall, 1979; Padilla et al.1981; Scholmerick, Sedak, Hoppe-Seyer, & Gerok, 1987). Furthermore, Steinhausen (1982) felt that there were subtle differences between psychological parameters of the two groups of IBD patients. Due to a small number of subjects, Steinhausen's data were not reliable. In view of the above information and the perception on the part of the enterostomal nurse, that the differing prognosis between the two groups required separating the ulcerative colitis and the Crohn's disease groups for psychoeducational sessions, this led to the choice by the investigator, of the disease-specific client group. Crohn's disease, the condition with a poorer long-term prognosis, due to the current inability to arrest the disease by surgical intervention, became the focus of the study.

Age group specification was related to Rose's (1984) observation, that children are more vulnerable during times of biological, social, and psychological transitions. Chronically ill adolescents are faced with integrating changes due to growth and development with factors related to their illness such as growth failure and delayed pubesence. Illness affects the youth's interactions with the physical and social environment in which he or she lives. Aspects of the young person's environment, including: parents, peers, and educational institutions are altered as a result of the illness (Perrin & Gerrity, 1984). Due to the complexity of developmental processes during adolescence, it seemed pertinent to delineate adsolescents as the target group for the intervention. Those individuals who were offered participation in the program ranged in age from 10 to 19 years, the lower range of age offered at the request of a paediatric gastroenterologist who stated that he thought his younger patients would benefit from the intervention in preparation for adolescence.

Further clarification of the target group was provided by the definition utilized by Jessop and Stein (1985) of characteristics constituting a chronic illness. A chronic illness was seen as a condition that lasted three months in a given year and required a period of hospitalization. Because many of the chronically ill youth are treated on an outpatient basis, despite extensive illness, the additional allowance of having required ongoing assessment in an outpatient center in lieu of admission, was added to the definition. The delineation of the disease entity as Crohn's disease as differentiated from IBD and IBS, Irritable Bowel Syndrome was completed by a paediatric gastroenterologist, most frequently using previous biopsy results for differential diagnosis. The CDAI was used as an indice of disease activity and severity. The initial plan was to exclude data from subjects with a CDAI value of less than 150 in the past year or a CDAI value of 400 or greater. It was postulated that a

CDAI value of less than 150 does not indicate significant disease whereas a young person with a CDAI value of 400 or greater is too ill to benefit from a psychosocial and psychoeducational intervention. However, due to low sample size and several examples of rapid exacerbation of disease, despite low baseline CDAI scores, all persons with definitive diagnosis were included in the study.

Delimitations of the Study

Eighteen families, a total of 19 young people with Crohn's disease participated in the study. Twelve families formed the intervention group and six families were in the control group. All family members were asked to participate in the study and totaled 71 persons. Participation of families with a youth with CD was sought from the client lists of paediatric gastroenterologists at three Ontario centres. If they were in the intervention group, they attended a five session program at one of, Hotel Dieu Hospital-Kingston, The Hospital for Sick Children - Toronto, or Children's Hospital of Eastern Ontario - Ottawa. Control subjects completed the same psychosocial tests and were examined physically at the same time intervals as the intervention group. Testing consisted of several measures related to family functioning and several physiological parameters that are indices of disease severity.

Limitations of the Study

Careful specification of the research group by diagnostic criteria, chronicity variables, and age range are sound principles of research, however, this dramatically reduced the number of available patients for the study. Nevertheless the criticism by Rustgi et al. (1985)

regarding the methodological inadequacy of the older studies held true, and so low incidence of Crohn's disease in this age group, imposed a major limitation to sample size. In addition to the low numbers of available patients, researchers frequently report difficulty in engaging persons with Crohn's disease in psychotherapeutic interventions (Bruce, 1986), which may further impede the study of this group.

Due to these sampling factors, stratification of the sample based on data such as: severity of illness, surgical intervention, length of illness and specific family characteristics was not possible. However, as numerous demographic factors and illness-specific data were collected, analysis subsequent to the intervention program was possible.

Furthermore, the need to utilize a number of health care centres and the primary staff of the patients, allowed for some diversity in therapeutic approach, as well as, introduced differing personality styles of care-givers. Although, the impact of this was reduced by preparation of group facilitators, the possibility of introducing confounding factors existed.

The reported difficulty of demonstated statistically significant change in chronically ill persons, from psychosocial and psychoeducational interventions (Nolan, Pless, & Zvagulis, 1987) was a concern, in formulating this type of research project. One difficulty noted by Leventhal (1984), related to data collection. He stated that information collection about human behaviors is complex and sensitive, thereby causing parents to minimize their problems, to seek reasurrance versus acknowledging the full impact of the disease, and to present information that demonstrates that they are successful in caring for their their child and their family's needs. For some parents, the acknowledgement of their feelings might be overwhelming and they may avoid settings where this might take place or they may gradually reveal the extent of the impact of an ill child on the family, thereby affecting the accuracy of the data. Leventhal (1984) stated, "some parents may not share their angry feelings toward the child, or the clinicians who cannot cure the child, for fear of being rejected by physicians"(p.72).

The use of visual analogue scales (VAS), although beneficial regarding sensitivity to change, ease of administration and avoidance of numerous descriptors, imposed a limitation. Those persons who chose a high self-perception score initially, had little room to move the score higher if they felt there had been an improvement. However, by utilizing standardized psychological tests and a factual knowledge quiz, insight was gained into the the magnitude of this problem and into the efficacy of VAS for psychosocial parameters.

The Hawthorne effect,or attention bias, was also a limitation related to comparative results of the control group, relative to the intervention group. Theoretically, attention paid to the control group by having their physical assessments completed and by having them respond to questionnaires could result in improved scores on the psychosocial instruments. However, it seemed unjustified to request families to participate in a placebo style of intervention, when it would involve five evenings and long travelling distances for many of the participants in the control group.

Collection of data may have been influenced by the relapsing course of Crohn's disease. Therefore, some false positive or negative data may have been obtained relative to psychosocial parameters. Tracking of

CDAI scores allowed statistical correlation of severity of disease parameters and was incorporated in the study, to reduce impact of false trends.

Lastly the influence of experimentor bias effect was of concern, as the person doing the psychological testing, functioned as group facilitator and as program co-ordinator. This may have influenced the results, but was a necessary limitation in terms of budgetary constraints.

Relevance

Despite reported past difficulty in demonstrating statistically significant change in chronically ill persons related to psychoeducational and psychosocial interventions (Pless,1984) research in this area remains essential. The development of compehensive, supportive psychosocial care that promotes resiliency in young people is as essential as other supportive measures such as drug therapy. Psychosocial interventions also require careful measurement and analysis including: the development of sensitive instruments, monitoring of programs, and correlation of psychological and physiological parameters. It was felt, that determinating the needs of young people with Crohn's disease, the provision of an intervention program, the application of research principles for precise data collection, and the utilization of both psychological and physical parameters in the design, were essential to providing wholistic care to patients and to assist in the clarification of some of the controversy about Crohn's disease.

CHAPTER TWO

LITERATURE REVIEW

The descriptive literature describes chronically ill persons as having: an increased sense of mastery, a heightened sense of belonging, greater involvement in relationships, a reduced sense of isolation, and improved coping skills resulting from involvement in support groups. The review of the literature, however focused on the research literature related to the characteristics of youth with chronic illnesses and their families. Group interventions that have been statistically analysed are presented.

Group Support Programs

Although, the use of support groups in psychiatric settings have been utilized extensively since the early sixties, few randomized studies of the effectiveness of support groups for chronically ill persons have been completed. Table 1 highlights the studies that have been reported.

In analysing the summary of research related to the effectiveness of support groups for chronically ill persons, it is important to note the diversity between studies. Differing diagnoses and severity of disease in terms of impact on lifestyle and prognosis are obvious. Similarly, the length of the intervention programs ranged from a total of nine hours to one and one-half hours weekly for twelve months. The age of participants ranged from elementary aged children to adults, also the numbers who participated in group work was from five to 30 participants. Group leaders were from a variety of backgrounds and numbers of group facilitators participating in the intervention program varied greatly as well. Three designs utilized randomized controls and reported on between-group differences while some studies reported a shortage of participants as an explanation for not utilizing a control group.

Variables studied were also diverse. These included: depression, self-esteem/self-concept, coping strategies, health-locus of control, anxiety, mood, and postretreat program evaluation. Statistically significant results from studies that utilized control groups, were related to less depression (Marrero,1980), improved group aptitude,

Table 1

Support Programs

Characteristic	Marrero/Booth * (1980)	Feric / Booth * (1979)	Spiegal/Booth * (1981)
Name of study	Adjustment to Misfortune: The use of an Adolescent Support Group for Diabetics	Group Counselling in Adult Patients With Advanced Cancer	Group Support for Patients with Metatastic Cancer
Sample size/ Control	10/13	30/30	16/14
Age of Participants	Adolescents	Adults	Adults
Study Design	RTC	RTC	RTC
Group Leaders	Social ecologist Social worker	Social worker plus either a nurse, doctor, chaplain, occupational therapist, or dietitian as content experts	Psychiatrist or social worker with a lay counselor who had breast cancer
Setting	Community hospital	Cancer hospital	Not stated
Frequency and Length of Intervention	Two hours bi-monthly X8 months	One and one half hours per week X2 weeks	One and one half hours weekly X12 months
Variables	Depression, self-esteem coping strategies, range and adequacy of social support networks	Group aptitude, hospital adjustment, relationship strength, information, death perception, self-concept.	Health LOC anxiety, depression, anger, vigor, fatigue, confusion, total mood disturbance, self-esteem, phobias, denial, and maladaptive coping responses.
Results Post-Intervention	Group participants significantly less depressed (p<0.02)	Statistically significant increase in all measures (p<0.001) with the exception of relationship strength.	Statistically significant decrease in tension, fatigue, depression, confusion as well as more vigor, fewer phobias and maladjusted coping responses (p<0.05).

*Adapted from Booth, 1985.

(table continued)

Table 1 (continued)

Characteristic	Williams/Baeker (1983)	Booth (1985)	Smith et al. (1985)
Name of Study	Use of Small Group with Chronically Ill Children	Peer Support and Self-Esteem in Adolescents with IBD	Issues of managing Diabetes in Children and Adolescents: A Multifamily Approach
Sample Size/ Control	6/0	5/4	11 families/0
Age of Participants	Elementary aged, Behavioral concern	Adolescents	Affected child aged 8-15 years
Study Design	Referred/teachers	Convenience sample	Convenience sample
Group Leaders	School nurse	Registered nurses	Clinical psychologists
Setting	School	Community hospital	Overnight retreat
Frequency and Length of Intervention	Not stated	One and one-half hours X6 weeks	Overnight retreat
Variables	Self-Concept (K-12)	Self-Esteem Inventory, Questionnaire re.experience	Questionnaire to determine group needs, Five point evaluation form
Results, Post-Intervention	Stated that Self-Concept improved - group size too small to note statistical significance.	No significant difference between groups immediately after the intervention or at 3 months	Rating Form/5 pts: Discussions-4.3 Leaders-4.5 Impact on diabetic management-1.7

hospital adjustment, knowledge base, death perception, and self-concept (Ferlic et al. 1979), as well as reduced tension, fatigue, and maladjusted coping responses (Spiegel et al. 1981). Studies that were unable to utilize randomized control groups due to difficulty finding adequate subjects, reported statistically non-significant findings (Booth, 1985: Williams & Baeker, 1983). The rating form utilized by Smith et al. (1989) is fascinating in that the participants rated the program highly, then indicated that it would have little impact on the child's diabetic management.

Psychosocial and psychoeducational support groups of necessity to maintain appropriate group dynamics, require small numbers of subjects. Seemingly the converse, statistical significance necessitates adequate sample sizes. Group interventions, wherein statistical significance is sought, require repetition of the intervention strategy with multiple groups of persons.

Characteristics of Young People with a Chronic Illness

The characteristics of children and adolescents with chronic illness and their families, have been explored in a number of settings and by a variety of methodologies. Table 2 summarizes studies pertaining to affected youths.

Adams et al. (1986) measured self-esteem and found that chronically ill youth had higher self-esteem than controls, although they experienced more stress than controls. This result contrasts McAnarney's (1985) review of larger studies that found no differences in self-esteem between controls and affected children and her review of smaller studies that found that patients had lower self-esteem than controls.

Steinhausen and Kies (1982) utilizing structured psychiatric interviews and the Childrens' Behavior Checklist, in a matched control design with small numbers of IBD patients, noted a 60% rate of psychiatric disturbance related mainly to affective disorders. Although, the interviewing technique had been normed on a large sample, the sample size was inadequate to produce reliable results. The need for further study, was however indicated by their results.

Steinhausen (1982) also reported that Crohn's Disease patients have lower or internal locus of control (LOC), as compared to the control groups and the children with other diagnoses. Asthmathics were found to have an external locus of control, thereby indicating that LOC is a disease-specific characteristic.

The literature review of chronically ill youth, indicates a clear need for further exploration and clarification of the psychosocial factors related to chronic illness in general, as well as regarding specific conditions.

Table 2

Characteristics of Chronically Ill Youth

Characteristic	Adams et al. (1986)	Steinhausen & Kies (1982)	Steinhausen (1982)
Name of Study	Self -Esteem and Stress in Young Adolescents with Chronic Illness.	Comparative Studies of Ulcerative Colitis and Crohn's Disease in Children and Adolescents.	Locus of Control Among Psychosomatically and Chronically Ill Children and Adolescents.
Sample Size/ Control	20/15	17/17	17/17
Age	10-16 years	Mean Age 13.3 years	4-14 years
Subjects	Clinic patients Mixed diagnosis Convenience sample	Total sample clinic patients West Berlin <18 years	Matched Design / gender and social class
Method of Evaluation	Piers-Harris Self-Concept Survey Lewis Feel Bad Scale	Structured Psychiatric Interview (Graham & Rutter) ICD-9 Psychiatric Diagnosis, Childrens' Behavior Questionnaire (CBQ)	Locus of Control Nowicki-Strickland
Variables	Self-Concept Perception of stress Self-reported Functional pain	ICD-Psychiatric Diagnosis CBQ-Subscales Related to Emotional and Conduct Disorders	Internal versus External LOC Physical parameters/ disease - specific
Results	Patients with chronic illness scored higher on Self-Concept than controls ($p<0.01$) CBQ controls scored lower on stress ($p<0.02$)	ICD Rate of Psychiatric Illness 60% Mainly emotional disorder ($p<0.05$) CD patients had significantly higher subscores for emotional disorders	CD Pts. had lower LOC scores than controls ($p=0.04$)

Characteristics of Siblings of Affected Adolescents

Tritt and Esses (1987) investigated psychosocial adaptation of siblings of children with chronic illness, utilizing the Behavior Problem Checklist, The Self-Appraisal Inventory and The What I Think and Feel Questionnaire. A finding that was significant at the $p<0.017$ level involved behavioral adjustment of siblings of chronically ill children. Perhaps, greater specificity of diagnosis and a larger sample size, as illustrated in the following summary, would have facilitated a greater number of significant findings.

Craft and Craft (1989) noted the low level of agreement on the Perceived Change Scale between parents and siblings. Siblings reported 519 changes and parents 252 alterations in lifestyle. Noteworthy also, are the differences in level of parental/child agreement between siblings of acutely-ill children and siblings of chronically-ill children.

Sibling concerns remain a relatively unexplored area by health professionals. Behavioral concerns are mentioned in the descriptive literature and documented by Tritt and Esses (1987). Seemingly, parents are not always aware of the magnitude of the impact of the ill child on the sibling, nor of the nature of sibling perception of the changes in their lifestyle.

Table 3

Characteristics of Siblings of Chronically Ill Youth

Characteristics	Tritt & Esses (1987)	Craft & Craft (1989)
Name of Study	Psychosocial Adaptation of Siblings of Children with Chronic Medical Illnesses.	Perceived Changes of Siblings of Hospitalized Children: A Comparison of Sibling and Adult Reports
Sample Size /Control	27 / 27	127 / 81 families
Age	Mean Age - 13.4 years	5-17 years
Subjects	Matched re. sociodemographic variables, Family physicians' patients	Parents and siblings of hospitalized children
Method of Evaluation	Behavior Problem Checklist (BPC) Self-Appraisal Inventory (SAI) Semi-Structured Interview What I Think and Feel Questionnaire (WIFT)	Perceived Change Scale (PCS) Structured interview for the younger siblings to complete the PCS
Variables	BPC - Personality and conduct problems SAI - Subjective feelings re. family / peer relationships, WIFT- Physiological anxiety, worry, fear, oversensitivity, concentration.	Parental perception of changes in behavior and feelings Sibling perception of changes in behavior and feelings Parent staying at hospital or not Acute vs. chronic illness
Results	Behavioral adjustment problems / BPC ($P<0.017$) as reported by parents No other statistically significant factors found.	Low levels of agreement / PBS between parents and siblings Number of reported changes: Parents - 252, Siblings - 519 ($p<0.01$) Higher level of agreement when the ill child had an acute vs. a chronic illness.

Characteristics of Parents of Young People with Chronic Conditions

Parental psychosocial characteristics were explored by Burke (1989), who studied mothers of physically disabled children. The degree of physical disability was incorporated into the research design. No statistically significant relationship was found between parental stress level and the severity of disability. A lower stress level was found between the mother's stress level and the length of contact with the community health nurse. It is interesting to note that ongoing community nurse support appeared to reduce stress. Methods of offering emotional support to parents requires further exploration into the efficacy of differing intervention appproaches, both for effectiveness and financial feasability.

Zimand and Wood (1986) stated their surprise in determining that the divorce rate of parents of children with Crohn's disease was one-third the divorce rate of parents of children with ulcerative colitis and recurrent abdominal pain syndrome. The large sample size of 173 parents of gastrointestional (GI) patients, including 59 whose children had Crohn's disease and the fact that diagnoses were verified at a GI clinic, lend credibility to the findings. The results were related by Zimand and Wood to the enmeshed family structure. However, they did not clearly articulate how a low divorce rate was established to be in conjunction with poor marital functioning. It would have been worthwhile to assess the marital functioning of the parents in the study to provide a reliable statement about enmeshment within the family structure. It is interesting to note that older studies (e.g. Bruce, 1986) discussed dysfunctional family relationships as related to the etiology of Crohn's disease. Clarity, utilizing instruments that assess family functioning, that have been normed on large samples of the population, should be sought.

Table 4

Characteristics of Parents of Chronically Ill Youth

Characteristics	Burke et al. (1989)	Zimand and Wood (1986)
Name of Study	Maternal Stress and Repeated Hospitalizations of Children who are Physically Disabled	Implications of Contrasting Patterns of Divorce in Families of Children with Gastrointestional Disorders
Sample size/ Control	60	173 (CD - 59)
Subjects	Mothers of physically disabled children and a control group of mothers whose children have been in hospital and are not disabled.	Parents of children with specified diseases (CD,UC, RAPS) between the ages of 6-19.
Method of Evaluation	Visual Life Events Schedule (VLES), Coping Health Inventory for Parents (5 pt. scale re. severity of illness and resilience) (CHIP), Child Behavior Checklist (CBC), Social and Activity Competence Scales (SACS) Developmental Profile II	Presence of Divorce Physiological Measures
Variables	VLES - duration, clustering, repetitive nature of life events experienced by mothers, CHIP - parental coping styles, family support, and support from the health care system, SACS - 5pt. scale rated by the community based nurse.	Divorce of parents related to specific GI disease.
Results	Highest stress at diagnosis of the child's disability, Order of the most stressful hospitalizations: 2nd, 1st, 3rd, and 4th, Second overall greatest stressor - Change in sleep patterns, Less stress reported related to the length of community health nurse contact, No relationship between severity of illness and low stress parents.	Divorce rates of parents of children with CD were one-third the rate for UC and RAPS ($p<0.05$), The divorce rate for UC and RAPS were similar to the normative rates.

Determining the Need for Psycheducational and Psychosocial Support and Relating Interventions to Illness-Specific Parameters

A pilot study was conducted by McKelvey, Waller, Stewart, Kennard, North, and Chipman (1989) to measure disease-specific behaviors in families with a diabetic child. The summary that follows, shows that a sample of 89 families was used for the study, that a disease-specific instrument was developed and that a standardized instrument, the Family Environment Scale was incorporated into the design for the later portion of the study. Additionally, glycosolated haemoglobin (HbAIC), an indice of the control of blood sugar, an important factor in diabetic management was utilized. Three FES scales were positively and significantly related to lower HbAIC: family cohesion, less conflict, and active recreational orientation. Three DFBS variables were also positively correlated with lower HbAIC; warm nurturance, consistent guidance, and effective problem solving ability.

The research described by McKelvey et. al. was described in the literature subsequent to the development of the research project for adolescents with Crohn's disease and their families. However, it verifies several essential components of psychosocial assessment of families with a chronically ill child, as well as addresses program development. These include: the utilization of an indice of disease severity/control, the use of a standardized instrument to validate the efficacy of a disease-specific instrument under development, and the importance of ascertaining the needs of families that are offered support, in order to adequately meet their needs.

Table 5

Family Support Related to Illness-Specific Outcome

Characteristic	McKelvey et al. (1989)
Name of Study	Family Support for Diabetes: A Pilot Study for Measuring Disease-Specific Behaviors
Sample Size/ Control	89 patients and their families/0
Age	7-17 years
Subjects	Clinic patients
Method of Evaluation	Diabetes-Specific Behavior Scale (DFBS) 5 pt. scale- "all of the time to never", Family Environment Scale (FES) (utilized for the later part of the study), Glycosolated Haemoglobin (HbA1C)
Variables	Three dimensions of family supportiveness (warm nurturance, consistent guidance, effective problem solving ability, FES scales, HbA1C.
Results	7 items on the DFBS relate significantly to HbA1C, FES was used for 34 subjects, 3 FES scores relate to HbA1C - cohesion ($P<0.002$), conflict ($p<0.02$), and active recreational orientation ($p<0.04$).

CHAPTER THREE

PROGRAM DEVELOPMENT

Program development was based on the literature review, a needs survey, the expertise of a multidisiplinary team and the experience of a young person who was one of three siblings with Crohn's disease. Due to a deficiency of research literature available, related to intervention strategies for youth with Crohn's disease, the descriptive literature was frequently utilized for program planning. Three areas were identified as important to families, measureable, and aspects that could be enhanced as a result of a psychosocial and psychoeducational intervention. The identified components were a knowledge, family coping style and social well-being. A schematic diagram of the program and its interaction with the research project is shown in Figure II.

Knowledge Component - Information about Crohn's Disease

Providing information about anatomy and physiology related to disease process has been shown to improve adjustment to the condition and to reduce anxiety (Pless, 1984; Smart, Mayberry, Calcraft, Morris, & Rhodes, 1986). Adolescents understand their illness at a new cognitive level and require information suitable to their maturation. Bruce (1986) notes that despite improved intellectual capacity, adolescents may still harbour old fantasies about their illness. An article by Perrin and Gerrity (1984) pointed out how these misconceptions were formed and White (1984) notes that these fears can become incapacitating.

Scholmerick et al. (1987) utilized a questionnaire to determine the information needs and fears of adult patients with Crohn's disease. Seventy-seven percent of the adult patients found that they had too little information about their disease and its treatment, particularly concerning the effects of drugs and surgery. Fifty-two percent of patients listed cancer as a fear factor despite the low incidence of this occuring. Preparatory films and information phamphlets were determined to be helpful by adult patients in a number of studies. However, 85% of patients in a study by Smart et al. (1981) stated that they required more information concerning prognosis, cancer risk, and inheritance of the disease. Half of the adults with Crohn's disease in Marshall's study (1979) concerning patients' knowledge about their disease stated that they had found, "difficulty finding all that they wanted to know". Providing information assists in correcting cognitive distortions and in reducing anxiety. This may allay the cycle described by Rosenthal, Wruble, Rosenthal, and Edwards (1986, p.109) who noted that "the degree to which patients worry and devote self-referent attention to their symptoms can augment functional impairment".

Knowledge about diet and the impact of malabsorption was considered to be essential for patients with Crohn's disease as it is a major aspect of treatment . Dietary education and nutritional counseling have been documented as improving the clinical course of diabetes by Imes (1984). Growth failure and delayed pubesence due to a malnourished state commonly associated with Crohn's disease were cited as having negative psychological rammifications by Steinhausen (1982, p.612-615). Young people with Crohn's disease are often faced with dietary alterations to lifestyle, such as low residue, high caloric diets, elemental diet by feeding tube, or total parenteral nutrition.

Appropriate dietary intake can vary greatly between remission and exacerbation of the disease. Children may become somewhat inflexible about their diet during remission of their disease, if they attribute a painful incident to a particular food during exacerbation of their disease. Conversly, some young people may abandon their diet with its altered texture and high caloric intake due to experimentation - a normal component of adolescence, or due to the attempt to deny their illness and be like their peers (McAnarney, 1985).

Hotel Dieu Hospital's paediatric dietitian and enterostomal nurse described the following cycle. They stated that the child experiences growth failure or weight loss and requires a special diet. The parent becomes involved due to the complexity of the procedures or due to the requirements of the diet, thereby decreasing the independence of the young person, who may then sabotage the dietary regime. This pattern of disrupting treatment has also been verified by Coupey (1984). It is important to integrate knowledge, independance, healthy experimentation with diet, and general dietary information to facilitate self-disciplined physical and emotional nourishment.

Needs Survey

The knowledge about Crohn's disease questionnaire was completed in September of 1989 (see appendix 3) utilizing a sample of 15 youths from 12 to 22 years of age, who were patients of the same paediatric gastroenterologist. They lived in an area that encompassed Kingston. The return rate was 75%, or ten respondents and resultant data are summarized in Appendix 4.

The questionnaire data resulted in several alterations to the initial plans for the program. Information related to symptoms in general and to basic nutrition was reduced while information related to sexuality, incidence of cancer, complications, cause, and specifics of the disease process were increased. Therapeutic dietary interventions were also stressed as these are related to severity of disease and to symptoms. These included enteral and parenteral nutrition, which program planners would have given little emphasis prior to analysis of the questionnaire results.

Knowledge components addressed by the five session intervention program included a review of physiology, pathophysiology, diagnostic procedures, dietary aspects of treatment, current research, genetic implications, and implications related to sexuality. Family members received this information in varying amounts of detail and according to the group's previous educational experience. Siblings, for example, who had less hospital experience received a tour of the facility to increase their knowledge of and comfort with departments where their sibling receives care.

Social Well Being

Repeated hospitalizations, growth failure, ongoing treatment regimes and the impact of the disease itself appear to reduce and delay the progress of chronically ill adolescents toward independence and to effect their peer relationships. Orr et al. (1984) found that chronically ill young adults were less likely to have a driver's licence, date, attend school full time, and have formed career plans. Chronically ill youth progress more slowly toward an adult role. McAnarney (1985) quoted a number of studies which reported that chronically ill children are less likely to acquire the social skills needed to be independent of their families and to seek a partner and a vocation. Bywater, cited in McAnarney (1985, p.97), stated that these adolescents "did not place themselves in a position where they might be rejected" and noted that they rarely went to dances. Coupey (1984) indicated that chronically ill female adolescents have an increased incidence of pregnancy due to risk-taking behavior to prove normalacy.

The intervention program provided a forum where a constructive approach to independence and peer relationships was fostered through discussion and group building activities. The process of coping described by Rose (1984), involves an inactive level, an orientating level and an active coping level. A group approach provided a social setting where children with Crohn's disease could progress along the coping continuum as described by Rose. It was important to emphasize and reinforce individual strengths and coping strategies during group interactions, for as Pless (1984, p.33) noted, "Overall the conclusion is drawn that the strengths and coping abilities of those with chronic disorders noticably outweigh their weaknesses". Bruce (1986) utilized ill adolescents to develop a booklet about Crohn's disease. Reframing the role to one of helper by developing materials to assist others can facilitate feelings of adequacy. The concept of encouraging young people to share their experience, perceptions and advice became a core element of the program. A cartoonist sketched as the group described feelings related to social situations, discussed symptoms of the disease and described hospitalizations. Group facilitators encourage participants to recall advice and information that they found to have been or was helpful near the time of diagnosis. This was [illegible] important to the development and furthering of an advocacy ro[illegible] perception of competency.

Peer relationships of adolescents with chronic illnesses are interrupted by repeated and often frequent admissions to hospital. These young people may have less stamina, be smaller than their peers due to malabsorption of nutrients, experience repeated abdominal pain, have an ostomy due to surgical intervention, be required to take medications regulary, and have changes in appearance as a result of medications. Consequently, patients with Crohn's disease may experience a heightened sense of inadequacy and social isolation (Weitzman, 1984;

Zimand & Wood, 1986). Chronically ill children often miss more school than can be attributed to their illness. Bruce (1986, p.100) described children with Crohn's disease as demonstrating school phobias due to a fear of "messing themselves". Adolescents struggle with the issue of imaginary audience. For young people with an illness, the issues become even more acute. According to Rodgers et al. (1981) a child's self-image develops in correlation to body image and is basic to all ego development and functioning. The adolescent may be vulnerable in the peer group setting and in need of support from their family and from professionals. Young people can be verbally reinforced by adults for compensatory activities that they have undertaken, such as substituting a new activity for one they may not be able to achieve physically during an exacerbation of their illness. However, as Weitzman (1984) concluded, as the youth tries to achieve independence, feedback from peers becomes "vitally important". The concept of marginality highlights the ambiguity that the teenager experiences in dealing with peers. When in remission, patients with Crohn's disease may pass as normal and when ill they suffer a great deal of ambiguity which they tend to resolve either by giving up medical requirements or by acknowledging their condition to their peers (Weitzman, 1984). Weitzman (1984) suggested that children can be assisted to explain their illness and restrictions to peers by rehearsal and that this may facilitate communication. The goal of the disease-specific grouping of the young people was to explore common concerns related to management of their illness in peer and school settings, to provide valuable practice opportunities, and to introduce role- models who have devised strategies that are valuable in maintaining positive peer relations. Williams and Baeker (1983) found that chronically ill children in a small group setting could share similar experiences, trust each other and discuss feelings openly in a group. The pilot program at Hotel Dieu offered numerous opportunities to observe effective group communication amongst the intervention group. Weitzman (1984) noted:

> It can be very reassuring to children to confide in a friend, openly discuss their illness, and still be accepted.
> Similarly it helps for children to know what other children have experienced. Such knowledge helps alleviate their sense of being

> alone, and their concerns about being different or defective, and it helps them recognize their feelings and reactions as being appropriate and acceptable (p.68-69).

The program planners brainstormed methods of assisting affected adolescents and their families to communicate concerns and issues. Concretizing using plasiticene, cartooning, role-playing, and developing a booklet for newly diagnosed patients with Crohn's disease were utilized. A fourth year psychology student from Queen's University, who is one of three siblings with Crohn's disease was a catalyst for discussion, by openly raising sensitive issues for discussion. Siblings dealt with issues and concerns related to having an ill sibling in a similar manner. Parents had an opportunity to focus on specific concerns as outlined in the program (Appendix 5) with other parents who shared similar concerns. Group work related to coping strategies, planning for the future, as well as an opportunity to network with members of the Canadian Foundation for Ileitis and Colitis (CFIC) were utilized. Opportunities to advocate for young people with Crohn's disease and to give feedback to health professionals were provided as part of the booklet preparation. The strategies were intended to encourage expression of feelings, provide some opportunities for humerous reframing of issues, and encourage discussion.

Family Coping Style

A chronically ill child places unique demands on the family and may disrupt a well functioning system (Thomas, 1984). Chronic illness precipitates the loss of the preillness identity of the family. When the onset of a chronic illness coincides with a transition in an individual such as adolescence, one can expect that issues will be magnified. A greater risk exists for the illness to be inappropriately ignored or unnecessarily embedded in planning for the next stage. This can be a major precursor of family dysfunction (Rolland, 1987). Family collages were utilized as an activity for the program. Magazines provided for participants, included some nursing magazines to provide a medium for illness-relatee themes to emerge. Group work directed towards future planning was thought to be helpful to parents of chronically ill adolescents.

Recent studies that utilized control groups and a precise definition of chronic disease, noted that parents of ill children have a higher incidence of depression (Sabbeth, 1984). Zimand and Wood (1986) stated that the configuration of families with a child with Crohn's disease is one of poor marital functioning and low divorce, a finding consistent with the enmeshed family structure which provides over-protection and lack of conflict resolution. Minuchin (1974) described the enmeshed family structure as one in which all family members are expected to have the same thoughts, feelings and attitudes and where attempting to assert independence is difficult. Whirshing and Stierlin (1985) noted that overprotection of the ill child can result in complete self-sacrifice in enmeshed families. Protection of the child may involve ignoring or avoiding marital problems. "When these highly stressed families seem to find patterns that seem to work, they are maintained at all costs---rigid patterns make changes very difficult to accomplish" (p.9). However these patterns designed to minimize stress , can function to increase rather than to decrease stress levels of the patient (Zimand & Wood, 1986).

Bruce (1986) described the parents of chronically ill children as experiencing ambivalence because they are afraid of letting the child fend for herself/himself, while wanting the child to be independent. Parents of children with Crohn's disease may be involved in discussing issues that are normally more private for adolescents, such as diet eaten outside of the home, stools, rest, and diagnostic tests relating to the bowel. Weitzman (1984) noted that disciplining ill children could be problematic and stated, "many such children develop behaviors that evoke more negative responses in social contexts than does the underlying disease itself". Sabbeth (1984) observed, that the impact of illness on the family involved numerous spheres including: financial, social, somatic, behavioral, conscious, and unconscious mental life. Furthermore, Sabbeth noted that some fathers tended to withdraw, spending long hours at work. She also commented, however, that some parents develop complementary coping styles, that serve to protect each other from being overwhelmed by their child's illness. A group setting provides an opportunity for parents with similar issues to learn from each others' experience and to observe coping styles.

Messner et al. (1985) stated that Crohn's disease involves many loses and that the individual may reexperience stages of the grieving process and progress back and forth on a coping continuum throughout the course of the illness. Not only do parents face assisting their grieving children, they must also deal with their own grief (Sabbeth, 1984). Schowalter, cited in Rodgers et al. (1981), points out that chronically ill childrenoften mourn, "normalacy loss, skills destroyed, and in some cases for anticipated physical failure and death" (p.268).

Siblings, according to Frey (1984), who live in homes where a chronically ill sibling demonstrates poor medical management of their illness, typically experience their family in one of two ways: as something to avoid and leave as soon as possible or as something impossible to leave, because any change would be threatening to the patient or parents. Sabbeth (1984) concured that siblings may find gaining independence to be extremely difficult. Featherstone, cited in Rodgers et al. (1981), noted that siblings experience guilt around their embarrassment about the ill siblings' condition. "Siblings often feel guilty that they are healthy and resent the parental time given to the child with the chronic disease, they may as a result, become depressed themselves" (p. 270). Researchers have suggested that siblings of chronically ill children are more prone to psychosocial problems, have more behavioral problems and are often underachievers (Sabbeth, 1984, p.53). Breslau (1983) studied the siblings of chronically ill children based on ordinal position of birth and compared siblings who had lived their early years with disabled children versus siblings that were older by the time the affected child entered the family. She found that younger male siblings, particularly those in close age spacing to a disabled child, scored higher on psychological impairment than older male siblings. In contrast, younger female siblings tested as "better" off psychologically than older female siblings. However, Breslau (1983) suggested that the later response of female siblings to early life experiences might be sex-contigent and that females may experience depressive-anxious feelings.

There was evidence that parents, experienced siblings of ill children as coping with less stress than indicated by the siblings (Craft & Craft, 1989). Siblings reported 519 changes that they experienced during the illness of a sibling, while parents reported 252 sibling changes. Behaviors, including nervousness and difficulty concentrating were reported more frequently by siblings than by parents. Parents and siblings of acutely ill children were in more agreement, than parents and siblings in families with a chronically ill child regarding sibling stress. Siblings categorized their perception of the most difficult issues in the separation from siblings and worry about their brother's or sister's illness and hospitalization (Craft & Craft, 1989). The needs of siblings of chronically ill children are underestimated by parents and often forgotten by the health care system. It seemed advantageous to utilize the group setting as an opportunity for siblings to share similar experiences with a peer group and express their concerns. As well, it was hoped that siblings would have an opportunity to become better informed about their sibling's illness and treatment. Furthermore, opportunities were provided for interaction with parent-sibling groups to facilitate communication about sibling needs.

Other aspects of the program that were designed to further communication related to family coping style included: family collages, role-playing, discussions, provision of role-models, future planning and attention to the mixing of groups. An outline of the five session intervention program is provided in Appendix Five.

The intervention program was initially designed to be given as a pilot program at HDH Hospital - Kingston, then refined further for the Hospital for Sick Children and Childrens' Hospital of Eastern Ontario. However, due to inadequate numbers of subjects to analyse the effectiveness of the HDH program, the pilot study was extended to all of the centres listed above. This necessitated careful preparation of group leaders, to promote consistency of the program. Demonstations of the techniques utilized , such as reframing fears with plasticene, as well as discussions about content were held with each center's facilitators on two occassions, for a total of five hours and reviewed prior to each session. Although specific information varied slightly, depending on the therapeutic perspective of the physician, the delivery was held as consistent as possible. Individual personality variables, are of course, unavoidable.

The three components upon which that the program was based were: a knowledge component, a portion to enhance family coping style, and a section to address social well-being. The instrument described in the methodology chapter (the CD-PSI) was developed to measure these characteristics.

CHAPTER FOUR

METHODOLOGY

Five session intervention programs were conducted at three different times in October and November, 1989 at the Hotel Dieu Hospital - Kingston, in January and February, at The Hospital for Sick Children - Toronto, and in March, 1990 at Childrens' Hospital of Eastern Ontario. Letters describing the project (Appendix 3), were sent to a total of 103 families. The gastroenterologists, had predicted a sample of 225 affected adolescents. However, with definitive diagnosis, based on biopsy and/or the evaluation of a paediatric gastroenterologist, only 103 potential subjects were found. Twenty-three families responded by phone or by letter to indicate that they would like to be involved in the program. The Kingston sample was randomly assigned, however in Toronto, a number of families either indicated interest after the first session had begun, or in one case could not attend on the specified evening. These persons were assigned to the control group. The Ottawa intervention group was therefore larger, with only one control subject. Although this sufficed for the pilot study, further study would necessitate, equal numbers of subjects per center. Four families who initially agreed to participate in the project and who were assigned to the control group, did not complete forms as requested. One family stated that it was a behavioral crisis time, regarding the youngest sibling of an adolecscent with CD, another family found that the questionnaires were too difficult for their developmentally delayed child, and the third family expressed great disappointment that they were assigned to the control group. A fourth family attended another intervention program, that was largely knowledge related and was of eight hours duration. One family, did not complete the intervention program. The mother of this family stated that although she and the affected child wished to continue, that the older sibling did not want to participate. Although there was no requirement that all family members attend all sessions, the family only attended one session.

All individuals were tested between October, 1989 and May,1990. Twelve families, a total of 45 persons participated in the intervention program, a total of 26 persons formed the control group. The total sample was 71 persons: including, 19 affected adolescents, 34 parents, and 18 siblings.

CD-PSI - Crohn's Disease Psychosocial Inventory

Assessment of the intervention program and the control group was completed utilizing a series of VAS (visual analogue scales), that presented dichotomous variables related to chronicity factors. These factors included: knowledge about Crohn's disease, social well-being and family coping style. All participating family members completed the VAS prior to the intervention program and three weeks following the program (two months following the administration of the VAS). The control subjects were assessed using the same time frame, with the initial VAS administration at week one and the subsequent testing at two months. The VAS were a series of ten centimetre horizontal lines with anchors on each end of the line near the response options. The point at the intersection of the vertical line made by the respondent crosses the horizontal line was measured to the nearest centimeter.

VAS have the advantage of ease of administration, of being readily accepted by respondents, (Cella & Perry, 1986) and of being understood conceptually by most children five years of age and older (Huskinsson, 1983). VAS have demonstrated sensitivity and validity for a broad range of variables (Lush, Jansen-Bejerclie, Carrieri & Lovejoy, 1988). The responsiveness of VAS instruments have enabled detection of clinically important change even though that change was small (Guyatt et al., 1987). The difficulty of finding enough descriptors, a difficulty with other test formats, was eliminated. Dr. Pat McGrath, who utilizes VAS for pain assessment verbally stated that in North American culture there is a convention of the left side of the scale being low and the right side being high. Therefore, the researcher thought that it was not advisable to reverse polarities of statements on the CD-PSI. The VAS have been utilized to produce reliable and reproducible ratings of subjective sensations of physiological data including pain and dyspnea. The use of VAS for psychosocial variables included: depression, anxiety, and distress. For psychosocial parameters, VAS has been used sucessfully by Bachu et al. (1983), Cella and Perry (1986), Morrison (1983), and Guyatt et al., (1986). Adult attitudes to children with epilepsy and its influence on lifestyle was assessed by Hoare (1986). The study demonstrated the usefulness of VAS with parents of chronically ill children.

Development of the CD-PSI was initiated to provide a rapidly administered instrument for the assessment of family members of youth with Crohn's Disease. This would allow practitioners to gain insight into various family member's perception of and knowledge about Crohn's disease, family coping style, and social well-being. At subsequent visits or following a disease-specific intervention program, these perceptions could be re-evaluated. In this study, two standardized instruments, the FAD, Family Assessment Device and the CF-Self-Esteem Inventory were used to measure the effectiveness of the program, while beginning validation of the CD-PSI. The CD-PSI has three forms: Form A (affected adolescents) Form S (siblings), and Form P (parents). Concerns regarding the use of VAS, and their use for instrument development, relate to the choice of descriptors and to an area of the VAS referred to as the "golden section of the line" (Huskinson, 1983). Athough the distribution of results in a random sample of patients is generally uniform and nearly equal numbers of measurements occur at all points on the line, there is a golden section of the line. This point occurs at the 6.2 cm. area. Statistical concerns also relate to the extreme ends of the scale, for if a client choses an extreme point on the scale and the symptom or concern increases they can only repeat the same mark. The use of extreme descriptors may cause a shift to the left and reduce the sensitivity of the scale (Sriwatanakul et al., 1983).

The scales of the CD-PSI are, Knowledge about Crohn's disease (KNCD), Family Coping Style (FCS) and Social Well-Being (SWB). The specific items that compose the scales are as listed.

Knowledge about Crohn's Disease:

1. KPT - Total knowledge about Crohn's Disease
2. KPI - Extent informed about Crohn's Disease
3. KPU - Understanding about disease process
4. KPD - Understanding of diet related to CD
5. KPH - Extent to which feel well informed by health professionals
6. KPY - Understanding of how CD affects day to day living
7. KPX - Understanding of diagnostic tests

8. KPM - Understanding of medications used for CD
9. KPG - Understanding of genetics related to CD

Family Coping Style

1. FPTT - Total FCS
2. FPT - Ability to talk openly about CD
3. FPSB - Sibling behavior
4. FPH - Extent that the affected adolescents illness alters holiday plans.
5. FPF - Effect of adolescents CD on family
6. FPU - Extent that the future is discussed
7. FPC - Seek comforting from family
8. FPAB - Affected adolescent's behavior
9. FGPI - Understanding of others' feelings in the family
10. FPP - Problem Solving

Social Well-Being

1. SPT - Total social well-being
2. SPAE - Affected adolescent's degree of ease with peers
3. SPD - Ability to discuss illness with friends
4. SPSI - Degree of sibling independence
5. SPC - Adult/adolescent communication
6. SPSE - Sibling's degree of ease with peers
7. SPAB - Affected adolescent's school behavior
8. SPSB - Sibling's school behavior
9. SPF - Ability to discuss feelings / peers

The content validity of the questionnaire was assessed prior to its distribution to respondents, by asking the multidisciplinary team at Hotel Dieu Hospital to review it, based on their knowledge of chronically ill families with a member with Crohn's disease. A family which consisted of three young adults with the disease and one unaffected sibling were also asked to complete the CD-PSI prior to its use with participants in the study. Minor changes to the wording were made and an omission of a statement on the sibling form of the CD-PSI was corrected. Ideally, the Kingston sample would have been large enough to have assessed the concurrent validity of the CD-PSI relative to the FAD and CF-SEI. Concurrent validity of the CD-PSI was determined by comparing CD-PSI results to the Family Assessment Device and the Culture Free Self-Esteem Inventory for the total population at Hotel Dieu Hospital - Kingston, at The Hospital for Sick Children - Toronto and at Childrens' Hospital of Eastern Ontario - Ottawa.

The Family Assessment Device

FAD, designed by Epstein, Baldwin and Bishop (1983), is a 60 item questionaire that utilizes statements that respondents complete by checking one of: strongly agree, agree, disagree, or strongly disagree. The FAD includes seven scales: problem solving, communication, roles, affective responsiveness, affective involvement, behavior control, and general functioning. The test-retest reliability ranges from .66 to .75 (Miller, Bishop, Epstein & Keitner, 1985). The scales, based on the McMaster model of family functioning, were designed to measure problem areas of functioning within families and to collect this information directly from family members. Family functioning is seen by Epstein et al. (1983) as related to "transactional and systemic properties of the family system" versus "intrapsychic characteristics of individual family members" (p.171). The FAD is used to collect information across multiple dimensions and from various family members' perspectives. The validity of predicting clinical from nonclinical populations of clients in their study was $p < 0.001$. The cut-off scores of the seven scales when utilized to determine clinical versus non-clinical groups, range from 1.9 to 2.2. Healthy scores from non-clinical samples range from 1.8 to 2.1 with a diagnostic confidence of 68 % to 89 %, as a proportion of correctly identified cases as compared to assessments by family therapists. Families rated as unhealthy on a given dimension of functioning by clinicians had significantly higher mean FAD scores (poor functioning). All scales were significant at either the 0.001 or 0.01 levels of significance except the general functioning scale, which was significant at the $p < 0.05$ level and the behavior control scale which was not significant (Miller, Bishop, Epstein, & Keitner, 1985). The FAD was found to be more sensitive to the enmeshed family than other comparison instruments (Miller, Epstein, Bishop, Keitner, 1985). This makes the FAD a useful instrument to facilitate further data collection related to previous studies. Zimand and Wood (1986) stated that the configuration of families containing a member with Crohn's disease was one of poor marital functioning and low divorce; this is a finding consistent with the enmeshed family, which is seen as overprotective and lacking conflict resolution. The test-retest reliability of the FAD was .66 to .71, with low correlations with social desirability and moderate correlations with other measures of family functioning such as the FACES II and The Family Unit Inventory (Epstein et al., 1983). The intervention program used in the project was for young people with Crohn's disease and was also based on a family systems approach with the belief that a serious chronic illness impacted on all family members. Data were collected from all family members able to adequately read and answer the questionaire. The CD-PSI scales of family coping style, and to a lesser extent social well being, were postulated to have features which weresimilar to the FAD scales.

The Culture-Free Self-Esteem Inventory

The purpose of The Culture-Free Self-Esteem Inventory (SEI) by Battle (1981) is to identify adolescents and adults with low self-esteem who may be in need of counselling. Self-esteem, by Battle's definition, refers to the perception that the individual possesses of his own worth (Buros, 1985, p.204). Test-retest correlations range from .79 to .82. Internal consistency for the subscales of self-esteem are as follows: general scale - .78, social scale - .57, personal scale -.72 and defensiveness scale - .54. Concurrent validity using The Stanley Coppersmith Self-Esteem Inventory ranged from .71 to.80 (Battle, 1981). The most useful aspect of the Culture-Free SEI for determining validity and reliability of the CD-PSI appeared to relate to the breakdown of self-esteem into general, social, and personal components which appeared valuable in assessing the total CD-PSI score and the social well-being parameter of the CD-PSI.

Method of Analysis

A statistical procedure, repeated measures ANOVA, was utilized to determine the interaction of post-intervention scores with pre-intervention scores on the CD-PSI. A repeated measures ANOVA provides statistical adjustment of post-test scores by the differences that existed between individuals on pre-test scores. The adjusted post-test scores are compared to the pre-test scores to ascertain the magnitude of the difference that existed following the intervention program. A control group of families who did not receive the intervention program and were tested with the same instruments administered to the intervention group, at the same time intervals were utilized for comparison data. The time intervals were three weeks post-intervention (at the two month point) and prior to the intervention. Variables included, scores on the CD-PSI, FAD, and CF-SEI as well as, factors indicative of disease severity, the CDAI, Crohn's Disease Activity Index and presence of growth failure. These were statistically analysed using SYSTAT. The following diagram indicates the data that were analysed for the study.

Table 6

Data Analysed for the Study

Sample	Post/CD-PSI,FAD, and CF-SEI.	CDAI	Growth Failure (Ht. and Wt.)	Pre/CD-PSI, FAD, and CF-SEI
Affected child (#)	CD-PSI- Knowledge Family Coping Style Social Well-Being FAD Scores CF-SEI Scores	Score	Percentiles	CD-PSI- Knowledge Family Coping Style Social Well-Being FAD Scores CF-SEI Scores
Siblings	CD-PSI- Knowledge Family Coping Style Social Well-Being FAD Scores CF-SEI Scores	Score	Percentiles	CD-PSI- Knowledge Family Coping Style Social Well-Being FAD Scores CF-SEI Scores
Parents	CD-PSI- Knowledge Family Coping Style Social Well-Being FAD Scores CF-SEI Scores	Score	Percentiles	CD-PSI- Knowledge Family Coping Style Social Well-Being FAD Scores CF-SEI Scores

Tritt and Esses (1988) highlighted a number of methodological issues relative to data collection for research concerning the impact of chronic illness. They cautioned that research findings relate to who was doing the reporting, as perspectives of various family members vary and therefore they recommended information gathering and comparison between various family members' responses. Therefore, data for this study were analysed according to family role: affected adolescent, sibling, or parent.

Instrument Validation

Utilizing TESTAT, a companion program of SYSTAT, preliminary data regarding the reliability of the CD-PSI was determined by comparing self-perception scores of knowledge of Crohn's disease, family coping style, and social well-being with a number of other measures. The perception of knowledge about Crohn's disease on the CD-PSI was compared to a quiz regarding basic knowledge about the bowel, Crohn's disease, and the diagnosis and treatment of the condition (Appendix 2). Family coping style was compared to problem solving, communicaton, roles, affective responsiveness, affective involvement, and general functioning scales of the FAD. The social well-being score was also compared to the FAD.

The remaining aspect of the methodology was the recording of a variety of parameters to ascertain the influence of disease-specific and related parameters that might relate causally, as well as aspects that might be confounding factors. Disease-specific parameters such as the CDAI, the presence of growth failure, and the specific location of disease (upper gastrointestional, lower small bowel, colon, anal, and perianal) were documented. Treatment factors were also noted, including medications (the use of prednisone in particular) and specific nutritional interventions. Prior psychosocial interventions, both individual and group, were noted. In order to assess confounding factors, age, socioeconomic factors, ethnicity, and religion were documented and this information analysed retrospectively.

CHAPTER FIVE

ANALYSIS OF RESULTS

Characteristics of the Study Population

The total sample consisted of 71 persons, including 19 affected adolescents, 34 parents, and 18 siblings. The following table provides data specific to physical parameters and treatment of the affected adolescents. There were 12 adolescents with CD in the treatment group and seven in the control group.

Table 7

Physical Parameters and Treatment of Affected Adolescents

Dimension	Parameters	Total Sample		Intervention		Control	
		n	M	n	M	n	M
Medication	Current Rx	14	0.7368	10	0.8333	4	0.5744
	Not RX.	5	0.2632	2	0.1666	3	0.4286
Prednisone	Current Rx	8	0.4210	5	0.4166	3	0.4285
	Not Rx.	11	0.5789	7	0.5833	4	0.5714
Surgical Intervention	Yes	6	0.3157	3	0.2500	3	0.4285
	No	13	0.6842	9	0.7500	4	0.5714
Ostomy	Yes	2	0.1052	1	0.083	1	0.1428
	No	17	0.8947	11	0.9167	6	0.8571
Affected Area of Bowel							
Upper GI	Yes	4	0.2105	2	0.1666	2	0.2857
	No	15	0.7895	10	0.8333	5	0.7143
Lower Small Bowel	Yes	16	0.8421	11	0.9166	3	0.4285
	No	3	0.1579	1	0.0833	4	0.5714
Colon	Yes	6	0.3157	2	0.1666	4	0.5714
	No	13	0.6842	10	0.8333	3	0.4286
Anal	Yes	4	0.0526	3	0.2500	1	0.1428
	No	15	0.7894	9	0.7500	6	0.8571
Perianal	Yes	6	0.3157	3	0.2500	3	0.4285
	No	13	0.6842	9	0.7500	4	0.5714

(table continued)

Table 7 (continued)

Dimension	Parameters	Total Sample		Intervention		Control	
		n	M	n	M	n	M
Diet (at baseline)	Regular	15	0.7894	9	0.7500	6	0.8571
	Low Fibre	0	-	0	-	0	-
	High Fibre	1	0.0526	1	0.0833	0	-
	Enteral	3	0.1578	2	0.1666	1	0.1428
	TPN	0	-	0	-	0	-
Number of Admissions to Hospital	Mean	-	2.333	-	2.271	-	2.500
	SD		2.401	-	2.363	-	1.643
Total Weeks in Hospital	Mean	-	6.667	-	5.250	-	9.500
	SD	-	7.382	-	4.869	-	10.895
Length of Diagnosis (years)	Mean	-	2.347	-	2.271	-	2.500
	SD	-	2.102	-	2.363	-	1.643
Gap Onset of Symptoms and Dx. (years)	Mean	-	1.309	-	0.746	-	2.342
	SD	-	1.961	-	0.659	-	3.076
Months Ill This Year	Mean	-	6.083	-	5.958	-	6.333
	SD	-	4.393	-	4.535	-	4.502
Height	≤5th %tile	5	0.3125	2	0.2222	3	0.4285
	≤10th %tile	3	0.1875	0	-	3	0.4286
	≤25th %tile	2	0.1250	2	0.2222	0	-
	≤50th %tile	0	-	0	0	0	-
	>50th %tile	6	0.3750	5	0.5555	1	0.1429
Weight	≤5th %tile	6	0.3158	4	0.3333	2	0.2857
	≤10th %tile	1	0.0526	1	0.0833	0	-
	≤25th %tile	2	0.1053	1	0.0833	1	0.1429
	≤50th %tile	5	0.2631	1	0.0833	4	0.5714
	>50th %tile	5	0.2631	5	0.4167	0	-
CDAI Score (pre-testing)	0-50	3	0.2143	1	0.0909	2	0.2857
	51-100	1	0.0714	4	0.3636	1	0.1429
	101-150	3	0.2143	2	0.1818	1	0.1429
	151-200	3	0.2143	1	0.0909	2	0.2857
	201-250	2	0.1429	2	0.1818	0	-
	251-300	1	0.0714	0	-	1	0.1429
	301-350	1	0.0714	1	0.0909	0	-

Comparison of Physical Parameters and Treatment Parameters Between Intervention and Control Groups

Table 7 lists baseline data relative to the control and intervention groups. Seventy-three percent of the youth were taking one or more medications at the time data were collected. Eighty-three percent of intervention subjects were taking medications, whereas 57% of control subjects had medications prescribed. However, nearly equal numbers of subjects per group were on prednisone, a drug that alters physical appearance.

Surgical intervention had been utilized for 25% of the intervention group and 43% of the control group. One person in each group had an ileostomy, an opening of the small bowel onto the abdomen, where stool is collected. The dietary regimes of the subjects were similar, in that 75-85 % ate a regular diet and 14-16% were treated with enteral feeds. Enteral feeds are partially digested nutrients using a nasogastric tube, often in conjunction with a feeding pump, usually as the person sleeps.

The intervention group had experienced a mean number of 1.9 hospitalizations and a mean of 5.2 weeks in hospital. The control group had a mean of 3.0 hospitalizations and a mean length of hospitalization of 9.5 weeks. The larger standard deviation of the control group data, related to hospitalization appears to be largely accounted for by one individual who has a serious malabsorption problem.

The subjects were asked to record all areas of the bowel that were affected. Lower small bowel disease was more prevalent in the intervention group than in the control group, while disease of the colon and perianal region was more common in the control group. Length of diagnosis was similar between groups, whereas the gap between the onset of symptoms and diagnosis was longer for control subjects. Both groups had been ill approximately the same length of time in the past year; between 6 and 6.3 months.

Indices of disease severity related to growth failure are noted on Table 7. Height and weight were categorized by percentile. Degrees of growth were listed as less than or equal to the 50th, 25th, 10th and 5th percentile or greater than 50th percentile. Failure to gain weight as indicated by weight ≤ to the 25th percentile occured in approximately half of the control and intervention groups. Thirty-three percent of the intervention group and 28% of the control group had severe growth retardation related to weight gain at ≤ the 5th percentile. Fifty percent of the intervention group and 57% of the control group were > 25th percentile for weight. There were greater differences between groups for height. Sixty-three percent of the total sample were < the 25th percentile, however this described 44% of the intervention group and 86% of the control group. Twenty-two percent of the intervention group were ≤ the 5th percentile and 42% of the control group were ≤ the 5th percentile for height. Fifty-five of the intervention group were in the > 25th percentile range, whereas only 14% of the control group were in this percentile range.

Affected adolescents from both the control and intervention groups whose weight was ≤ to the 25th percentile scored lower on the FAD on all scales, indicating healthier scores than those whose weight fell in the >25th percentile range. In addition they scored higher on the knowledge quiz (KQCD) as well as perception of knowledge (KPT). Results for youth who were ≤ to the 25th percentile for height, were similar to those described relative to weight, as outlined on Table 8. This study

Table 8

Relationship / Growth Status and Psychosocial Parameters

Dimension		Wt.≤ 25%th Percentile	Wt. > 25th Percentile	Ht ≤ 25th Percentile	Ht. > 25th Percentile
FAP	M	2.136	2.450	2.167	2.457
	SD	0.573	0.756	0.557	0.690
FAC	M	2.273	2.417	2.275	2.400
	SD	0.478	0.319	0.456	0.294
FAR	M	2.291	2.533	2.275	2.471
	SD	0.391	0.327	0.377	0.340
FAAR	M	2.036	2.750	2.117	2.786
	SD	0.514	0.394	0.564	0.372
FAAI	M	2.209	2.533	2.192	2.457
	SD	0.520	0.463	0.500	0.469
FAB	M	1.818	2.267	1.833	2.229
	SD	0.471	0.599	0.452	0.556
FAE	M	1.891	2.000	1.900	2.000
	SD	0.545	0.587	0.520	0.535
SPT	M	7.053	8.024	7.234	8.174
	SD	1.058	0.759	1.187	0.821
FPTT	M	7.246	7.444	7.216	7.375
	SD	1.324	1.392	1.266	1.304
KPT	M	7.246	5.893	6.760	6.203
	SD	1.324	2.070	1.591	2.108
KQCD	M	6.614	3.771	6.045	4.263
	SD	1.582	1.541	3.057	1.991

*See list of abbreviations

constitutes only a small percentage of adolescents with Crohn's disease, however, this information may correspond to the concern that marginally ill adolescents are at as much or more at risk than youth who are clearly defined as ill by other persons.

CDAI scores for subjects ranged from 18-312 on the first testing. As previously explained, all persons were accepted for the study regardless of their CDAI score. The second CDAI, revealed change within one subject of 191 points. In retrospect, it appears that the CDAI is a sensitive measure of current disease severity. However, an initial low CDAI should not preclude entry into the study. Fifty-eight percent of the control group and 57% of the intervention group had CDAI scores ≤ 150. However, approximately half of this group were low in weight and 31% had severe growth failure relative to weight gain. Greater than half of the subjects were ≤ to the 25th percentile for height. Only 16% of intervention subjects and 14% of control subjects had CDAI scores between 250 and 350, a finding relative to growth failure that indicates current evidence of inflammatory process is only a partial guide to the morbidity of the disease. CDAI scores did not relate to psychosocial parameters of the FAD and the CD-PSI. This finding may indicate that severity of disease and psychological functioning are not directly related in youth with Crohn's disease or that other parameters such as, correlating delayed pubescence with psychosocial measures might be more helpful if correlated with psychosocial issues.

In summary, regarding physical parameters and treatment, the intervention and control groups were similar. The intervention group had a greater frequency of disease of the small bowel versus disease of the colon and perianal region, as was typical of the control group. The intervention group had been diagnosed more promptly and had received less surgical intervention, however they took more medication than the control group.

Demographic Factors

The demographic data which related to parents included: marital status, vocation, total family income and ethnic group of both parents. Table 9 lists the demographic data. Of the 32 parents in the study, 94% were married and had not been previously divorced. One parent had remarried and one parent was a widow; both persons were in the intervention group. Although the sample was small, this corresponds with the Zimand and Wood study (1986). They found that a contrasting pattern of low divorce existed in families of children with Crohn's disease relative to parents of children with other gastrointestional diseases or from the normative population.

Both intervention and control groups were similar with respect to vocation of parents. The control group had eight percent more skilled parents in the category related to vocation and nine percent fewer professional parents. Parents defined as unskilled members of the work force accounted for approximately 16% of both groups. Income for both groups was also similar, with 20% of family incomes falling between $20,000 and $49,000. Thirty percent of the intervention group and 20% of the control group made between $50,000 and $69,000. Fifty percent of the intervention group and 60% of the control group made between $70,000 and $100,000. These families were for the most-part, middle to upper income families.

Table 9

Demographic Data

Dimension	Parameters	Total Sample		Intervention Group		Co[illegible] Group	
		n	M	n	M	n	M
Income (Parents)	20,000-29,000	1	0.1333	1	0.1000	0	-
	40,000-49,000	2	0.1333	1	0.1000	1	0.2000
	50,000-59,000	2	0.1333	1	0.1000	1	0.2000
	60,000-69,000	2	0.1333	2	0.2000	0	-
	70,000-99,000	4	0.2667	3	0.3000	1	0.2000
	100,000+	4	0.2667	2	0.2000	2	0.4000
Marital Status	Married	30	0.9375	20	0.9090	10	1.000
	Remarried	1	0.0313	1	0.0450	0	-
	Widowed	1	0.0313	1	0.0450	0	-
Religion	Anglican	2	0.1111	2	0.8889	0	-
	R/C	11	0.6111	8	0.1111	3	0.4285
	Jewish	3	0.1667	1	-	2	0.2857
	U/C	0	-	0	-	0	-
	Other	0	-	0	-	0	-
	Not Specified	2	0.1111	0	-	2	0.2857
Vocation	Professional	12	0.3871	8	0.4210	4	0.3333
	Skilled	14	0.4516	8	0.4210	6	0.5000
	Unskilled	5	0.1612	3	0.1578	2	0.1666
Ethnic Group (Both Parents)	Western European	8	0.2581	5	0.2380	3	0.3000
	Eastern European	7	0.2258	2	0.0952	5	0.5000
	Mediterranean	2	0.0645	2	0.0952	0	-
	North American	14	0.4516	12	0.5714	2	0.2000
Ordinal Position	Eldest	3	0.1579	2	0.1666	1	0.1428
	Middle	7	0.3684	5	0.4166	2	0.2897
	Youngest	8	0.4211	4	0.3333	4	0.5714
	Only Child	1	0.0526	1	0.0833	0	-
Age	Parents						
	<40	4	0.1176	4	0.0218	0	-
	41-50	27	0.7911	16	0.7273	11	0.9167
	51-60	2	0.0588	1	0.0556	1	0.0833
	>60	1	0.0294	1	0.0556	0	-
	Adolescent with CD						
	9-11	4	0.2105	2	0.1667	2	0.2857
	11-14	7	0.3684	6	0.0500	1	0.1429
	14-17	4	0.2105	2	0.1667	2	0.2857
	17-19	4	0.2105	2	0.1667	2	0.2857
	Siblings						
	9-11	3	0.1765	3	0.3000	0	-
	11-14	2	0.1176	1	0.1000	1	0.1429
	15-17	7	0.4118	6	0.6000	1	[illegible]
	17-19	3	0.1765	0	-	3	[illegible]
	>19	2	0.1176	0	-	2	[illegible]

Ethnic grouping varied between the groups as shown in Table 9 with 37% fewer persons in the control group identifying with North America. Forty percent more persons in the control group identified with Eastern Europe. Religious affiliation, was also less comparable between groups than other parameters. In both groups the largest religious group represented was Roman Catholic, however 24% more of the intervention group belonged to that denomination than the control group. The Jewish faith was represented by only 8% of the intervention group and 29% of the control group. If parents were of different faiths, the affected adolescent's religious affiliation was recorded.

The ages of family members are grouped and listed in the Table 9. Sixty-seven percent of the affected adolescents in the intervention group and 43% of the control group were between 9 and 14 years of age. Thirty-three percent of the intervention group and 57% of the control group were between 15 and 19 years of age. It is interesting to note the ages of the intervention and control group siblings. Forty percent of the intervention group siblings were between the ages of 9 to 14, 57% were between 15 and 19 years and 29% were over 19 years of age. Although greater than half of the siblings in both groups were between 15 and 19 years of age, the lower age range and the upper age range were opposite, with no older siblings in the intervention group and few younger siblings in the control group. Ordinal position of the affected youth varied accordingly, with 57% of the control group being youngest siblings and 74% of the intervention group being either middle or eldest children in their families.

In summary, demographic comparisons between the control and intervention groups showed some diversity relative to ethnicity and religious affilation. The ages of siblings in the lower and upper age ranges were dissimilar, and the intervention group tended to have more persons in early adolescence.

Psychosocial Baseline Data

The data for the psychosocial parameters are contained in Table 10. Seventy-three percent of youth with Crohn's disease discussed emotional concerns with their gastroenterologist. This included 85% of the control and 67% of the intervention group. However 50% of the intervention group met with one of: a social worker, a psychologist and/or a psychiatrist whereas only 14% of the control group had received this intervention. Fifty percent of the intervention group and 28% of the control group, had participated in group work related to Crohn's disease in the past. These group sessions appeared to be either CFIC meetings or large annual information sessions or in a few cases unstructured support groups. Equal numbers of affected adolescents had discussed emotional concerns with a nurse or a general practitioner.

In summary, it appeared that there had been considerable effort, to meet the emotional needs of these young people, on the part of health professionals. It also appeared, that although both groups had received assistance, sources of support varied between groups; support from the gastroenterologist was more often utilized by the control group and support from psychosocial professionals more frequently chosen by the intervention group.

Table 10

Psychosocial Data - Adolescents

Dimension	Parameters	Total Sample		Intervention		Control	
		n	M	n	M	n	M
Prior Group Work	Yes	8	0.4210	6	0.5000	2	0.2857
	No	11	0.5789	6	0.5000	5	0.7142
Discuss Emotional Concerns with a Nurse or G.P.	Yes	9	0.4736	6	0.5000	3	0.4285
	No	10	0.5263	6	0.5000	4	0.5714
Discuss Emotional Concerns with Gastroenterologist	Yes	14	0.7368	8	0.6666	6	0.8571
	No	5	0.2631	4	0.3333	1	0.1428
Discuss Emotional Concerns with Psychologist +/or Psychiatrist +/or Social Worker	Yes	7	0.3684	6	0.5000	1	0.1428
	No	12	0.6315	6	0.5000	6	0.8571

Family Assessment Device

The results of the Family Assessment device, completed as baseline data for the total sample noted the need for psychosocial support for families with a youth with Crohn's disease. The mean scores and the healthy/unhealthy cut-off scores are indicated on the histograms that follow. Unhealthy scores for the FAD are the higher range of scores while healthy scores are indicated by the lower range of scores. Cut-off scores vary between 1.8 and 2.2 for individual scales of the FAD. Results as shown by histogram in Figures 11 to 16, indicate that 43% of the sample were in the unhealthy range for problem solving, 68% for communication, 56% for roles, 61% for affective responsiveness, 71% for affective involvement, 65% for behavior control and 47% for general family functioning.

Problem solving, the family's ability to resolve problems (issues which threaten the integrity and functional capacity of the family) to maintain effective family functioning was in the unhealthy range for 43% of the sample. Communication as measured by the FAD, focuses on whether or not the verbal messages are clear with regard to content, and direct, in that the person spoken to, is the person for whom the message is intended. In this sample 56% of family members were in the unhealthy range.

Roles or the pattern of behavior for handling a set of family functions, included items related to provision of resources, nurturance and support, opportunities for personal development and management of family systems. Equitable assignment of tasks and the extent to which tasks are carried out responsibly were measured. Fifty-six percent of the sample scored in the unhealthy range.

Affective responsiveness, the measure of appropriate affect over a range of responses, was in the unhealthy range for 61% of the sample. Affective involvement is considered healthy if in the intermediate range and is a measure of the value placed on each other's activities and concerns. Seventy-one percent of these families were in the unhealthy range on this parameter. This finding is similar to those of Steinhausen (1982), relative to youth with Crohn's disease; 60% had psychiatric disturbance related mainly to affective disorders. Both samples are small. Although, 19 to 36 % of nonclinical families might score in the unhealthy range on one or more parameters of the FAD, both the number of parameters and the percentage of family members scoring in the unhealthy range, were of concern for the well-being of these families.

Forty-seven percent of the sample scored in the unhealthy range for general family functioning. Less than half of the family members, were in the unhealthy range for general functioning and for problem solving. Yet a very high proportion of families were unhealthy on other parameters.

Comparison of the control and intervention groups on FAD parameters at baseline are listed on the Table 11. The list of abbreviations, available to the reader assists interpretation of results. Overall, the intervention group and the control group are very similar on FAC, FAAI, FAR, FAB, and FAE. Scores are either similar or identical and are within 0.1 points. The standard deviation scores indicate a greater degree of variability within the control group. The FAP and FAAR scores

Table 11

Family Assessment Device / Comparison of Groups *

Dimension		TG	TP	TA	TS	TIG	IP	IA	IS	TCG	CP	CA	CS
FAP	M	2.154	1.991	2.261	2.397	2.090	1.967	2.118	2.320	2.260	2.036	2.486	2.386
	SD	0.530	0.390	0.622	0.591	0.485	0.448	0.392	0.601	0.594	0.258	0.863	0.620
FAC	M	2.206	2.025	2.322	2.424	2.221	2.029	2.364	2.470	2.180	2.018	2.257	2.357
	SD	0.432	0.389	0.411	0.405	0.437	0.423	0.335	0.408	0.430	0.334	0.532	0.424
FAR	M	2.227	2.134	2.361	2.259	2.245	2.167	2.373	2.270	2.196	2.073	2.343	2.243
	SD	0.365	0.347	0.373	0.361	0.337	0.318	0.320	0.377	0.414	0.405	0.472	0.364
FAAR	M	2.203	2.041	2.328	2.376	2.283	2.124	2.509	2.370	2.068	1.882	2.043	2.386
	SD	0.555	0.447	0.588	0.642	0.520	0.443	0.478	0.643	0.594	0.431	0.665	0.691
FAAI	M	2.115	1.938	2.306	2.247	2.129	1.938	2.373	2.260	2.092	1.936	2.200	2.229
	SD	0.528	0.458	0.502	0.593	0.524	0.483	0.469	0.556	0.545	0.430	0.472	0.687
FAB	M	1.872	1.738	1.978	2.012	1.919	1.748	2.118	2.060	1.792	1.718	1.757	1.943
	SD	0.433	0.352	0.531	0.406	0.385	0.343	0.407	0.303	0.512	0.384	0.655	0.541
FAE	M	1.919	1.750	1.933	2.224	1.862	1.748	1.864	2.100	2.016	1.755	2.043	2.400
	SD	0.532	0.472	0.528	0.530	0.488	0.493	0.490	0.432	0.595	0.455	0.605	0.638

*See list of abbreviations

differ by only 0.2, with the control group scoring as less healthy relative to the intervention group. Table 11 lists comparative means and standard deviations for the siblings, affected youth and parents. The between group comparisons appear similar, however, the size of the control and intervention groups alerts one to the danger of generalizing current results as there are only 19 affected youth in the study.

Culture-Free SEI, Self-Esteem Inventory

The literature related to self-esteem of chronically ill children is contradictory. Self-esteem of chronically ill children has been shown to be higher, equivalent and lower than controls depending on the study (Adams et al., 1986; McAnarney, 1985). This study has not added any clarity to the self-esteem issue. The scales, general self-esteem, social self-esteem, personal self-esteem, total self-esteem and defensiveness had mean scores between 29 and 76 and standard deviations between 6.8 and 37.6. When scores were separately analysed for the intervention and control groups, by family role, the SD scores remained between 6.8 and 37.6. Several factors may account for the variability of with-in group scores. The fact that the raw scores were converted to percentile rank according to the CF-SEI manual (Battle,1981) and then entered as the data, can result in a polarized impression of the group. However, variability of self-esteem concerning persons with chronic illness, also existed in the literature. Thus, it was decided that there would be little gained in re-entering the raw scores data since there were no significant correlations between the FAD and the CF-SEI, nor between the CD-PSI and the CF-SEI.

A one item, self-esteem scale on the CD-PSI correlated significantly ($p<0.001$) with FAC (communication) on the FAD. At the left polarity of the scale was the statement, I always feel good about myself, and at the right polarity was the statement, I never feel good about myself. Clearly, this is a simplistic way of looking at self-esteem relative to the categories determined by Battle (1981). Although, the relationship of self-esteem and communication has face validity, little has been gained in determining levels of self-esteem in families with an adolescent member who has Crohn's disease.

The Crohn's Disease Psychosocial Inventory

Knowledge Component

The KPT was intended to test differing perspectives of family members related to perception of knowledge about Crohn's disease. Table 12 lists all of the subscales that form KPT and lists the scores of the total sample, the control group, and the intervention group. As well, the above groups are broken down by family role. The list of abbreviations is helpful to clarify the meaning of this information.

The control group, relative to all family members perceived themselves, as better informed than did the intervention group. This group, also seemed to view their gastroenterologists, as persons to discuss concerns with more than the intervention group, who listed psychosocial professionals as supportive. The lower perception of knowledge by the siblings is predictable relative to other family members and the very low KPH scores reflect the nature of the lack of contact that health care professionals have with siblings. What was rather surprising to the researcher, was that parents from both groups

Table 12

Knowledge (CD-PSI) - Comparison of Groups

Dimension *		TG	TP	TA	TS	TIG	IP	IA	IS	TCG	CP	CA	CS
KPT	M	5.650	6.008	6.441	4.160	5.144	5.602	6.073	3.216	6.560	6.818	7.071	5.643
	SD	2.066	1.859	1.778	2.044	2.098	1.735	1.906	1.859	1.692	1.910	1.445	1.370
KPU	M	4.657	4.606	5.684	3.500	3.778	3.727	5.083	2.455	6.240	6.636	6.714	5.143
	SD	2.598	2.604	2.262	2.572	2.504	2.394	2.234	2.464	1.964	1.859	2.059	1.864
KPI	M	4.857	5.182	5.474	3.611	3.933	4.318	4.750	2.273	6.520	6.909	6.714	5.714
	SD	2.931	2,920	2.894	2.768	2.799	2.679	2.989	2.328	2.417	2.700	2.430	2.059
KPD	M	5.300	5.030	6.789	4.222	5.133	4.909	6.633	3.727	5.600	5.273	6.714	5.000
	SD	3.205	3.368	2.800	2.861	3.259	3.477	2.517	2.936	3.149	3.289	3.450	2.769
KPH	M	6.014	7.485	6.526	2.778	6.089	7.182	7.417	2.455	5.880	8.091	5.000	3.286
	SD	3.356	2.785	2.776	2.713	3.528	2.970	2.466	3.205	3.087	2.386	2.769	1.799
KPX	M	5.934	6.455	6.263	4.667	5.667	6.364	5.833	4.091	6.440	6.636	7.000	5.571
	SD	2.936	2.948	2.766	2.970	3.090	2.904	2.623	3.590	2.709	3.171	3.055	1.397
KPM	M	6.433	6.909	7.211	4.778	5.667	6.227	6.583	3.545	7.840	8.273	8.286	5.714
	SD	2.652	2.376	2.123	3.021	2.736	2.369	2.275	3.078	1.748	1.794	1.380	1.704
KPG	M	5.571	5.636	6.579	4.389	4.978	5.545	3.750	3.000	6.640	5.818	8.000	6.571
	SD	3.174	3.324	2.912	2.913	3.056	2.972	3.019	2.608	3.161	4.094	2.236	1.902

* *See list of abbreviations*

scored lower on a number of scales than did the affected youth. Parents in the control group perceived that they were better informed by health professionals relative to the intervention group, while intervention group affected adolescents, perceived that they were better informed than the comparative control group.

Use of the KQCD (see Appendix 8), a factual knowledge quiz, was an attempt to determine if KPT, (perception of knowledge), corresponded with a written measure of knowledge. The mean and standard deviation KQCD scores are listed in Table 13. The intervention group scored lower on this knowledge parameter than the control group, indicating some accuracy of perception of knowlege, because they also had lower KPT scores. Mothers and fathers were also compared, with fathers scoring about eight percent lower than mothers on the KQCD.

Table 14 compares KQCD and KPT. Total KQCD and KPT are correlated at $r=0.559$ and with a significance of $p<0.001$. KQCD and all individual KPT scores are correlated for the total sample and the table also lists futher breakdown of groups and correlations significant to the $p<0.05$ level.

As was anticipated by the researcher, KPT did not correlate significantly with FPTT, SPT, FAD, nor the CF-SEI. As KPT correlated well with KNCD, it seems this is an independent measure of perception of knowledge. Furthermore, this supports the clinical judgement that patients and their families, frequently are correct in their estimation of knowledge.

Table 13

KQCD - Comparison of Groups

Dimension		TIG	TCG	TA	IA	CA	TP	IP	CP	
KQCD	M	4.683	6.776	5.161	4.000	6.986	6.255	5.795	7.058	
	SD	2.445	2.687	2.763	2.478	2.245	2.648	2.040	3.423	
KQCD	M	TPM	IPM	CPM	TPF	IPF	CPF	TS	IS	CS
	SD	5.838	5.360	6.663	6.647	6.191	7.483	4.175	3.100	5.967
		2.310	0.862	3.668	2.946	2.701	3.449	2.367	2.218	1.335

Table 14

Knowledge Component (CD-PSI) and Knowledge Correlation Table

Dimension CD-PSI		KQCD TG	KQCD TIG	KQCD TCG	KQCD TA	KQCD TS	KQCD TP	KQCD XP	KQCD CP	KQCD TPM
KPT	p	<0.001 *	0.002 **	0.001 *	0.238	0.027 **	<0.001 *	0.003 **	0.010 **	0.010 **
	r	0.559	0.460	0.612	0.293	0.549	0.674	0.620	0.732	0.624
KPI	p	<0.001 *	0.051 ***	0.049 **	0.052 ***	0.026 **	0.036 ***	0.174	0.239	0.473
	r	0.437	0.304	0.406	0.464	0.547	0.372	0.309	0.388	0.193
KPU	p	<0.001 *	0.003 **	0.001 *	0.062	0.026 ***	0.001 *	0.012 **	0.001 *	0.001 *
	r	0.592	0.443	0.682	0.448	0.552	0.662	0.535	0.834	0.746
KPD	p	0.016 ***	0.213	0.021 **	0.600	0.773	0.005 **	0.068	0.036 ***	0.057
	r	0.294	0.196	0.470	0.133	0.078	0.483	0.406	0.634	0.485
KPH	p	0.010 **	0.003 **	0.440	0.728	0.257	0.086	0.019 ***	0.958	0.597
	r	0.314	0.451	0.165	0.088	0.301	0.309	0.506	0.018	0.0143
KPY	p	<0.001*	0.011 **	0.028 ***	0.650	0.046 ***	0.001 *	0.008 **	0.042 ***	0.002 **
	r	0.449	0.388	0.488	0.155	0.506	0.557	0.564	0.620	0.716
KPX	p	0.002 **	0.040 ***	0.021 ***	0.763	0.775	0.001 *	0.032 ***	0.015 **	0.017 ***
	r	0.371	0.318	0.468	0.077	0.078	0.564	0.459	0.708	0.588
KPM	p	0.006 **	0.068	0.569	0.279	0.036 ***	0.390	0.802	0.694	0.976
	r	0.322	0.284	0.122	0.270	0.527	0.157	0.058	0.134	0.008
KPG	p	0.002 **	0.208	0.016 ***	0.363	0.082	0.033 ***	0.362	0.094	0.063
	r	0.367	0.198	0.484	0.228	0.447	0.378	0.209	0.530	0.475

p<0.001 *
p<0.01 **
p<0.05 ***

Family Coping Style

The FCS was intended to measure the impact of CD on the family and the effectiveness of the family in adapting to the stress of having a chronically ill family member. The scores on the FCS scales are presented in a similar manner to the KPT scores. The scores are in the mid to higher range of the scale, especially related to parental perception of family coping style, perhaps indicating the impact of social desirability. The affected adolescent and sibling scores are lower than the parent scores. Sibling scores were lower for the total FCS score, the FPTT, as well as for FPSB (sibling behavior), FPC (communication), and FGPI (understanding of others' feelings in the family). FPP (problem solving) was rated higher by siblings than by affected adolescents. The intervention group siblings and the control group siblings scored in opposite directions on FPT (ability to talk openly about Crohn's disease), FPU (the extent that the affected youths' illness alters holidays), FPF (extent of adolescent's CD on the family), FPU (extent to which the future is discussed), and FPSB (sibling's behavior). This may reflect the differences of age of siblings, between the control and intervention groups, as well as ordinal position of the siblings in the two groups. However, any interpretation of results with this number of parameters and a small sample size should procede with caution and with limited generalizability.

The table of correlations of the FAD scales with the CD-PSI scales follows. FAE, (the general scale of the FAD) and FPTT, the total score of the FCS were significantly related, (r=-0.449) at the p<0.001 level of significance (the scales are scored in opposite directions which

Table 15

Family Coping Style (CD-PSI) Comparison of Groups

Dimension *		TG	TP	TA	TS	TIG	IP	IA	IS	TCG	CP	CA	CS
FPTT	M	6.975	7.532	6.530	6.417	6.972	7.261	7.078	6.280	6.154	8.029	8.143	6.633
	SD	1.645	1.318	1.955	1.572	1.438	1.343	1.336	1.622	2.444	1.164	1.574	1.590
FPT	M	8.042	8.147	7.947	7.944	7.800	7.682	7.833	8.000	8.462	9.000	8.143	7.857
	SD	2.277	2.595	1.870	2.127	2.590	3.077	2.082	2.191	1.555	0.953	1.574	2.193
FPSB	M	7.103	7.656	6.722	6.500	7.070	7.524	6.727	6.545	7.160	7.909	6.714	6.429
	SD	2.948	2.925	3.102	2.813	2.764	2.657	2.832	3.012	3,300	3.506	3.729	2.699
FPH	M	7.141	7.500	6.474	7.167	6.733	6.864	6.667	6.545	7.846	8.667	6.143	8.143
	SD	2.820	3.018	2.220	3.015	3.070	3.427	2.270	3.328	2.203	1.614	2.268	2.340
FPP	M	7.071	7.559	6.526	6.706	7.156	7.273	7.000	7.091	6.920	8.083	5.714	6.000
	SD	2.475	2.286	2.653	2.592	2.316	2.529	1.859	2.508	2.783	1.730	3.684	2.828
FPF	M	6.099	6.265	6.158	5.722	6.067	6.273	6.333	5.364	6.154	6.250	5.857	6.286
	SD	2.619	2.609	2.713	2.653	2.742	2.622	2.741	3.107	2.444	2.701	2.854	1.799
FPU	M	6.662	7.559	6.316	5.333	6.556	7.455	6.500	4.818	6.846	7.750	6.000	6.143
	SD	2.449	2.092	2.518	2.425	2.510	2.154	2.316	2.639	2.378	2.650	3.000	1.952
FPC	M	6.710	6.794	7.211	5.938	6.860	6.545	7.667	6.556	6.462	7.250	6.429	5.143
	SD	2.739	2.879	2.679	2.489	2.522	2.807	2.270	2.068	3.101	3.079	3.309	2.911
FPAB	M	7.870	8.906	7.421	6.500	7.844	8.773	7.917	5.909	7.917	9.200	6.571	7.429
	SD	2.388	1.174	2.411	3.148	2.296	1.343	1.730	3.177	2.603	0.632	3.259	3.101
FGPI	M	7.014	7.303	7.105	6.389	6.864	6.905	7.083	6.545	7.269	8.000	7.143	6.143
	SD	2.039	1.759	2.079	2.429	2.120	1.868	2.151	2.659	1.909	1.348	2.116	2.193

* See list of abbreviations

Table 16

FCS (CD-PSI) and FAD Correlations (pre-testing)

Dimension		FAP	FAC	FAR	FAAR	FAAI	FAB	FAE
FPTT	p	0.003**	0.007 **	0.017 ***	0.015 **	0.058	0.014 *	<0.001 *
	r	-0.360	-0.328	-0.292	-0.297	-0.235	-0.301	-0.449
FPT	p	0.365	0.174	0.084	0.203	0.021 ***	0.125	0.354
	r	-0.114	-0.171	-0.216	-0.160	-0.286	-0.192	-0.117
FPSB	p	0.063	0.289	0.204	0.013	0.007 **	0.001 *	0.009**
	r	-0.238	-0.137	-0.016	-0.315	-0.342	-0.414	-0.329
FPH	p	0.375	0.513	0.965	0.827	0.899	0.579	0.614
	r	-0.112	-0.083	-0.006	0.028	-0.016	-0.070	0.064
FPF	p	0.535	0.174	0.174	0.582	0.807	0.574	0.126
	r	-0.078	-0.171	-0.017	-0.069	-0.031	-0.071	-0.192
FPU	p	0.001 *	0.001 *	0.001 *	0.001 *	0.018 ***	0.001 *	<0.001 *
	r	-0.409	-0.408	-0.393	-0.446	-0.294	-0.392	-0.487
FPC	p	-	<0.001 *	0.002 **	0.007 **	0.007 **	0.045 ***	<0.001 *
	r	-	-0.474	-0.386	-0.339	-0.335	-0.254	-0.610
FPAB	p	0.027 ***	0.081	0.066	0.660	0.060	0.001 *	0.135
	r	-0.279	-0.222	-0.233	-0.057	-0.238	-0.410	-0.191
FGPI	p	0.004 **	0.034 **	0.002 **	0.001*	0.008 **	0.001 *	<0.001 *
	r	-2.996	-0.265	-0.381	-0.417	-0.329	-0.423	-0.487
FPP	p	0.001 *	<0.001 *	<0.001 *	0.001*	0.001 *	<0.001 *	<0.001*
	r	-0.666	-0.474	-0.441	-0.575	-0.503	-0.514	-0.688

$p \leq 0.001$ *
$p \leq 0.01$ **
$p \leq 0.05$ ***

Table 17

Comparison of Parents and the Total Sample - FPTT and FAD

Dimension		FAP	FAC	FAR	FAAR	FAAI	FAB	FAE
FPTT (Parents)	p	<0.001 *	0.032 ***	0.001*	<0.001 ***	<0.001 *	0.028 **	<0.001 *
	r	-0.633	-0.380	-0.539	-0.636	-0.615	-0.389	-0.696
FPTT (Total Sample)	p	0.003 **	0.007 **	0.017 ***	0.015 **	0.058	0.014 **	<0.001 *
	r	-0.360	-0.328	-0.292	-0.297	-0.235	-0.301	-0.449

P<0.001 *
P<0.01 **
P<0.05 ***

accounts for the negative correlations). Sibling behavior was significantly correlated (r=-0.414) with FAB (behavior), at the 0.001 level of significance as is the affected adolescent's behavior (r=-0.413). Understanding others' feelings in the family (FGPI) and problem solving (FPP) are also significant at the 0.001 level. FPP, in fact is significant at the 0.001 level with all FAD measures. As FAP, consists of one visual analogue scale, this may reflect the emphasis of the FAD on problem solving with-in the construct of family functioning. FAR, roles with-in the family was significant at the 0.001 level with FPU-the extent to which the future is discussed (r=-0.393) and was significant at the 0.002 level with FPC-communication (r=-0.386) and FGPI-understanding of others' feeling in the family (r=-0.381). FPU and FPC were also correlated with FAC-communication. FAP-problem solving, was significant at the 0.001 level with FPP and FPU.

It is of interest, that as the group is specified related to family role, as shown on the Table 18 that correlations between FAD and FPTT increase. The level of significance of the correlation of FPTT with FAP, FAR, FAAR, FAAI, and FAE is p<0.001 whereas only FPTT and FAE are at this level of significance with the total sample. Also, the correlations increase; FAE for the total sample is correlated at -0.449 and for the parent group is correlated at -0.696.

Social Well-Being

Table 19 provides the means and standard deviations for all subjects, as well as, according to family role for the social well-being scale (SWB) of the CD-PSI. The control group families perceive themselves as healthier relative to the intervention group's perception

Table 18

Social Well-Being (CD-PSI) Comparison Between Groups

Dimension *		TG	TP	TA	TS	TIG	IP	IA	IS	TCG	CP	CA	CS
SPT	M	7.657	8.026	7.525	7.119	7.535	7.898	7.347	7.013	7.876	8.281	7.830	7.286
	SD	1.289	1.190	1.098	1.488	1.324	1.228	0.872	1.753	1.220	1.121	1.432	1.046
SPAE	M	7.514	7.424	7.368	7.833	7.467	7.318	7.250	8.000	7.600	7.637	7.591	7.571
	SD	2.524	2.705	2.409	2.407	2.581	2.679	2.221	2.989	2.466	2.873	2.878	1.512
SPAI	M	7.652	8.036	7.842	6.706	7.386	7.909	7.750	5.800	8.120	8.273	8.000	8.000
	SD	1.908	1.610	1.772	2.339	2.082	1.659	2.137	2.251	1.481	1.555	1.000	1.915
SPD	M	7.014	7.697	6.632	6.167	6.800	7.227	6.750	6.000	7.400	8.636	6.429	6.429
	SD	2.976	2.568	3.004	3.485	3.138	2.959	2.896	3.821	2.677	1.120	3.409	3.155
SPAB	M	7.971	8.879	7.579	6.722	7.800	8.818	7.500	6.091	8.280	9.600	7.714	7.714
	SD	2.610	1.556	2.795	3.375	2.744	1.622	2.970	3.506	2.372	1.483	2.690	3.147
SPSI	M	7.955	8.355	7.833	7.389	7.605	8.190	6.818	7.273	8.583	8.700	9.429	7.571
	SD	2.246	2.090	2.684	2.004	2.461	2.112	3.027	2.412	1.666	2.111	0.535	1.272
SPSB	M	7.938	8.300	8.000	7.278	7.976	8.476	7.400	7.545	7.864	7.889	9.000	6.857
	SD	2.225	2.168	1.966	2.492	1.906	1.834	2.011	1.864	2.783	2.892	1.549	3.388
SPC	M	7.729	7.788	7.474	7.889	7.511	7.591	7.000	7.909	8.120	8.182	8.286	7.857
	SD	1.978	2.147	1.712	1.997	2.107	2.302	1.537	2.300	1.691	1.834	1.799	1.574
SPSE	M	8.348	8.097	8.529	8.611	8.333	8.000	8.545	8.727	8.375	8.273	8.500	8.429
	SD	2.257	2.315	2.035	2.429	2.216	2.052	1.635	3.003	2.374	2.832	2.811	1.272
SPF	M	7.029	7.879	7.000	5.500	7.044	7.500	7.417	5.727	7.000	8.636	6.286	5.143
	SD	2.654	2.509	1.915	2.995	2.820	2.874	1.832	3.379	2.380	1.362	1.976	2.478

* See list of Abbreviations

of themselves by approximately 0.4 points overall and are slightly more positive in their perception of all SWB scales, except sibling behavior at school. However, the family scores are generally similar between groups. Parents in the control group scored slightly higher on all scales except for sibling behavior at school (SPSB), which was 0.6 points less than the intervention group. Control group siblings' perception of their school behavior was lower than their parents' perception by 1.0, while the affected adolescents rated their school behavior more positively (2.2 points higher than the siblings had perceived their behavior). The siblings in the intervention group were younger and rated their school behavior as similar to the affected adolescents. Parents, [illegible] the sibling's school behavior higher than the young people had perceived the school behavior of the sibling. Similar differences of perception of SWB between sibling groups are evident on the SPAE, SPAI, and SPF scales. The differences in opinion between the affected adolescents regarding SPSI, SPAE, and SPSB might also be explained by the different ages of siblings. Further study of age and ordinal position of siblings of chronically ill youth would be valuable, however, as the current information is not generalizable.

Although the control group siblings perceive their communication skills positively, they rate their understanding of other persons' feelings 1.2 points lower than the intervention group at baseline and as 2.0 points lower than they rated SPC. Overall, the groups seem similar with the exception of some of the sibling parameters.

Table 20 lists correlations between the FAD and SWB of the CD-PSI follows. A relationship between the social parameters of the CD-PSI and the FAD occured on a number of parameters. As the FAD is a measure of

Table 19

SWB (CD-PSI) and FAD Correlations (pre-testing)

Dimension		FAP	FAC	FAR	FAAR	FAAI	FAB	FAE
SPT	p	0.001 *	0.001 *	0.006 *	0.028	<0.001 *	0.003 **	<0.001 *
	r	-0.429	-0.401	-0.333	-0.059	-0.438	-0.357	-0.423
SPAE	p	0.080	0.137	0.066	-	0.010 **	0.328	0.043 **
	r	-0.217	-0.135	-0,213	-	-0.316	-0.122	-0.249
SPAI	p	0.296	0.270	0.900	0.060	0.410	0.316	0.050 ***
	r	-0.132	-0.139	-0.016	0.235	-0.104	-0.126	-0.245
SPD	p	0.206	0.084	0.595	0.867	0.276	0.189	0.421
	r	-0.158	-0.214	-0.067	0.021	-0.136	-0.164	-0.101
SPSI	p	0.017 ***	0.088	0.027 ***	0.017 ***	0.040 ***	0.005 **	0.042
	r	-0.301	-0.217	-0.279	-0.293	-0.260	-0.351	-0.183
SPC	p	0.028 ***	0.086	0.166	0.056	0.008 **	0.731	0.063
	r	-0.270	-0.213	-0.173	-0.237	-0.322	-0.043	-0.238
SPSE	p	0.061	0.046 ***	0.070	0.973	0.162	0.227	0.259
	r	-0.239	-0.255	-0.232	0.004	-0.180	-0.156	-0.141
SPAB	p	0.700	0.854	0.595	0.697	0.010 **	0.199	0.005 **
	r	-0.348	-0.023	0.067	0.049	-0.316	-0.160	-0.355
SPSB	p	0.024 ***	0.011 **	0.038 ***	<0.001 *	<0.001 *	0.016 ***	0.005 **
	r	-0.289	-0.323	-0.266	-0.447	-0.447	-0.306	-0.355
SPF	p	<0.001 *	0.002 **	0.007	0.007 **	0.035 ***	0.019 ***	0.002 **
	r	-0.441	-0.372	-0.328	-0.328	-0.250	-0.287	-0.369

p≤0.001 *
p≤0.01 **
p≤0.05 ***

family functioning, the relationship is not as strong as with the FCS of the CD-PSI. SPT correlated with FAP (r=-0.429), FAC (r=-0.401), FAAI (r=-0.438) and FAE (-0.423) at a significance level of p<0.001. FAAI correlated with sibling behavior (r=-0.447) at a significance level of p<0.001. This is of interest in terms of parent/sibling dynamics, as a large proportion of these families had unhealthy scores on affective parameters on the FAD and because the literature pointed to behavioral issues with siblings of chronically ill children (Chapters 2 and 3). Ability to discuss feelings, SPF and FAP are correlated (r=-0.441) at the p<0.001 level and SPF is also correlated to communication (r=-0.372) at the p=0.002 level. The relationship between SWB and FAP is understandably less than between FCS and FAD, however social skills and family related skills such as communication and problem solving overlap.

Additional Scales of the CD-PSI and their Relationship to FAD

Several additional scales of the CD-PSI were included in this study more out of curiosity than in the hope of determining any significant relationships. Steinhausen (1982) had determined that youth with CD had an internal locus of control, and this parameter correlates with the FAE scale (r=0.376, p=0.002) of the FAD. Mood, was significantly correlated with FAP (r=-0.505) and FAC (r=-0.437) at the p<0.001 level of significance and with FAE (r=-0.366) at the p=0.003 level with general functioning. SESTE (self-esteem) as measured by a sole VAS of the CD-PSI was also significantly correlated with FAC (r=-0.435) at the p<0.001 level. All of these parameters need futher study.

Table 20

Additional Scales of the CD-PSI and FAD Correlation

Dimension		FAP	FAC	FAR	FAAR	FAAI	FAB	FAE
SESTE	p	0.001 *	<0.001 *	0.143	0.287	0.030 ***	0.514	0.009 *
	r	-0.387	-0.435	-0.182	-0.133	-0.268	-0.082	-0.319
MOOD	p	<0.001 *	<0.001 *	0.036 ***	0.034 ***	0.013 **	0.078	0.003 *
	r	-0.505	-0.437	-0.258	-0.261	-0.303	-0.218	-0.366
HLOC	p	0.008 **	0.022 ***	0.012 **	0.331	0.175	0.528	0.002 *
	r	-0.328	-0.283	-0.308	-0.122	-0.170	-0.080	-0.376

p<0.001 *
p<0.01 **
<0.005 ***

Efficacy of the Intervention Program

Table 21 lists the within-group and between-group pretest and posttest differences for the control and intervention groups. The intervention group demonstrated significant with-in group improvement at the 0.001 level for KPT, KQCD, FAAR and FAAI. Prior to the research this researcher expected the knowledge score to improve following the intervention program. However, the improvement in an affective domain (FAAR) following the intervention was quite exciting. The FPTT scores also showed significance improvement. None of the control group psychosocial or knowledge parameters improved with the designated range of significance ($p<0.01$) for this number of measures.

Repeated measures ANOVA for between group comparison, demonstrated that the intervention group improved significantly ($p<0.001$) in relationship to the control group for KPT (knowledge parameter) of the CD-PSI and for KQCD (knowledge questionnaire). A probability level of 0.010 was obtained for FAAR (affective responsiveness scale) of the FAD. These findings indicate that the five session intervention program was effective in improving a psychosocial parameter and several knowledge components. If the research were repeated with a larger sample of subjects, with-in group statistics offer the possibility of demonstrating improvement on additional parameters of psychosocial functioning.

The program evaluation summary (Table 22), lists rankings on a Likert scale by participants of activities and presentations in the five session intervention program. The participants were positive about the factual information presented concerning CD and its treatment. They rated activities related to psychosocial parameters in the moderate

Table 21

Pre-test/Post-test Within Group and Between Group Differences

Dimension	Pre/post test Intervention Group		Test/two month Control Group		Between Group	
	F	P	F	P	F	P
FPTT	7.630	0.010 **	4.865	0.045 ***	0.496	0.485
SPT	7.492	0.036 ***	7.984	0.830	1.214	0.245
KPT	52.272	0.001 *	3.468	0.082	10.325	0.001 *
KQCD	54.386	0.001 *	0.027	0.871	24.213	0.001 *
FAP	3.238	0.082	0.345	0.566	0.387	0.537
FAC	5.553	0.025 ***	0.133	0.742	1.664	0.204
FAR	3.545	0.069	1.144	0.302	0.215	0.645
FAAR	13.509	0.001 *	0.200	0.661	6.862	0.012 **
FAAI	3.960	0.055	1.348	0.264	0.244	0.624
FAB	3.227	0.082	0.626	0.441	2.865	0.097
FAE	1.479	0.233	0.385	0.544	0.069	0.795

$p<0.001$ *
$p<0.01$ **
$p<0.05$ ***

range, with the exception of siblings who rated those activities more positively. The affected adolescents also rated the cartoons (Figures 1-10) at a higher level. The purpose of the activities had been to concretize issues and to facilitate expression of issues and feelings. Immediacy was encouraged and intellectualization was discouraged in terms of the active, participatory nature of the activities. One young person, when asked to shape a fear with plasticene, shaped a coffin and described his fear of not surviving into adulthood. In reshaping his fear into hope, he made a sailboat and described how he, like the sailboat, must go with the wind, as the nature of his illness was similarly unpredictable. When activities such as making family collages and drawing personal shields were in progress, considerable discussion took place regarding the day to day impact of the disease. Some parents challenged others about the extent that they focused on the disease and many themes emerged related to the youth's future. However, supportive comments were also shared by the group, although it appeared that a number of sensitive issues were raised. One parent noted on the evaluation form, that she would have prefered a more "intellectual" approach. The activities appeared to facilitate going beneath "surface issues" and to enhance non-verbal and affective aspects of communication.

The cartoons provided a medium for reframing numerous issues related to the disease, treatments, hospitalization and the day to day impact of Crohn's disease. The affected adolescents seemed enthusiastic about this activity, requested copies of the cartoons and rated the activity most favorably of the family members. It is interesting to note that the adolescents ranked planning for the future the highest, at 4.4 out

Table 22

Program Evaluation

Opinion of Usefulness / 5 Point Likert Scale	Total	Parents	Siblings	Youth /CD
Information about CD	4.2	4.3	4.0	4.2
Information about Dx. and Rx. of CD	4.3	4.5	4.0	4.0
Information about nutrition	3.2	3.0	3.3	3.3
Getting acquainted activity	2.8	2.9	2.7	2.5
Drawing /discussing personal shield	2.7	2.6	3.5	2.7
Nutritional management of CD symptoms	3.1	3.0	-	3.2
Family collage and discussion	2.9	2.8	4.0	2.9
Current research re. CD	-	4.8	-	-
What siblings go through discussion	-	3.2	3.0	-
Tour of hospital	-	-	4.3	-
Concerns re. sibling with CD	-	-	4.7	-
Concerns re. having CD (plasticene)	-	-	-	3.3
CD and school / peers	-	-	-	3.2
Cartoons / booklet re. CD	3.4	3.1	4.0	3.5
CFIC Speakers	3.9	3.8	3.5	4.1
Planning for the future	-	3.1	-	4.4
Planning free time / leisure	-	-	-	3.3
Adult / Sibling Discussion	-	-	4.0	-
Adult speaker with CD	-	3.9	-	3.5
Coping strategies / youth with CD	-	3.3	-	-
Average Scores	3.4	3.5	3.8	3.4

of 5 on the scale. Parents were less positive about this activity which was conducted independently for adolescents and parents. One couple could not imagine a single occupation for their son, or even their son leaving home, despite the fact that he was moderately well and 18 years of age. Most of the parents descibed concerns related to medical management when their son or daughter leaves home. The group facilitator with Crohn's disease assisted with problem solving related to these issues.

Siblings seemed pleased to have the opportunity to discuss psychosocial issues and particularly their concern for their brother or sister with CD. From discussions and as illustrated in figure 4, Siblings are often asked about their brother's or sister's health, yet feel the least qualified of the family members to answer this question. Parental discussion about siblings was interesting, in that parents within the same family often differed in their view of the impact of the adolescent's CD on the sibling.

The evaluation will be useful for the multidisciplinary team at Hotel Dieu to reassess and revise aspects of the program. It appears that another form of introductory activity is required and that the personal shield activity will need revision. Although parents seem to favor concrete activities less than other family members, the value of such activities may relate to an improvement in the affective parameters.

Instrument Validation

Table 23 lists the correlations between FAD and all measures of the CD-PSI. There were no correlations computed between the CF-SEI,

Table 23

CD-PSI and FAD Correlations <0.001 (pre-testing)

Dimension		FAP	FAC	FAR	FAAR	FAAI	FAB	FAE
SPT	p	<0.001	0.001			<0.001		<0.001
	r	-0.429	-0.401			-0.438		-0.423
SPSB	p					<0.001		
	r					-0.447		
SPF	p	<0.001						
	r	-0.441						
FPTT	p							<0.001
	r							-0.449
FPSB	p						0.001	
	r						-0.414	
FPU	p	0.001	0.001	0.001	<0.001		0.001	0.001
	r	-0.409	-0.408	-0.393	-0.466		-0.392	-0.487
FPC	p		<0.001					<0.001
	r		-0.474					-0.610
FPAB	p						0.001	
	r						-0.401	
FGPI	p				0.001		0.001	<0.001
	r				-0.417		-0.423	-0.487
FPP	p	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001	<0.001
	r	-0.666	-0.474	-0.441	-0.575	-0.503	-0.514	-0.688
SESTE	p		<0.001					
	r		-0.435					
Mood	p	<0.001	<0.001					
	r	-0.505	-0.437					

Self-Esteem Inventory and CD-PSI nor between CF-SEI and FAD. Therefore it was assumed that different constructs were being measured. FAD and FCS, Family coping Style were correlated to a greater extent than SWB, social well-being and FAD.

Reliability statistics for the FCS and SWB are detailed in Table 24. The reliabilities were in the moderate range with FPP having the highest reliability of 0.727 and SPAB having the lowest at 0.441. However, these are respectable reliabilities for single item scales on a sample of this size. The instrument is also moderately consistent as demonstrated by internal consistency data.

Principal component factor analysis data for FAD and the FCS scales of the CD-PSI are included in Table 25. Seven factors accounted for 92% of the varience. The first factor accounted for 21.6 % of the varience. All of the FAD measures and FPP, problem solving composed the first factor with factor loadings greater than 0.6.

The second factor, accounted for 9.1 % of the varience and related to sibling behavior (FBSB), communication and sibling comfort level with peers. The third factor accounted for 11.3 % of the varience and was related to impact of CD on family and peer issues. Included were, FPH, FPP, FPTT, SPT, SPAE, and SPSE. Behavioral, affective, and independence issues composed the fourth factor that accounted for 11.5% of the varience. Scales included were FAAI, FPSB, FPAB, FGPI, FPTT, SPSI, and SPSB.

The fifth factor dealt with communication related to illness and included FPT and SPD. This factor accounted for 6.9% of the

Table 24

CD-PSI Reliability

```
                          ITEM RELIABILITY STATISTICS

                                              ITEM-                         EXCLUDING
                                   STANDARD   TOTAL   RELIABILITY          THIS ITEM
ITEM      LABEL           MEAN     DEVIATION    R        INDEX             R     ALPHA
   1        FPT          8.125       2.193    .529       1.159          .378     .707
   2       FPSB          7.238       2.666    .566       1.510          .386     .706
   3        FPH          7.488       2.520    .510       1.284          .330     .716
   4        FPP          6.888       2.480    .727       1.804          .605     .663
   5        FPF          6.225       2.583    .481       1.243          .291     .724
   6        FPU          6.613       2.437    .588       1.432          .430     .697
   7        FPC          6.875       2.652    .515       1.366          .325     .718
   8       FPAB          8.063       1.996    .560       1.117          .429     .700
   9       FGPI          7.188       1.824    .620       1.131          .513     .690
>es spae spai spd spab spsi spsb spc spse spf
                                              ITEM-                         EXCLUDING
                                   STANDARD   TOTAL   RELIABILITY          THIS ITEM
ITEM      LABEL           MEAN     DEVIATION    R        INDEX             R     ALPHA
   1       SPAE          7.699       2.423    .716       1.735          .586     .666
   2       SPAI          7.819       1.883    .466        .878          .323     .715
   3        SPD          7.313       2.912    .610       1.776          .410     .704
   4       SPAB          8.048       2.369    .441       1.045          .253     .729
   5       SPSI          7.964       2.079    .548       1.139          .401     .703
   6       SPSB          7.928       2.183    .559       1.221          .406     .702
   7        SPC          7.663       2.002    .495        .990          .346     .712
   8       SPSE          8.434       1.971    .581       1.145          .449     .696
   9        SPF          7.108       2.464    .623       1.536          .463     .691
```

Table 25

Factor Analysis

ROTATED LOADINGS

	1	2	3	4	5	6	7
FAP	-0.845	-0.048	-0.171	-0.109	-0.059	-0.015	-0.206
FAC	-0.818	-0.049	-0.186	0.061	-0.165	0.019	-0.185
FAR	-0.748	-0.197	0.013	-0.140	-0.090	-0.173	-0.034
FAAR	-0.808	-0.073	-0.098	-0.205	-0.050	0.110	-0.073
FAAI	-0.781	-0.334	0.020	-0.203	-0.079	-0.118	0.066
FAB	-0.628	0.060	0.081	-0.456	-0.044	0.186	0.059
FAE	-0.762	-0.109	-0.217	-0.115	0.035	0.063	-0.403
FPT	0.100	0.299	-0.086	0.287	0.707	-0.001	0.223
FPSB	0.074	0.516	-0.045	0.560	-0.013	-0.323	0.175
FPH	-0.116	-0.030	0.680	0.303	0.015	-0.041	-0.010
FPP	0.649	0.165	0.382	0.326	-0.082	-0.195	0.088
FPF	0.119	0.085	0.768	-0.124	0.027	0.011	0.212
FPU	0.453	-0.196	0.119	0.408	0.091	0.109	0.400
FPC	0.365	0.137	0.074	-0.008	0.138	0.065	0.786
FPAB	0.333	-0.009	0.157	0.664	0.186	0.332	-0.084
FGPI	0.426	0.079	0.283	0.552	-0.053	-0.110	0.184
FPTT	0.458	0.207	0.463	0.536	0.188	-0.041	0.411
SPAE	0.127	0.480	0.630	0.118	0.087	0.039	-0.050
SPAI	0.154	-0.158	0.519	0.194	0.412	0.173	-0.073
SPD	0.058	0.066	0.179	0.009	0.890	-0.102	0.030
SPAB	-0.081	0.167	0.037	0.042	-0.073	0.892	0.061
SPSI	0.150	0.130	0.102	0.648	0.128	0.090	-0.091
SPSB	0.097	0.378	0.002	0.564	0.133	-0.092	0.390
SPC	0.185	0.677	0.218	0.174	0.095	0.127	-0.103
SPSE	0.142	0.771	-0.010	-0.000	0.093	0.093	0.197
SPF	0.367	0.061	0.604	0.001	0.026	0.024	0.001
SPT	0.254	0.524	0.501	0.353	0.422	0.230	0.072

VARIANCE EXPLAINED BY ROTATED COMPONENTS

1	2	3	4	5	6	7
5.821	2.451	3.046	3.095	1.865	1.311	1.601

PERCENT OF TOTAL VARIANCE EXPLAINED

1	2	3	4	5	6	7
21.560	9.077	11.281	11.463	6.907	4.856	5.930

varience. The sixth factor was comprised of only one item, affected adolescent's behavior as it relates to school. The reliability for this scale is low and further clarification is needed. The factor loading was very high for a single scale, at 0.892 and accounted for 4.9% of the total varience. The seventh factor related to comforting sought from the family (FAC). FAC was not related to FAAI or FAAR in the factor analysis.

It appears that further analysis of the instrument (CD-PSI) should not utilize total family and social parameters and should focus on factors that appear to be pertinent chronicity factors related to psychosocial well-being. Restructuring the instrument for use with a broad range of chronic illnesses, would facilitate comparison of the relative impact and characteristics associated with a number of chronic illnesses.

Discussion

In summary, results indicated by the standardized instrument, the FAD, illustrated that this sample of families with a youth with CD were in need of intervention, particularly in the affective domain. There was evidence of improvement in knowledge, perception of knowledge and affective responsiveness within the intervention group as well as between the intervention group and control group. The program appears to have strengths related to knowledge and affective responsiveness, however could potentially be strengthened with revision of the program. Modification of the CD-PSI appears worthwhile as an instrument to measure the psychosocial impact of chronic illness.

CHAPTER SIX

IMPLICATIONS AND FUTURE DIRECTIONS

The Interplay of Psychological and Physiological Factors

Controversy regarding psychosomatism, the interplay of psychosocial components and physiological factors of disease, remains unanswered relative to Crohn's disease. A significant relationship between CDAI scores and psychosocial dimensions, was not found in relation to any of the psychological measures. An inverse relationship was found between growth failure and indices of psychological [illegible]-being. This may lend credence to the impact of marginality. However, this is opposite to the findings of Steinhausen (1982), who [illegible] that growth failure was detrimental to mental health. Clearly, a [illegible] sample size is required to study these factors, as well as the cumulative impact of multiple physical and psychological factors.

Questions for further research might include the following. What is the relative level of psychosocial support received by children with serious chronic illnesses, relative to those who are less symptomatic? What are the chronicity factors and symptoms of disease that impact most strongly upon youth in social settings? How does the peer group respond to seriously ill children versus less symptomatic children? What indices of physiological impact should be considered? For example, in this study, it is possible that other physical factors, such as delayed pubescence, might have been more pertinent to social functioning. Specific areas of the bowel affected, such as the lower small bowel, which relates to malabsorption and may require additional medical intervention, should be studied in terms of psychological impact. The relationship of the relative psychological impact of treatments, such as, enteral feeding and total parenteral feeding, should be assessed relative to growth failure. What are the social ramifications of advanced nutritional therapy, steroid therapy and surgical interventions for chronically ill youth? One might ask, whether some treatments are more iatrogenic psychologically and socially than the outcomes of the disease process.

Treatment regimes that afford a balance of physical and psychological well-being should be sought through utilizing multiple measures of wellness and by drawing upon the expertise of the multidisciplinary teams. Regardless of the etiology of chronic illnesses, psychological considerations must be weighed systematically in relationship to physical health and treatment regimes, to afford the best possible care to patients.

Psychosocial Characteristics of Families with a Youth with Crohn's Disease

Previous studies expressed concern about the psychological well being of patients with CD (Rustgi et al., 1985). The work of Steinhausren (1982) indicated that disproportionate psychopathology, particularly affective disorders were evident amongst a small sample of youth with CD. More than half of the family members in this study of 71 persons, scored in the unhealthy range for communication, roles, affective responsiveness, and affective involvement on the FAD. Although, the number of subjects in the later two studies was small, the nature of the concerns raised regarding the psychological characteristics of these families and youth are similar. Similar findings using dissimilar methodologies and in differing social settings, should not be ignored in determining future research directions. Perhaps, it can no longer be categorically stated that there isn't evidence that psychological factors contribute to CD. Larger samples of CD patients and their families, only available through multicenter research, are needed to answer questions about the psychological characteristics of CD patients and their families. Only then, can thoughtful statements be made about the psychosocial needs of this group.

Intervention Strategies

The five session intervention program improved the outcome of the intervention group relative to the control group (probability level between 0.001 and 0.01) regarding, perception of knowledge (CD-PSI), the factual knowledge quiz (KQCD), and the affective responsiveness parameter (FAAR) of the FAD. The with-in group pre and post testing demonstrated improvement of the intervention group (probability level 0.001 to 0.01) in family coping style (FCS / CD-PSI), factual knowledge (KQCD), and affective responsiveness (FAAR); also, improvement at the 0.05 probability level was shown for social well-being (SWB / CD-PSI), and communication (FAC). A larger sample size may provide data indicating that significant improvement is also possible, between control and intervention groups, in the later dimensions using a similar intervention program.

Also of interest to persons planning intervention programs would be the relative merit of surveying patients' psychoeducational needs, utilizing professional judgement of multidisciplinary teams, involving CD patients and their families in program planning, and relying on post-evaluation instruments or psychosocial outcome measures. Although an eclectic approach was utilized for this study, with some success, research to determine the efficacy of these program development strategies for youth with chronic illness and their families would be useful.

It is noteworthy that family members' perception of knowledge about CD correlated highly with the factual knowledge quiz. Futhermore, the intervention group improved on KQCD and also perceived that they had improved in that knowledge as measured by the CD-PSI. This may lend credence to what nurses have frequently indicated in terms of teaching families; that is, to trust the families' perception of their knowledge level. Are patients and families able to determine their needs related to social well-being and family coping style? Perhaps, the related literature describing the enmeshed family structure is accurrate in depicting resistence to change. It could be that defense mechanisms for example, intellectualization, impede self-awareness. Research designs that determine the relative merit of care-giver input, client advice and mixed sources of expertise would facilitate a clearer path to program planning. Utilization of ongoing follow-up and longitudinal studies of randomized groups of patients and families are essential to a clearer understanding of the efficecy of intervention programs. The disadvantage or advantage of specifying a client group by chronic illness versus including persons with a variety of illnesses in programs, poses yet another interesting research question.

Efficacy of the CD-PSI

Instrument development sesitive to psychological characteristics of chronically ill youth and their families is an imporatant aspect of patient care. Frequently, families who appear to develop chronically poor coping strategies in response to chronic illness of a family member are seen in hospital settings. Instruments to alert clinicians to families in need of early intervention and to highlight families who are declining in their ability to manage effectively are needed to prevent situations where psychosocial concerns outweigh physical concerns.

The FAD appears to be a sensitive instrument for determining family dynamics amongst families with a member with Crohn's disease. Whether this relates to enmeshment as postulated by Zimand and Wood (1986) or to other family characteristics, would require further study with a larger sample of subjects. Although the FAD is a very useful instrument and should be included in further study of CD families, it seems advantageous to continue with the development of the more rapidly administered and diverse CD-PSI.

The CD-PSI appears useful in measuring perception of knowledge, family coping style, and social well-being. The numerous significant correlations observed in this study between the KQCD and components of the knowledge parameter of the CD-PSI, without correlations with psychosocial components, suggest content validity of the knowledge parameter. The correlations between the the FCS and SWB dimensions of the CD-PSI with the FAD infer a degree of concurrent validity of psychosocial domains. However, considerable work is still required in rethinking subcomponents of the psychosocial scales of the CD-PSI and in establishing the most useful categories. These results provide encouragement regarding the efficacy of VAS for measuring knowledge and psychosocial components.

Conclusion

It was hypothesized that the five session intervention program would be perceived as beneficial to the intervention group relative to knowledge about CD, family coping style, and social well-being. It was also hypothesized that the intervention group would demonstrate improvement on a number of psychosocial parameters relative to the control group. A number of significant findings as previously described were achieved. However, it is clear that many more questions were raised than were answered. To clarify these concerns and to attempt to meet the psychosocial needs of youth with CD and their families, will require considerable investment in research. The Canadian Foundation for Ileitis and Colitis utilizes a picture of a knot and a statement, "the pain is real" on their posters. This encourages empathy for the physical suffering of GI patients. With what degree of enthusiasm, will the medical community address the probable psychic pain and psychosocial complexities of Crohn's disease?

REFERENCES

Adams, J.A., & Weaver, J., (1986). Self-esteem and perceived stress in young adolescents with chronic disease. *Journal of Adolescent Care*, *7*, 173-177.

Bachu, H.S., Kay, B., Healy, T.E., & Beatty, P. (1983). Grading of pain and anxiety. Comparison between a linear analogue and a curvilinear audiovisual analogue scale. *Anaesthesia*, *385*(9), 875-878.

Battle, J. (1981), *Culture-Free SEI, Self-Esteem Inventories for Children and Adults*. Seattle: Special Child Publications.

Binder, V., Hendriksen, C., & Kreiner, S., (1986). A more proper perspective on the prognosis in Crohn's disease? *Gastroenterology*, *90*(1), 247-248.

Booth, M. (1986). Peer support and self-esteem in adolescents with I.B.D., Unpublished Masters Thesis, Hamilton: McMaster University.

Breslau, N., (1983). The psychological study of chronically ill and disabled children. Are healthy siblings appropriate controls? *Journal of Abnormal Child Psychology*, *11*(3), 379-391.

Bruce, T., (1986). Emotional sequelae of chronic inflammatory bowel disease in children and adolescents. *Clinical Gastroenterology*, *15*(1), 89-104.

Burke, S.O., (1989) Maternal stress and repeated hospitalization of children who are physically disabled. *Childrens' Health Care* *18*(2), 82-89.

Buros, O.K. (1985) *The Ninth Mental Measurements Yearbook* (Volume II), USA: The Gryphon Press.

Campbell, D.T., & Fiske, D.W., (1959). Convergent and discriminant validation by the multitrait-multimethod matrix. *Psychological Bulletin* 81-105.

Cella, D.F., & Perry, S.W., (1986). Reliability and concurrent validity of three visual - analogue mood scales. *Psychological Reports*, *59*(2 pt 2), 827-833.

Cooley, W.W., & Sohnes, P.R., (1976). *Evaluation Research In Theory, Principles and Practice*. New York: Wiley and Sons.

Coupey, S.M., & Cohen, M.I., (1984). Special considerations for the health care of adolescents with chronic illnesses. *The Paediatric Clinics of North America*, *313*(1), 211-219.

Craft, M.J., & Craft, J.L., (1989). Perceived changes in siblings hospitalized children: A comparison of siblings and parent reports. *Childrens' Health Care*, *18*(1), 42-48.

Drotar, D., & Crawford, P., (1985). Psychological adaptation of siblings of chronically ill children: Research and practice implications. *Journal of Developmental and Behavioral Pediatrics*, *6*(6), 355-362.

Epstein, N.B., Baldwin, L.M., & Bishop, D.S. (1983) The McMaster Family Assessment Device. *Journal of Marital and Family Therapy* *9*(2), 171-180.

Ferlic, M., Goldman, A., & Kennedy, B.J. (1979) Group counselling in adult patients with advanced cancer. *Cancer*, *43*, 760-766.

Frey, J., 3d., (1984). A family systems approach to illness-maintaining behaviors in chronically ill adolescents. *Family Process*, *23*(2), 251-260.

Griffith, J.L., & Griffith M.E., (1987). Structural family therapy in chronic illness. Invervention can help produce a more adaptive family structure. *Psychosomatrics* *28*(4), 202-205.

Guyatt, G.H., Townsend, M., Berman L.B., & Keller, J.L., (1987). A comparison of Likert and visual analogue scales for measuring change in function. *Journal of Chronic Disease* *40*(12), 1129-1133.

Haase, J.E., (1987). Components of courage in chronically ill adolescents: A phenomenological study. *Advanced Nursing Science*, *9*(2), 64-80.

Hoare, P. (1986) Adults' attitudes to children with epilepsy: The use of visual analogue scale questionnaire. *Journal of Psychosomatic Research* *30*(4) 471-479.

Holaday, B., (1984). Challenges of rearing a chronically ill child. Caring and coping. *Nursing Clinics of North America*, *19*(2), 361-368.

Holroyd, J., (1988). A review of criterion validation research on the questionnaire on resources and stress for families with chronically ill or handicapped members. *Journal of Clinical Psychology*, *44*(3), 338-354.

Horner, M.M., Rawlins, P., & Giles, K. (1987). How parents of children with chronic conditions perceive their own needs. *Maternal Child Nursing* *12*(1), 40-43.

Hymovich, D.P., (1984). Development of the chronicity impact and coping instrument parent questionnaire. *Nursing Reviews*, *33*(4), 281-222.

Jessop, D.J., & Stein, R.E., (1985). Uncertainty and its relationship to the psychological and social correlates of chronic illness in children. Social Science Medicine, 20,(10), 993-999.

Johnson, M.R., White, J.K., & Martin, B. (1987). The effect of fantasy facilitation of anxiety in chronically ill and healthy children. Journal of Pediatric Psychology 12(2), 273-284.

Kaplan, R.M., & Saccuzzo, D.P. Psychological Testing: Principles, Applications, and Issues. Monterey, California: Brooks/Cole Publishing Co.

Leventhal, J.M., (1984). Psychosocial assessment of children with chronic physical disease. The Pediatric Clinics of North America, 31(1), 71-86.

Lenaerts, C., Roy, C.C. Vaillancourt, M., Weber, A.M., Morin, C.L., & Seidman, E. (1988). High Incidence of Upper G.I. Tract Involvement in Children with Crohn's Disease. Manuscript - Paediatric G.I. Unit, Hopital Ste-justine and Department of Paediatrics, Universite de Montreal.

Lewis, K., (1983). Grief in chronic illness and disability. Journal of Rehabilitation, 49(3), 8-11.

Lush, M., Janson-Bjerclie, S., Carrieri, & V.K., Lovejoy, N. (1988). Dyspnea in the ventilator-assisted patient. Heart and Lung, 17(5), 528-531.

Marrero, D.G., Myers, G.L., Golden, M.P., West, D., Kershnar, A., & Lau, N. (1980). Adjustment to misfortune: The use of a social support group for adolescent diabetics. Unpublished manuscript. University fo California, Department of Social Ecology.

Mayberry, F.F., Morris J.S., Calcraft, B, Rhodes, J. et al. (1985) Information assessment by patients of a booklet on Crohn's disease. Public Health, 99(4), 339-42.

McAnarney, E.R., (1985). Social maturation. A challenge for handicapped and chronically ill adolescents. Journal of Adolescent Health Care, 6(2), 90-101.

McKelvey, J., Waller, D.A., Stewart, S., Kennard, B.D., North, A.J., & Chipman, J.J., (1989) Family Support for diabetes: A pilot study for measuring disease - specific behaviors. Children's Health Care, 18(1), 37-41.

McMillan, J.H. & Schumaker, S. (1984). Research in Education: A Conceptual Introduction. Boston: Little, Brown and Company.

Messner, R.K, Gardener, S., & Lewis, S. (1985). Crohn's disease - more than a chronic illness. Occupational Health Nursing, 33(12), 604-609.

Miller, I.W., Bishop, D.S., Epstein, N.B., & Keitner, G.I. (1985). *The McMaster Family Assessment Device: Reliability and Validity*, Providence R.I., Brown University/Butler Hospital.

Minuchin, S., (1974). Families and Family therapy. Cambridge, Mass.: Harvard University Press.

Mitchell, J.J., (1985). *The Adolescent Predicament* Toronto: Holt, Rinehart and Winston of Canada, Ltd.

Morrison, D.P., (1983). The Crichton Visual Analogue Scale for the assessment of behaviour in the elderly. *Acta Psychiatrica Scandinavia*, *68*(6), 408-413.

Moulton, P.J., (1984). Chronic illness, grief and the family. *Journal of Community Health Nursing*, *1*(2), 20-22.

Neufeldt, J., (1987). Helping the I.B.D. patient cope with the unpredictable. *Nursing*, *17*(8), 47-49.

Nolan, T., Pless, B., Zvagulis, I., (1987). Controlled Trial of Social Work in Childhood Chronic Illness. *Lancet*, *2* 411-415.

Orr, D.P., Weller, S.C., Satterwhite, M.A., & Pless, I.B., (1984). Psychosocial implications of chronic illness in adolescence. *Journal of Pediatrics*, *104*(1), 152-157.

Padilla, G.V., et al. (1981). Distress reduction and the Effects of Preparatory Teaching Films and Patient Control. *Research in Nursing and Health*, *4* 375-387.

Pedhazur, E. (1982). *Multiple regression in behavioral research 2nd ed*. New York: Holt, Rinehart and Winston.

Pereira, B.A., (1984). Loss and grief in chronic illness. *Rehabilitation Nursing*, *9*(2), 20-22.

Perrin, E.C., Ramsey, B.K., & Sandler, H.M., (1987). Competent kids: children and adolescents with a chronic illness. *Child Health Development*, *13*(1), 13-32.

Perrin, E.C., & Gerrity, P.S., (1984). Development of children with a chronic illness. *The Paediatric Clinics of North America*, *31*(1), 33-36.

Pless, I.B., & Roghmann, K.J. (1971). chronic illness and its consequences: Observations based on three epidemiologic surveys. Journal of Paediatrics, *79*(3), 351-359.

Pless, I.B., (1984). Clinical assessment: Physical and Psychological Functioning. *The Pediatric Clincis of North America*, *31*(1), 33-36.

Polit, B., & Hunger, B., (1978). Nursing Research: Principles and Methods. New York: J.B Lippincott.

Powers, G.M., Gaudet, L.M., & Powers, S. (1986). Coping patterns of parents of chronically ill children. Psychological Reports, 59, 591-622.

Preece, M.A., (1986). The growth of children with chronic paediatric disease. Clinical Endocrinology, 15(3), 453-477.

Rae-Grant, Q., et al., (1985). Psychological problems in the medically ill child. Psychiatric Clinics of North America, 8, 553-563.

Rapoff, M.A., (1986). Helping parents to help their children comply with treatment regimens for chronic diseases. Issues in Comprehensive Pediatric Nursing, 9(3), 147-156.

Rees, J.E., Mayberry, J.F., Calcraft, B., (1983). What the patient wants to know about Crohn's disease. Journal of Clinical Gastroenterol, 5,(3), 221-222.

Robinson, C.A., (1984). When hospitalization becomes an everyday thing. Issues in Comprehensive Pediatric Nursing 7, 363-370.

Rodgers, B.M., Hillemeier, M.M., O'Neill, E., & Slonim, M.B. (1981) Depression in the chronically ill on handicapped school-aged children. Maternal Child Nursing, 6, 266-273.

Rolland, J.S., (1987) Chronic illness and the life cycle: a conceptual framework, Family Process, Inc., 26, 203-221.

Rose, M.H., (1984). The concepts of coping and vulnerability as applied to children whith chronic conditions. Issues in Contemporary Nursing, 7(6), 177-186.

Rosenthal, E., L., Wruble, L.D., Rosenthal, R.H., & Edwards, N.B., (1987). Complaint patterns of patients with irritable bowel syndrome, Crohn's disease and acute gastroenterological illness. Behaviour Research and Therapy, 25(2), 99-112

Rustgi, V.K., T.N., Wise, & Boyle, E., (1985). Psychiatric Manifestations of Inflammatory Bowel Disease. Critical Review and Future Strategies. Psychiatric Medicine, 2(4), 337-349.

Sabbeth, B., (1984). Understanding the impact of chronic childhood illness on families. Pediatric Clinics of North America, 31(1), 47-57.

Sabbeth, B.F., & Leventhal, J.M., (1984). Marital adjustment to chronic childhood illness: a critique of the literature. Paediatrica, 73(6), 762-768.

Sanderson,I.R., (1986). Chronic inflammatory bowel disease. Clinical Gastroenterology, 15(1), 71-87.

Sanderson, I.R., & Walker-Smith, J.A., (1985). Crohn's disease in childhood. *Symposium XIV - Crohn's disease: Special problems*. British Journal of Surgery, Suppl. 387-S96.

Scholmerich,J., Sedlak, P.K., Hoppe-Seyler, P., & Gerok, W. (1987). The information needs and fears of patients with inflammatory bowel disease. 36 questions and nine "fear factors". *Hepatogastroenterology*, 34(4), 182-185.

Scriven, M., (1967). The Methodology of Evaluation in *Perspectives of Curriculum Evaluation*. AERA Monograph Series on Curriculum Evaluation. No. 1 Chicago: Rand McNally.

Scriven, M., (1974). Evaluation Perspectives and Procedures in W.J. Poham (ED.). *Evaluation in Education: Current Applications*, Berkeley, C.A., McCutchan Publishing

Seligman, M., (1987). Adaptation of children to a chronically ill or mentally handicapped sibling. *Canadian Medical Association Journal*, 136, (12), 1249-1252.

Shields, C.[illegible], (1985). Grief in chronic illness; assessment and management. *Archives of Physical Medicine and Rehabilitation*, 49 (3), [illegible].

Siemon, M., (1984). Siblings of the chronically ill or disabled children. Meeting their needs. *Nursing Clinics of North America*, 19(2), 295-307.

Smart, H., Mayberry, J., Calcraft, B., Morris, J.S., & Rhodes, J., (1986). Effect of information booklet on patients' anxiety levels and consultation rates in Crohn's disease. *Public Health*, 100(3), 184-186.

Smith, K.E., Dickerson, P., Saylor, C.F., & Jones, C. (1989) Issues of managing diabetes in children and adolescents: a multifamily approach. *Children's Health Care*, 18(1), 49-58.

Sparacino, L.L., (1984). Psychosocial considerations for the adolescent and young adult with inflammatory bowel disease. *Nursing Clinics of North America*, 19(1), 41-49.

Spiegel, D., Bloom, J.R., & Yalom, J. (1981). Group Support for patients with metatastic cancer. *Archives of General Psychiatry*, 38, 527-533.

Sriwatanakul, K., Kelvie, W., Lasagna, L., Calimlim, J.F., Weiss, O.F., & Mehta, G. (1983). Studies with different types of visual analog scales for measurement of pain. *Clinical Pharmacology and Therapeutics*, 34(2), 234-239.

Steinhausen, H.C., (1982). Locus of control amoung psychosomatically and chronically ill children and adolescents. *Journal of Abnormal Child Psychology*, 10, 609-615.

Steinhausen, H.C., & Kies, H., (1982). Comparative studies of ulcerative colitis and Chrohn's disease in children and adolescents. Journal of Psychology, Psychiatry and Allied Disciplines, 23(1), 33-42.

Steinhausen, H.C., (1983). Life events in relation to psychopathology among severely and chronically ill children and adolescents. Child Psychiatry and Human Development, 13(4), 249-258.

Thomas, R.B., (1984). Nursing assessment of childhood chronic conditions. Issue in Comprehensive Pediatric Nursing, 7 (4-5), 165-176.

Tridon, P., Vidailhet, C., & Detre, A., (1983). Abandonment or refusal of therapy: rite of passage in the handicapped and chronically ill adolescent. Neuropsychiatrie de l'enfance et de l'adolescence, 31(8-9), 407-408.

Tritt, S.G., & Esses, L.M., (1988). Psychosocial adaptation of children with chronic medical illness. American Journal of Orthopsychiatry, 58(2), 211-220.

Vogelsang, J., (1988). The Visual Analog Scale: an accurate and sensitive method for self-reporting preoperative anxiety. Journal of Post Anaesthesia Nursing, 3(4), 235-239.

Walker, D.K., (1984). Care of chronically ill children in schools. The Paediatric Clinics of North America, 31(1), 221-234.

Weitzman, M., (1984). School and Peer Relations. The Paediatric Clinics of North America, 31(1), 59-69.

White, M. (1979) Structural and Strategic Approaches to Psychosomatic families. Family Process Inc., 303-314.

White, M., (1984). Fear busting and monster taming: An approach to fears of young children. Dulwich Centre, 29-34.

Wilson, V., (1984). The diagnostic work-up for the patient with inflammatory bowel disease. What the patient wants to know about Crohn's disease. Nursing Clinics of North America, 19(1), 51-59.

Williams, K., & Baeker, M., (1983). Use of small group with chronically ill children. Journal of School Health, 53(3), 205-207.

Wirshing, M., & Stierlin, H., (1985). Psychosocial characteristics of psychosomatic patients and their families. Family Systems Medicine, 3(1), 6-16.

Wood, B., Watkins, J.B., Boyle, J., Nogueira, J., Zimand, B.A., & Carroll, L, (1987). Psychological Functioning in children with Crohn's disease and ulcerative colitis: Implications for models of psychobiological interaction. American Academy of Child and Adolescent Psychiatry.

Zoltler, L.K., & Le Baron, S. (1986). Fanta adolescents with chronic illness. *Journal* *Behavioral Pediatrics*, *7*(3), 195-198.

Zimand, E., & Wood, B., (1986). Implications o of divorce in families of children with gastr *Family Systems Medicine*, *4*(4), 385-397.

Appendix 1

___ ___ ___ ___ Patient Study I.D. Number

___ ___ ___ ___ ___ ___ ___ ___ ___ Hospital I.D. Number

CROHN'S DISEASE ACTIVITY INDEX

WEEK TWO, THREE, FOUR OR FIVE (check one only)

☐ ☐ ☐ ☐

		Days 1 2 3 4 5 6 7	Sum	x	Factor	=	Subtotal
X_1	Number of liquid or very soft stools	___ ___ ___ ___ ___ ___ ___	___ ___ ___	x	2	=	______
X_2	Abdominal pain rating (0=none, 1=mild, 2=moderate, 3=severe)	___ ___ ___ ___ ___ ___ ___	___ ___	x	5	=	______
X_3	General well-being (0=gen. well, 1=slightly under par, 2=poor, 3=very poor, 4=terrible)	___ ___ ___ ___ ___ ___ ___	___ ___	x	7	=	______
X_4	Number of 6 listed categories patient has now (Check all that apply):		SUM ___	x	20	=	______

NO	YES	
☐$_1$	☐$_2$	1) Arthritis/arthralgia
☐$_1$	☐$_2$	2) Iritis/uveitis
☐$_1$	☐$_2$	3) Erythema nodosum/pyoderma gangrenosum/apthous stomatitis
☐$_1$	☐$_2$	4) Anal fissure, fistula, or abscess
☐$_1$	☐$_2$	5) Other fistula
☐$_1$	☐$_2$	6) Fever over 37.8° C during past week

			x	Factor	=	Subtotal
X_5	Taking Lomotil/opiates for diarrhea (0 = NO, 1 = YES)	___	x	30	=	______
X_6	Abdominal mass (0 = none, 2 = questionable, 5 = definite)	___	x	10	=	______
X_7	Hematocrit: ___ ___ ___ Males: (47-Hct) Females: (42-Hct)	Subtotal: ______	x	6	=	______
X_8	Body weight: ___ ___ ___ (Kg) Standard weight: ___ ___ ___ (Kg) Percent below standard weight (nomogram): — — %		x	1	=	______

Add (underweight) or subtract (overweight) by sign, to give Crohn's Disease Activity Index, CDAI ___ ___ ___

(X_1, X_2, X_3 measured with patient diary card during the week preceeding evaluation.)

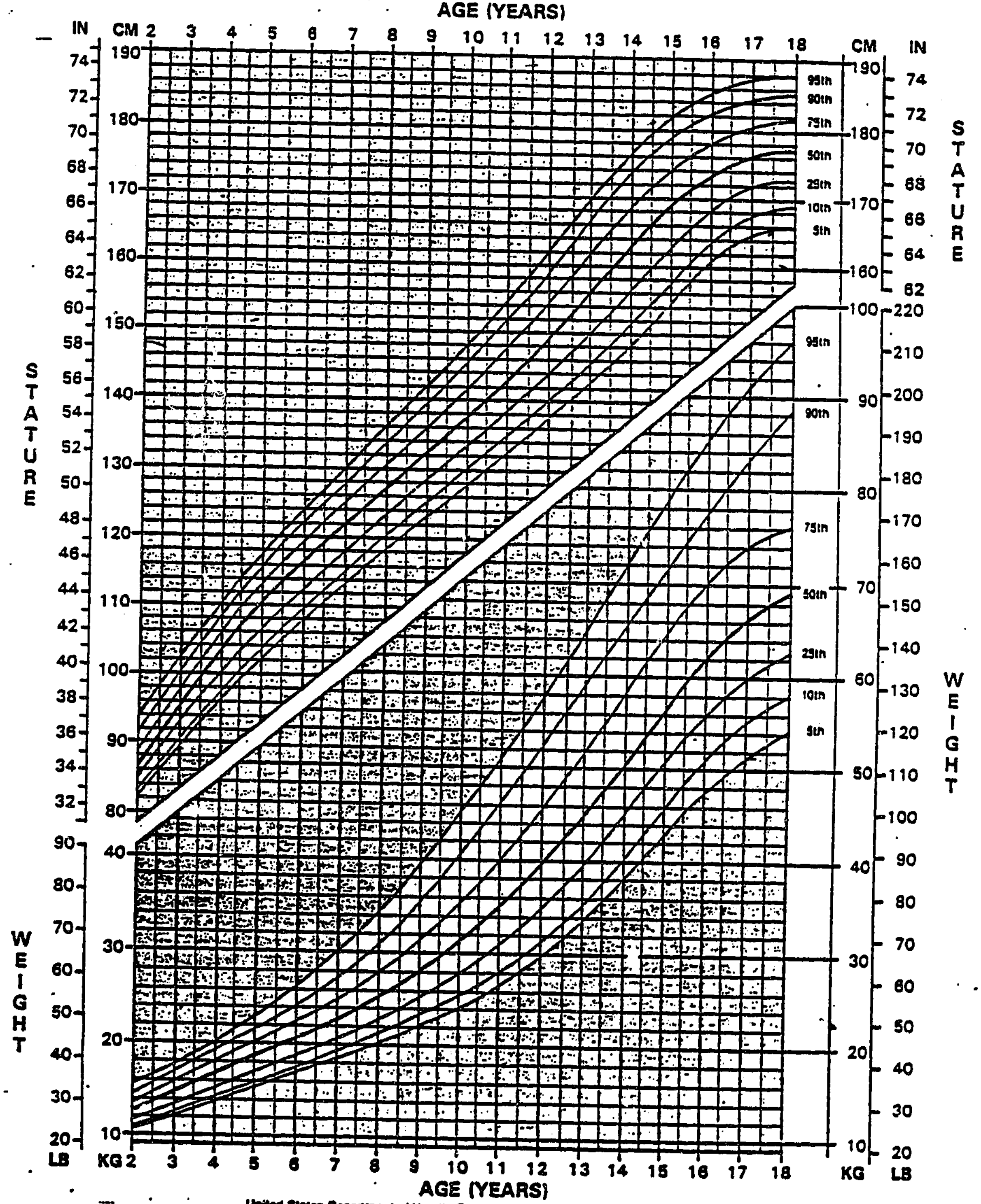
Next scheduled clinic visit ___ ___ ___
M D Y

BOYS: 2 TO 18 YEARS

STATURE FOR AGE &
WEIGHT FOR AGE

NAME______________________________

RECORD #______________________________

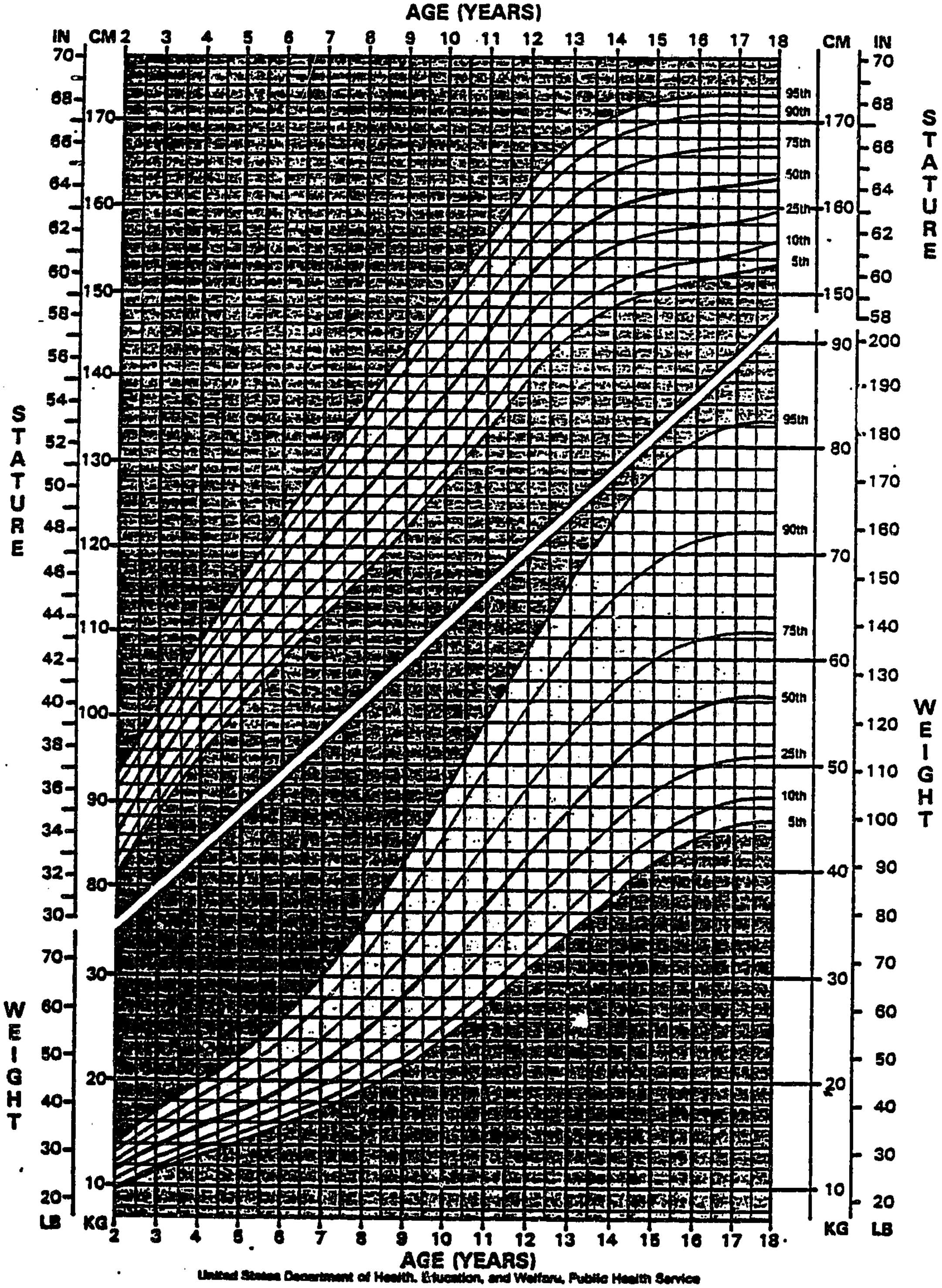


United States Department of Health, Education, and Welfare, Public Health Service

GIRLS: 2 TO 18 YEARS
STATURE FOR AGE & WEIGHT FOR AGE

NAME____________________________________

RECORD #____________________________________



United States Department of Health, Education, and Welfare, Public Health Service

Appendix 3

QUESTIONNAIRE - KNOWLEDGE ABOUT CROHN'S DISEASE

PLEASE COMPLETE THE FOLLOWING QUESTIONS

1. Age: _______________ years

2. Sex: F M (circle one)

3. When were you diagnosed as having Crohn's disease _______________ (year) (month, if within the last year)

4. What was the length of time between the start of your symptoms and the diagnosis of Crohn's disease. __________.

5. Number of hospitalizations due to Crohn's disease __________.

6. Approximate total length of stay of those hospitalizations __________.

7. How many months of the past year have you had symptoms of Crohn's disease ________.

8. Number and ages of brothers and sisters

____

____.

9. Are you:

an only child __________
the eldest child __________
the middle child __________
the youngest child __________

or please indicate eg.: I am the fourth of five children

____.

10. Are you presently on enteral feedings ______________
TPN (total parenteral nutrition) ______________
Low residue diet ______________
Regular diet ______________

11. Are you currently taking medication for Crohn's disease?

__________________________.

12. Please specify Name and Dosage of current Medications

Name: ______________________.

Dose: ______________________.

Name: ______________________.

Dose: ______________________.

13. Have you ever had surgery related to Crohn's disease?

__________________________.

14. What area(s) of your gastrointestional tract is involved?

upper gastrointestional tract	____
lower small bowel	____
colon	____
anal area	____
anal/perianal area	____

15. Have you discussed Crohn's disease with a group of persons who have Crohn's disease in the past?

Yes ____ No ____

16. Have you discussed Crohn's disease and its impact on your lifestyle with any of the following persons:

a nurse ________ a general practicioner ________

a gastroenterologist ____ a psychologist ________

a psychiatrist ________ a social worker ________

THIS IS A QUESTIONNAIRE TO FIND HOW MUCH KNOWLEDGE YOU FEEL YOU HAVE ABOUT THE FOLLOWING:

Place the appropriate number on indicated line:

1. too much knowledge
2. enough knowledge
3. little knowledge
4. too little knowledge

A. 1. What causes your disease ______

2. How your disease affects your life ______

3. How your disease changes over time ______

4. How many people in Canada have Crohn's disease ______

5. Who gets Crohn's disease ______

6. What are the symptoms of your disease (an example of a symptom is abdominal pain) ______

7. What these symptoms mean ______

8. What brings about these symptoms ______

9. What happens to you when you have these symptoms ______

10. How the disease will affect your future ______

11. What parts of your body can be involved in Crohn's disease ______

12. What is the chance of developing cancer during the course of your disease ______

13. How the length of your disease influences its course ______

14. What complications can occur ______

15. How you can influence the course of your disease ______

16. How the disease can affect your sexuality ______

17. How diet influences your disease ______

18. How sport activities are influenced by your disease ______

19. How travel is affected by your disease ______

20. What diagnostic methods are available (diagnostic methods mean the way doctors find out about a disease) ______

21. What is the value of these diagnostic methods ______

22. What are the possible side effects of these diagnostic methods ____

23. What therapeutic methods are generally available (therapeutic methods are treatments such as a special diet or medication) ____

24. What therapeutic methods are used for a specific symptom ____

25. When surgery is necessary ____

26. What is enteral or parenteral nutrition ____

27. How enteral or parenteral nutrition helps ____

28. What effects and side effects drugs used to treat Crohn's disease have ____

OF THE QUESTIONS YOU HAVE ANSWERED, WHICH 5 ARE THE MOST IMPORTANT TO YOU

Question number ____
____
____
____
____

WHICH ARE THE LEAST IMPORTANT TO YOU

Question number ____
____
____
____
____

B. DO YOU WANT TO KNOW MORE ABOUT THE FOLLOWING

Place a check mark on the line beside topics you would like to have more information on.

	I want to know more about the following
1. Cause of Crohn's disease	____
2. Long term outlook of Crohn's disease	____
3. Symptoms of Crohn's disease	____
4. Complications of the disease	____
5. Drug treatment	____
6. Side effects of drug treatment	____
7. Self-management of drugs	____
8. Surgical treatment	____
9. Diet in Crohn's disease	____
10. Reasons for blood tests	____
11. Reasons for x-ray investigations	____
12. Reasons for diagnostic procedures	____
13. Risk of relatives developing the disease	____
14. Effect on dating	____
15. Effect on sexuality	____
16. Effect on pregnancy	____
17. Effect on work and/or employment	____
18. Current research works	____
19. Belonging to the Ileitis and Colitis Foundation	____

C. WHICH OF THE FOLLOWING BEST DESCRIBES HOW YOU FEEL

	Place a check mark on one of the indicated lines
I have enough information and I have clear understanding of the concerns relating to my disease	____
I do not have enough information and I would like more	____
I do not have much information but I am not interested in finding out more	____

D. WHERE WOULD YOU LOOK FOR MORE INFORMATION ON CROHN'S DISEASE

Place a check mark on one of the indicated lines

booklets ____

video recording ____

a health practitioner (eg. nurse/doctor) ____

a discussion group with other young people who have Crohn's disease ____

Ileitis and Colitis Society ____

E. WHO ARE YOU THE MOST COMFORTABLE WITH WHEN TALKING ABOUT CROHN'S DISEASE

Place a check mark on one of the indicated lines

a parent ____

a brother or sister ____

another young person who also has Crohn's disease ____

a friend who does not have Crohn's disease ____

a doctor ____

a nurse ____

F. WHERE WOULD YOU PREFER TO LEARN ABOUT CROHN'S DISEASE

Place a check mark on one of the indicated lines

home ____

hospital ____

school ____

This questionnaire was developed by Debbie Brophy, 4th year Occupational student, Queen's University.

Appendix 4

SUMMARY OF THE KNOWLEDGE ABOUT CROHN'S DISEASE QUESTIONNAIRE

The following information was obtained thanks to the willingness of 10 Kingston and area young people to complete the questionnaire.

The mean age of the group who answered the form was 18.1 years with an age range of 14 to 22. The numbers of males to females was approximately equal. Length of illness varied from one to eight years with a mean of 5.2 years. The average number of hospitalizations was 2.8 with a range from 0 to 7 admissions. The mean number of weeks spent in hospital was 4 weeks with a range of 0 to 13 weeks.

The average number of siblings (brothers and sisters) was 2.2 with a range of 1 to 5 siblings. Eighty percent of the young people were the youngest child in their family. Most of the young people were on a regular diet with 20% of the sample taking a low residue diet. Seventy percent of the group were taking medications related to Crohn's Disease.

The questionnaire sought to determine the individuals perception of knowledge related to Crohn's Disease. A low score - 1 indicated too much knowledge whereas a high score - 4 indicated too little knowledge. The following average scores were obtained in order of the perception of having too little knowledge.

SCORES	TOPIC
3.5	How the disease can affect your sexuality.
3.4	The chance of developing cancer during the course of your disease.
3.4	How the length of your disease influences its course.
3.2	How the disease affects your future.
3.1	What complications can occur.
3.1	What causes your disease.
3.1	Who gets Crohn's disease.
3.0	How your disease changes over time.
2.9	When surgery is necessary.
2.9	How many people in Canada have Crohn's disease.
2.9	What parts of your body can be involved in Crohn's Disease.
2.8	Enteral or parenteral nutrition.
2.7	How you can influence the course of your disease.
2.6	What brings about symptoms.

Low scores indicating "too much knowledge" related to how diet influences disease, symptoms of the disease, therapeutic interventions, side effects, and effects on sports and travel.

The topics listed as being the five most important were: Cause, of Disease, How the Disease Changes over time, How the Disease Affects the Future, How the length of the Disease affects the Course of the disease, Chances of Developing Cancer and the Side Effects of Drugs. Least important were listed as follows: Number of People with the Disease, Who gets Crohn's Disease, Sports, Travel, and several Questions relating to Symptoms and diet.

All young people answering the questionnaire stated that they wanted more information about research, complications and long term outlook. Also very important were information related to sexuality, surgery, cause, side effects and self-management of drugs, diet, risk of relatives developing the disease and the effect on employment.

Ninety percent of respondents stated that they did not have enough information and would like more. The majority would seek this information from the Ileitis and Colitis Foundation. Most respondents preferred to learn about Crohn's disease in a hospital setting although home was also mentioned by nearly half of respondents as a place to learn about their illness.

This information will be of assistance in determining a program for young people age 10 to 19 who have Crohn's disease and their families. Due to the average age of 18 years of the respondent, information will need to be sensitive to the needs of a younger audience as well as the older adolescents.

Appendix 5

OUTLINE OF THE INTERVENTION PROGRAM

Adolescents with Crohn's Disease and their Families: Characteristics and Response to Small Group Work

PROGRAM OBJECTIVES:

1. To clarify the nature of Crohn's disease, diagnostic methods, treatment and current research at an appropriate cognitive level for all family members.

2. To increase basic knowledge of nutrition, teach management of disease-specific symptoms, and promote positive attitudes toward attainment of nutritional health.

3. To facilitate communication about Crohn's disease and the impact of chronicity within the family structure.

4. To provide an opportunity for all family members to discuss issues related to adolescence such as independence, planning for the future, lifestyle adjustments, peer relationships, coping strategies, and dealing with issues within the context of a family where a member has Crohn's disease.

5. To provide setting where family members can reframe the role of recipient of help from the health care system to helper or advocate through the development of a self-help booklet for adolescents, a sibling letter to their parents and a letter from parents to new physicians.

H.D.H - KINGSTON Multidisciplinary Team.

Mary Bird - Ostomy Nurse

Evelyn Cameron - Outpatient Nurse

Wayne Greenway - Child Life

Dr. Aubrey Groll - Gastroenterologist

Jean Hughes - Pediatric Dietitian

Nancy Roblin - Clinical Nurse Specialist
- Pediatrics.

* The patients' primary care-givers will facilitate sessions in their individual centers with Roblin and Hughes who will be responsible for maintaining program consistency at each center as well as being co-facilitators. Careful preparation of the facilitators at each centre will be essential in addition to monitoring each session of the program.

SESSION 1

TOTAL GROUP:

Introductions, overview of the 5 sessions, getting acquainted will be facilitated using a circle - "giving your name and why you were given that name". (This may encourage communication as to reason for name between parent and child as well as providing an ice-breaker. (20 minutes)

TOTAL GROUP:

I. A review of physiology, pathophysiology, and a discussion period. (35 mins.)

Stress:

1. A & P if GI System, Incidence of Crohn's Disease
2. Theories re cause of Crohn's Disease.
3. Parts of body involved in Crohn's Disease.
4. Low incidence of developing cancer.
5. Changes re disease process over time.
6. How the length of illness influences the course.

Snack - Total group.

II SIBLING/PARENT GROUP

I. What siblings go through. Information session and group discussion. (35 minutes)
Brief Summary of Literature and discussion, Standing in the Sibling's Shoes.

Stress:

1. Siblings have been found to have more concerns than parents believed they had (Craft and Craft 1989).
2. Common concerns - genetics, programs of siblings.
3. Stress on the sibling when the affected child is ill/hospitalized.

Speaker - Adult sibling of a chronically ill person. Role-modelling. (30 minutes)

Katherine's brother Dan will discuss sibling issues/concerns with parents and siblings together.

YOUNG PERSONS WITH CROHN'S DISEASE

II. Dealing with fears - Concretizing old myths and current fears using plasticine. (Myths learned at a young age may still persist and current fears may be largely unfounded eg. incidence of cancer is very low yet it is a large fear factor, some youth may have extreme fears related to social settings.) (30 minutes)

HSC- SESSION 2

TOTAL GROUP

Personal shields drawn and discussed in small groups o
facilitate increased awareness of self/others. To
beginning with concrete drawings. (20 minutes)

TOTAL GROUP:

I. Review of Basic Nutrition

1. Basic Nutrition Review
2. Nutrition/Remission/Exacerbation
3. Enteral/Parenteral Nutrition

(VCR required)

SNACK - 20 Minutes

PARENT GROUP

II. **Coping strategies** related to having an ill child.
strengths and coping). Discussion.

Sharing concerns they felt at the time of diagnosis an
relapses and subsequent hospitalizations. Utilizin
regarding parental concerns as determined by Burke
(1989) (35 minutes)

YOUNG PERSON WITH CROHN'S DISEASE

II. **Working on a booklet** for new diagnosed teen wit
(Reframing the role from ill child to helper.) The gr
cartoonist to sketch topics identified in the previ
concretizing of issues (eg. siblings after asked for
parent or ill child) and the addition of humor are use
assist the young persons with discussing issues related
Disease and being a sibling of a person with Crohn's Di

SIBLINGS

II. Concerns related to having a sibling with Crohn's
for the sibling and for self. Concretizing with plastic
(35 minutes)

SESSION 3

TOTAL GROUP

Family collage - This is who we are! Collages made and discussed in small groups.
(20 minutes)

The purpose of the activity is to acknowledge shared interests, values, strengths. These may be unrelated to illness themes or may demonstrate coping behaviours and adaptations made to their situation.

YOUNG PERSON WITH CROHN'S DISEASE

I. Blackboard teaching about Crohn's disease and answering questions. Clarifying concerns from the needs survey. Opportunity to have questions answered and perhaps cognitive distortions/myths corrected.
(45 minutes)

Stress:

1. Diagnostic Tests/Relevance to Rx.
2. Complications and Rx, including surgery.
3. Medications.
4. Genetics.

SNACK - 20 MINUTES

II. PARENT GROUP

II. Discussion and Role-playing. Explaining and reinforcing the importance of diagnostic procedures and treatments to your son/daughter. (35 mins)

DISCUSSION

Overview of diagnostic procedures (20 minutes)

STRESS:

1. Purpose and use of information gained by doing procedure relative to treatment.

Role Play (15 Minutes)

One parent explaining a procedure to another parent who is in the role of young person. (Due to Crohn's disease affecting the bowel the procedures are often embarrassing to discuss for both parent and child.)

(Pamphlets for parents will be available on a table if they wish further information.) (Total time 35 minutes.)

SESSION 3
YOUNG PEOPLE WITH CROHN'S DISEASE.

II. **Future planning.** Brainstorming a list of concerns and discussions as mini-topics. eg. vocation, peers, dating and marriage, sexuality. Discussion.

Provision of a role modelling of a young person who has dealt effectively with Crohn's disease. Provision of an opportunity for participants to discuss post-high school adjustments.
(35 minutes)

II. SIBLING GROUP

I. Walking tour of various hospital departments including Radiology, O.R., and Dietary. To pick up snack for the group at Dietary.
(35 minutes)

The purpose of this is to familiarize siblings with areas of the hopsital that are well known to the affected youth. This may encourage communication within the family unit and encourage openness about procedures.

SESSION 4

TOTAL GROUP

Disease specific information.
- (45 minutes)

1. Nutrition/Remission/Exacerbation of Crohn's Disease
2. Enteral and Parenteral Nutrition.

PARENT GROUP

I. **Cartooning/Cartoonist** regarding parent's perceptions of health care professionals, medical students and student nurses. Feelings, frustrations and how best they could help. (30 minutes)

Providing an opportunity for parents to reframe complaints about the system into positive action and advocacy. Providing this article to students may facilitate more empathic communication.

YOUNG PERSON WITH CROHN'S DISEASE/SIBLING GROUP

I. **What I do now with my free time and planning leisure for life.** Utilization of a pie chart to determine available free time and usual activities. Some idea of illness related time per day will also be indicated. Planning for goal-related leisure activities and developing an alternative plan(s) for when not physically well.
(35 minutes)

SNACK - 20 Minutes

Parent Group

II. **Future Planning.** Brainstorming a list of concerns and discussions as mini-topics. eg. vocation, peers, dating and marriage, sexuality, eg. pregnancy, impact of medications on fertility. Small group discussion.
(35 minutes)

II. Young Person with Crohn's Disease/Sibling Group

Cartooning - Social situations, hospital concerns, school issues, sibling issues.

SESSION 5

ALL GROUPS

I. Canadian Foundation for Ileitis and Colitis Speaker - Networking with Community Resources

It is important to link families who may be in need of additional support, want more information or have an interest in furthering research with the CFIC.

II. COMPLETING BOOKLETS

Family members will work in small groups selected at random to write informative statements beneath cartoons so that the themes of the past five weeks are connected and also to make the booklet of use to newly diagnosed teens and their families. It is hoped that this activity will provide an opportunity for the families to reframe difficulties into an opportunity to help others.

INFORMATION LETTER AND CONSENT FORM Appendix 6

555 UNIVERSITY AVENUE
TORONTO, ONTARIO
CANADA M5G 1X8
PHONE (416) 597-1500

THE HOSPITAL FOR SICK CHILDREN

HSC

A program for young people with Crohn's disease and their families is being offered at a number of centers this year. The five-session program will be available on Thursday evenings from 7:00 to 9:00 PM at the Hospital for Sick Children, January 25, to February 22, 1990.

Participants will learn more about Crohn's disease, nutritional management and treatment. Group activities and an opportunity to talk about concerns related to having an illness or an ill family member will be provided. Parents, the young person with Crohn's disease and brothers and sisters are asked to attend.

A research study is also being completed. All persons participating would be asked to complete several questionnaires three times over a period of five months. Questions are related to your impressions about how Crohns disease influences the lifestyle of the young person with the illness and their family. Information related to severity of the child's illness will also be requested from their physician who will see your son or daughter at the clinic at H.S.C. You are encouraged to ask questions during the program and are free to withdraw from the study at any time without jeopardizing your child's treatment in any way. All medical information and questionnaires will be treated confidentially.

Two groups will be formed from those persons who agree to participate in this program and research study. One group will be asked to attend and complete questionnaires. The other group will be asked to complete questionnaires and will attend the program at a later date providing it has proven to be helpful.

We are optimistic that this program will prove to be beneficial to young people and their families as well as furthering knowledge about Crohn's disease. All records will be handled without identifying you or your child in any way.

Resourse persons at the Hospital for Sick Children will be:

Marilyn Booth, Director, Nursing Administration
Dr. Anne Marie Griffiths, Gastroenterologist
Jean Hughes, Dietician
Nancy Roblin, Clinical Nurse Specialist, Paediatrics
Cindy MacDonald, Paediatric Nurse
Judy Savage, Child Life Department

Please address questions about the program/research study to:

Nancy Roblin
Clinical Nurse Specialist
- Paediatrics
166 Brock St.
Kingston, Ontario
K7L 5G2
(613) 544-3310, Ext. 2399

Marilyn Booth
Director
Nursing Administration
Hospital for Sick Children
555 University Ave.
Toronto, Ontario
(416)597-1500

555 UNIVERSITY AVENUE
TORONTO, ONTARIO
CANADA M5G 1X8
PHONE (416) 597-1500

THE HOSPITAL FOR SICK CHILDREN

CONSENT FORM

Title of Research Project: Program and Research Project for Adolescents with Crohn's Disease and their Families

Investigator(s): Nancy Roblin/Jean Hughes

I acknowledge that the research procedures described on the attached form and of which I have a copy, have been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of the alternatives to participation in this study. I also understand the benefits (if any) of joining the research study. The possible risk and discomforts have been explained to me. I know that I may ask now, or in the future, any questions I have about the study or the research procedures. I have been assured that records relating to me/my child and my/his/her care will be kept confidential and that no information will be released or printed that would disclose personal identity without my permission.

I understand that I am free to withdraw (my child) from the study at any time. I further understand that if I/my child do not participate in the study, or if there is withdrawal from it at any time, the quality of medical care for me/my child and for other members of my family at the The Hospital for Sick Children will not be affected.

I hereby consent (for my child__________________________to) participate.

____
Name

____
Signature & Capacity e.g. Parent

____
Name of another adult who will be attending the program if applicable.

____
Name of Patient

____
Signature of Patient & Age

____
Name(s) of Brother/Sister Attending Program

____
Signature(s) of Brother/Sister Attending Program

The Person who may be contacted about the research is:

Marilyn Booth, Director
Nursing Administration
who may be reached at
telephone #416-597-1500

____
Date

____
Witness

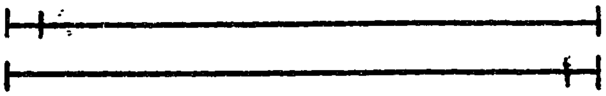
Appendix 7

P1

CD-PSI **FORM P**

Please place a vertical mark on each of the lines below that describes where you see yourself right now on the line.

EXAMPLES:



I have very little information about Crohn's disease.	I have complete information about Crohn's disease.
I have no or very little understanding of what happens to the bowel in Crohn's disease.	I have complete understanding of what happens to the bowel in Crohn's disease
I am totally unable to talk about Crohn's disease with my children.	I am able to talk totally openly about Crohn's disease with my children.
My son/daughter with Crohn's disease is completely uncomfortable with kids his/her own age.	My son/daughter with Crohn's disease is completely at ease with kids his/her own age.
One of my children who does not have Crohn's disease is always in trouble.	One of my children who does not have Crohn's disease is rarely or never in trouble.
It is extremely difficult to plan activities and holidays because of my son's/daughter's Crohn's disease.	My son's/daughter's Crohn's disease does not change our plans for activities and holidays at all.

Note - Size of Questionnaire Reduced

P2

I have no understanding of diet related to Crohn's disease.	I have a complete understanding of diet related to Crohn's disease
My son/daughter with Crohn's disease is not independent at all.	My son/daughter with Crohn's disease is totally independent.
I am completely unable to discuss my son's/daughter's Crohn's disease with my friends	I am able to explain all aspects of my son's/daugther's Crohn's disease to my friends.
Health professionals do not tell me anything about Crohn's disease.	Health professionals tell me everything about Crohn's disease.
In school my son/daughter with Crohn's disease is poorly behaved.	In school my son/daughter with Crohn's disease is very well behaved.
I find adolescents extremely difficult to talk to.	I find adolescent extremely easey to talk to.
My family has great difficulty solving problems.	My family is extremely good at solving problems.
I don't understand how Crohn's disease effects day to day living at all.	I have a complete understanding of how Crohn's disease effects day to day living.

P3

I never feel good about myself.	├──────────────┤	I always feel good about myself.
One of my children who does not have Crohn's disease is not independent at all.	├──────────────┤	One of my children who does not have Crohn's disease is completely independent.
My son's/ daughter's Crohn's disease affects my family to a great degree.	├──────────────┤	My son's/ daughter's Crohn's disease does not affect my family at all.
One of my children who does not have Crohn's disease is poorly behaved in school.	├──────────────┤	One of my children who does not have Crohn's disease is very well behaved in school.
I can not discuss my feelings at all.	├──────────────┤	I can discuss my feelings totally honestly.
I don't understand anything about tests used to decide that my son/daughter has Crohn's disease.	├──────────────┤	I understand everything about tests used to decide that my son/ daughter has Crohn's disease.
In our family the less said about the future the better.	├──────────────┤	In our family the future is talked about a lot.

P4

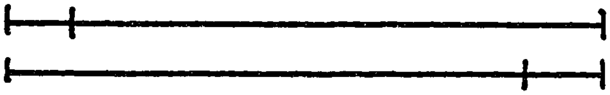
I do not know anything about the medicine that my son/daughter with Crohn's disease takes or used to take.	I have a complete understanding about the medicine that my son/daughter with Crohn's disease takes or used to take.
I find it impossible to understand other people's feelings in my family.	I find it extremely easy to understand other peoples' feelings in my family.
One of my children who does not have Crohn's disease is completely uncomfortable with kids his/her own age.	One of my children who does not have Crohn's disease is completely at ease with kids his/her own age.
I do not understand at all if family members can get Crohn's disease.	I have a complete understanding of family members chances of getting Crohn's disease
When I need to feel comforted I never go to my family.	When I need to feel comforted I always go to my family.
I am always moody.	I am never moody.
I am not in control of looking after my health.	I am totally in control of looking after my health.
My child who has Crohn's Disease is always in trouble.	My child who has Crohn's disease is rarely or never in trouble.

A1

CD-PSI FORM A

Please place a vertical mark on each of the lines below that describes where you see yourself right now on the line.

EXAMPLES:



I have very little information about Crohn's disease.	I have complete information about Crohn's disease.
I have no or very little understanding of what happens to the bowel in Crohn's disease.	I have complete understanding of what happens to the bowel in Crohn's disease
I am totally unable to talk about Crohn's disease with my parents.	I am able to talk totally openly about Crohn's disease with my parents
I am completely uncomfortable with kids my own age.	I am completely at ease with kids my own age
It is extremely difficult to plan activities and holidays because of my illness.	My illness does not change our plans for activities and holidays at all
I have no understanding of diet related to Crohn's disease.	I have a complete understanding of diet related to Crohn's disease
I am not independent at all.	I am totally independent.

A2

I am completely unable to discuss my illness with my friends.	I am able to explain all aspects of my illness to friends.
Health professionals do not tell me anything about my disease	Health professionals tell me everything about my disease.
In school I am poorly behaved.	In school I am very well behaved.
I find adults extremely difficult to talk to.	I find adults extremely easy to talk to.
My family has great difficulty solving problems.	My family is extremely good at solving problems.
I don't understand how Crohn's disease affects day to day living at all.	I have a complete understanding of how Crohn's disease affects day to day living.
I never feel good about myself.	I always feel good about myself.
My illness affects my family to a great degree.	My illness does not effect my family at all.
I find I am always in trouble.	I am rarely or never in trouble.

A3

I can not discuss my feelings at all.	I can discuss my feelings totally honestly.
I don't understand anything about tests used to decide that I have Crohn's disease.	I understand everything about tests used to decide that I have Crohn's disease
I have a brother or sister who is always in trouble.	I have a brother or sister who is always very well behaved.
In our family the less said about the future the better.	In our family the future is talked about a lot.
I do not know anything about the medicine that I take or used to take.	I have a complete understanding about the medicine that I take or used to take.
I find it impossible to understand other peoples' feelings in my family.	I find it extremely easy to understand other peoples' feelings in my family.
I do not understand at all if family members can get Crohn's disease.	I have a complete understanding of family members chances of getting Crohn's disease

When I need to feel comforted I never go to my family.	W f I m
I am always moody.	I m
I am not in control of looking after my health.	I i l m
I have a brother or sister who is not independent at all.	I h
My brother/ who does not have Crohn's disease is completely uncomfortable with kids his/her own age.	C i h
In school my brother/ sister who does not have Crohn's Disease is poorly behaved.	h d v t

S1

CD-PSI FORM S

Please place a vertical mark on __each__ of the lines below that describes where you see yourself __right now__ on the line.

EXAMPLES:

I have very little information about Crohn's disease.	I have complete information about Crohn's disease.
I have no or very little understanding of what happens to the bowel in Crohn's disease.	I have complete understanding of what happens to the bowel in Crohn's disease
I am totally unable to talk about Crohn's disease with my parents.	I am able to talk totally openly about Crohn's disease with my parents
I am completely uncomfortable with kids my own age.	I am completely at ease with kids my own age
It is extremely difficult to plan activities and holidays because of my my brother's/sister's illness.	My brother's/sister's illness does not change our plans for activities and holidays at all
I have no understanding of diet related to Crohn's disease.	I have a complete understanding of diet related to Crohn's disease
I am not independent at all.	I am totally independent.

S2

I am completely unable to discuss my brother's/ sister's illness with my friends.	I am able to explain all aspects of my brother's/ sister's illness to friends
Health professionals do not tell me anything about my brother's/ sister's disease.	Health professionals tell me everything about my brother's/ sister/s disease.
In school I am poorly behaved.	In school I am very well behaved.
I find adults extremely difficult to talk to.	I find adults extremely easy to talk to.
My family has great difficulty solving problems.	My family is extremely good at solving problems.
I don't understand how Crohn's disease affects day to day living at all.	I have a complete understanding of how Crohn's disease affects day to day living.
I never feel good about myself.	I always feel good about myself.
My brother's/ sister's illness affects my family to a great degree.	My brother's/ sister's illness does not affect my family at all.

S3

I find I am always in trouble.	I am rarely or never in trouble.
I can not discuss my feelings at all.	I can discuss my feelings totally honestly.
I don't understand anything about tests used to decide that my brother/sister has Crohn's disease.	I understand everything about tests used to decide that my brother/sister has Crohn's disease.
I have a brother/sister with Crohn's disease who is always in trouble.	I have a brother/sister with Crohn's disease who is always very well behaved.
In our family the less said about the future the better.	In our family the future is talkad about a lot.
I do not know anything about the medicine that my brother/sister takes or used to take.	I have a complete understanding about the medicine that my brother/sister takes or used to take.
I find it impossible to understand other peoples' feelings in my family.	I find it extremely easy to understand other peoples' feelings in my family.

S4

I do not understand at all if family members can get Crohn's disease.	├──────────────┤	I have a complete understanding of family members chances of getting Crohn's disease
When I need to feel comforted I never go to my family.	├──────────────┤	When I need to feel comforted I always go to my family.
I am always moody.	├──────────────┤	I am never moody.
I am not in control of looking after my health.	├──────────────┤	I am totally in control of looking after my health.
My brother/ sister with Crohn's disease is not independent at all.	├──────────────┤	My brother/ sister with Crohn's disease is completely independent.
My brother/ sister with Crohn's disease is always in trouble in school.	├──────────────┤	My brother/ sister with Crohn's disease is always very well behaved in school.
My brother/ sister with Crohn's Disease is completely uncomfortable with kids his/her own age.	├──────────────┤	My brother/ sister with Crohn's disease is completely at ease with kids his/her own age.

Appendix 8

PROGRAM EVALUATION - FORM P

Please indicate your opinion of the usefulness of different aspects of the program by circling a number on each scale.	Not Helpful at all 1	2	3	4	Very Helpful 5
1. Information about Crohn's Disease	1	2	3	4	5
2. Information about how Crohn's Disease is diagnosed and treated.	1	2	3	4	5
3. Information about nutrition.	1	2	3	4	5
4. Getting acquainted by giving your name and why you were given it.	1	2	3	4	5
5. Drawing and discussing your personal "shield".	1	2	3	4	5
6. Nutritional management of symptoms of Crohn's disease.	1	2	3	4	5
7. Making a Family Collage and discussion.	1	2	3	4	5
8. Current research being done about Crohn's Disease.	1	2	3	4	5
9. "What Siblings go through" session. With adult sibling. (Dan)		1	2	3	4
10. Speaker from the Ileitis and Colitis Foundation.	1	2	3	4	5
11. "Coping strategies" related to having an ill child.	1	2	3	4	5
12. Planning for "the future" with a child with Crohn's Disease.	1	2	3	4	5
13. Cartooning and writing part of a booklet for families and students in the health care field.	1	2	3	4	5
14. Speaker about growing up with Crohn's disease (Kato).	1	2	3	4	5

ADDITIONAL COMMENTS/RECOMMENDATIONS FOR FUTURE PROGRAMS.

PROGRAM EVALUATION - FORM S

Please indicate your opinion of the usefulness of different aspects of the program by circling a number on each scale.	Not Helpful at all 1	2	3	4	Very Helpful 5
1. Information about Crohn's Disease	1	2	3	4	5
2. Information about how Crohn's Disease is diagnosed and treated.	1	2	3	4	5
3. Information about nutrition.	1	2	3	4	5
4. Getting acquainted by giving your name and why you were given it.	1	2	3	4	5
5. Drawing and discussing your personal "shield".	1	2	3	4	5
6. Making a Family Collage and discussion.	1	2	3	4	5
7. Tour of the hospital.	1	2	3	4	5
8. Talking about concerns related to having a brother/sister with Crohn's disease.	1	2	3	4	5
9. Talking about difficulties and ways to "cope" with having an ill brother or sister using plasticene.	1	2	3	4	5
10. Cartooning and making a booklet for families and students.	1	2	3	4	5
11. Person who spoke who had a brother/sister with Crohn's disease.(Dan)	1	2	3	4	5
12. Cartooning feelings and issues.	1	2	3	4	5
17. Speaker from the Ileitis and Colitis Foundation.	1	2	3	4	5

<u>ADDITIONAL COMMENTS/RECOMMENDATIONS FOR FUTURE PROGRAMS</u>.

PROGRAM EVALUATION - FORM A

Please indicate your opinion of the usefulness of different aspects of the program by circling a number on each scale.	Not Helpful at all 1	2	3	4	Very Helpful 5
1. Information about Crohn's Disease	1	2	3	4	5
2. Information about how Crohn's Disease is diagnosed and treated.	1	2	3	4	5
3. Information about nutrition.	1	2	3	4	5
4. Getting acquainted by giving your name and why you were given it.	1	2	3	4	5
5. Drawing and discussing your personal "shield".	1	2	3	4	5
6. Nutritional management of symptoms of Crohn's disease.	1	2	3	4	5
7. Making a Family Collage and discussion.	1	2	3	4	5
8. Discussion concerns related to having Crohn's disease and using plasticene.	1	2	3	4	5
9. Talking about having Crohn's disease and dealing with kids at school.	1	2	3	4	5
10. Cartooning and making a booklet for young people who get Crohn's disease.	1	2	3	4	5
11. Planning free-time and thinking about recreation.	1	2	3	4	5
12. Speaker about growing up with Crohn's disease.	1	2	3	4	5
13. Speaker from the Ileitis and Colitis Foundation.	1	2	3	4	5
14. "Me at 21". Planning for the future. Speaker about Crohn's Disease. (Kato)	1	2	3	4	5

ADDITIONAL COMMENTS/RECOMMENDATIONS FOR FUTURE PROGRAMS.

Appendix 9

Quiz about Crohn's Disease

1. Two purposes of the small intestine are

a) ______________________________

b) ______________________________

2. Two purposes of the large intestine are

a) ______________________________

b) ______________________________

3. Five signs or symptoms of having Crohn's disease are:

a) ____________________

b) ____________________

c) ____________________

d) ____________________

e) ____________________

4. Three ways the physician would diagnose or check-up on Crohn's disease are:

a) ____________________

b) ____________________

c) ____________________

5. Although the cause of Crohn's disease is unclear list three factors that may be involved.

a) ____________________

b) ____________________

c) ____________________

6. List five treatments available

a) ____________________

b) ____________________

c) ____________________

d) ____________________

e) ____________________

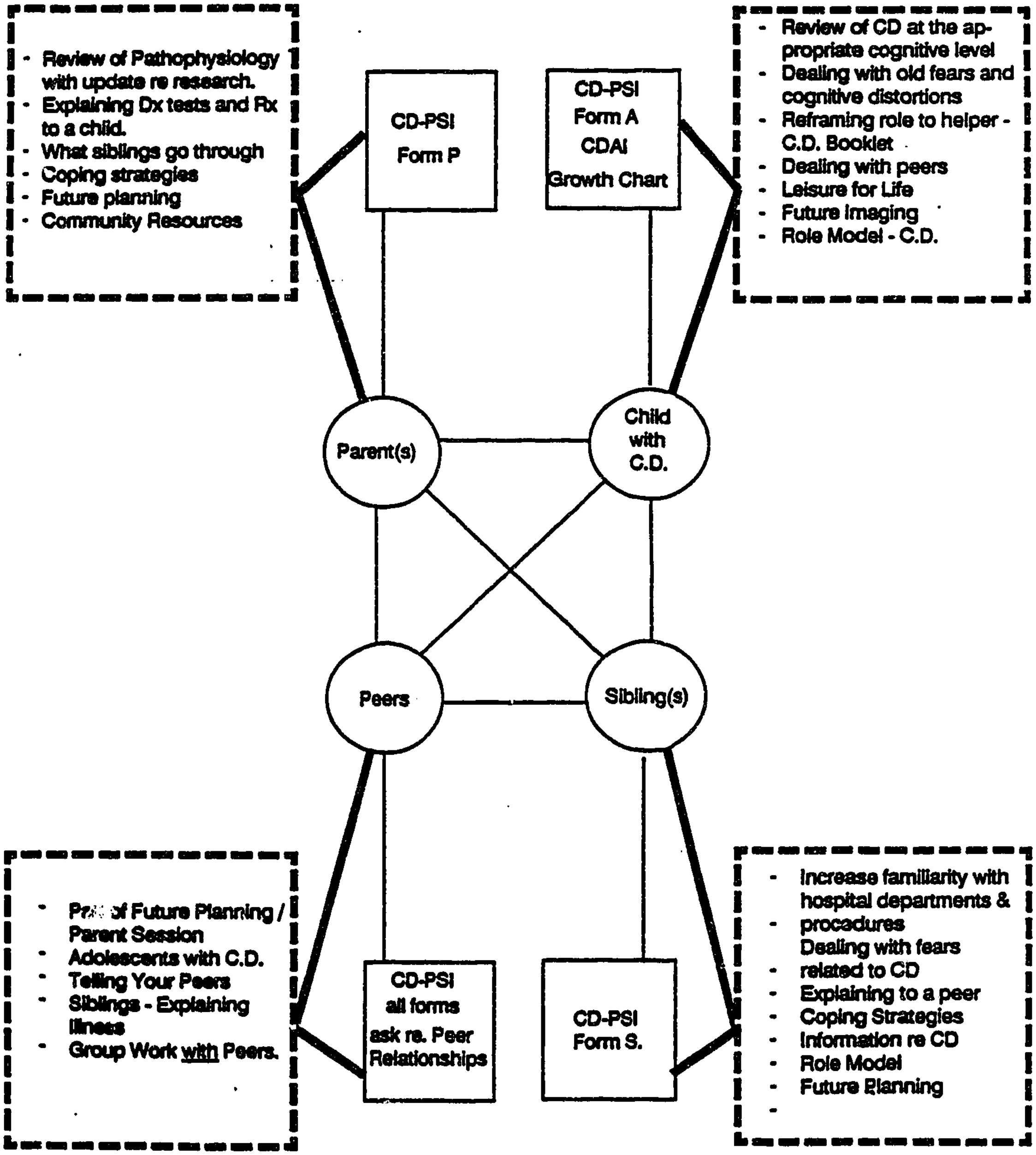
8. Why is regular medical follow-up important?

____

____

Appendix 10

CHILDREN WITH CROHN'S DISEASE AND THEIR FAMILIES: Characteristics and Response to Small Group Work



- Review of Pathophysiology with update re research.
- Explaining Dx tests and Rx to a child.
- What siblings go through
- Coping strategies
- Future planning
- Community Resources

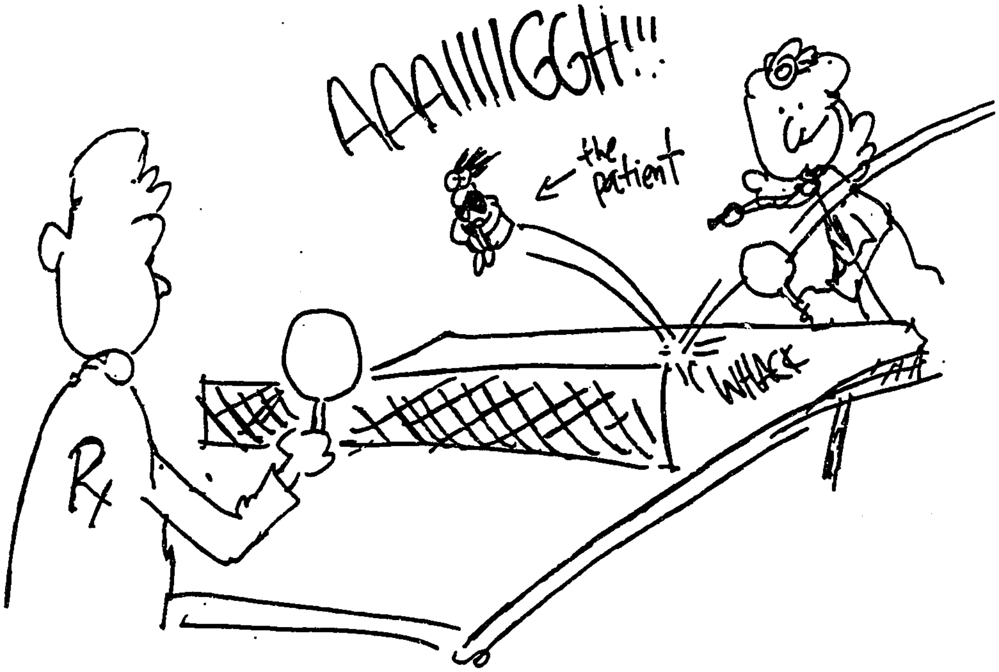
- Review of CD at the appropriate cognitive level
- Dealing with old fears and cognitive distortions
- Reframing role to helper - C.D. Booklet
- Dealing with peers
- Leisure for Life
- Future Imaging
- Role Model - C.D.

- Pr[illegible] of Future Planning / Parent Session
- Adolescents with C.D.
- Telling Your Peers
- Siblings - Explaining Illness
- Group Work <u>with</u> Peers.

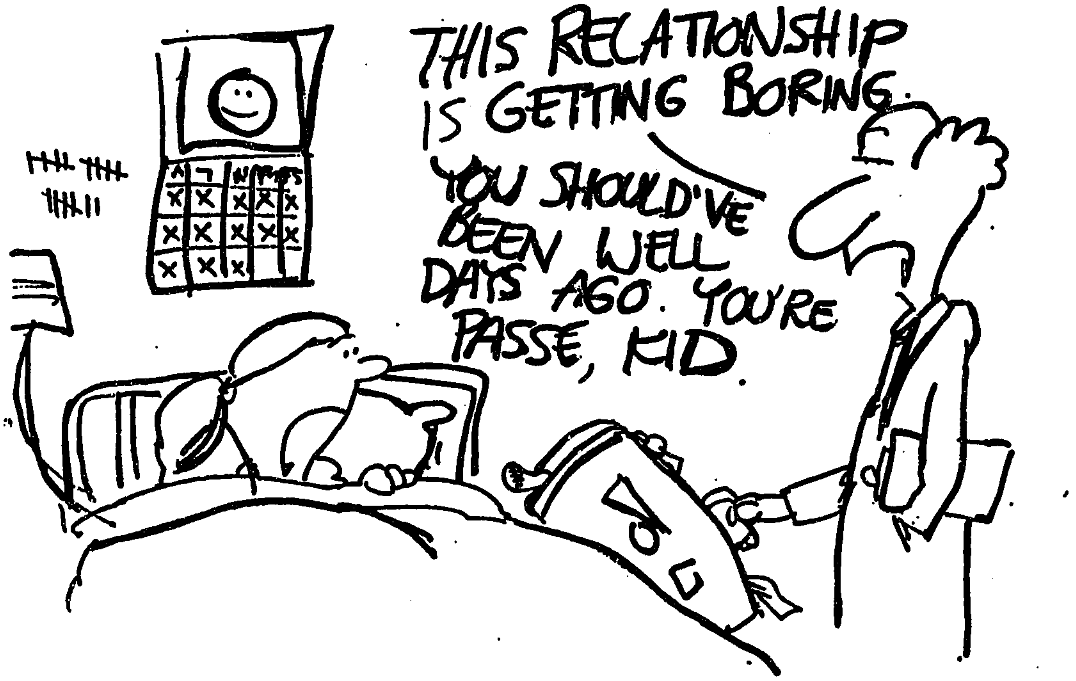
- Increase familiarity with hospital departments & procedures
- Dealing with fears related to CD
- Explaining to a peer
- Coping Strategies
- Information re CD
- Role Model
- Future Planning

INTERVENTION AND ASSESSMENT MODEL

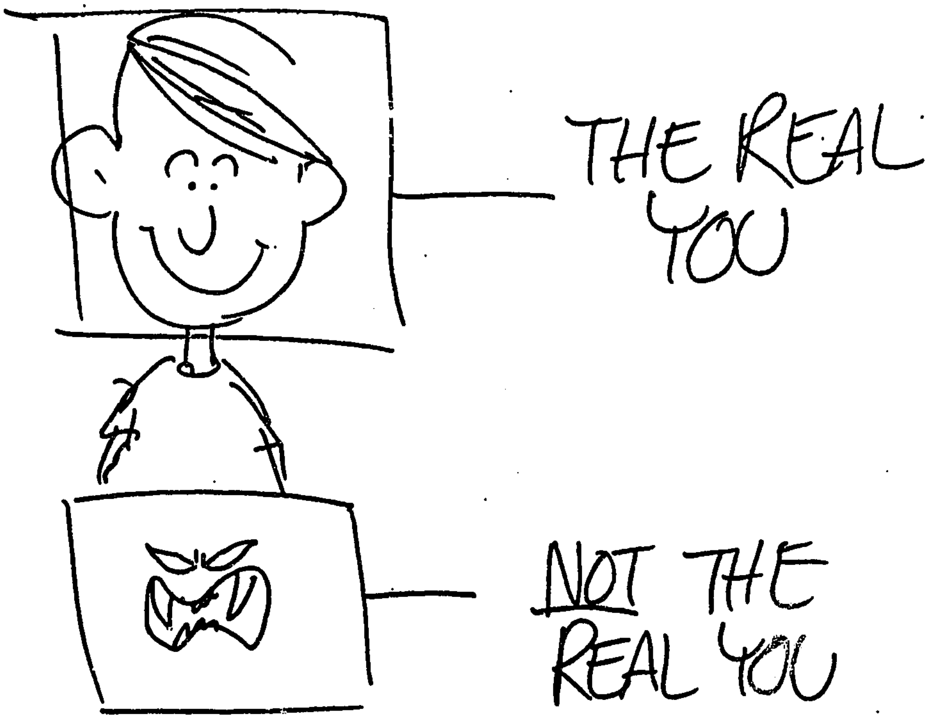
Fiqure/Illustration 1



GETTING BOUNCED AROUND

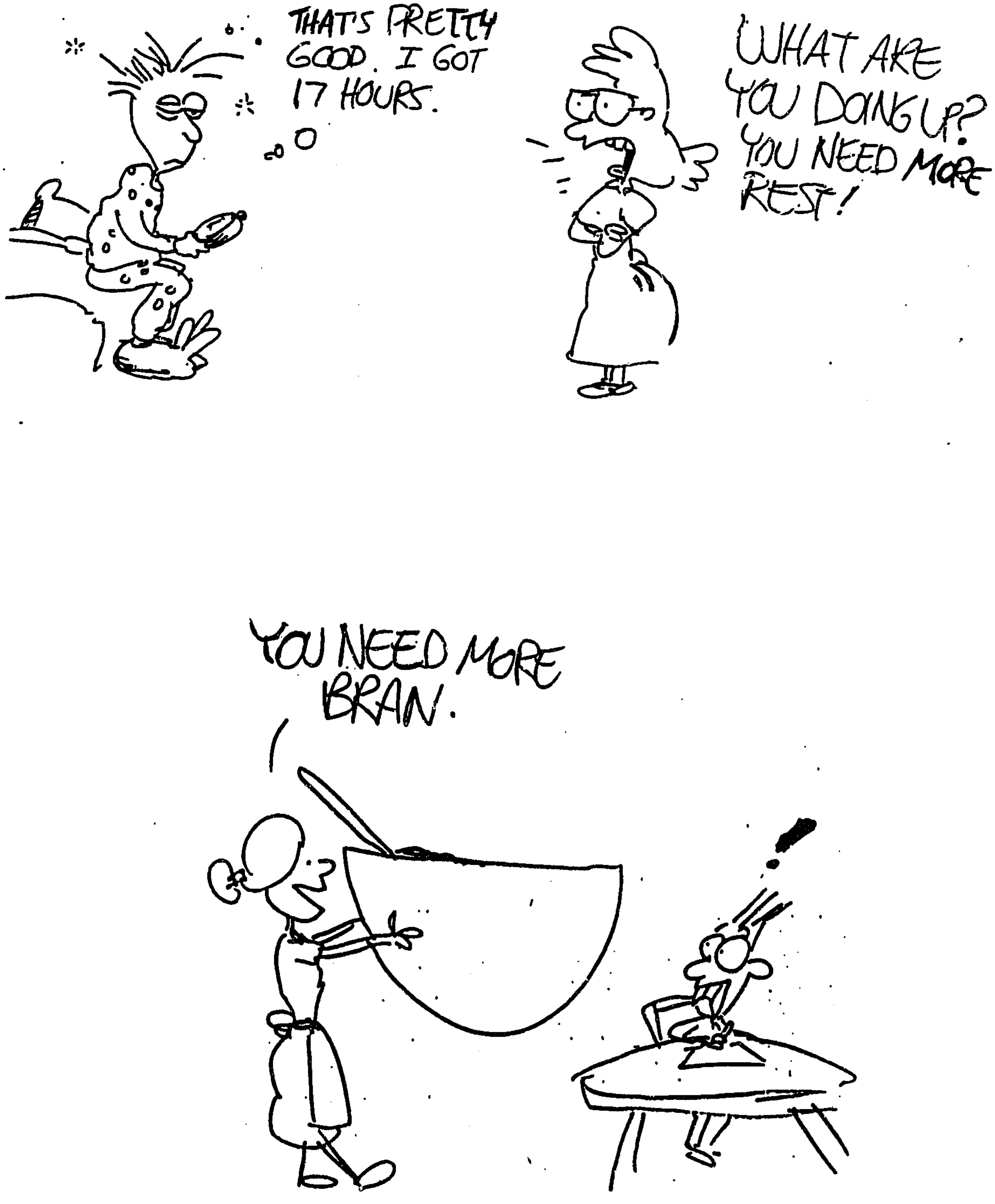


Figure/Illustration 2



Figure/Illustration 3

Figure/Illustration 4



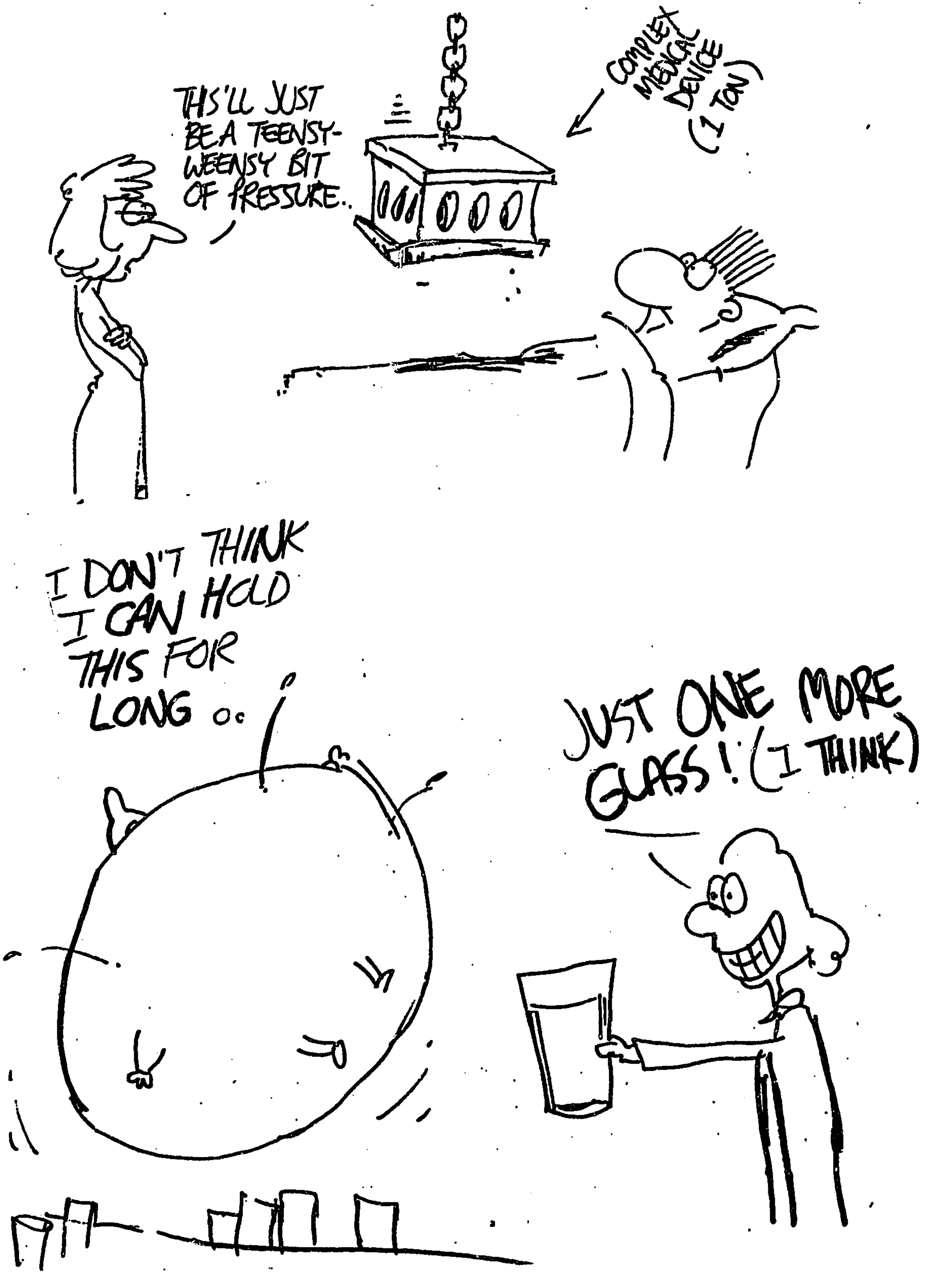
Figure/Illustr

Figure/Illustration 6

Figure/Illustration 7

Figure/Illustration 8

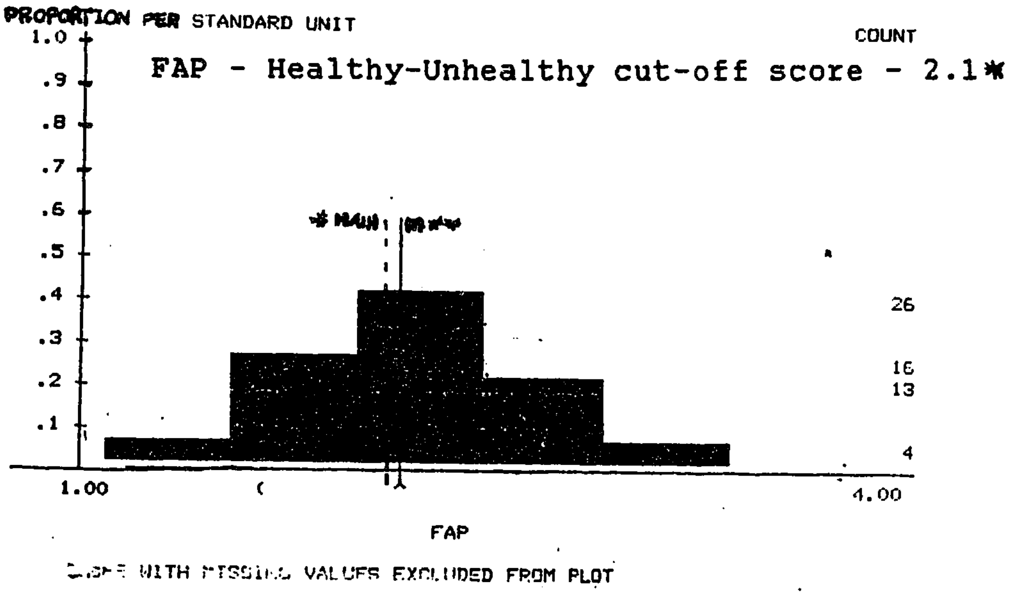
Figure/Illustration 9



Figure/Illustration 10

Figure 11

Histogram - Total Sample - Problem Solving (FAD)

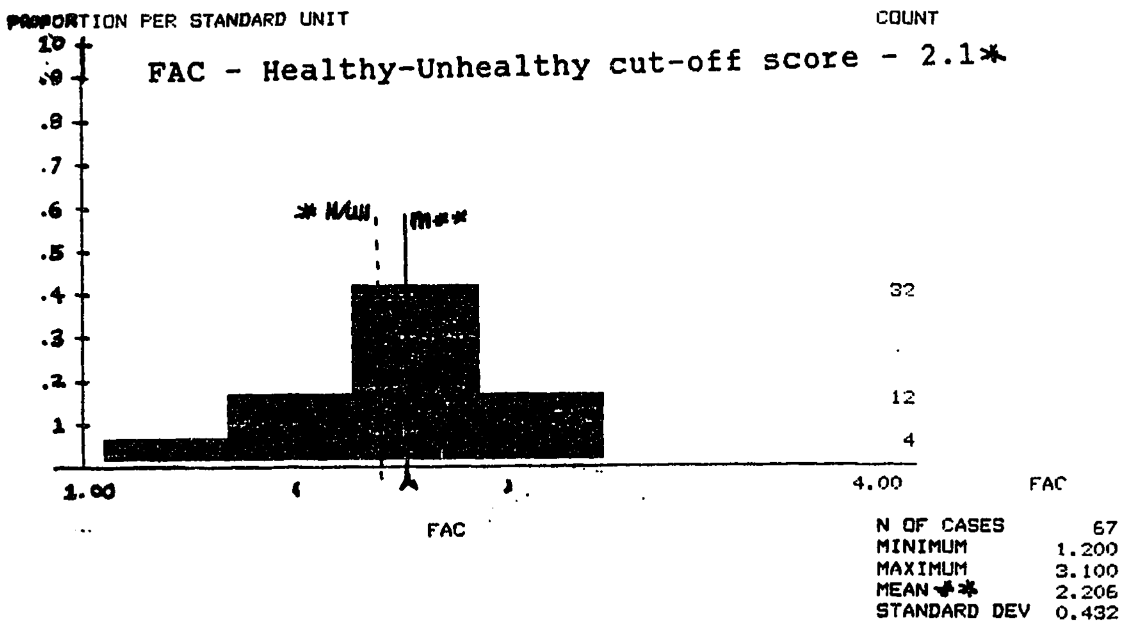


```
                                   FAP
N OF CASES                          67
MINIMUM                          1.200
MAXIMUM                          3.800
MEAN **                          2.154
STANDARD DEV                     0.530
```

FAP - 43% of the total sample scored in the unhealthy range *

FIGURE 12

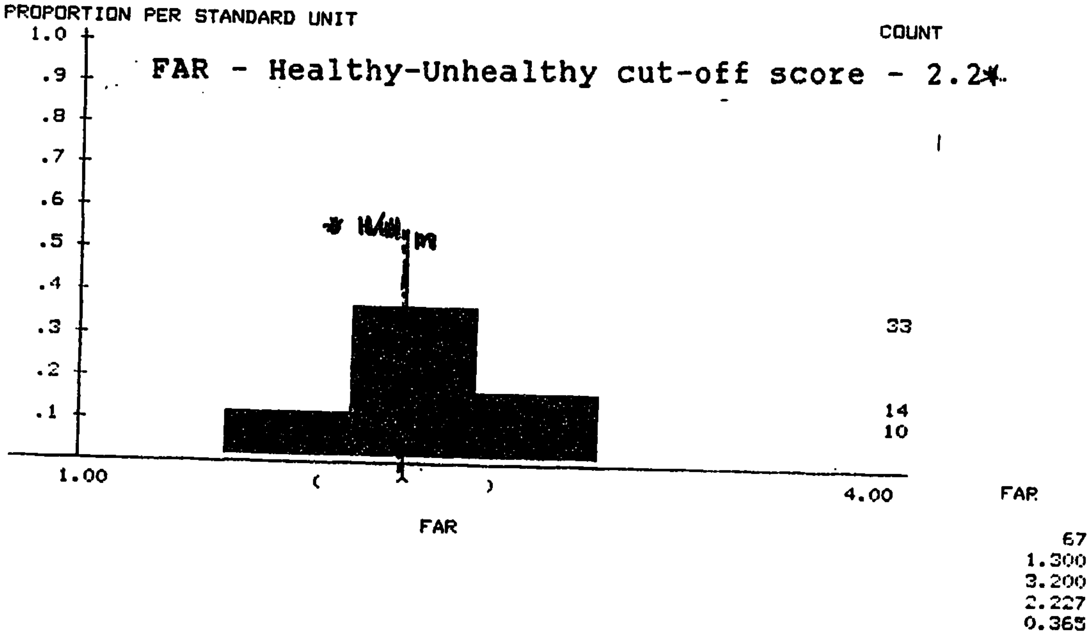
Histogram - Total Sample - Communication (FAD)



FAC - 68% of the total sample scored in the unhealthy range *

FIGURE 13

Histogram - Total Sample - Roles (FAD)

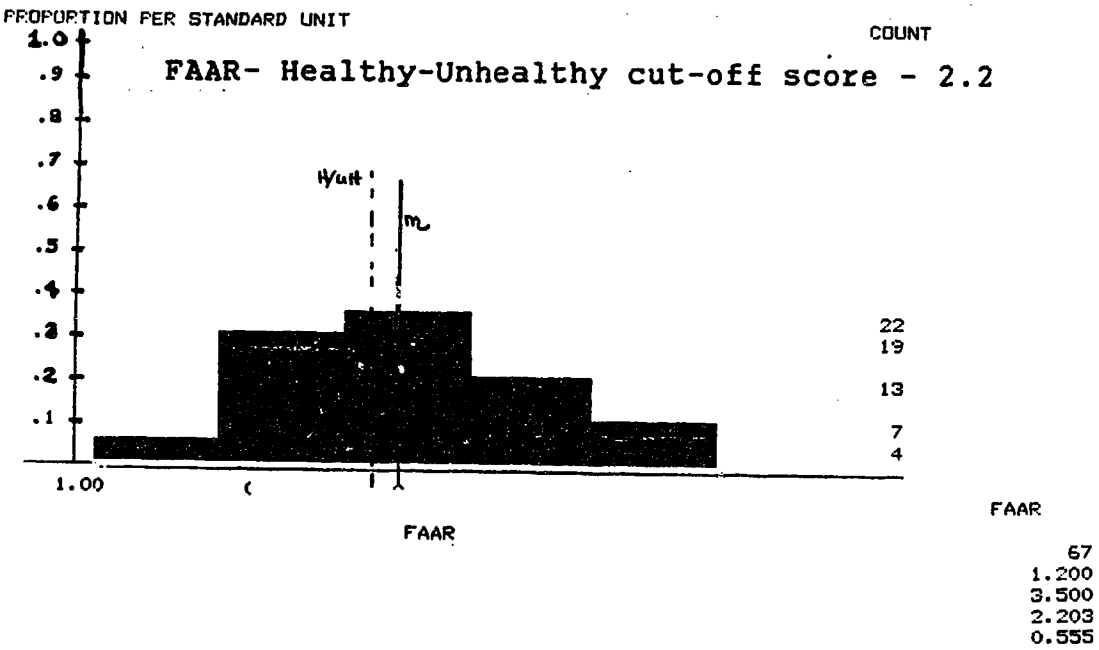


FAR - Healthy-Unhealthy cut-off score - 2.2*

FAR - 56% of the total sample scored in the unhealthy range *

FIGURE 14

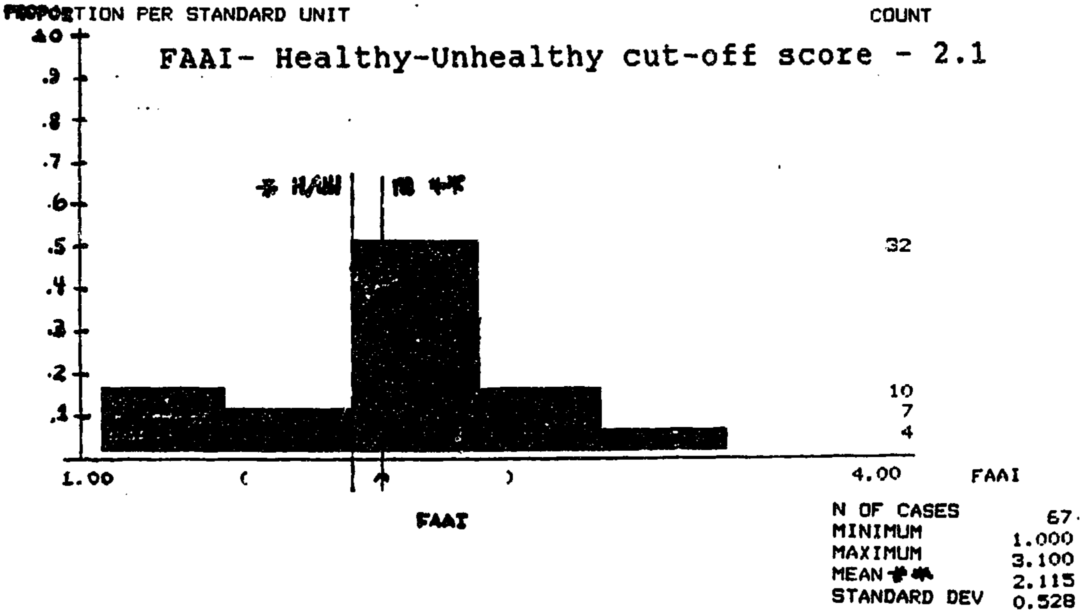
Histogram - Total Sample - Affective Responsiveness (FAD)



FAAR - 61% of the total sample scored in the unhealthy range *

FIGURE 15

Histogram - Total Sample - Affective Involvement (FAD)

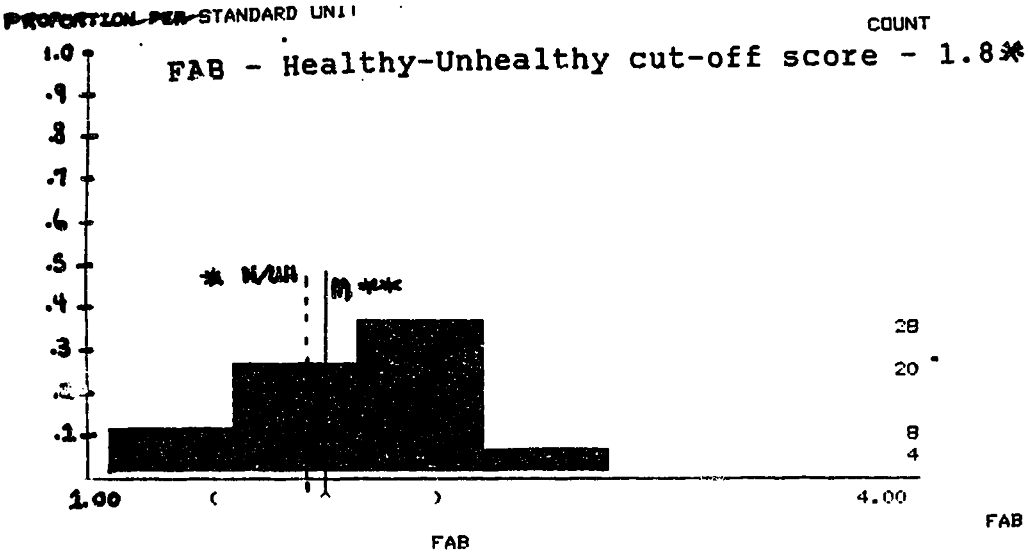


```
N OF CASES        67
MINIMUM        1.000
MAXIMUM        3.100
MEAN           2.115
STANDARD DEV   0.528
```

FAAI - 71% of the total sample scored in the unhealthy range *

Figure 16

Histogram -Total Sample - Behavior (FAD)

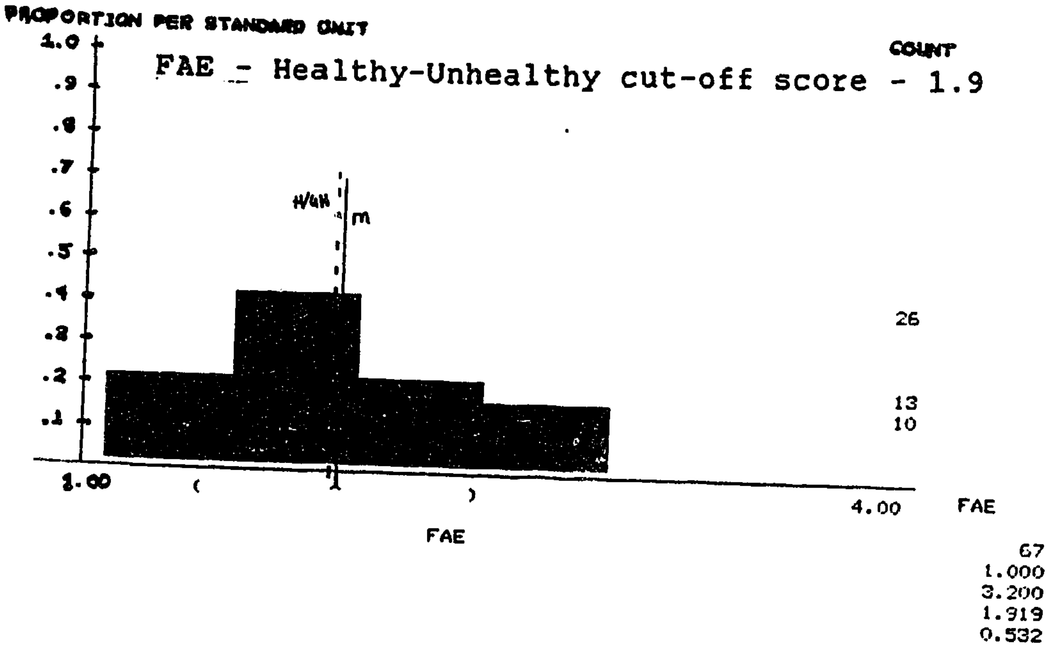


	FAB
N OF CASES	67
MINIMUM	1.000
MAXIMUM	3.000
MEAN **	1.872
STANDARD DEV	0.433

FAB - 65% of the total sample scored in the unhealthy range

FIGURE 17

Histogram - Total Sample - General Functioning (FAE)



FAE - 47% of the total sample scored in the unhealthy range

SUMMARY TABLE OF ABBREVIATIONS AND RELATED DIMENSIONS MEASURED

FAD - Family Assessment Device
(based on the McMaster Model of Family Functioning)

Dimensions of FAD

FAP - Problem Solving
FAC - Communication
FAR - Roles.
FAAR - Affective Responsiveness
FAAI - Affective Involvement
FAB - Behaviour Control
FAE - General Functioning

CD PSI - Crohn's Disease Psychosocial Inventory-Dimensions of CD PSI

FCS - Family Coping Style
SWB - Social Well Being
KnCD - Knowledge related to Crohn's Disease

FCS Items

FPTT - Total FCS
FPT - Ability to talk openly about Crohn's Disease (Family)
FPSB - Sibling behaviour
FPH - Extent that affected adolescent's CD alters holiday
FPF - Effect of adolescents CD on family
FPU - Extent that the Future is discussed
FPC - Comforting sought from Family
FPAB - Affected adolescent's behaviour
FGPI - Understanding of other's feelings in the family
FPP - Problem solving

SWB Items

SPT - Total Social Well Being
SPAE - Affected Adolescents degree of being at ease with peers.
SPAI - Affected adolescents independence
SPD - Ability to discuss illness with friends
SPSI - Degree of sibling independence
SPC - Adult/Adolescent Communication
SPSE - Sibling's degree of being at ease with peers
SPAB - Affected adolescents' school behaviour
SPSB - Sibling's school behaviour
SPF - Ability to discuss feelings

KnCD Items

KPT - Total Knowledge about Crohn's Disease
KPI - Extent informed about Crohn's Disease
KPU - Understanding about disease process

KPD - Understanding of diet related to CD
KPH - Extent to which feel well-informed by health profes
KPY - Understanding of how CD effects day to day living
KPX - Understanding of diagnostic tests
KPM - Understanding of medications used for C.D.
KPG - Understanding of genetics related to C.D.
KQCD - Factual knowledge Quiz used to compare Perception related to C.D. (KNCD) with knowledge as demonst quiz (KQCD)
SESTE - Self-Esteem VAS (visual analogue scale - CDPSI)
Mood - Mood VAS (CD PSI)
HLOC - Health Locus of Control - VAS (CD PSI)
CDAI - Crohn's Disease Activity Index
CFSEI - Culture Free Self-Esteem Inventory
SEG - General Self-Esteem
SES - Social Self-Esteem
SEP - Personal Self-Esteem
SET - Total Self-Esteem
SED - Defensiveness (Lie) Scale

COMPARISON CHART ABBREVIATIONS RE RESPONSES/DATA

TG - All Groups
TP - All Parents
TA - All Affected Adolescents
TS - All Siblings
TIG - All Intervention Group
TIP - Intervention Group Parents
TIA - Intervention Group Affected Adolescents
TIS - Intervention Group Siblings
TCG - Control Group
TCP - Control Group Parents
TCA - Control Affected Adolescents
TCS - Control Group Siblings

Adol-A - Affected Adolescent (C.D.)

TPM - All mothers
TPF - All fathers
IPM - Intervention Group Mothers
IPF - Intervention Group Fathers
CPM - Control Group Mothers
CPF - Control Group Fathers