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Children with Inflammatory Bowel Disease (IBD): Finding Strategies to Cope with  
Physical Symptoms in School

Maria Gordon

A Thesis

in

The Department of Education

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## Abstract

### Children with Inflammatory Bowel Disease (IBD): Finding Strategies to Cope with Physical Symptoms in School

Maria Gordon

This qualitative study was comprised of interviews conducted with English speaking elementary school children in Montreal, Quebec. The eight children were 6 ½ to 11 years of age and afflicted with Inflammatory Bowel Disease (IBD). The study attempted to uncover the coping strategies that enabled these IBD children manage the social and learning elements of their elementary school environment.

What has been missing from the literature is a systematic description of coping processes that IBD school-age children use. Through self-reports the children expressed the particular techniques that they used to help them cope with the physical symptoms that accompanied their illness while at school.

Findings from this study have shown that IBD elementary school-aged children report a diverse range of coping strategies. The strategies that they employed helped them strike a balance between managing their chronic symptoms and participating in their daily school activities. The children's reported IBD coping strategies, though diverse, had similarities. The similarities in responses were arranged into themes and categories from which a conceptual framework of coping was created. From this new framework, IBD elementary school-aged children's coping can be explored in future studies and hopefully, a model of IBD children's coping can one day be derived so that healthcare workers, social workers, teachers, parents and others can provide these children with better support.

## Acknowledgements

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This work is in honor of my mother who is the role model I try to follow and to my father who has always been so wise and last but most certainly never least, my little sister Coretta, whose love, encouragement and help was unwavering. Words will never be able to express the love and gratitude I have for you.

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## Introduction

Many children have an illness that interferes with the usual activities of childhood and perhaps most importantly this can interfere with their schooling. A chronic illness is defined as a condition that lasts at least three months, requires extensive hospitalization or in-home health services, or is likely to do so either at the time of diagnosis or during the course of the illness. Ten to fifteen percent of American children are affected by such chronic illnesses, two to four percent of which are severe and interfere with the daily activities of childhood (Gortmaker & Sappenfield, 1984). Gortmaker also notes that comprehensive data on the prevalence of childhood disorders are not readily available. The fundamental problem is the small number of these children: few population studies can obtain enough cases of any given disease to make reliable estimates, and studies based upon hospital or clinic samples are usually difficult to generalize to other settings.

Inflammatory Bowel Disease (IBD) is an example of a chronic illness that can strike children as well as adults at any time and at any age. In the last several decades, the incidence of IBD in adults has increased (Logan, 1998) and studies have shown similar patterns of increases in IBD children. The reasons for the increase are unclear, and the contributing factors may occur early in life. IBD has not been well described in infants and young children (Mamula, Telega, Markowitz, Brown, Russo et al. 2002). Recently, evidence for increased incidence of IBD not only in adults but also in children and adolescents has caused renewed interest in the younger age group (Grybowski, 1993). At this time, there is neither a known cure for the illness nor any definite idea as to how one acquires it. Mamula goes further to emphasize that very young patients with IBD require special attention because of the potentially large impact of the disease on

their growth and development and on the overall quality of their lives. This point establishes an important reason for conducting research in this area.

There is also a need to increase knowledge about coping strategies, of which little is known with regard to IBD in children. For this reason, the research proposed here will add data to the limited literature available on how children afflicted with Crohn's and Ulcerative Colitis create ways of coping with their chronic illness while in their school environment. Recent studies on coping have focused almost exclusively on pain or medical procedures (Billings & Moos, 1981). By performing this type of research and acquiring knowledge about IBD in children the result may be better planning and organization of health and educational services.

This study aimed to uncover how elementary school-aged children in Montreal, Quebec, afflicted with IBD coped with the physical symptoms of their illness while participating in their school environment. Specifically, the goal was to allow for elementary IBD school-aged children to express in their own words the various techniques or coping strategies that they used in order to manage their daily school routines. This research was exploratory in nature and as such, did not have a specific research question. However, previous studies on children's coping found that children's ways of coping with stressful life events could be organized and structured into a conceptual framework. Would this hold true for elementary school-aged children with IBD?

After collecting the IBD children's various coping strategies, this study sought to determine if IBD children's coping strategies could be arranged into a model. This new model would be similar in structure to previous models found in coping studies.

However, this new model would be specific to a population of IBD children. Such a model would help to create a structured picture of IBD children and their ways of coping within a school environment. This type of IBD coping model does not exist in the literature and information on IBD children's coping is limited, hence, the importance of this study.

It is my hope that once an IBD model of children's coping is created it will then be possible to design tools to measure these outcomes in future studies.

This study did not, however, refer to the population of IBD school-aged children as children with special needs. Nor were these IBD children ever perceived as children disabled or in need of placement in special education programs. I have not examined these children from any of these specific education perspectives. In meeting with these children and their parents it was clear that they did not perceive themselves as belonging to any of these 'special' education categories. Though both parents and their ill children acknowledged that IBD is a chronic illness that required that some special needs to be met, the children and their parents did not perceive this illness to be 'special' enough to warrant being labeled or viewed as 'special needs' students. Such labeling would only classify these children as being handicapped or disabled and that is not how they nor their families saw them despite the existence of the chronic illness. It was the parents' opinion that educational instruction should be the same for children with chronic illness as for other children and institutional goals and expectations should be commensurate with their child's individual intellectual abilities. The parents' concern was that their IBD children might experience failure at school not because of intellectual deficits, lack of motivation

or physical disabilities, but simply because of inappropriate responses by school personnel to their child's special needs.

This paper is arranged in chapters. The first chapter provides background information about IBD. The nature of this illness is defined and a review of the literature on children afflicted with chronic illness and the impact on their school environment is examined. In the second chapter, the study is outlined and described. All the steps in the research process are highlighted and the chosen methodology is explained. Chapter three describes the various themes and categories that emerged from interviews with the IBD children. These themes were later coded and structured into categories to create a conceptual framework of coping for IBD elementary school-aged children. In the fourth chapter the focus is placed on uncovering meaning from the children's self-reports. Similarities in the children's responses are analyzed and grouped into four IBD coping categories.

The paper concludes with an emphasis on the importance of conducting this type of qualitative research. Recommendations based on the information obtained from the IBD children's interviews are provided. The potential for future research in the area of IBD elementary school-aged children's coping is also discussed.

## Chapter 1

### Background to the Study

#### **What is Inflammatory Bowel Disease (IBD)?**

Inflammatory bowel disease encompasses two main clinical entities, namely Crohn's disease (CD), named after Dr. Burrill Crohn and Ulcerative Colitis (UC). Although the pathophysiology may differ somewhat for each, the symptomatology as well as diagnostic and therapeutic approaches are very similar. Both diseases are characterized by chronic recurrent inflammation of intestinal tissue, evolving in periods of relapse and remission. CD can affect any part of the gastrointestinal tract, from the mouth to the anus. Patches of inflammation occur, with healthy tissue between the diseased areas. The inflammation can extend in depth through every layer of affected bowel tissue. UC affects only the inner layer (mucosa) of the colon. It involves the rectum in practically all cases, and extends proximally as continuous inflammation over a variable length of the colon.

Symptoms associated with IBD episodes and flare-ups range from mild to severe abdominal pain, frequent diarrhea with or without bleeding, vomiting, weight loss, fever and malaise. Treatment often involves a combination of drugs, some steroid-based, to help ease some of the pain and reduce the intestinal inflammation, and may at times even require surgical intervention. Severity of symptoms can vary widely, and flare-ups of the disease can occur without warning, sometimes resulting in hospitalization and surgery. In some cases, this may involve placement of a colostomy or ileostomy, whereby an opening is surgically created at the skin level through which fecal material is eliminated into a special appliance.

Factors that increase the likelihood of IBD:

- Jewish heritage (three to six times more likely than the general population)
- European (particularly Scandinavian) ancestry
- Family history of IBD
- Living in an industrialized country (particularly urban area)
- Diet high in sugar and hydrogenated fat and low in fruit and vegetables

(Cited from, [www.medformation.com](http://www.medformation.com))

Although recent medical and surgical advances have markedly improved the clinical outcome for these chronically ill children, several studies have outlined the significant impact of IBD on the quality of life, educational experience as well as career prospects (Mayberry, 1999). Most importantly, these studies have noted that IBD children face many challenges at school. They often experience high absenteeism rates, periods of low self-esteem, and distortion of body image secondary to the side effects of steroidal medications. IBD children also experience episodes of stomach cramps when seated for long periods of time, and social isolation from school personnel and peers who do not understand their illness nor their special needs.



## **Chronic Illness at School**

Children with a health problem are different. Their appearance may be changed either by the disorder itself or by the medication, as is often the case with IBD. Sick children are often misunderstood at school and their symptoms misinterpreted depending on peoples' (school staff and peers) attitudes and their level of knowledge about the illness.

### **The school environment**

According to Weitzman (1984), not only is school the setting in which children undertake academic activities, it is the situation in which they learn many of the interpersonal and social skills which are necessary for daily life. The successes, failures and social relationships that children experience in school have a very strong influence on their evolving sense of self, relatedness to others, and their perceptions of their ability to perform academically and to cope effectively.

From six to 12 years of age, elementary school-aged children spend an increasing proportion of their time away from their home and family and so much of their emotional support comes from an ever-widening circle (Perrin & Gerrity, 1984) that includes the school environment. With such importance attached to school as a place of much needed social acceptance, many children with chronic illness are often excluded from many age appropriate activities and peer interactions because of frequent illness episodes. Thus, the reason for examining the school environment in this study is that school may represent a predominant social and recreational opportunity for many of these IBD

children. While academics are of course important, these aspects of the school experience should not be overlooked.

Most children experience some degree of difficulty in adjusting and coping with the social environment of the school at various times during the course of their childhood. However, children with a chronic health condition have long been considered at greater risk for psychosocial difficulty (Pless & Pinkerton, 1975). Despite an increasing prevalence of chronic childhood conditions and heightened concerns for the quality of life of the chronically ill, population-based studies of behavior problems among children with chronic physical conditions are rare (Gortmaker, Walker, et al. 1990).

There are numerous school related issues that chronically ill children share with their healthy peers such as concerns about physical appearance, peer acceptance, competition, anxiety about academic achievement, athletic abilities, and sexual development. Many of these concerns are accentuated for chronically ill children. For example, IBD children often need to go to the bathroom frequently. Sometimes they require a special diet that may make them feel self conscious when eating in the school lunchroom, group gatherings or at parties. These children frequently have to interrupt their activities to take their medications at regular intervals. IBD children experience pain due mainly to stomach cramps. This can in turn make them irritable, sad or drained of energy. These differences are inevitably noticed by their peers and school staff, and sometimes commented upon. It is these types of issues that this study plans to explore as IBD children share their insights into their school experiences.

### **Coping with peers at school**

The presence of a chronic condition may limit or alter social interactions and distinguish elementary school-aged children from their peers, which in turn increases the risk of problems with normal psychosocial adjustment (Pless & Pinkerton, 1975). In addition to their physical condition, children with a chronic illness must also cope with their own reactions to the illness and its care. They must also cope with as well the reactions of friends, teachers and others, (Perrin, Ramsey & Sandler, 1987). The additional stress created for children by their chronic condition and by the reactions of others is frequently manifested as emotional behavioral problems or difficulties in social relationships and self-esteem.

Children with a chronic illness may worry about being different and the interference of their illness within their widening peer group relationships. Peers often label a child who requires frequent visits to the doctor, or even regular medication, as different. This difference becomes the primary identification of the child. According to Perrin & Geritty (1984), it is no use to say that John is just like every other child except that he is blind, or that Mary is like all the other kids except that she is deaf. These differences are noticed immediately by the child's peers. In the IBD child's struggle for conformity and acceptance these differences become critical, and can make them feel uncomfortable, embarrassed and may often lead them to avoid or ostracize the ill child.

Although afflicted children may wish that their disorders could remain hidden to avoid possible rejection by their peers, this wish may be paired with a longing to share information about their illness to a trusted friend. The experience of confiding in a trusted friend and then realizing that they are still accepted and valued despite their

differences can be deeply meaningful and reassuring for a child. Sharing the secret about their illness is also a testing out of their acceptability. Children sense that they are putting themselves on the line, and so it is an exposure that they may think about with considerable apprehension (Perrin & Gerrity, 1984).

### **Gender differences in peer relationships**

According to McCollum (1981), in mid-childhood, classmates are the most significant peer groups. McCollum explains that one of the most prominent characteristics of middle childhood is a child's need to be the same as other children, to be accepted by peers, and to develop a sense of membership with their peer group. A child with a physical disorder worries about how their peers will react to the fact that they are different. And even though their appearance may resemble their peers, the IBD child's physical functions may be obviously different. As children strive to gain increasing independence from their parents, they strongly need a sense of belonging. A feeling of kinship with peers gives a child some emotional support, although girls and boys experience this in somewhat different ways.

Girls are often expected, even encouraged to maintain a closer attachment to their mothers than boys are usually permitted. So, girls may have less of an urgent need for group or "gang" membership. They may associate within smaller groups; perhaps intimate twosomes or threesomes (McCollum, 1981).

For boys however, the peer group is an extremely important proving ground. Especially for boys approaching puberty (10 and 11 year olds), they may have heightened concerns about their maleness. It is within their peer groups that boys develop their

identities. Basically, children fear rejection, although their fears may be expressed in a variety of ways.

The chronically ill child may imagine that other children will think that they are "weird" or a "freak." They may fear that they will be teased, or picked on or talked about (McCollum, 1981).

### **School absenteeism a way of coping?**

Another topic that is of relevance to the chronically ill elementary school-aged child is school absenteeism. The ways in which they choose to cope with being absent from school forms another important dimension to their coping. Weitzman, Klerman, et al. (1982) have looked at the important role of school absenteeism and has concluded that both prolonged and brief absences can interfere with a child's academic performance and peer relationships in a school setting. They go further to note that many chronically ill children miss much more school than can be attributed to the severity of their underlying biologic problem or the functional limitations imposed by it. These children report multiple minor or psychosomatic complaints, such as frequent upper respiratory infections, headaches, stomachs, or menstrual cramps as the cause of their absences. If indeed this were the case that the reasons for the absences were due to minor complaints then why would these children be missing multiple days of school? One must therefore begin to look at alternative reasons for their school absenteeism. If their school absenteeism is not a result of acute exacerbation of their condition, outpatient health care-related appointments, or hospitalizations then other considerations must be looked at. Other explanations must be sought outside of the child's medical problem or treatment that may interfere with the child's participation in regular school attendance. The importance of regular school attendance is stressed because this as well as success in school suggests overall adjustment and an ability to compensate for their problem (illness) and utilize residual skills without succumbing to a sense of despair (Weitzman, Klerman, Lamb, et al., 1982).

### **The impact of parents and school staff on coping**

Helping a child deal successfully with his/her disorder in school requires the active participation of parents, principals, teachers (including physical education teachers) and school nurses. Many parents may attempt to conceal their child's condition from school staff, fearing that knowledge of it might somehow arouse negative, pitying, preferential, or discriminatory attitudes and treatment of the child.

In reality, the opposite is normally the case. The school staff will, without accurate information, be forced to make their own interpretations of what they observe. These interpretations, perhaps based on what is imagined or rumored about the child's disorder, may be incorrect and lead to unrealistic expectations. For example, teachers sometimes mistakenly suppose that children with certain chronic illnesses are likely to be intellectually dull. Therefore, they may expect low level performance from the child. Children with chronic illnesses are sometimes smaller than average as is often the case with IBD children. Frequently the steroid-based medications tend to stunt their growth over time. Due to this, teachers (and others) may tend to perceive these children as being younger than their actual age, and respond accordingly (Perrin, Ramsey et al., 1987).

## Models of Coping

Drotar (1981) notes that research on the effects of chronic illness on children's lives has been dominated by a personality paradigm with a focus on differences between chronically ill and physically healthy children. Factors that influence successful coping have been neglected and it is Drotar's suggestion that research concentrate on adjustment, the efficacy of psychosocial interventions and more broadly, on successful coping. While there is relatively little current empirical data on the positive processes by which IBD children cope with the stresses of their chronic illness, Wertlieb, Weigel & Fieldstein, (1987) have used a transactional model of stress and coping processes developed by Lazarus and colleagues (Lazarus & Folkman, 1984), Lazarus & Launier, 1978). This transactional model was created to measure how children cope with stressful life experiences. In particular, they were interested in what problem solving and emotion-management strategies children used. These researchers created a methodology for assessing children's self-reports about coping, what Wertlieb, Weigel et al. (1987) refer to as "meta-coping". Essentially, "meta-coping" refers to the way in which an individual expresses their coping (which may result in a dimension of coping in and of itself). Wertlieb noted most importantly that the child literature on this approach is limited, underlining one of the main reasons for carrying out the study that is being reported here.

My research aims to build on Wertlieb and Lazarus's work by expanding their framework to include IBD school-aged children. From the children's self-reports, themes will be derived which can be later grouped into categories. Parallels may be drawn between the previous transactional coping categories and these new IBD coping



categories. In addition, it is intended to add to Wertlieb and Lazarus's work by detailing the coping techniques of IBD elementary school-aged children.

The end result will be a structured picture of coping used specifically by IBD school-aged children in Montreal that can be further explored in future research.

Lazarus and colleagues had determined that some of the coping strategies that chronically ill children might choose to employ may involve:

- 1) denial or minimizing the seriousness of the situation
- 2) seeking relevant information
- 3) rehearsing possible outcomes
- 4) seeking emotional support from family, friends, medical staff
- 5) setting concrete goals, finding a purpose or meaning in life events
- 6) the mastering of illness related self-care tasks

This structure helped me to design the interview guide (Appendix A). The previous research findings helped me to determine those areas that may be potential areas of coping within my own IBD study population. I was then able to adapt the previous categories into open-ended study questions used in the interview guide. The present study asked if IBD elementary school-aged children used similar coping strategies to other chronically ill children. And if so, in what ways were they employing these strategies in their daily school routines?

Wertlieb and colleagues conducted a longitudinal study of stress and coping on a hundred and seventy-six school-aged children. In their study they analyzed responses to questions about how the children dealt with stressful experiences in their lives. The data was coded along the following dimensions:

1. Focus of coping behaviors. (Self, environment, or other)
2. Function (Instrumental problem-solving behavior versus emotion-management coping behavior)
3. Mode (Information seeking, direct action, inhibition of action, or intrapsychic)

Similarly, this study was interested in school-aged children's responses about how they dealt with stressful life experiences, however, in this study stressful life experiences have been limited to IBD symptoms experienced at school. At the outset, it was not known if the three coping modes derived by Wertlieb and colleagues would apply to this specific population. This study used Wertlieb 's coping framework to begin to examine the variety of coping strategies that IBD children employed and the factors that affected their use of self versus environment-directed modes of coping.

## Chapter 2

### Research Methodology

#### Purpose

The goal of this study was to uncover the type of coping strategies used by a small group of eight school children in Montreal, Quebec aged 6 1/2-11 and afflicted with IBD. In particular, the study explored through self-reports the techniques the children employed to help them to cope with the physical symptoms that accompanied their illness while they were at school.

The school environment involves psychological/social and learning elements. The focus of this research was to determine how these IBD children managed or coped with these two elements in their school environment. Thus, the study sought to determine the specific strategies that these children used that enabled them to manage or cope with the social and learning elements of school. As well, the present research sought to identify, from the children's perspectives, any major obstacles that they encountered and had to surmount in order to achieve a daily routine similar to that of their peers.

For the purposes of this study, 'type of coping strategy' was defined as the means or the way in which an ill child arranged his or her life in relation to their education. Strategy involved techniques actually employed by the ill child to deal with his/her illness and its consequences.

## **Study design**

A qualitative methodological approach was used. That is, the study was exploratory rather than experimental. The purpose was to illuminate experience (social phenomena) from the point of view of the participants (Denzin & Lincoln, 1998). It sought to raise possible questions for further study rather than test specific hypotheses.

Qualitative research places great emphasis on the influence of the researcher. Unlike quantitative research where replicability is essential to validity, qualitative research places importance on the researcher's point of view. The goal of this study was not to pool results from a large population of IBD children in order to generalize their experiences to all IBD children. Rather the goal was to provide a platform and a forum in which eight Montreal IBD elementary school-aged children could express their thoughts, feelings and recount their experiences for others to learn from. This study captured ill children's personal experiences so that school personnel and others involved in the children's schooling could understand the problem and be better prepared in the future to assist the children in their efforts to persevere in school and realize their full potential.

The study provided a context in which children's views about their illness were heard as it related to their experience at school. Their stories, or narratives, elicited through 'informal interviews' took the form of friendly discussions and were then analyzed thematically as well as for 'exceptional' cases. In qualitative methodology it is sometimes the exceptional case that provides insight into a larger problem.

The research methodology employed in this study was 'Grounded Theory' (Dey, 1999) because it was most suited to this particular situation. In grounded theory, the researcher begins with a research situation, as was the case in this study. The researchers'

task is to try to understand the situation through observation, informal conversation and interviews. In my case, the intent was to comprehend how the participants managed their roles or in this case how IBD children managed their symptoms while at school.

The discussion/interview technique was particularly suited for use with these children. In grounded theory, interviews are often the main source of information from which a researcher develops their theory. This approach allowed for each unique story to be told and tape recorded. What emerged was what Glaser (1998) termed an “emerging theory”. This is a theory that is born out of a situation. It is the “situation” that fits the theory and therefore helps the participants to comprehend their experiences.

An "elite" type of discussion-interview was used because the children were the experts about their disease and their experiences. They were asked open-ended questions (Appendix A) which allowed for the role of the researcher to be played in a non-intrusive and non-threatening manner. This is a role that my prior research experience with IBD and other chronically ill children had prepared me to play.

In grounded theory, the interviews are the main source of information from which the theory is developed (Dick, 2002). Using grounded theory methodology, the first interview was truly exploratory in nature. The questions were asked to try to gain a sense of the “situation” and the meaning of the situation from the participants’ perception. Subsequent interviews built on the first interview and used key-word notes to establish categories, which in turn built an emerging theory. This process is called “constant comparison” since the first interview or set of data was then compared to subsequent ones and then later served to be compared to an existing theory (Dick, 2002). Categories were

created once certain ideas or key words were noted with high frequency. That is, categories are themes or variables, which makes sense of what a participant has said.

One of the unique features of 'constant comparison' is that in the first interview I was merely trying to get a sense of how an IBD child managed and arranged their school environment. Bearing the first interview in mind in the second interview I listened for similar topics to emerge and after transcribed, coded and highlighted similar key words and phrases that were used. Subsequent interviews followed the same procedure, each interview building on the previous one, which in turn helped to form a clearer picture of the situation each time.

## **Recruitment of participants**

A list of 195 patients presently being followed at the pediatric IBD clinic of the Montreal Children's Hospital (MCH) in Montreal, Quebec, was obtained from the attending Gastroenterologist who co-supervised this study. From this large pool only 15 patients met age (between 6 ½ and 11 years of age) and language (English speakers) criteria for the study.

Following this, I met with the two MCH Gastroenterology (GI) nurses to discuss which of the 15 patients would be particularly engaging, reflective and thoughtful, or would have had significant disease-related experiences to provide the most insightful information. At this meeting the 3 patients were further excluded for any of the following reasons:

1. Psychiatric/emotional problems that contraindicate admissibility of being included;
2. Language or cognitive difficulties that might affect the content of the interview;
3. Additional major chronic illnesses that might distract from the focus on IBD in children.

This resulted in a list of 12 potential participants (10 boys and 2 girls) of which I proposed to interview only eight. The end result was a sample of seven English-speaking boys and one English-speaking girl between 6 1/2 and 11 years of age.

Limited demographic data was collected on all participants. A patient data form for each child was created to record their age, gender, level of education, duration of symptoms/diagnosis, medications and type of disease (CD or UC).

## **Procedure**

For the study to proceed, ethical approval was obtained from Concordia University's Board of Ethics (Appendix B), the McGill University-MCH Research Institutes Research Ethics Board (Scientific Review Committee) (Appendix C) and the MCH's Research Ethics Board (REB) (Appendix D). Obtaining ethical approval from these various institutions was a lengthy process, spanning close to a year. I have outlined the steps in the process below:

1. Concordia University Board of Ethics, granted approval February 2003
2. Approval required from McGill University-MCH Scientific Review Committee
  - a) First submission to McGill-MCH's 3 Scientific Reviewer's June 2003.
  - b) Revisions to proposal made.
  - c) Scientific approval granted, September 2003.
3. Approval required from MCH's Research Ethics Board (REB)
  - a) Revisions made to consent, assent and introductory letter, October 2003.
  - b) All forms used in study translated into French, November 2003.
  - c) Translations examined by MCH's translator and approved.
  - d) Final MCH's REB approval granted, December 2003.

Upon receiving ethical approval from all the required institutions the twelve IBD families were mailed an introductory letter (Appendix E) that explained the study and invited them to participate. A week later these families were contacted by telephone to ensure that they had received the letter and to determine if they were interested in participating in the study. One parent contacted the interviewer directly to arrange an interview date. Of the eight interviews that were scheduled two took place at the



Gastroenterology clinic at the MCH while the remaining six were held at the participants' homes.

### **Ethics**

Study participants were assigned a study number, which was used to identify all recorded data (taped or written). None of the participants were identifiable in any verbal or written reports. Patient hospital chart information remained strictly confidential and could only be reviewed while in the MCH. Personal identification data such as participants' name, telephone number, or personal address were kept in a separate participant log and matched to a study ID. Parents of study participants signed and received copies of an informed consent form; study participants signed an assent form, prior to enrolment into the study. Participation was purely voluntary. Participants were permitted to withdraw from the study at any time without jeopardizing their care at the MCH. Once again all information will be held confidential and will not be released to any third parties. In order to ensure confidentiality, participant's actual names were not used within this document. The names chosen were arbitrary and did not resemble the participants real names in anyway.

## The Setting

### **The Montreal Children's Hospital Gastroenterology clinic**

Participants arrived on a day in which they already had an IBD appointment scheduled. They waited in the waiting room. When it was time for their interview the researcher paged the participant over the clinic intercom. The researcher then led both the participant and their parent/guardian into one of the clinic's examination rooms where the interview would be conducted. Before the interview could begin two copies of a consent form were provided (Appendix F) in order to obtain parental consent. Both copies were signed and the parent kept a copy and the researcher kept the other copy. Once parental consent was given the participating child was given two copies of an assent form (Appendix G) that they signed twice. The child kept a copy and the researcher kept the other. A final form was presented (Appendix H) for the parent/guardian to sign that granted the researcher permission to review the child's MCH medical chart.

The study was further explained and the researcher made sure to inform the parent and the child of their right to stop or withdraw from the interview or the study at any time without any repercussions or consequences to their future care at the MCH. Following this, if the parent or child had no further questions then the parent was asked to please wait for their child in the waiting room for the duration of the interview.

## **Home visits**

Most of the IBD families were unable to go to the MCH's IBD clinic or did not have a clinic appointment scheduled within the time frame of this study. Therefore, they found it more convenient to do the interviews in their homes. During the home visits a quiet area or room (usually the living room) in the participants' home was used to conduct the interviews.

The same procedure for obtaining consent that was used at the MCH IBD clinic was followed and parent and child signed the same consent and assent forms. The researcher provided the same information regarding voluntary withdrawal from the study. Then the interviews began. At times parents or siblings were present during the interviews but were asked to let only the participant speak and to refrain from asking any questions until the interview was completed.

I interviewed the eight children once. Interviews took the form of open discussions but all participants were asked the questions outlined in the 'Interview Guide' (Appendix A). The interviews ranged from 30 minutes to 1 hour 30 minutes in length. The average interview lasted approximately 45 minutes. All the interviews were followed by a discussion with a parent, which was usually the mother. These discussions proved to be of great importance; they served as an opportunity for me to verify and often clarify the child's statements as well as gain additional information regarding the child's school and IBD experiences. Essentially, this final stage served as a method of 'triangulation' and validation. That is, data came from three main sources: the child, the parent and the child's medical charts.

After each interview the contents of the tapes and notes were transcribed. Upon completion of the eight interviews, analysis of the data consisted of looking for themes and similarities among the stories. For example, I sought to determine if there were specific, staff, friends, or family members that IBD children reported that they leaned on when they were suffering from their symptoms at school. I also sought to identify any 'action plan' that they employed when feeling ill at school.

## Chapter 3

### Analysis of Data

#### General patient characteristics

The sample population was a heterogeneous mix of eight English speaking IBD children from different socio-economic backgrounds, races, and cultures. Six of the children had CD, and two had UC. Two of the eight children were of Jewish Heritage and two had a family history of a father with IBD. Three were representatives of ethnic groups (Black, East Indian, and Greek). Two children had either a twin brother or sister. Seven of the eight children attended an educational institution while one child was home schooled. Of the seven that attended school three were enrolled in private schools while the other four attended public schools. The sample was limited in terms of gender; there were seven boys and a single girl.

This sample had a good mixture of varied personalities; some children were very much introverted while others were extroverted and heavily involved in their schools' activities. The children also had varied academic abilities, from being in advanced classes within their grade level to being diagnosed with various learning disabilities and lagging behind in their grade level. The families were socio-economically diverse, including upper middle class, middle and working class and low-income families receiving public assistance. The parents included married couples, and single mothers. Interestingly, despite there being two-parent families, seven participants had mothers as the primary caregivers in regards to attending to their child's IBD needs. The children ranged in age from 6 1/2 to 11 years of age. Some of the children were newly diagnosed

while others had been hospitalized or had surgeries for their IBD. Some children were taken off all medications; some were balancing their prescribed medications with homeopathic medicines, while others relied solely on their prescribed medications. Despite their IBD symptoms these children in general, were candid and for the most part spoke openly during the interviews.

From our conversations, it became apparent to me that these children shared some important qualities when talking about their school experience:

1. All eight children liked school or their learning environment as in the case of the child that was home-schooled.
2. They all had specific classes or courses that they enjoyed at school.
3. They were all physically active often participating in sports in gym, during recess, and after school activities.
4. They all had friends that they interacted and played with at school and outside of the school environment.

### **Emerging themes on IBD coping strategies**

Interviews were tape-recorded and brief notes were taken. A component of grounded theory uses key word note taking, therefore I took down notes that were later coded and translated into themes during the analysis phase.

A number of themes emerged from the interview data. For example, in the first interview Paul mentioned that when he doesn't feel well in class he simply rests his head on the desk. He also complained of having headaches at school, rather than stomach cramps as I had anticipated hearing about. Keeping Paul's responses in mind, when

conducting my second interview with Peter I asked once again what strategies were used when not feeling well in class. He responded somewhat similarly in that again he mentioned that he too occasionally rested his head on his desk and waited until the class was over. As I coded like responses, patterns developed and I was able to group like responses into four major categories. I have grouped the children's responses into the following four main categories:

1. Self
2. Parent(s)
3. School
4. Friends

These four categories are arranged in a hierarchical fashion. The coping strategies that I was interested in establishing first were those strategies that emanated first from the child's own initiatives or actions. There were two coping categories in which the child was the primary instigator for deriving a solution to their IBD woes. Within each of these four categories there are smaller units that summarize the major ways in which the children coped with their IBD while at school.

## Chapter 4

### Interpretation of Data

#### **The Four IBD Coping Categories**

The IBD children's responses became themes that were grouped into the following four IBD coping categories:

##### 1. Self

After talking and listening to these children it became clear to me that there were three major areas in which they assumed responsibility for looking within themselves for solutions to their IBD needs while at school.

##### **❖ Deciding what to tell friends and peers regarding IBD**

The parent(s) in all cases were responsible for alerting the school staff regarding their child's IBD and the accompanying symptoms; however, in the child's daily school routine it was the child's responsibility to tell their friends and find ways to explain to their peers why they had been absent or had prolonged absences, why they had particular facial disfigurements (i.e. cushioned cheeks) and why they had to take particular medications at lunch time. In general, the children chose to disclose very little about their illness often replying simply that they had missed school because they weren't feeling well or because they were sick. Only Anne and David were forthcoming with others stating matter of factly that they had CD, had to have blood tests done or had to be hospitalized for their CD.



### ❖ **Monitoring own health and medications**

No one knows nor seems more knowledgeable about their bodies than these young children. This fact became evident as all eight children shared their stories of surgeries, trials on various medications and the myriad of side effects that often accompanied their prescriptions. They vividly described the IBD symptoms they suffered while at school. None of the children were actually able to give me the name of their particular medications. However, they were all able to describe it's flavor and form (liquid or pill) as well as tell me the frequency and times at which they needed to take their medications. David had recently been taken off all of his medications and was able to recount why this had occurred. He described the terrible stomach cramps and aggravated IBD symptoms that he had endured that forced his GI staff to discontinue all medications for a trial period. Having information about their medication use is extremely important and in the case Anne, being knowledgeable about her medications and being able to administer them by herself will present her with an opportunity to gain a sense of independence when going away to Girl Guide camp this summer.

Information about their bodies and health is also critical to keeping them safe and helps to minimize possible flare-ups (recurrence of symptoms after a period of good health,) as George told me, "I like bacon and sausages but I'm not allowed to have it". David shared that he was allowed to eat most foods except popcorn but that, "it's alright because I don't like it anyways". As for Tom, he complained that it wasn't fair that he couldn't eat candies or any of the other foods that his brother and sisters ate. Despite his feelings of difference and knowing that he has to eat gluten free spaghetti and his mothers' homemade candies made of pure organic honey, Tom was very conscious that

should he eat like his brother and sisters the repercussions would be disastrous. He could experience anything from anal swelling forming puss and sores from the frequent bathroom use to recurrent bloody diarrhea and cramping stomach pain.

❖ **Changing the school environment to accommodate IBD needs**

One of the most insightful findings came from David's actions or initiatives to make his school environment better. He had recently been elected class ambassador and when I asked what this entailed he shared that he had formed a committee mandated to create and enforce changes to their school. Upon further probing I learned that the first areas that were transformed were the bathrooms. A massive transformation had taken place as the committee created posters with slogans to inspire their peers to help to maintain a clean bathroom. As this story unfolded, I was able to deduce that this major bathroom clean up was of great importance to this IBD child because of the simple fact that he spent so much time in that particular room due to his IBD symptoms. David's frequent trips to an unsanitary bathroom prompted him to insight change to his school environment. He became cognitively aware that there was something in his power that he could do that would not only benefit him but his peers as well. David was an exception as most of the IBD children I interviewed relied mainly on a parent or school official to help create any needed changes that would help to alleviate their IBD symptoms while at school.

## 2. Parent(s)

IBD children appeared to rely heavily on the intimate relationships that they had established with their parents. The connection seemed vital to their ability to cope with their IBD while at school. Unlike the previous category of 'self' here the strategy that the children are utilizing involves looking outside of themselves to their parent(s) to aid them with their needs within their school environment. Sometimes this was due in part by the fact that their voice and actions were either not enough or went unheard. For example, George's homeroom teacher was constantly stamping his school agenda with 'frowning faces'. These pictures of sad faces were given to him because his teacher reported frequently that he was lazy and did not participate enough. George brought his agenda to his mother's attention and explained that this was not the case. He had tried to explain to his teacher that he was indeed trying his best. The negative attention from his teacher was making George quite unhappy. George's mother wrote and had to approach her son's homeroom teacher. She had to explain that due to George's IBD there would be periods when his medications and/ or symptoms would make him feel tired or fatigued. However, this did not reflect his disinterest or an undesired to participate fully in class. Had George's mother not confronted this teacher, George would have remained unhappy and misunderstood by his homeroom teacher.

In my brief encounters with the IBD parent(s) and their children, (whether it was in their homes or at the MCH) I observed that the love and open communication between these children and their parents was quite evident. Despite their young age the children dialogued frequently with their parents, so these parents were fully aware of any difficulties that their children were encountering at school and all parents were very

proactive in fighting for certain rights that they felt their child deserved or had asked for. Love, caring and tenderness were exhibited often. Regularly during my encounters I witnessed parents hugging or caressing their child (Example stroking their face or patting them on the head) before, during or after the interviews. It was also common to find a parent (mother) speaking about their IBD child with great emotion that reflected in their tone of voice and facial expressions (Example, eyes filling with tears or a fearful expression).

❖ **Updating parents regarding teachers' behavior(s) and any school concerns**

A good example of this came from Tom who was home schooled. According to his mother she actively fought for changes within her sons' public French Immersion School. However, she lamented that she was often left dissatisfied. She explained to me that every morning she would kiss Tom and send him off to school with a positive attitude and he would return home a changed child, one with low self-esteem and very sad. Her son would explain that he was often asked to sit in the corner as punishment as he was often behind in assignments due to absences from school that were usually due to his illness. Also, his teachers would not permit him to go to the bathroom as frequently as he needed which left him having accidents (diarrhea) in his pants. Upon receiving this kind of feedback from her child she decided to educate at home all four of her children with what appears to be great love, devotion and a full academic curriculum. This unique case will be further discussed later. This example illustrates the importance IBD children place in relaying information regarding school staff and peers' behaviors in relation to

their IBD symptoms. Without this coping strategy the IBD child is left alone to suffer in silence with their symptoms while at school.

❖ **Updating parents regarding any bodily concerns**

This topic appeared several times in the transcripts and was echoed frequently by all of the IBD children interviewed. In our conversations they disclosed discussions they had had with their parents whenever they didn't feel well. These talks and frequent dialogues between child and parent revolved around the child's bodily concerns or the outcome while on their medications. These talks lead parents to come to decisions as to what actions they should take to address their child's concerns. It seemed imperative to these children that their parents be made well aware of any IBD symptoms that they might have been experiencing while they were at school. I came to realize that these children relied greatly on providing current information to their parents about how they were feeling, who in turn they trusted to make any necessary arrangements. Such arrangements included granting permission to stay home from school, making follow-up hospital appointments, asking their teachers for free passes to the bathroom, asking physicians to alter prescriptions, alerting school staff of any side effects their child might experience while at school due to their prescribed medications, etc. From the numerous examples provided, I will present one case that illustrates the ways in which an IBD child used 'updating parents regarding bodily concerns' as a coping technique at school. In an interview with George, I was told that he had difficulty seeing the blackboard and had asked his teacher if he could possibly change seats and seat nearer to her, which would also place him closer to the blackboard. George's frequent requests were ignored and so

he shared his problem with his parents. His parents in turn, made an appointment to meet with the teacher to discuss the issue. According to the George's mother, the teacher was still most unwilling to relocate him, however, she did promise to move him. Had George not approached his parents, it is highly unlikely that any change would have occurred at all. George did not wear glasses, however, a complication of IBD is 'uveitis' which is redness and discomfort of the eyes which may be a reason that he may have been experiencing difficulties seeing and wanted to sit closer to the blackboard.

### 3. School

The school environment was examined solely from the child's perspective. That is to say, school staff was not consulted to present their point of view of the IBD child's situation nor behavior within their specific school. However, the children had many insightful examples of their IBD experiences and the different methods that they used to cope with their various IBD symptoms while participating in their daily school activities. The coping strategies mentioned most frequently are presented as follows:

❖ **Establishing or knowing their support system when IBD symptoms present themselves**

In some cases the parents instructed their children how to proceed when feeling ill at school. A typical set of instructions were usually to first alert their teacher who in turn would grant the child permission to either see the school nurse or visit the principals' office to place a call to a parent. Some children were more proactive and would provide their parent with their own system or process that they would engage in should they not

feel well at school. For example, David, one of the more extroverted IBD children that I spoke to, is very independent and if he feels unwell in the morning he approaches his mother and tells her that he will not be able to attend school and needs to stay home. His mother allows him to gauge how he is feeling and determine if he will be able to cope with his school environment that day. What makes this a good example is that academically David is not negatively affected by his decisions regarding when he needs to be absent from school. He is in advanced classes for his grade level. There were other children like the two 11 year olds (Anne and Scott) who similarly played a large role in establishing their own support systems at school and relayed the procedure to their parents.

#### ❖ **Alerting teachers when not feeling well**

For all the study participants, teachers were usually the first person they contacted when feeling unwell in class. The children spoke of the different approaches that the teachers took to their disclosures. The approaches seemed to vary according to the relationship the teacher had established with the child, the role the teacher played (eg, gym teacher versus a homeroom teacher) the teacher's personality, the amount of knowledge or information the teacher had about the child's illness and the length of time the teacher had known and interacted with the child.

According to the seven children, they usually had at least one teacher that knew them from Kindergarten that is to say from age 5 or 6. In these cases, the children perceived their teachers as being more empathetic since they had previous knowledge and experience of the child and their illness. Coping was often easier for these children as

they were often permitted to leave the classroom when needed and teachers were more willing to help in the arrangement of missed assignments. Unfortunately, this was not always the case, of the seven IBD children attending school, four still had teachers that were neither empathetic nor sympathetic to certain IBD needs. For example, teachers' responses to the IBD child ranged from ignoring the child's bathroom requests to yelling and punishing them. Punishments ranged from giving stickers and stamps with frowning faces in their assignment books, poor participation marks on their report cards noting that the child is often lazy and unwilling to participate, being made to sit in a corner, or ignoring certain requests like changing seating locations. I must also emphasize that these behaviors continued despite parental influence and attempts at educating and informing the respective teacher about their child's IBD.

❖ **Arrange homework with friends, family or school staff**

Usually being unwell for lengthy periods of time as well as having a myriad of hospital appointments resulted in multiple school absences. I was therefore interested in discovering what happened to the assignments that were missed. Were the children able to catch up, and if so, how? Were they able to stay abreast of the classroom material? In this mixed group of eight children some were able to keep abreast of their assignments while others were struggling and falling behind. The reasons for academic success versus failure stretched beyond IBD itself. There were often factors involved that were unrelated to IBD such as speech impediments and learning disabilities. The IBD factors that influenced a lag in the child's school success usually had to do with the gravity and duration of their symptoms. The worse their IBD symptoms, the more likely that the



child would be hospitalized and miss many school days. It is important to stress however, that school absenteeism often did not equal school failure. At least five of the eight children (Anne, Scott, Paul, Chris, David,) were performing at their appropriate grade level or higher despite their school absenteeism. They would often employ the help of classmates, friends, siblings, parents or school staff who would either bring assignments to the child's home or to the hospital. Once again, some children assumed responsibility for their homework arrangements while other children relied on others (parents, friends, siblings or teachers) to help. What I found particularly touching was that Paul who had to be hospitalized at the MCH for almost 2 weeks had his assignments hand delivered to him at the hospital by his homeroom teacher. I found this story particularly touching because IBD children typically reported scenarios that were contrary to this example. Quite often they had experienced teachers who were not at all empathetic to their IBD needs, a point I will explore further in the section on 'recommendations (page 48).

#### ❖ **Talking to school staff**

The children reported that even though their parents had contacted the school and alerted the appropriate school officials, they still had to spend time dialoging with various school staff to further explain their IBD needs. For example, David spoke to his school nurse about his CD, and she allowed him to stay in her office as long as he needed whenever he was experiencing his IBD symptoms.

#### ❖ **Obtaining missed homework**

Some IBD children were fortunate enough to have teachers who would collect missed assignments and either hand deliver them to the ill child or assembled them to be picked up. Other children contacted friends to inquire about assignments they'd missed while some parents assumed responsibility for gathering and supplying all the missed assignments.

#### ❖ **Obtaining a school pass granting free access to bathroom facilities**

Interestingly, about half of the IBD children interviewed had received permission from their teachers to exit the classroom whenever they deemed necessary. This access was called 'a free pass'. I was unaware that this concept existed and the children as well as their parents appreciated that this option was available to them. With the 'free pass' the child did not have to draw unnecessary attention to her/himself and did not have to remain in the classroom in pain. This also helped them to minimize any 'accidents' (defecating in their pants) that they often encountered when having to wait too long to be granted permission to leave the classroom by their teacher.

#### 4. Friends

##### ❖ **A resource for homework and play (socialization)**

All eight children spoke often of their relationship with their friends. They all had friends though the number varied; some noted that they had many friends while others named only a few. The role that their friends played in terms of being helpful to their coping was that friends provided an environment for play (socialization). This was important to these children because despite their illness they were active energetic children who enjoyed playing sports at recess and gym, as well as engaging in extra-curricular activities in and outside of school with the same friends. So it was common to find that they interacted with the same set of friends in and outside of school. When with their friends these IBD children were having fun and were given the opportunity to be distracted for awhile from their symptoms. The after school activities mentioned most often were sports, playing video games, birthday parties and visiting one another's homes.

The friends were also a helpful resource when it came to providing missed assignments. Usually it was a friend that would bring the IBD child's homework to their home when the child was sick in bed. Friends also served as a link keeping these IBD children abreast of the current school news that they may have missed while absent. The eight children spoke fondly and enthusiastically about their friends leading me to conclude that they are an important component to an IBD child's world of coping.

## **Suffering Through It**

The information provided by the eight children really made me aware of their resilience in the constant daily challenges they faced when coping with their illness. This category is entitled, 'suffering through it' because it appears that all of the children found themselves experiencing their IBD symptoms and there was often little that they could do to better the situation. The coping strategies in this category could be further grouped into three main areas.

### **Area 1: Altering school environment**

In the first area, the IBD child tried to alter their school environment in a way that helped them to bear the brunt of their symptoms. Some examples given were bringing a box to class to elevate legs or bringing a hemorrhoid cushion to class.

### **Area 2: Suffering in silence**

Whereas in the second area their coping strategies were not at all proactive, it appeared that sometimes they chose for whatever reasons to simply 'suffer through' their symptoms until they subsided without alerting or initiating any assistance. In this area it was as if trying to change their school environment seemed futile and it was easier just to suffer in silence. Some examples given were putting head on desk for duration of class, remaining in soiled pants, in pain but remaining until class is over and or refraining from taking medications at school.

At least half of the IBD children interviewed had or continued to refrain from taking their prescriptions while at school. Their reasons varied from forgetting to take their medications to experiencing difficulty in taking their medications while their classmates were around them at lunchtime. For example, David described how he has to quickly swallow his medication before his friends see him at lunchtime. He does this by holding his lunch bag to in front of his face so that his mouth is hidden and then with his other hand he grabs his bottle of medication and quickly drinks it.

### **Area 3: Taking action**

In the last area the child's IBD symptoms sparked them to initiate some type of action. Unlike the previous category, they chose to do something to alleviate their symptoms. Some examples visiting the school nurse, staying indoors during recess, spending half days at school, sitting out of gym class.

### **How do IBD children use the three 'Suffering through it' areas of coping?**

Despite the children's varied personalities they all drew from at least 2 of the 3 areas at different times. Their choice of which area to draw from was dependent on how severe they perceived their symptoms, their established system of support when IBD symptoms presented themselves, their personality, and how they felt about themselves when among their peers. It was not uncommon for a child to use one coping technique from each area or a combination of techniques within a given area. The following example illustrates these coping areas and how they were used. George chose to abstain from taking his medications at lunch time because he felt self conscious around the other children (Area

2) and this was a daily occurrence. Then on some days if he wasn't feeling very well he'd choose to stay inside during recess and spend his time on his drawings which he loved to give to his classmates (Area 3). This was a sporadic occurrence.

On occasion, George would experience difficulty at the end of the school day because he would find himself in soiled pants either on the bus rides home or at school (Area 2). These accidents resulted from a sudden flare-up, not being permitted to go to the bathroom soon enough, or the bathroom being located too far from his classroom.

## Chapter 5

### Relevance of Study and Limitations

#### Study relevance

Available data on the impact of chronic illness on children's cognitive and social-emotional functioning suggests that most children with chronic illness do not manifest intellectual impairments nor psychological disturbance and that there is no "personality type" characteristic of this population. However, most research on the impact of pediatric IBD has focused on potential psychopathology or dysfunction, and there is to date very little information concerning clinically ill children's coping styles, their understanding of coping processes ("meta-coping"), or the factors that contribute to successful coping in this population. In addition, children's perceptions of the chronic illness experience and its effects on their lives and their families have not been well studied.

Fact that the course and symptoms of IBD can fluctuate in an unpredictable fashion, often requiring long-term medication, hospitalization, or surgery, raises coping techniques and strategies as key factors in helping sufferers maintain their emotional and social function. The high North American prevalence and rising incidence of the pediatric IBD over the last few decades places emphasis on the importance of finding ways to help patients deal with its consequences while awaiting a cure.

In view of the above, this research generated potential avenues of inquiry and hopefully provided a framework to further study the use or misuse of coping mechanisms by pediatric IBD patients. Conducting this type of research is of critical importance in generating awareness about this illness and helping to address changes that need to be made to the school environment in order to maximize these children's potential for

academic success. Hopefully, it will give some attention and insight into possible issues for IBD children to be studied within a larger population. It is also anticipated that the findings may benefit children with other forms of chronic illness.

### **Study Limitations**

The fact that childrens' viewpoint was sought may be perceived as a limitation of this study, as readers may question the ability of children to elaborate on abstractions such as feelings, attitudes and perceptions, or reliably report on their own behavior. However, previous studies on quality of life in pediatric chronic conditions have shown that children as young as age 12 were able to place a value on their own health state, which often differed from ratings by their parents (Saigal, Furlong, Rosenbaum & Feeny, 1995).

It is also questionable whether parents can reliably report on experiences that almost exclusively occur in school, hence in their absence. According to Haggerty (1975), studies have shown that parent reports tend to overestimate the prevalence of clinically diagnosed chronic conditions; this over-reporting declines with the severity or perceived stigma of the condition. And although teachers could be conceived as reporters for observable behaviors, they cannot report accurately feelings, attitudes and perceptions of children. It is for this reason that this study relied solely on children's responses, as they were the ones afflicted with IBD and were best capable of expressing their needs, fears, goals, and difficulties at school.

IBD children proved challenging to interview; interviews had to be conducted whenever and wherever possible. There were times when an interview was scheduled on a specific day and at a particular time but had to be postponed because they child had to



be admitted to hospital, or the interview had to be initiated right away since the child was finally feeling well at that particular moment. As a result some interviews took place while the child was physically feeling well and other times when they were actually physically quite ill. This may have impacted the way in which the children responded to the questions I asked. Also, as an interviewer meeting these children for the first time I felt that I required more than one visit to build on their initial answers and ask them even more questions.

Some children were really quite shy and required a lot of prompting and distracting before the interviews could actually begin. This was probably due to the fact that I was a stranger to these children; it was our first encounter and so I had not had the opportunity to build rapport with them. Had rapport been already established conversation would have flowed easily since an element of trust and familiarity would have been in place and they may have been more forthcoming with painful and problematic situations that they may have encountered at school.

## **Recommendations**

If we are to continue to have school systems that purport to support inclusive education, then IBD children become important; unlike their healthy peers, they require some additional needs from their school environment. Meeting their special and particular needs is essential to helping these children to cope and thrive with the same opportunities as any other school child.

I would like to stress at this point that my research findings led me to conclude that in general schools whether public or private were making efforts to accommodate the diversities in their schools and their hard work is reflected in the seven IBD children's positive responses regarding their schools. They articulated their admiration for their school and they were unable to provide many suggestions as to changes that should be made to their schools' environment. Therefore, it appears that in general elementary schools have established a structure that supports these children. However, my observations have led me to suggest that there is still more that can be done to make the school environment even better for these children. In this section I will outline a few recommendations that were raised by the children and their parents that would help in aiding IBD children to cope more effectively with their illness while at school.

### **More IBD psycho-social and health information is necessary for all**

Create a liaison person sometimes referred to as a 'School Clinician'.

This person would be knowledgeable about chronic illnesses in pediatric populations and be hired specifically to bridge the gulf between parents and school staff. This individual

employed by the school, school board, hospital or a community agency would be responsible for fielding calls from concerned parents and setting up information workshops. One of their main tasks would involve disseminating current IBD information to parents and school officials as well as communicating with school staff. This individual would also be required to survey the IBD child's school environment and making suggestions to school officials for improvements. Their ultimate goal would be to act as a liaison between parents, schools and occasionally hospital staff to ensure that appropriate information is delivered and IBD concerns are addressed and resolved.

#### **Support groups for parents of IBD children needed in Montreal.**

There are a host of IBD or Gastrointestinal groups and associations located in the United States. However, there is very little support for IBD families here in Montreal. Due to the scarcity of support, IBD parents have shared their feelings of isolation and their frustration in searching for answers to their questions. What is needed is a chapter of IBD support here in Montréal with scheduled activities, meetings, community presentations, online chat groups and a phone number that anyone can call to receive any IBD information.

#### **Internet**

I am in the process of creating a website ([www.ibdkids.freemove.com](http://www.ibdkids.freemove.com)) devoted to the issues raised in this paper. The purpose of this website will be to fill the void noted previously that arises from the lack of Canadian and, more specifically, local IBD resources and information. This website will take the form of a forum in which IBD

parents can finally share their experiences as well as seek inspiration from the stories of children and families who are employing proactive coping strategies at school.

### **Finding balance**

Public schools accommodate a diverse population and for the most part teachers try to be sensitive to the varied needs of all students. However, sometimes teachers mean well but their actions worsen the situation for the IBD child. For example, Ann tearfully retold an encounter she had had with her gym teacher one day at school. She had been playing with the other children in her gym class when one of her classmates hit her quite forcefully with a ball. In pain, she began to cry at which point her teacher stopped the class and made a point of telling all the students that they need to be careful with this IBD child because of her illness. Anne shared with me that this was an upsetting experience for her because she was singled out and made to feel different. She articulated that being hit hard with a ball would have hurt and made her cry whether she had IBD or not.

The opposite scenario may also be true in that allowing certain privileges to an IBD child may lead to their taking advantage of their given freedoms. For example, Chris informed me that he had been given a 'free pass' to exit the classroom and use the bathroom facilities whenever he felt he needed to. However, this has become a problematic situation. Chris has begun to arrange to meet his friends in the bathroom. He has begun to use his bathroom time for socialization. So, Chris is now abusing a privilege that was granted to him for his health reasons. This situation calls for the teacher to assume some responsibility in regulating the 'free pass'.

The goal in any school environment should be to strive for instituting a school structure that is balanced. However, as these examples demonstrate, it is not a simple

task to establish balance that will always satisfy all parties concerned. At times a child may feel alienated or may take advantage of the privileges they are given.

### **School physical layout**

A school's physical layout is of crucial importance to an IBD child. Most specifically the distance of the nearest bathroom in relation to their classrooms is of prime importance to these children. Having to walk great distances or having to climb a number of stairs to get to the bathroom can prove disastrous resulting in accidents (defecating) in their pants. In designing school structures bathroom facilities should be constructed as close to prime locations (classrooms, cafeteria, gyms etc.) as possible.

### **Home school a viable option?**

For those parents experiencing difficulties with their IBD child's elementary school, (public or private) they may wish to consider engaging their child in the world of home schooling. After interviewing one IBD family who has chosen to pursue this avenue, I was fascinated by how organized and active home schooling has become. In this particular case, this option was chosen because an IBD child's experience in both public and private school were negative. After repeated attempts by his mother to inform and educate school staff regarding her child's illness and not being acknowledged, she made the decision to remove all four of her children from both public and private schools and educate them herself. She possessed a basic education and was unsure as to how to proceed with educating all four of her children. She engaged in a lengthy internet search which brought her to the Association of Christian Parent-Educators of Québec (ACPEQ). With this association she was provided with a support system, an introduction to other

parents and children engaged in home-schooling, a curriculum designed for each of her children's abilities, and a religious (Christian) approach that she also felt was missing from her children's previous educational programs. She was also provided with legal counsel from the Home school Legal Defense Association of Canada (HSLDA). There are various fees involved in pursuing this route of education, however three of the seven IBD children interviewed in this study were attending private schools and had parents who were paying high fees for their child's enrollment but were still dissatisfied with various facets of the school and their child's education. In this particular home-schooling program the parent chooses which disciplines their child will pursue. This IBD family chose Math, English, Gym and Social Studies. They occasionally did some French, however, this was not a requirement of their curriculum. The children were taught at their own pace, and they were not permitted to advance to the next lesson if they incurred too many mistakes in their first attempts. Their mother corrected lessons and then the assignments were mailed to the ACEPQ to be re-checked and graded. Final report cards were issued by the ACEPQ after the children had sat their final exams. Final exams were conducted at home in a specific area designated for tests. In this IBD home their designated test area looked similar to the desks and chairs found in a classroom. The difference was that the desks were separated by a partition so that the children could not see what they were each working on.

In the ACPEQ curriculum daily attendance is taken and there is a daily lesson plan for each discipline (including gym) that is established for the year. The home-school calendar includes Christian holidays like Christmas and days in which a school trip may be taken.

In this case, the IBD child increased his self-esteem as well as his grades by participating in home-school. He also has an active social life as he participates in an activity group for young people held on Saturdays in the Little Burgundy community.

Note: For more information about home-school the reader may consult the Home-schooling magazine [www.homeschoolinghorizons.com](http://www.homeschoolinghorizons.com) or attend one of the home-school conferences by consulting Quebec Home Education Conferences [www.homeschoolcanada.com](http://www.homeschoolcanada.com).

## Conclusion

Montreal IBD elementary school-age children have conveyed important information about coping at school. The findings from this study have shown that IBD school-aged children reported a diverse range of IBD coping strategies. They employed these strategies to help them strike a balance between managing their chronic symptoms and participating in their daily school activities. For some, when this balance could not be achieved in their school environment, alternatives like home schooling became viable options. However, contrary to my assumption, the majority of the IBD children interviewed for this study were satisfied and enjoyed their school environment and had few suggestions in regards to changes that could or should be made.

The research findings from this study show that some coping strategies were used more frequently than others and some strategies required the child's initiative where as other techniques required parents to play a more vital role. Among the most prevalent coping strategies used were those found in the 'Suffering Through it Category'. It appeared that in general the seven IBD elementary school-aged children have learned that the way to cope most of the time at school is just to remain in their environment and suffer through the pain. They choose to suffer until the symptoms subside at which point they can proceed to their next activity or decide to return home for care.

What has been missing from the literature is a systematic description of coping processes that IBD children use. The schema offered in this paper is a step towards studying children's coping processes and the transactional model of stress and coping



provided by Lazarus and Wertlieb provide a conceptual framework for arranging IBD coping strategies into themes and categories that can now be measured in future studies.

With a framework for examining IBD school-aged children's coping in place, we can now move towards achieving a better understanding of how children cope with their illness while attending school. This information is imperative if we are to gain an understanding of sick children's coping processes which has long been considered a crucial task for professionals concerned with children's health and development.

Figure 1

IBD Participant Characteristics

Child	Male/Female	Heritage	Age (years)	Twin	Grade level at school	Type of school	Parent with IBD	Home/Hospital interview
Paul	Male	East Indian	10	None	Grade 5	English Public	None	Home
Anne	Female	Caucasian	11	Has a twin brother	Grade 6	English Public	None	Hospital
David	Male	Jewish	9	None	Grade 4	Jewish school	Father	Home
Chris	Male	Jewish	8	None	Grade 2	Private Jewish	None	Home
Peter	Male	Caucasian	6 ½	Has a twin sister	Kindergarten	English Public	Father	Home
Tom	Male	Black	8	None	Grade 2	Home schooled	None	Home
George	Male	Greek	7	None	Grade 2	Private Greek	None	Home
Scott	Male	Caucasian	11	None	Grade 6	English Public	None	Hospital

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Association of Christian Parent-Educators of Québec (ACPEQ): <http://www.acpeq.org>.

NACC-Services Medical Terms Used in IBD:  
[http://www.nacc.org.uk/serv\\_medical\\_terms.asp](http://www.nacc.org.uk/serv_medical_terms.asp)

Home-schooling magazine: <http://www.homeschoolinghorizons.com>

## **Appendix A**

### **Interview Guide**

## Revised Interview Guide

**1. What do you like to do for fun at school?**

-Interviewer is seeking a description and attempting to determine with whom?

**2. Let's talk about your classroom, could you describe the room to me?**

-Interviewer is attempting to uncover seating, bathroom, stair location as well as likes vs dislikes of the room.

**3. If you could change one thing about your classroom what would it be?**

-Interviewer is seeking an explanation and possible examples.

**4. We all have good and bad days, describe what a good day would be like. Describe a bad day.**

-Interviewer is attempting to uncover description of physical symptoms that accompany the illness, time when such events may occur (lunch time, before a test etc.) and could good days include having IBD symptoms?

**5. How many days of school have you missed? Why were you absent?**

-Interviewer is seeking coping strategies/resources employed especially regarding schoolwork (homework).

**6. Who do you like/enjoy talking to at school? When you're not feeling well who do you go to?**

-Interviewer is searching for strategies/resources used i.e. call a parent, see school nurse etc., and the reason for these choices.

**7. What do you do if you feel the need to rush to the bathroom while in class?**

-Interviewer is trying to establish school environment & it's resources as well as the perception of others from the participant's point of view.

**8. What do you tell your friends and teachers about your IBD?**

-Interviewer is attempting to establish if IBD is being discussed and with whom (Teacher, students, principal, friends).

**9. Which medication(s) are you taking for your IBD?**

-Interviewer is attempting to uncover the relationship between taking medication at school and the reaction among peers and staff as well as participants thoughts about coping with it.

**10. If you could change one thing about your school what would it be?**

-Interviewer is trying to uncover the participant's school environment, it's resources and the participant's sense of belonging within this environment.

**Appendix B**  
**Approval Letter from Concordia University's Board of**  
**Ethics**





Concordia  
UNIVERSITY

EDUCATION DEPARTMENT  
LB-579  
SIR GEORGE WILLIAMS CAMPUS

TO: Maria Gordon

FROM: Ellen Jacobs, Chair

DATE: February 24, 2003

RE: Children with Inflammatory Bowel Disease: Finding strategies to cope with physical symptoms in school

This note is to inform you that your thesis proposal has successfully passed the scrutiny of the Department's Ethics Committee and has been accepted.

We take this opportunity to wish you every success with this project.

*Ellen Jacobs*

**Appendix C**  
**Approval Letter from McGill University-MCH**  
**Research Institutes Research Board of Ethics (Scientific**  
**Review Committee)**

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Institut de recherche de l'Université McGill-Hôpital de Montréal pour Enfants  
McGill University-Montreal Children's Hospital Research Institute  
Place Toulon 205 Tel (514)412-4300 Fax (514)412-4331

MEMORANDUM

September 15, 2003

DEST./TO: Dr. Sylviane Forget, Gastroenterology  
Ms. Maria Gordon

EXP./FROM: Danuta Rylski, Manager, Admin. Services, PT-204

OBJET/SUBJECT: Clinical Investigation Protocol entitled: "*Children with  
Inflammatory Bowel Disease: Finding strategies to cope with  
physical symptoms in school.*"

---

I am pleased to inform you that the above-named protocol has been re-evaluated and approved for scientific merit.

This protocol may now be submitted to the Research Ethics Board for ethical approval. Please note that the next meeting of the REB is scheduled for:

September 22, 2003.

Documents required include four complete copies of the protocol and 14 copies of the consent forms. These must reach the REB office, MCH Room C-1240, (telephone (514)412-4400 x 22319) by:

→ Monday, September 15, 2003.

  
\_\_\_\_\_  
dr/ab

Encls.

cc. Dr. I.B. Pless, Clinical Research Director  
Ms. M. Hollingdrake, REB

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**Appendix D**  
**Approval Letter from the MCH's Research Ethics**  
**Board (REB)**



Centre universitaire de santé McGill  
McGill University Health Centre

November 27, 2003

Dr. Sylviane Forget  
Division of Gastroenterology  
Montreal Children's Hospital

Re. MCH003-45 Children with Inflammatory Bowel Disease: Finding Strategies to Cope with Physical Symptoms in School

Dear Dr. Forget,

The above-named research proposal received Full Board review at the convened meeting of the Montreal Children's Hospital Research Ethics Board on September 22, 2003 was found to be within ethical guidelines for conduct at the McGill University Health Centre, and was entered into the minutes of the Research Ethics Board (REB) meeting. At the MUHC, sponsored research activities that require US federal assurance are conducted under Federal Wide Assurance (FWA) 00000840.

Final approval for the research protocol and informed consent and assent documents (English and French versions October 31, 2003) was provided by the Chair on November 27, 2003.

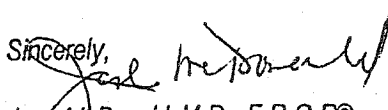
All research involving human subjects requires review at a recurring interval and the current study approval is in effect until September 21, 2004 (*anniversary of the original review*). It is the responsibility of the principal investigator to submit an Application for Continuing Review to the REB prior to the expiration of approval to comply with the regulation for continuing review of "at least once per year". Any further modification to the REB approved and certified consent documents must be identified by a revised date in the document footer, and re-submitted for review prior to its use.

The Research Ethics Boards (REBs) of the McGill University Health Centre are registered REBs working under the published guidelines of the Tri-Council Policy Statement, in compliance with the "Plan d'action ministériel en éthique de la recherche et en intégrité scientifique" (MSSS, 1998) and the Food and Drugs Act (7 June, 2001), acting in conformity with standards set forth in the (US) Code of Federal Regulations governing human subjects research, and functioning in a manner consistent with internationally accepted principles of good clinical practice.

We wish to advise you that this document completely satisfies the requirement for Research Ethics Board Attestation as stipulated by Health Canada.

The project was assigned MUHC Study Number MCH003-45 that is required as MUHC reference when communicating about the research. Should any revision to the study, or other unanticipated development occur prior to the next required review, you must advise the REB without delay. Regulation does not permit initiation of a proposed study modification prior to REB approval for the amendment.

Sincerely,

  
Jane McDonald, M.D., F.R.C.P.C.

Chairperson

Montreal Children's Hospital Research Ethics Board

Cc: Danuta Rylski, Montreal Children's Hospital Research Institute



**Appendix E**  
**Introductory Letter Sent to the IBD Families**



Dear Parent/Guardian,

Your child has been diagnosed with Inflammatory Bowel Disease. We are conducting a study at the Montreal Children's Hospital with IBD children aged 8-12 in order to understand from their perspective how they cope with the physical symptoms that accompany their illness while they're at school.

We are inviting your child to participate in an audio taped interview in which he/she will be encouraged to talk about his/her thoughts, feelings and experiences of his/her physical symptoms of IBD while at school. The interview conducted by Maria Gordon, one of the study investigators, will last for an hour and will take place in the Montreal Children's Hospital's Gastroenterology Department, Room D-563. Should your child participate in this study but is unable to travel to the hospital, then a home visit will be offered.

Your child's participation in this study is completely voluntary. In addition to your permission, your child will also be asked if he or she would like to take part in this project. Please note that you are free to withdraw your permission for your child's participation at anytime without penalty. Withdrawal from the study will not affect your child's care at the Montreal Children's Hospital.

The information obtained during this research project will be kept strictly confidential and will not be released to any third parties. Any sharing or publication of the research results will not identify any of the participants by name.

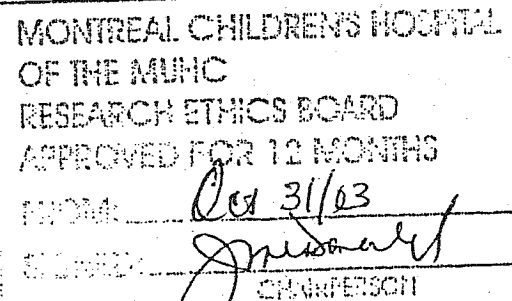
If you are agreeable to your child participating in the study you should call Maria Gordon at (514) 920-4303 to arrange an appointment day and time will be arranged to conduct the interview.

If you have any questions about this project, please contact, Dr. Sylviane Forget at (514) 412-4474.

We look forward to meeting you and your child and think that this study may in the future help school personnel and other's involved in children's schooling to better assist IBD children with their education.

Sincerely,

Dr. Sylviane Forget, MD  
Montreal Children's Hospital  
Department of Gastroenterology  
Tel: (514) 412-4474



**Appendix F**  
**Parent/Guardian Consent Form**





Consent Form  
(Parent/Guardian)

Title: Children with Inflammatory bowel disease: Finding strategies to cope with physical symptoms in school.

**Principal Investigators:**

Maria Gordon (MA Graduate student)  
Concordia University  
Tel: (514) 920-4303

Dr. Sylviane Forget, MD  
Department of Gastroenterology, Montreal Children's Hospital  
Tel: (514) 412-4474

Dr. Ailie Cleghorn, PhD  
Department of Graduate Studies in Education, Concordia University  
Tel: (514) 848-2424 ext.2041

**Purpose of the study:** Your child has been diagnosed with Inflammatory Bowel Disease. We are conducting a study with IBD children aged 8-12 in order to understand from their perspective how they cope with the physical symptoms that accompany their illness while they are at school.

**Description of the research:** This study involves audio taped interviews with your child in which he/she will be encouraged to talk about his/her thoughts, feelings and experiences of their physical symptoms of IBD while at school. The audio tapes will be kept for 3 years to be used for a larger IBD study. The interviews will take place in the Montreal Children's Hospital's Gastroenterology department, room D-563 and should last about an hour. Should your child participate in this study but is unable to travel to the hospital, then a home visit will be offered.

**Risks/Benefits:** There is no risk and no immediate personal benefits. The information gathered from this study may help school personnel and others involved in children's schooling to better assist IBD children with their education. Due to the nature of the subject matter in this study, sensitive issues may come up during the interviews. Should this occur, Dr. Forget will be notified and will assess if parental/guardian intervention is necessary.

**Confidentiality:** Only personnel involved in this study have access to information pertaining to your child. Your child will not be identifiable in any reports about the study, nor will any personal information be released to any third parties.

**Participation:** Participation in this research is entirely voluntary. You are entirely free to refuse to let your child participate. If you decide to allow your child to participate, you may withdraw your consent at any time. If you choose not to allow your child to participate or to withdraw, this will not affect the quality of your child's care at the Montreal Children's Hospital.



Contact persons: Should you have any questions or concerns you may contact Maria Gordon at (514) 920-4303 or Dr. Sylviane Forget at (514) 412-4474.

Should you have questions regarding your rights or the rights of your child as a research participant in this study, you may contact the Ombudsman at the Montreal Children's Hospital (Elizabeth Gibbon, 514-412-4400 ext.22223).

Consent: I hereby grant consent to my child's participation in the research described above.

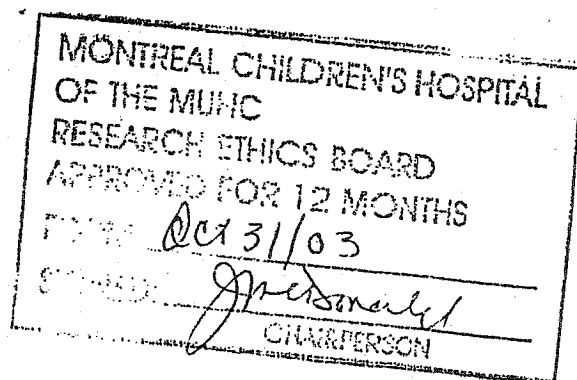
\_\_\_\_\_  
Name of parent /guardian

\_\_\_\_\_  
Parent/guardian's signature

\_\_\_\_\_  
Name of child, age

Consent obtained by: \_\_\_\_\_  
Signature

Date: \_\_\_\_\_



**Appendix G**  
**Assent Form**



Assent Form  
(Minors aged 7-18 years)

Title: Children with Inflammatory bowel disease: Finding strategies to cope with physical symptoms in school.

**Principal Investigators:**

Maria Gordon (MA Graduate student)  
Concordia University  
Tel: (514) 920-4303

Dr. Sylviane Forget, MD  
Department of Gastroenterology, Montreal Children's Hospital  
Tel: (514) 412-4474

Dr. Ailie Cleghorn, PhD  
Department of Graduate Studies in Education, Concordia University  
Tel: (514) 848-2424 ext. 2041

**Purpose of the study:** You have been diagnosed with Inflammatory Bowel Disease (IBD). We are doing a study with IBD children like you aged 8-12 because we want to understand and learn from you about how you cope with the physical symptoms of your IBD while you're at school.

**Description of the research:** This study involves audio taped interviews with you. The audio tapes will be kept for 3 years to be used in a larger IBD study. In the interviews you'll be encouraged to talk about your thoughts, feelings and your experiences of physical symptoms of IBD while at school. The interviews will take place in the Montreal Children's Hospital's Gastroenterology department, room D-563 and should last about an hour. If you participate in this study but unable to travel to the hospital, then a home visit will be offered.

**Risks/Benefits:** There is no risk and no personal benefits to participating in this study. However, the information from this study may help school staff and others involved in children's schooling to better help children like you with their education. Due to the topic some sensitive issues may come up during the interview. If this happens, Dr. Forget will be alerted and will assess if a parent/guardian needs to be informed.

**Confidentiality:** Only personnel involved in this study will have access to your information. You will not be identifiable in any reports, nor will any personal information be released to any third parties.

**Participation:** Participation in this study is completely voluntary. You are completely free to decide not to participate. If you decide to participate, you may withdraw at any time. If you decide not to participate or to withdraw, this will not affect the quality of your care at the Montreal Children's Hospital.



Contact persons: Should you have any questions or concerns you may contact Maria Gordon at (514) 920-4303 or Dr. Sylviane Forget at (514) 412-4474.

Should you have questions about your rights as a research participant in this study, you may contact the Ombudsman at the Montreal Children's Hospital (Elizabeth Gibbon, 514-412-4400 ext. 22223).

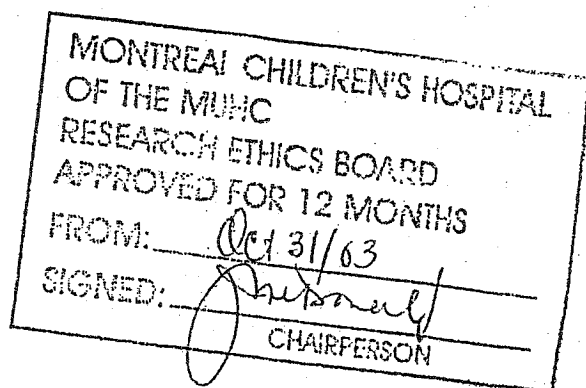
Assent: I consent to participate in the research described above.

\_\_\_\_\_  
Name of child, age

\_\_\_\_\_  
Witness

Assent obtained by: \_\_\_\_\_  
Signature

Date: \_\_\_\_\_



**Appendix H**  
**MCH Form Granting Permission to View Child's**  
**Medical Chart**

# AUTORISATION DE COMMUNIQUER DES RENSEIGNEMENTS CONTENUS AU DOSSIER

Nom et prénom à la naissance			
Nom actuellement utilisé			
Adresse actuelle de l'usager			
N° de la RAMQ	Date de naissance		N° de dossier: _____ Date d'admission: _____
	a                      m.                      d		
Nom et prénom du père		Nom et prénom de la mère	
Autres noms utilisés antérieurement			

Je, soussigné-e, \_\_\_\_\_  
Nom et adresse

En ma qualité de \_\_\_\_\_  
Usager ou personne autorisée

Autorise l'établissement \_\_\_\_\_

À faire parvenir à \_\_\_\_\_

Les renseignements suivants: \_\_\_\_\_

Pour les soins ou services reçus se rapportant à la période suivante: \_\_\_\_\_

Contenus dans le dossier de l'usager ci-dessus identifié.

Cette autorisation est valable pour une période de \_\_\_\_\_ jours à compter de la date de la signature de ce document.

\_\_\_\_\_  
 Signataire: usager ou personne autorisée

a	m.	d
Date		

\_\_\_\_\_  
 Témoin à la signature

a	m.	d
Date		

**N.B.:** On doit s'assurer que les signataires de cette formule sont autorisés à le faire conformément aux textes législatifs en vigueur. Et le cas échéant, prière de mentionner à quel titre (curateur ou titulaire de l'autorité parentale) la personne est autorisée à signer.