

**Experiences of Children with Inflammatory Bowel Disease and their Families in General
Education Classrooms**

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Thesis submitted to the
Faculty of Graduate and Postdoctoral Studies
In partial fulfillment of the requirements
For the Ph.D. degree in Education

Teaching, Learning, and Evaluation Concentration
Faculty of Education
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Abstract

The purpose of this study was to investigate how children with Inflammatory Bowel Disease (IBD) and their families perceived their school experiences in Québec. IBD is one of many “invisible” chronic diseases. It is considered invisible because it occurs internally without significant observable external symptoms. However, children with IBD experience painful and fluctuating physical symptoms caused by intestinal inflammation, as well as the side effects from medications. As a result, they require special accommodations while they attend public or private school. The Québec Education Act (2010) stipulates that adequate services for a diverse student population must be provided. Consequently, the research sought to answer the following questions: What are the experiences of parents and children with IBD enrolled in general education classrooms? And, what are the experiences of their brother or sister? To research these questions, a case study method was used with five families. The two instruments used to collect the data were, (1) individual semi-structured interviews that followed a modified version of Seidman’s (2006) in-depth interviewing approach and (2) drawings of the family by siblings. The data were analyzed inductively.

This study was the first to use a qualitative approach with multiple methods that were guided by Bronfenbrenner’s ecological systems theory (1979) and Turnbull and Turnbull’s family systems theory (2001). The findings revealed that, unlike many studies on families of children with special needs, these families with a child with IBD functioned relatively well. At the microsystem level, mothers assumed responsibility as the primary caregiver. Siblings experienced their own challenges, such as feelings of parental neglect. Nonetheless, they also maintained nurturing roles. Within the mesosystem level, the home and school relationship was impacted. Parents and children with IBD experienced school personnel who lacked awareness of

IBD and provided insufficient classroom support, especially at public schools. Hence, parents- (predominantly mothers) played an integral role in advocating for necessary accommodations on their child's behalf. In contrast to many studies on children with disabilities, children with IBD in this research had many friends in and outside of school. In the exosystem, parents struggled with feelings of guilt at having to balance employment and the high financial expense of caring for a child with IBD. They relied on assistance from government services and their IBD association. At the macrosystem level, family members believed that children with IBD were perceived negatively by society because of the lack of public awareness and the stigma that surrounds the topic of incontinence. This study makes contributions to systems theories and provides practical recommendations to school personnel and parents.

Dedication

As I am walking, I am listening and searching for a deeper way. At the cross roads, I am lost. Suddenly, my ancestors appear. They stand before me and say, "Be still! Be patient! Watch, learn, listen and remember always to give. You are the result of the love of thousands. The way for you is clear."

Excerpt adapted from the writings' of Linda Hogan (1947).

A key factor that emerged from this research on families with a child with IBD was the important role that each family member played in the attainment of school success. I could not have succeeded alone. It is for this reason, that I dedicate my doctoral thesis to my family.

This book was especially written in honor of my dear parents, Mr. Rudolph and Dr. Joan Gordon, and my precious sister, Ms. Coretta-Mae Florence Gordon. Had it not been for their love, unwavering faith, tireless efforts and constant encouragement, this work would surely not have materialized. This thesis is also dedicated with great affection and admiration to my grandparents, Rev'd. Dr. Claude and Mrs. Lola Cadogan.

Acknowledgements

I would also like to express my gratitude to the many wonderful people who have supported me on my five year doctoral journey. My professors and friends have provided continuous guidance and friendship through the years and that has helped me to remain motivated. Their assistance has been instrumental in helping me to make my dream of this research project a reality. I thank my thesis supervisor Dr. Cheryll Duquette for all of her hard work and diligence and the members of my thesis committee (Dr. Angus Mc Murtry, Dr. Raymond Leblanc and Dr. Cynthia Morawski). I would especially like to acknowledge Dr., Awad Ibrahim, Dr. Bosire Mwebi, Dr. Lindiwe Sibeko, Dr. Barbara Graves and Dr. Janice Huber who always saw the value in my work and remain brilliant mentors.

I would also like to thank all of my friends near and far including: Dr. Kaneez Hasna, Shamini Ruthirananthan and the Babic, Huang and Saidi families. I would also like to recognize all of the doctoral students and graduates (PiPsters) in the faculty of Education at the University of Ottawa who studied with me and cheered me on: Veena Balsawer, Amy Chen, Julie Comber, Eric Duku, Osnat Fellus , Natalie Gougeon, Dr. Joan Harrison, Christine Johnson, Dr. Shari Orders. I wish you all great success in the future. I know that you can do it and that you will make it through!

Lastly, I am extremely grateful to the five families with children with IBD who participated in this study. They took the time to share their poignant and inspirational stories with me. As well, as many thanks to the Crohn's and Colitis Foundation of Canada. I am hopeful that one day a cure will be found for this invisible disease.

Table of Contents

Abstract	i
Dedications	iii
Acknowledgements	iv
Chapter 1	1
Background	1
Position of the Researcher	2
Statement of the Problem	2
Aim of the Study and Research Questions	7
Significance of the Study	8
Outline of the Thesis	9
Chapter 2-Review of the Literature	11
Introduction	11
What is Inflammatory Bowel Disease?	12
Educational Experiences of Children with IBD	13
Studies on Family Quality of Life and IBD	15
Quality of Life of Children with IBD	16
A Similar Invisible Disease-Children with Cancer and their School Experiences	17
Overview of Québec's Educational System	18
Québec Kindergarten, Elementary and Secondary Education system	18
Québec's Educational Reform towards a System of Integration	20
Parental Concerns with Education of Children with Special Needs	23
Experiences of Public versus Private schooling in Québec	24
Chapter 3-Theories Guiding the Research	27
Introduction	27
Bronfenbrenner's Ecological Theory	27
Turnbull and Turnbull's Family Systems	32
Limitations of Turnbull and Turnbull's Family Systems	33
Sibling Research within Systems Theories	36
Children's Family Experiences Expressed through Drawing	37
Chapter 4-Methodology	39
Introduction	39
Case Study Design	39
The Use of Narratives	40
Children's Narratives	41
Children as Research Participants	41
Children's Drawings	42
Individual Interviews	43
Research Instruments	45
Recruitment of Family Participants	46
Study Criteria of Selected Family Participants	48

Participant Family Demographics	49
Data Collection Process	50
Data Analysis	52
Sibling Drawings	54
Trustworthiness	54
Chapter Summary	55
Chapter 5-Family Case Studies	57
Introduction	57
Case Study 1-The Anderson Family: At Home in the Daycare	58
Family Introduction	58
Microsystem from the Perspective of the Parent	59
Mrs. Anderson's Past, Present and Reflection: Experiences of IBD at Home	
Microsystem from the Perspective of the Child with IBD	60
Claire's Past, Present and Reflection: Experiences of IBD at Home	
Microsystem from the Perspective of the Sibling	60
Lisa's Past, Present and Reflection: Experiences of IBD at Home	
Lisa's Family Drawing	62
Family Relationships	63
Mesosystem from the Perspective of the Parent	64
Mrs. Anderson's Past, Present and Reflection: School Experiences	
Mesosystem from the Perspective of the Child with IBD	68
Claire's Past, Present and Reflection: School Experiences	
Exosystem from the Perspective of the Parent	
Mrs. Anderson's Past, Present and Reflection: Experiences in her Community and Beliefs	70
Macrosystem from the Perspective of the Parent	73
Mrs. Anderson's Past, Present and Reflection: Beliefs Regarding societal Perceptions of IBD	
Macrosystem from the Perspective of the Child with IBD	73
Claire's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD	
Macrosystem from the Perspective of the Sibling	74
Lisa's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD	
Summary of Family 1: The Andersons	74
Case Study 2-The Clarkson Family: A Cohesive and Active Family of Five	78
Family Introduction	78
Microsystem from the Perspective of the Parent	79
He-Man and She-Rah's Past, Present and Reflection: Experiences of IBD at Home	
Microsystem from the Perspective of the Child with IBD	82

Geddy Lee’s Past, Present and Reflection: Experiences of IBD at Home	
Microsystem from the Perspective of the Sibling	83
Daniel’s Past, Present and Reflection: Experiences of IBD at Home	83
Squirtle’s Family Drawing	85
Family Relationships	86
Mesosystem from the Perspective of the Parent	87
He-Man and She-Rah’s Past, Present and Reflection: School Experiences	
Mesosystem from the Perspective of the Child with IBD	88
Geddy Lee’s Past, Present and Reflection: School Experiences	
Exosystem from the Perspective of the Parent	90
He-Man and She-Rah’s Past, Present and Reflection: Experiences in their Community and Beliefs	
Macrosystem from the Perspective of the Parent	91
He-Man and She-Rah’s Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD	
Macrosystem from the Perspective of the Child with IBD	91
Geddy Lee’s Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD	
Macrosystem from the Perspective of the Sibling	92
Daniel’s Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD	
Summary of Family 2: The Clarksons	92
Case Study 3-The Campbell Family: Widowed Mother of Four Re-visited by IBD in the Family	95
Family Introduction	95
Microsystem from the Perspective of the Parent	96
Mrs. Campbell’s Past, Present and Reflection: Experiences of IBD at Home	
Microsystem from the Perspective of the Child with IBD	97
William’s Past, Present and Reflection: Experiences of IBD at Home	
Microsystem from the Perspective of the Sibling	98
Nancy’s Past, Present and Reflection: Experiences of IBD at Home	
Nancy’s Family Drawing	100
Family Relationships	101
Mesosystem from the Perspective of the Parent	102
Mrs. Campbell’s Past, Present and Reflection: School Experiences	
Mesosystem from the Perspective of the Child with IBD	106
William’s, Past, Present and Reflection: School Experiences	

Exosystem from the Perspective of the Parent	110
Mrs. Campbell's Past, Present and Reflection: Experiences in her Community and Beliefs	
Macrosystem from the Perspective of the Parent	111
Mrs. Campbell's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD	
Macrosystem from the Perspective of the Child with IBD	112
William's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD	
Macrosystem from the Perspective of the Sibling	112
Nancy's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD	
Summary of Family 3: The Campbells	113
Case Study 4-The Keller Family: A Critical Case of Crohn's Disease and a Family in Transition	116
Family Introduction	116
Microsystem from the Perspective of the Parent	117
Mrs. Keller's Past, Present and Reflection: Experiences of IBD at Home	
Microsystem from the Perspective of the Child with IBD	119
Michael's Past, Present and Reflection: Experiences of IBD at Home	
Microsystem from the Perspective of the Sibling	121
Sophia's Past, Present and Reflection: Experiences of IBD at Home	
Sophia's Family Drawing	123
Family Relationships	124
Mesosystem from the Perspective of the Parent	124
Mrs. Keller's Past, Present and Reflection: School Experiences	
Mesosystem from the Perspective of the Child with IBD	126
Michael's Past, Present and Reflection: School Experiences	
Exosystem from the Perspective of the Parent	129
Mrs. Keller's Past, Present and Reflection: Experiences in her Community and Beliefs	
Macrosystem from the Perspective of the Parent	130
Mrs. Keller's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD	
Macrosystem from the Perspective of the Child with IBD.	131
Michael's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD	
Macrosystem from the Perspective of the Sibling	131
Sophia's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD	
Summary of Family 4: The Kellers	132
Case Study 5-The Lévesque Family: Making School Success a Family Affair	135

despite a Legacy of IBD	
Family Introduction	135
Microsystem from the Perspective of the Parent	137
Mr. and Mrs. Lévesque's Past, Present and Reflection: Experiences of IBD at Home	
Microsystem from the Perspective of the Child with IBD	138
Alex's Past, Present and Reflection: Experiences of IBD at Home	
Microsystem from the Perspective of the Sibling	139
Paige's Past, Present and Reflection: Experiences of IBD at Home	
Paige's Family Drawing	140
Family Relationships	141
Mesosystem from the Perspective of the Parent	143
Mr. and Mrs. Lévesque's Past, Present and Reflection: School Experiences	
Mesosystem from the Perspective of the Child with IBD	146
Alex's Past, Present and Reflection: School Experiences	
Exosystem from the Perspective of the Parent	149
Mr. and Mrs. Lévesque's Past, Present and Reflection: Experiences in their Community and Beliefs	
Macrosystem from the Perspective of the Parent	149
Mr. and Mrs. Lévesque's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD	
Macrosystem from the Perspective of the Child with IBD	150
Alex's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD	
Macrosystem from the Perspective of the Sibling.	151
Paige's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD	
Summary of Family 5: The Lévesques	151
Chapter 6: Cross-Case Analysis	153
Introduction	153
Microsystem	153
Parent's Past Experiences of Diagnosis of a Child with IBD	153
Parent's Present Experiences of Child with IBD.	155
Child with IBD's Past Experiences of Diagnosis.	158
Child with IBD's Present Experiences	158
Sibling's Past Experiences of Brother or Sister's Diagnosis	158
Sibling's Present Experiences of Brother or Sister's Diagnosis	159
Summary of Findings in Family Relationships	159
1. Parent and Child with IBD Family Relationships	160
2. Parent-Sibling Family Relationships	160
3. Sibling-Family Relationships	161

Mesosystem	161
Parent's Past School Experiences with their Children with IBD	161
Parent's Present School Experiences	163
Parents as Advocates	164
Child with IBD's Past School Experiences	166
Child with IBD's Present School Experiences	166
Summary of Findings at the Mesosystem	167
Exosystem	168
Parent's Past Experiences in their Community	168
Parent's Present Experiences in their Community	169
Summary of Findings at the Exosystem	170
Macrosystem	170
Parents Past and Present: Beliefs Regarding Societal Perceptions of IBD	170
Child with IBD's Past and Present: Beliefs Regarding Societal Perceptions of IBD	171
Sibling's Past and Present: Beliefs Regarding Societal Perception of IBD	171
Chapter 7-Discussion	172
Summary of the Study	172
Education	172
Answers to Research Questions	174
Research Question 1: What are the Experiences of Children with IBD	174
Enrolled in General Education Classrooms?	
Research Question 2: What are the Experiences of Parents of Children with IBD	175
Enrolled in General Education Classrooms?	
Research Question 3: What are the Experiences of Siblings of Children with IBD	177
Study Findings in Terms of Systems Theory	178
Microsystem	178
Bronfenbrenner's Ecological Theory	178
Turnbull and Turnbull's Family Systems Theory	180
Mesosystem.	181
Parent-School Relationship	181
Child with IBD-School Relationship	182
Exosystem	183
Family Finances	183
Macrosystem	185
Societal Perceptions of IBD	185
Contributions to Theory and Practice	186
Contributions to Theory	186
Contributions to Data Collection Strategy	186
Contributions to Practice	187
Recommendations made by Parents	187
Recommendations made by Children with IBD	188
Recommendations made by Siblings	188

Recommendations to Québec Educational System	188
Limitation of the Research	189
Implications for Practice and Future Research	190
Conclusion	193
References	197
Appendices	215
Appendix A Parent(s) Interview Questions	215
Appendix B Child with IBD Interview Questions	217
Appendix C Sibling Interview Questions	219
Appendix D Modified Interview Questions	221
Appendix E Recruitment Notices	222
Appendix F Interview Timeline 2010-2011 and Consent forms	227

List of Tables

Table 1	Initial Study Criteria	232
Table 2	Participant Family Demographics	233
Table 3	Anticipated Categories and Codes	236
Table 4	Central Themes and Study Categories	240

List of Figures

Figure 1	Diagram of Bronfenbrenner's Ecological Theory Applied to Family Experiences of Education in Québec	31
Figure 2	Diagram of Relationships Examined at the Level of Bronfenbrenner and Turnbull and Turnbull's Systems Theories	35

Figure 3	Art Supplies	51
Figure 4	Family Drawing by Lisa	62
Figure 5	Family Drawing by Squirtle	85
Figure 6	Family Drawing by Nancy	100
Figure 7	Family Drawing by Sophia	123
Figure 8	Family Drawing by Paige	140
Figure 9	Study Outcomes and Findings	194
Figure 10	New Findings and Contributions to Bronfenbrenner and Turnbull and Turnbull's Systems Theories	196

Chapter 1

Background

In Canada, children with a variety of physical, psychological, and behavioral disorders have the choice of being enrolled in public or private school and they may require some form of special accommodations. Children with Inflammatory Bowel Disease (IBD) are an example of students with specific health needs who are placed in general education classrooms. Most children with IBD require special accommodations while they are in school because of the fluctuating physical symptoms of their disease and the side effects from their medications (Mackner, Sisson, & Crandall, 2004).

The responsibility of providing adequate accommodations for a diverse student population rests with school administrators and teachers, and sometimes the service delivery in classrooms is inadequate for children with IBD (Gordon, 2012, 2004). It is interesting to note that although Canada has the highest reported rate of IBD in the world (Bernstein, Wajda, Svenson, MacKenzie, Koehoorn, Jackson, Fedorak, Israel, & Blanchard, 2006; Crohn's and Colitis Foundation of Canada 2008), there are few teachers who are knowledgeable about this incurable disease (Gordon 2012, 2004). One of the reasons for this lack of knowledge about IBD among educators is because it is not visible.

As noted above, Canadian children attend school with varying types of illnesses and exceptionalities. Some of these illnesses are apparent to the eye, but some are not so obvious. For example, a child with cerebral palsy, or any form of physical disability, will likely be noticed in school and for the most part, will receive the necessary accommodations. However, a child who has an illness such as inflammatory bowel disease, would not be immediately recognized as having special needs in the classroom because of the invisibility of the disease. Hence, for this

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

reason, and the disparity between the children's ordinary appearance and the severity of their internal suffering, they may not receive the accommodations they need at school.

Position of the Researcher

I was first introduced to families of children with IBD in 1999 while conducting research on the quality of life of children with IBD in the department of Gastroenterology at a Montreal hospital. While interviewing those families, I gained insights into their daily struggles and the many school challenges that they encountered. After hearing their stories, I decided to conduct a Master's thesis that focused on the coping strategies used by children with IBD in their classrooms. This was the first study to collect stories of children with IBD and it was found that parents, siblings, and friends were key advocates in helping the children cope with many of their problems at school (Gordon, 2004). However, I realized that more research was needed to establish a clearer picture of their experiences. This heightened my interest to investigate the issue of children with IBD and their families in order to gain an understanding of how family members assist these children to navigate the course of the educational system in Québec. Currently, a review of the literature reveals that there are studies examining the role of parents within school settings although not, from the perspectives of families of children with IBD. As such, this research will add to the body of literature on the school experiences of families with children with special needs.

Statement of the Problem

Québec's Education Act requires that schools should educate all children. The term "all children" includes those students with any form of disability or who may need special accommodation in classrooms. In Québec, schools are governed by a policy of integration, but students with IBD and their families often report that they encounter obstacles when they ask for

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

special accommodations for their children (Crohn's and Colitis Foundation of Canada 2008; Gordon 2012, 2004). For example, it has been reported that children with IBD are often denied permission to make frequent visits to the bathroom during class time—necessary and urgent, though these visits usually need to be (Casati, Toner, de Rooy, Drossman, & Maunder, 2000).

In examining the issue of the experience of children with IBD and their families, the many challenges faced by them are important factors in this study. Researchers describe the obstacles the children face while they are in school and suggest that they tend to add grief and stress to students and their families. Therefore, these negative experiences may further impact their wellbeing, socially, and psychologically. Some of the challenges include absenteeism and underachievement in school (Fergusson, Sedgwick, & Drummond, 1994; Mackner, Bickmeier & Crandall, 2012; Mayberry, Probert, Srivastava et. al.,1992) and being denied their request to make frequent visits to the bathroom during class (Casati, Toner, de Rooy, Drossman, & Maunder, 2000). Some students with IBD may have side effects from medications such as, facial swelling, acne, and hair growth (Mackner, Sisson, & Crandall, 2004).

In North America, school programs began for children with disabilities in the 1950s and 1960s, almost all of them were conducted in special schools or centres for youth with disabilities. It was then believed that the students were better able to learn with others of “their own kind.” (Crawford, 2005; Porter, 2008). Most educators also thought that it would be virtually impossible to educate children with mental and physical disabilities in general education classrooms. However, during the 1970s and 1980s, a major thrust toward integrating children with disabilities into school programs with typically developing children occurred (Reynolds & Birch, 1982; Schifani, Anderson, & Odle, 1980). This change was an outgrowth of a number of important social, political, and educational factors such as the overall trend towards community

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

integration. Additionally, the work of parents and advocates to obtain access to regular public schools and the research that identified the learning potential of children with disabilities placed in general education classrooms helped to bring about changes. Moreover, the demonstration projects that illustrated methods and results of integration efforts (Curtin & Clarke, 2005; Turnbull & Turnbull, 2001; UNESCO, 1994; United Nations, 1989) also bolstered the cause.

Now, throughout North America, policies are in place to provide all students with disabilities the opportunity to be educated “in the least restrictive environment.” For the most part, this means that “to the maximum extent appropriate, exceptional children should be educated with non-exceptional children” (Schifani, Anderson, & Odle, 1980, p. 8). In 1979, the Québec policy stated that children with disabilities should be educated with non-disabled children in the “most normal” setting as possible (Ministère de l’Éducation du Québec, 1979).

Since then, the issue of school integration and the rights of children with special needs have remained a hot topic of debate. In the province of Québec, the last amendments to the Education Act were made in 1999, but even so the debate continues. Opponents of integration argue for a return to special education classrooms for children with disabilities (Kauffman, 1995; Kavale & Forness, 2000; Macmillan, Gresham, & Forness, 1996; Zigmond & Baker, 1995), while the proponents of integrated education have moved beyond integration and are now supporting inclusive education classrooms (Bucalos & Lingo, 2005; Burnstein, Sears, Wilcoxon, Cabello, & Spagna, 2004; Idol, 2006; Voltz, Sims, Nelson, & Bivens, 2005). Inclusive education presents a paradigm shift in the way children with disabilities are placed in general education classrooms. Proponents of inclusive education express the notion that children with disabilities should begin their education placed in general education classrooms. Then it is incumbent on educators and school administrators to provide the appropriate support and services for all

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

students. However, the Education Act in Québec is based on the premise of integration and although the Act does not explicitly mention providing support to children with chronic diseases, the education reform stipulates that an environment conducive to learning and success for all students must be provided. This implies that accommodations required by children with chronic illnesses such as IBD should be met, but there remains much room for improvement in the area of appropriate service delivery for these children in general education classrooms (Gordon, 2004). It is imperative that certain accommodations, such as going to the bathroom when needed, be permitted, because the ongoing symptoms of the disease include frequent diarrhea, bloody watery stools, and abdominal pain. When needs are not met at school, children with IBD are left with feelings of insecurity, embarrassment and low self-esteem (Hill, Lewindon, Muir, Grangé et al., 2010).

Merely including children with disabilities in general education classrooms does not guarantee them educational success (Wallace et. al., 2002). If children with disabilities are to be successful in general education classrooms, then appropriate mechanisms must be put in place to ensure that they receive adequate delivery of service. In order to foster school success for children with IBD in general education classrooms, it is important that the teachers understand their disease and how to support them when they become sick in class. Knowledge of IBD enables teachers to organize and manage their classes to meet the needs of the students with IBD and encourage their engagement in learning. Like all children who need support in general education classrooms, when children with IBD do not have such mechanisms in place, problems may appear. They may experience emotional problems which may aggravate their physical illness (Gordon, 2004). These claims have been supported by previous researchers (Nicholas, Otley, Smith, Avolio et. al., 2007) who argue that children with chronic illnesses are seen as

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

being “different” by their teachers. As a result of this view, teachers may treat them differently from other students who are deemed “normal.” For example, Ryan (2006) suggests that this type of mistreatment is not uncommon as those defined as “different” are often unable to gain access to the same rights and opportunities made available to all of the non-disabled students.

Consequently, the family’s involvement in children’s education is considered crucial to school success—especially of those with special needs. Specifically, it is the parents who advocate for the needs of students with disabilities and support (Duquette, Stodel, Fullarton, & Hagglund, 2007; Duquette, Orders, Fullarton, & Robertson, 2011).

The prevailing view of the family has been shaped by researchers, including Bronfenbrenner (1979), Mandell and Duffy (2005), Mitchell (2009), Turnbull and Turnbull (2001) and Winzer (2005), who suggest that the family is an independent group of people affiliated by blood, affinity or co-residence. Researchers who focus on the nature of the links between family members as well as the factors that influence them (Turnbull and Turnbull, 2001) suggest that the relationship between family members can be very strong. The family can be viewed as a “system” whereby each individual and every relationship within the family affects every other individual and relationship through mutual influence. As such, when a family member has a chronic disease, it can place a heavy burden (financially, physically, and emotionally) on other members of the family. This burden is related to families of children with IBD. Families whose children have the disease are beset with not only the children’s health issues, but also how their school experiences impact them.

Children with IBD communicate their experiences of ill treatment at school to their parents. In turn, the children rely on their parents to advocate for their needs at school (Dyson, 2010; Duquette, et al., 2007; Duquette, et al., 2011). Therefore, this study focused on examining

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

the experiences of children with IBD, and their parents and siblings. Specifically, the study sought to understand the impact schooling in general education classrooms had on these children and their family members.

Aim of the Study and Research Questions

This study examined the experiences of children with IBD and their families within integrated educational settings in the province of Québec. The aim of the study was to discover what it is like for a child with a chronic invisible disease, such as IBD, in general education classrooms and how these experiences impacted his or her family, community and society.

To achieve this aim, a qualitative research design was used that permitted the researcher to listen to the personal stories of children with IBD and their family members (parent(s) and siblings). The stories regarding their experiences and their perceptions of general education classrooms in Québec were examined. Through this examination, an understanding of the social, psychological, and physical wellbeing of each family member emerged. Furthermore, this allowed for the roles that each family member played in the daily lives of a child with IBD to surface. In order to gain an understanding of the relationship between family members, as well as the complexity of the relationships between the home, school, community and society the study was placed within the framework of Bronfenbrenner's (1979) ecological theory and Turnbull and Turnbull's (2001) family systems theory.

The two frameworks guiding this study provided a systematic way to analyze and comprehend the dynamic and complex relationships involved between family members. Both theories suggest that a child's surroundings including the school, community and society impact his or her development positively or negatively. Gaining an understanding of these factors,

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

which may hinder or assist families of a child with IBD, may serve to facilitate better home-school collaborations in the future.

A qualitative case study of five families, each with a child with IBD and a sibling, was conducted. The ages of the participants in the research ranged between seven to 18 years. In order to structure the families' stories, the study was guided by the following three research questions:

- What are the experiences of children with IBD enrolled in general education classrooms?
- What are the experiences of parents of children with IBD enrolled in general education classrooms?
- What are the experiences of a brother or sister of a child with IBD?

The research methodology employed in this study was based on a modified version of Seidman's (2006) one-on-one, in-depth phenomenological three-phased interviewing technique as well as the use of sibling drawings. Within each family the parent(s), the child with IBD and a sibling were interviewed over the course of two days. On the second day following their interviews, siblings were asked to draw a picture of their family. By drawing, siblings were provided with an additional way to express their thoughts, feelings, and position within their family.

Significance of the Study

The Québec Education Act (1999) requires that all children in the province are to be educated in general education classrooms and that their special needs are to be met by the school. Québec teachers' unions find this situation troubling and are calling for limits to the number of students with disabilities integrated into the general education classrooms. The teachers find it

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

demanding to accommodate multiple students with diverse needs in class (Montreal Gazette Oct. 27, 2010). Since the Education Act was revised to have schools adapt to the needs of all students, then the special needs of children with IBD should also be met. However, it has been found that their needs (such as unconditional bathroom access) are not being met by their teachers in general education classrooms. The invisibility of IBD symptoms and the child's healthy appearance may pose challenges for teachers who are often unfamiliar with IBD and are therefore less willing to accommodate children with IBD's special needs. Hence, it is important to this study to uncover the experiences of children with IBD and their families in general education classrooms. In this study, family members' stories were described to gain an understanding of their relationships at home, with school personnel, within their community, and within society. In so doing, the researcher attempted to explain how the negative elements in the school environment were addressed and dealt with so that the children with IBD could cope with the daily rigour and routine of a general education classroom.

Outline of the Thesis

This section describes the structure of each chapter of the thesis and the salient topics explored within them. The thesis opens with Chapter 1 which provides an overview of the research and pertinent background information about the study, as well as the researcher's personal experiences. Following that, Chapter 2 provides a review of the literature beginning with a full description of IBD and accompanying symptoms. Also explored in this chapter is the impact of the disease on schooling and quality of family life. Then, the elements that characterize the educational system in Québec are discussed and current educational debates surrounding student integration are presented.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

In Chapter 3, the concept of family is explored in a broader social context by framing the discussion within two systems theories namely, Bronfenbrenner's (1979) ecological systems and the family systems theory proposed by Turnbull and Turnbull (2001). These theories provide a framework for examining the complex and dynamic relationship between family members and home-school collaboration. Furthermore, the impact of external influences such as community involvement and society's perception of children with IBD were also explored. In addition, a review of the research on siblings is described. The chapter concludes with an exploration of the rationale for using children's drawings in research.

Chapter 4 outlines the qualitative research methods employed in the study. Seidman's (2006) phenomenological in-depth interviewing technique is explained. The lengthy recruitment process is traced and the two instruments designed to collect and analyze the data are described. The five families' case stories are contained in Chapter 5 and include a summarized description of each sibling's drawing.

Chapter 6 provides a detailed cross-case analysis of the research outcomes and establishes the re-occurring themes that emerged from the study. The thesis concludes with Chapter 7. The objective of this final chapter is to summarize the research and provide a full discussion of the findings of the study. In this chapter, there is also a section on the contributions that this study will have on theory and practice within the field of education. Additionally, suggestions as to possible directions for future research are discussed.

Chapter 2-Review of the Literature

Introduction

In this chapter, a critical review of the current literature relating to the experiences of families of a child with IBD was conducted. Specifically, the focus of this study was to describe and investigate the school experiences of children with IBD and their family members. The purpose was to understand family member's relationships at home, school, community, and society. In order to examine these relationships it is important to first clarify what IBD is and the symptoms associated with the disease. Following a full description of the disease, a review of the literature regarding the educational experiences of children with IBD is presented. Overwhelmingly, the literature in this area emphasized the many challenges that children with IBD faced at school. Study results indicated that the children's negative school experiences in turn impacted their home environment. As a result, a detailed review of the studies on the quality of life of families with IBD was performed and discussed in this chapter. Once again, the research in this area concluded that children with IBD and their families had a significantly impaired quality of life. Further support for these outcomes was found in studies that involved the school experiences of children with cancer. The literature review included the experiences of children with cancer because parallels could be drawn between the invisible nature of cancer and the experiences of children with IBD. Chapter 2 concludes with an overview of the studies and policies concerning the Québec education system and current debates regarding the integration of children with special needs in public and private general education classrooms in the province.

What is Inflammatory Bowel Disease?

Inflammatory bowel disease is categorized by two main diseases, namely, Crohn's disease and ulcerative colitis. These two diseases, though similar in nature, differ in the physical location in which they occur. Both diseases are characterized by chronic recurrent inflammation

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

of intestinal tissue, evolving in periods of relapse and remission. However, Crohn's disease 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. Ulcerative colitis affects only the inner layer (mucosa) of the colon. It involves the rectum practically in all cases, and extends proximally and continuously over variable lengths of the colon (Baumgart & Carding, 2007; Baumgart & Sandborn, 2007).

Currently, it is unknown how one contracts the disease and there is no known cure for IBD. Therefore, treatments focus on controlling the inflammation (Crohn's and Colitis Foundation of Canada, 2008). People with IBD may take medications several times a day, and many of the medications often have negative side effects ranging from weight gain and acne to more severe effects, such as bone disease, high blood pressure, cataracts, diabetes, pancreatitis, suppression of the immune system, and increased cancer risk (Baumgart & Carding, 2007). Surgery is the last medical option, and more than a third of people with childhood-onset IBD will require surgery to manage the disease within 20 years of diagnosis (Langholz, Munkholm, Krasilnikoff, & Binder, 1997). Removal of the colon (colostomy) essentially results in curing ulcerative colitis, but inflammation and extra intestinal symptoms can still occur (Crohn's and Colitis Foundation of Canada, 2008).

Psychosocial issues have been investigated in adults with IBD, but these issues in pediatric IBD have received less attention (Kilroy, Nolan, & Sarma, 2011; Mackner, Sisson, & Crandall, 2004). In the last several decades, the incidence of IBD in adults has risen (Logan, 1998) and pediatric studies have shown similar patterns of increases in both types of IBD. The reasons for the proliferation are unclear, as the contributing factors may occur early in life.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Recently, evidence of the rise in incidence of IBD not only in adults but also in children and adolescents has caused renewed interest in the younger age group (Gryboski, 1994). The predominance of the disease—especially in children, has also played a role in heightening my interest in this research topic.

Educational Experiences of Children with IBD

Children with IBD are different from most students attending school because their illness is debilitating and it is a type of invisible chronic disease. IBD affects children at any age, is unpredictable, and involves uncontrolled periods of incontinence. As such, these children can be reluctant to talk about their symptoms, while some limit their daily activities to those with ready access to a bathroom (Crohn's and Colitis Foundation of Canada, 2008). Their frequent visits to the toilet can be a source of embarrassment, and they may fear becoming the target of the “bathroom humour” that is popular among children and adolescents (Casati, Toner, de Rooy, Drossman, & Maunder, 2000).

Associated symptoms can include fever, fatigue, decreased appetite, arthritis, perianal disease, and colon cancer. Short stature and delayed puberty can also contribute to feeling different from peers (Crohn's and Colitis Foundation of Canada, 2008). Steroidal medication is commonly used to treat IBD and frequently results in negative side effects such as facial swelling, increased acne, hair growth, and emotional liability, all of which may have additional implications for psychosocial adjustment (Mackner, Sisson, & Crandall, 2004).

One of the educational challenges of children with IBD is absenteeism. High rates of school absences among 50 adolescents with IBD (11 to 17 years of age) was a key finding in the current 2012 study by Mackner, Bickmeier and Crandal. They concluded that, absenteeism has the potential to disrupt school functioning. Additionally, Akobeng, Mirajkar and colleagues

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

(1999) demonstrated in a qualitative study that IBD significantly impacted the school attendance of British school children. These researchers found that children between five and 17 years of age were frequently absent on an average of three to four months during the school year. In discussing their school experiences, the researchers learned that most children thought that their teachers lacked knowledge about IBD. The children also found that their teachers lacked empathy regarding their physical IBD symptoms, and their required school accommodations. Consequently, most children felt that their ill health contributed to their poor examination results; and they were unable to participate in sports on a regular basis. Lastly, the children reported that their primary source of information about IBD had come from doctors, information pamphlets, and nursing staff.

This research which is similar in some ways to the study that I conducted in 2004 (Gordon, 2004), concluded that children with IBD have a significantly impaired quality of life. They worry about everyday childhood activities and have concerns about their future opportunities. Hence, there is evidence that children with IBD need to be in a supportive environment where people have knowledge of the illness and understand the concerns of the individuals with disease. Efforts should be concentrated on improving their day-to-day existence to enable these children to lead as normal a life as possible. Moreover, this chronic disease can make school experiences difficult and unique for children with IBD. Other researchers also concluded that children with IBD are often unable to gain a sense of whether their teachers know about their disease or have empathy for the situation in which they find themselves, when they are in school (Kilroy, Nolan, & Sarma, 2011; Gordon, 2004; Akobeng, Mirajkar, et al. 1999). Their requests to be able to go to the bathroom at will or to decline from participating in certain activities when feeling unwell are often ignored by their teachers (Gordon, 2004). Children with

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

IBD are often excluded in many ways from their school environments. Ryan (2006) states that, “Inclusion’s alter ego is exclusion. They are intimately related. When people are not included, they are excluded” (p.19) and research has shown that children with IBD are sometimes excluded from school activities, misunderstood, and ill-treated by school personnel in varying degrees (Gordon, 2012, 2010, 2004; Ryan 2006). Therefore, it appears that children with IBD may be powerless and voiceless at school, unable to claim or act upon their rights to have their needs met as participants in general education classrooms. As such, this lack of inclusion may negatively impact their educational attainment, as well as the selection of a career in the future.

Studies on Family Quality of Life and IBD

Poston et al. (2003) defined *family quality of life* as the conditions under which the family's needs are met. Family members enjoy their life together as a unit, and members have the chance to do things that are important to them.

Families with a child with IBD have been shown to experience impairment of their quality of life in relation to their loved one’s illness (Cheung, Garratt, Russell, & Williams, 2000). Consequently, families with a child with IBD may have an impaired quality of life.

Quality of life (QOL) research emanated from the field of health science and has traditionally been based on the *pathology* model of health and dependency (Cummins, 2005). The medical model has focused on the measurement of physical and mental decline, impaired role, and social function. In short, this view has measured the individual’s performance of activities that are essential for the continuing functioning of the wider society (the model of *functionalism*) (Cummins, 2005). This approach has led to a negative focus on measurement, at the expense of the positive. For example, scales have been developed to measure levels of functional disabilities, rather than balanced scales with equal measures of levels of ability

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

(Bowling, 2001). For example, Engstrom (1999) found that mothers of children with IBD reported significantly greater family dysfunction than did mothers of healthy children. Kocoshis and colleagues (1990) found that the problems most frequently mentioned by parents included concerns about their child's future, problems at school, and medication side effects. Problems most frequently identified by siblings were the lack of information about the disease, concerns about siblings being teased, and "fear about disease and treatment."

Therefore, the research in family functioning suggests that families with a child with IBD may have greater family dysfunction and parental psychological distress than families without an ill child. Also, siblings of children with Crohn's disease may have more behavioural and emotional difficulties than do children in healthy families (Kocoshis, 1990). Poorer family functioning appears to be related to increased disease severity.

Quality of Life of Children with IBD

Up to this point, the discussion of this section on quality of life has focused on examining the experiences and challenges faced by family members in relation to children with IBD and their school experiences. What has yet to be discussed, however, is how these children perceive the quality of their lives. Research in this area is sparse and it is for this reason that I conducted this study in the hopes of adding to the body of literature in this field.

The QOL research in children with IBD has primarily focused on describing and ranking IBD related concerns, using IBD-specific measures such as the IMPACT questionnaire (Griffiths et al., 1999). These studies were typically conducted through interviews and focus groups in which children were asked how IBD affected their lives. It was found that the primary concerns identified were pain, frequent school absences, lack of energy, concerns about medicine, worries about flare-ups, and concerns about having a lifelong condition (Richardson et al., 2001).

A Similar Invisible Disease-Children with Cancer and their School Experiences

Although IBD is a chronic disease with unique characteristics, it is possible to find similarities in the school experiences of children with other invisible chronic diseases. Like children with IBD, children with cancer also have an invisible chronic disease and experience many of the same school challenges. In fact similar to children with IBD, Kline, Silver, and Russell (2001) state that, “children with cancer experience numerous obstacles to school attendance and academic performance” (p. 36). These obstacles include increased absenteeism because of medical appointments, illness as a result of treatments, and negative changes in social interaction with peers and adults in the school.

With respect to teachers and the experiences of children with cancer, research by Bessell (2001) found that teachers have a responsibility to provide children with cancer, with a successful educational experience. Further to this, Best, Heller, and Bigge (2005) state:

As they do for all students with chronic conditions, teachers and others must maintain consistency in educational programming, while assisting the student to cope with missed school time, social and academic reintegration after hospitalization, or altered appearance as a result of treatment and/or disease progression (p. 70).

However, teachers had not received the training nor emotional preparation needed in order to deal with the issues that accompany the diagnosis and subsequent treatment of a child with cancer. Consequently, Heller and colleagues (2009) determined that there is a need for educators to become knowledgeable about the eight types of childhood cancers (the most common being leukemia), the treatments and their side effects, and the impact that all these factors may have on the child’s success in the educational environment. Therefore, children with

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

cancer, much like children with IBD, face a number of distinct challenges which need to be met if they are to be successful in general education classrooms.

Overview of Québec's Educational System

Québec is the only province in Canada that is still governed by an educational system of integration rather than an inclusive educational system (Hutchinson, 2010). The Ministère de l'Éducation, du Loisir et du Sport Québec (MEQ) is the government body responsible for promoting access to all forms of educational, leisure, and sports services in the province in both languages—French and English. This governing body also oversees the coordination of educational activities for communities in line with government policies that meet the economic, social, and cultural needs of Québec society. Québec's education system is based upon shared responsibilities between the government, universities, CEGEPs (Collège d'Enseignement Général et Professionnel), school boards, and schools. It also offers a wide range of educational programs and services from Kindergarten to university (MEQ, 2003).

Québec Kindergarten, Elementary, and Secondary Education System

Like most provinces, Québec offers non-compulsory Kindergarten or “maternelle” programs to prepare five year olds for Grade 1. Children with disabilities, learning or adjustment difficulties account for 1.5% of the students (MEQ, 2003). For girls, the proportion was 1.0% and it was almost doubled at 2.0% for boys (MEQ, 2003).

Elementary education consists of six years of schooling and is divided into three cycles of two years each. Children, who are six years of age by October 1, may be admitted to their first year of elementary schooling. Grades 1 to 6 are termed in French—*école primaire* and in English—Elementary or Primary levels. Elementary education is offered in French, English, or a First Nation language. Students deemed eligible to study in English are those whose father or

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

mother attended an English elementary school in Canada. Elementary education focuses on basic subjects (reading, writing, and arithmetic) and the goal at this level is to foster the progressive development of independence and to prepare students for secondary schooling.

At the end of the elementary school period, children automatically move on to high school in English or French—*école secondaire*. As a general rule, there are no tests or entrance exams for admittance to public high schools, but in Québec there are a few exceptions to that rule. The public schools that do require entrance exams for admission are operated under the same principles as private schools.

The length of stay in secondary schools is five years and it consists of two levels: Secondary 1 and 2 (Grades 7 to 8) and Secondary 3 to 5 (Grades 9 to 11). At the end of Secondary 5, students who have successfully completed the program obtain the governmental *Diplôme d'études secondaires*.

Public elementary and secondary schools fall under the jurisdiction of school boards governed by school commissioners who are elected by residents in the territory under the school board's jurisdiction. The school boards hire the staff they need to provide educational services. Elementary and secondary education is also provided by private institutions, some of which are subsidized by the *Ministère de l'Éducation*. The private school system accounts for 5.0% of elementary and 17% of secondary students (Cowley, 2008). Almost half of the operating expenses of subsidized private institutions are funded by the Québec government (MEQ, 2003). Elementary and secondary education are also offered by some public institutions that are not part of the school board system but fall under the Québec or federal government's jurisdiction, such as schools on First Nation reserves. These institutions account for 0.3% of students (MEQ, 2003).

Québec's Educational Reform towards a System of Integration

In the 1970s Québec closed the vast majority of its special education schools (Horth, 1998). As a result, public schools were obliged to accept all students no matter what exceptionalities the students might have had. Segregated special schools were replaced by a system of integration. Integration is viewed as a system in which individual students are expected to adapt to conditions and practices in general education classrooms (Armstrong, Armstrong, & Barton, 2000).

It is a structure designed to fit children into pre-existing systems and focuses on where pupils are educated rather than how they are educated (Armstrong & Moore, 2004). In other words, students with exceptionalities are expected to arrive at school ready to adapt to the school's already established structure and environment. In this system, it is not the school's responsibility to accommodate the specific needs of an exceptional student. Interestingly to note as well, is that sometimes admission to a "normal" school, is in fact admission to only a special section of a regular school, and may involve very little mixing of the students (Thomazet, 2009). Wolfensberger and Thomas (1983), further explain that integration can be viewed as taking place in three separate ways. A school can maintain a system of simple physical integration. This occurs when students with special educational needs are present in the school but do not take part in any activities with the students without special needs. Then, there is a pedagogic integration where the children are present in the classroom and actually participate in the academic program given within the general education classroom but with differentiated objectives. Lastly, there is social integration where children with special needs only join with other students outside of classes (for example, project work, clubs, recreational activities, library, school canteen, etc.).

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Nonetheless the process of integration is meant to ensure that all students are given as “regular” an education as possible as compared to their peers. However, this remains a constant debate within the province of Québec and some argue that what is needed is a system of inclusive education, whereby schools and school staff assume the responsibility for meeting all students’ needs. Therefore, in an attempt to rectify the education system within the province, the former Minister of Education, Mrs. Pauline Marois, amended the *Education Act of Québec* in 1996 in order to have it better reflect Québec society’s changing educational needs.

The revised legislation sought to accommodate the needs of students with disabilities within the pre-existing general education elementary and secondary classroom structure. The Education Act was also modified to afford more power and autonomy to elementary and secondary schools, in particular by creating governing boards. These boards consist of an equal number of parents and school staff, and served to unite these two groups as key partners in school administration. In so doing, parents and school staff were given more decision making power with regard to pedagogical and budgetary issues (MEQ, 2006).

Although the education of students with special needs has been legislated, it has been implemented differently within the province according to the category or label ascribed to students and the school boards’ policies and procedures (Conseil supérieur de l’éducation, 1996, p. 33). Additionally, each student requires his or her individual special accommodations to function successfully in the school environments. According to the revised Québec Education Act (April, 2010) which legally governs Québec’s education system:

The right of the student with special needs to receive educational services is reaffirmed; for students with handicaps, this right extends to the age of 21 (s. 1). The emphasis is still on the adaptation of services. School boards must adapt educational services to

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

students with special needs according to the student's needs and in keeping with the student's abilities as evaluated by the school board (s. 234).

As of April 2010 the Education Act of Québec stipulates that:

In the case of a handicapped student or a student with a social maladjustment or a learning disability, the principal, with the assistance of the student's parents, and the staff providing services to the student, and of the student himself, unless the student is unable to do so, shall establish an Individualized Education Plan (IEP) adapted to the needs of the student. The plan must be consistent with the school board's policy concerning the organization of services for handicapped students and students with social maladjustments or learning disabilities and in keeping with the ability and needs of the student as evaluated by the school board before the student's placement and enrolment at the school (Education Act of Québec as of April, 2010).

What does this mean for a child with IBD? One could argue that the Education Act implies that school boards do have a legal obligation to adapt their school's services to meet student's special needs; however, I note that nowhere in the Education Act is it explicitly stated that the special needs of children with chronic illnesses, or health challenges must be met. Rather, the Education Act clearly notes that the special needs of students with handicaps, social maladjustments and learning disabilities, specifically, mental and learning disabilities must be served. At first appearance these categories do not seem to bare any relationship to children with IBD. They rarely suffer from mental impairments, rather their special needs stem largely from physical internal health issues. However, children with IBD are listed in the Education act under "handicaps". Similar to the obscurity of the disease, to find mention of IBD within the category of handicap one needs to further search within another category. IBD is listed under

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

“Impairments” and more specifically under “organic impairments”. Therefore, in order to be able to qualify for an IEP and accommodations, it is incumbent on parents to have knowledge of these key words. However, children with IBD have a chronic disease and do not consider that they are handicapped. Therefore, the label ascribed by the Education Act appears to be at odds with how the children and their families may perceive their situation. Hence, it is not surprising that few students with IBD in this study have IEPs that addressed their health issues (Gordon, 2004).

Parental Concerns with Education of Children with Special Needs

A qualitative study by Wang, Mannan, Poston, Turnbull, and Summers (2004) examined parents' perceptions of their advocacy activities and the impact on their family's quality of life in the U.S. A total of 104 family members with a child with a disability participated in individual interviews and focus groups. Their research affirmed that the foremost concern of parents regarding the education of their child with a disability is whether an appropriate education is being provided to meet their child's needs. Subsequently, the authors concluded that parents made frequent comments related to the educational system's denial or deferment of services and teachers' inappropriate practices. These findings are consistent with one of the key findings in the U.S. report of the President's Commission on Excellence in Special Education–PCESE (2002), which indicated that "parents want an education system that is results-oriented and focused on the child's needs" (p. 8).

Wang and colleagues (2004) highlight that, parents' observations of educational systems seem to be "babysitting" rather than "educating and serving" students with disabilities. This is consistent with findings of the PCESE (2002), which stated that for many schools "simply qualifying for special education becomes an end-point" rather than a “gateway” (p. 7) for

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

students with disabilities to gain more effective instruction and intervention. Furthermore, parents' comments about the "can't do syndrome," their perceptions of negligence, and problematic IEP practices indicate that some schools still may functionally exclude some students with disabilities (i.e., students are enrolled but do not benefit sufficiently) (Turnbull & Turnbull, 2000).

Overall, these findings indicate that the poor quality of educational services are barriers to successful educational experiences for children with disabilities. For these reasons, parents believe that they must support their children in school. Such barriers can become significant sources of stress and can impact many aspects of family life. For example, poor service provision may result in parents having to redirect their time and energy away from family activities by investing it in attending meetings, gathering information, and otherwise engaging in advocacy activities (Turnbull & Turnbull, 2000).

Experiences of Public versus Private Schooling in Québec

Although not directly linked to poor quality educational services for students with disabilities in the public school sector, more parents in Québec are choosing to send their children to private schools (Caputo, 2007). This is evidenced by the steady decline in the number of students enrolled in Québec public schools in the last two decades (Caputo, 2007). Consequently, there has been a sharp increase in the number of students attending private schools, particularly at the secondary level in Québec. Of all the Canadian provinces, Québec maintains the highest rate of private subsidized education with more than 17% of students in attendance at the secondary level. Meanwhile, public school enrolment has steadily declined by 4% since 1999 (Cowley, 2008).

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

In the debate, proponents of private schooling contend that there are notable advantages to students and their parents to pursue this system of education. For example, Québec private schools permit children to be educated within the context of a particular faith-based practice such as Catholic, Jewish, Muslim, and Adventist schools. Other families prefer private schools because they offer a particular way of teaching, such as the Montessori Method while still others require a school that serves their child's special needs (Cowley, 2008). Typically, private schools have smaller class sizes, thereby, providing a more personal learning environment where the emphasis is frequently focused on student discipline, support, and achievement. Parents tend to play a more active role in the management, educational projects, and financial funding of these schools. Additionally, private schools must conform to the same legal and regulatory requirements mandated by the MEQ, such as maintaining a system of integration.

The opponents of private schooling argue that although private schools must adhere to the requirements of the MEQ, they are not similar to public schools. By law public schools must integrate students with difficulties, as well as students from low-income families and from various ethnic backgrounds. The two sectors are also dissimilar in matters of student-teacher ratio and the cost to attend a private school. Although, the government subsidizes the tuition of every child who enters a private school, the high cost associated with access to these schools places children from low income families at a great disadvantage to gain admission to them. For example, in order to attend Lower Canada College in 2010-2011, the tuition costs ranged between \$14,000 (elementary level) and \$18,000 (secondary level) year. Also, in order to qualify for admission, most private schools require students to pass an entrance exam (such as the Common Admissions Test) and a personal interview (http://www.lcc.ca/uploaded/1_Publications/Admissions_Publications/FeeSchedule_2010_11_Final.pdf). Thus, students with

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

learning or behavioral difficulties may struggle to meet these stringent admission criteria. They further argue that public schools are at a disadvantage because these schools are required by law to retain all students regardless of their behavioural problems or poor academic performance; whereas, private schools are not obligated to accept or retain students who demonstrate unacceptable behaviours, or poor academic performance (Caputo, 2007). Consequently, Québec's students attending public schools experience high failure rates on provincial exams compared to private schools (Cowley, 2008). Québec's high dropout rate in public schools is also a cause for concern in comparison to private schools. According to statistics released by the MEQ in 2009, the dropout rate in Québec increased from 26% to 29% between the years 2000 and 2007. The former Premier Jacque Parizeau, called these results "scandalous," while Daniel Audet of the Employers' Council of Québec stated that the results were "disastrous" (CBC News Canada, April, 2010).

Presently, the trend continues where students from families with the socio-economic means continue to leave public schools and attend private institutions. In turn, this leaves a number of students from disadvantaged backgrounds, as well as those requiring support with special needs in attending public schools. Consequently, the focus of this research is on the experiences in public and private schools of students with IBD and their families.

Chapter 3-Theories Guiding the Study

Introduction

Bronfenbrenner's ecological theory and Turnbull and Turnbull's family systems theory were the two principal theories used to explore the phenomenon under investigation (family member's school experiences) in this study. In this chapter, the discussion of these two theories was further supported by an examination of sibling research within systems theory and children's family experiences through drawing. Also, the rationale for incorporating information on siblings and the use of their drawings was addressed in this chapter.

Bronfenbrenner's Ecological Theory

Bronfenbrenner's (1979) ecological theory was selected for use in this study for three reasons. Firstly, Bronfenbrenner's (1979) theory provides a structure to investigate each of the family member's experiences (parent(s), sibling, and child with IBD) and his or her relationships within the four systems. Secondly, the theory shows the interconnectedness of the system to assist in understanding the multiple interactions that can occur and the impact of those interactions on each family member in each of the four environments. Lastly, the theory affords explanations of possible outcomes as a result of a family member interacting and being impacted by each of their four environments.

Bronfenbrenner (1979) developed his ecological systems theory in an attempt to define and understand human development within the context of the system of relationships that form the person's environment. His definition (1986) of the theory is as follows:

The ecology of human development is the scientific study of the progressive, mutual accommodation throughout the life course between an active, growing human being and the changing properties of the immediate settings in which the

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

developing person lives. [This] process is affected by the relations between these settings and by the larger contexts in which the settings are embedded. (p. 188)

According to Bronfenbrenner's initial theory (1979) the environment, comprises four layers of systems which interact in complex ways and can both affect and be affected by the person's development. This theory can be extended to model the development of an organization as well, and is particularly appropriate for describing the complex systems of a school district or even of an individual school (Bronfenbrenner, 2005).

Bronfenbrenner's (1979) four systems are the microsystem, the mesosystem, the exosystem, and the macrosystem. The microsystem is defined as the pattern of activities, roles, and interpersonal relationships experienced by a developing person in a particular setting with particular physical and material features and containing other persons with distinctive characteristics of temperament, personality, and systems of belief (Bronfenbrenner, 1995, p. 227). An example of the microsystem in this study was the home environment which included a child with IBD and family members (parent(s) and a brother or sister) and their interactions and relationships. This level also includes the biological context of a child, which can also be described as the genetic makeup and development stage of a child.

The second level is the mesosystem. Bronfenbrenner (1979) defines the mesosystem as a set of interrelations between two or more settings in which the developing person becomes an active participant. The mesosystem, simply stated, comprises the linkages between microsystems (Bronfenbrenner, 1995, p. 227). In this study, the school environment was examined in two ways at this level. One focus was the relationships between the children with IBD and their teachers, principals, and peers in a general education classroom. The second was, the relationship between parents of children with IBD and their teachers and principals.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

The third level of Bronfenbrenner's theory (1979) is the exosystem. He defines the exosystem as consisting of one or more settings that do not involve the developing person as an active participant but in which events occur that affect, or are affected by, what happens in that setting. For this study, the exosystem focused on the parents' relationships with their community. The community included the parents' workplace/employment, participation in an IBD Association, the role of school boards, and the use of government services. Each of these people, places, services, and events found in the families' community can have an impact negatively or positively on children with IBD and the family members.

The final level in Bronfenbrenner's theory is the macrosystem. Bronfenbrenner (1979) states that the macrosystem refers to the consistency observed within a given culture or subculture in the form and content of its constituent micro-, meso-, and exo- systems, as well as any belief systems or ideology underlying such consistencies. The way in which a culture values the importance of education would be considered an example of the macrosystem. In this study, societal values and beliefs about IBD were examined in relation to the family member's experiences.

This theory suggests that children's surroundings, including their home, school, and community, can impact their development positively or negatively. Specifically, Bronfenbrenner's theory suggests that if children grow up in a high risk environment that their development will be strongly influenced in a negative way by that environment, possibly causing them to lead an unhealthy and unfulfilling life. Each system contains roles, norms, and rules that can powerfully shape children's development (Bronfenbrenner, 1995). In order to visualize how these factors impact them, Bronfenbrenner created a map of nested concentric circles (See Figure 1). The child is considered to be at the center of a series of concentric circles. The elements in

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

each circle influence the circles inside it. In this model, a child-initially consisting of his or her biological makeup-is most directly influenced by the *immediate environment* or microsystem. For most children, this includes the family. The microsystem is influenced by the school, social, economic, and cultural context. For example, the family will be influenced by such factors as the degree to which the child feels attended to or neglected at school (mesosystem) and whether a parent is able to have a job that permits frequent contact with the child (exosystem). The school, social, and economic context is influenced by the cultural context-the beliefs, values, and guidelines that people in a particular society tend to share (macrosystem).

Figure 1 Diagram of Bronfenbrenner's Ecological Theory Applied to Family Experiences of Education in Québec

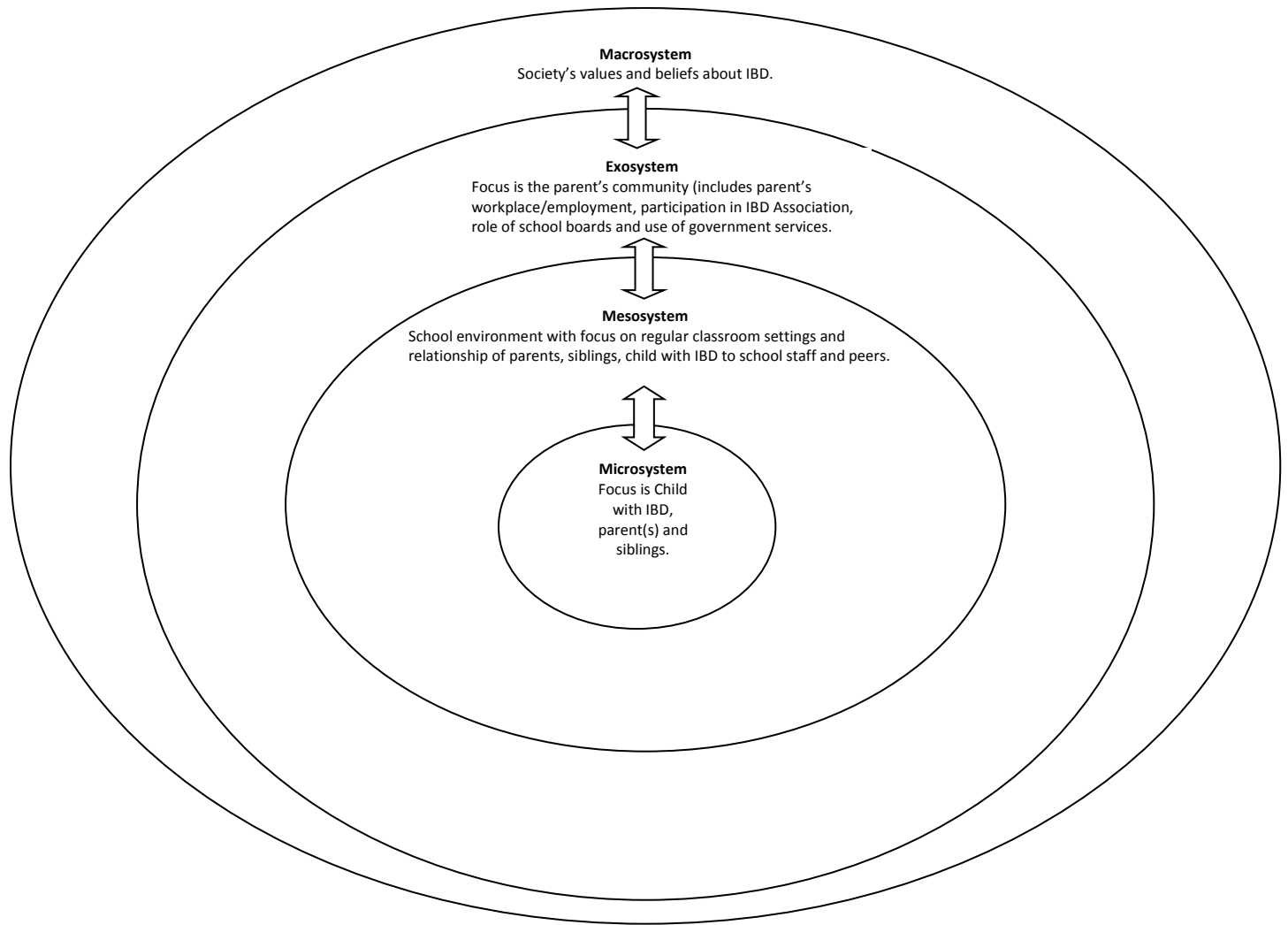


Illustration of Bronfenbrenner's nested concentric circles and the multiple interactions occurring within each of the four systems. In this study, family members' experiences of the educational system in Québec are influenced and impacted by all four systems. At the level of the microsystem, the experiences of the family members and their relationships are examined. In the mesosystem, the focus is the school environment of the child with IBD and family's experiences particularly in regular classrooms. At the level of the exosystem, the parents' experiences in their community are impacted by their workplace/employment, participation in an IBD association, the role of the school board, and the use of services offered by the government. In the macrosystem, societal beliefs and values about IBD and the impact on the family is examined.

Bronfenbrenner's (1979) framework does provide a more extended and elaborated conception of the environment. However, this theory is limited in that little consideration was given to the role that adults (in particular parents) and children play in selecting and shaping the settings in which they find themselves, for people are agents of their own actions. Therefore,

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Turnbull and Turnbull's (2001) family systems theory was added to address some of these shortcomings.

Turnbull and Turnbull's Family Systems

In order to gain insights into the dynamic, complex, and multifaceted phenomenon of family interaction, Turnbull and Turnbull's family systems theory (2001) and Bronfenbrenner's ecological theory (1979) were used as my theoretical framework. Although these theories present two different perspectives, both offer a means for investigating the external and internal factors that can impact families.

According to Winzer (2005), a family is viewed as more than individuals bound by a biological relationship. Whether the family is nuclear, single-parent or extended, the action of each member plays a powerful role in the child's social, emotional, behavioural, and academic development. Turnbull and Turnbull (2001) posit that within family systems theory the family is as an interrelated social system with unique characteristics and needs. It is based on the assumption that an experience affecting one family member will affect all family members (Turnbull & Turnbull, 2001). They contend that there is a direct relationship between the child who has special needs and his or her family (Turnbull & Turnbull, 2001). Interaction between family members deeply influences the child's opportunities and barriers, challenges, expectations, frustrations, ambitions, and general quality of life.

In family systems theory, a child with IBD would be viewed as a component of the system. A chronic illness would not simply belong to the child but would impact the entire family. Factors such as a child's illness, family size, and socioeconomic status all influence the ways families thrive and develop. Also important is the physical and mental health of family members, as it has a direct bearing on the family's ability to understand the needs of a child with

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

exceptionalities and to cope with the associated demands and pressures, especially within school settings (Baum, 2008).

Family pressures, such as economic stresses, coupled with the additional demands of supporting a child with a disability, may affect school-home collaborations (Baum, 2008). Often overlooked, are other family considerations, such as the needs of other siblings (Cramer, Erzkus, Mayweather, Pope, Roeder, & Tone, 1997), and changes in the traditional role of fathers in the care and support of the child (Ballard, Bray, Shelton, & Clarkson, 1997).

Limitations of Turnbull and Turnbull's Family Theory

Turnbull and Turnbull's (2001) framework for understanding the emotions, dynamics, and elements of family systems has allowed professionals to work more effectively with families. The eight elements of this framework focus on the areas of a family's needs in terms of economic, daily care, socialization and recreational, self-esteem, affection, spiritual, and educational needs (Turnbull & Turnbull, 2001). As well, this theory takes into consideration the roles and needs of each family member (Turnbull et al., 1985). What this theory lacks is an examination of the importance of each family member's perception of his or her role in the family and the individual experiences in the family. Consequently, the current study examines this missing part of the theory with a view to include the results to the present body of literature.

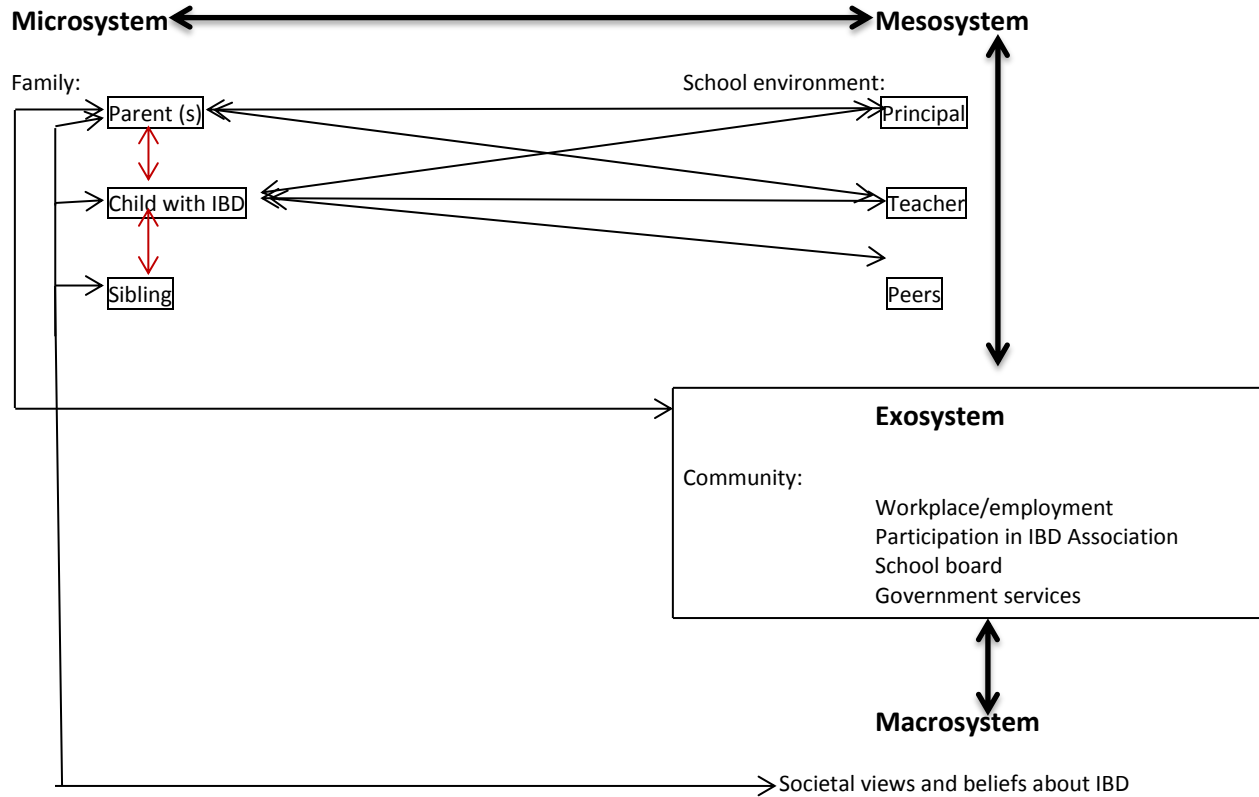
Bronfenbrenner's ecological theory complements family systems theory by examining the impact of factors that occur not only within families but also within external environments (school, community, and society). To the extent that they are perceived to be involved in some way with their child, family members are a part of a child with IBD's microsystem. Parents, siblings, and extended family can influence a child with IBD's microsystem by the quantity and quality of their interactions with the child and other family members. The family systems theory

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

and the ecological theory are essentially two theories that focus on the way a child develops in relation to his or her environment and these theories guide this study (See Figure 2).

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Figure 2 Diagram of Relationships Examined at the Level of Bronfenbrenner and Turnbull and Turnbull's Systems Theories



The diagram displays all the environments and family relationships examined in this study. Red lines demonstrate the relationships maintained between family members as explained by Turnbull and Turnbull's (2001) family systems theory. All black lines display the relationships between the four systems presented in Bronfenbrenner's (1979) ecological systems theory and the factors explored in this study.

Sibling Research within Systems Theories

In order to learn how to support siblings in different family contexts, I think that it is imperative that we address family complexity and include siblings in research designs. In the early years of sibling research, investigators studied siblings in isolation, as if the families in which they lived were irrelevant (Kluger, 2011). Now researchers routinely consider family contexts, but the wider ecological environment is ignored. Sibling roles and interactions are shaped, in part, by contexts and environments beyond the home.

A study conducted by Edwards, Hadfield and Mauthner (2005) with 58 children between seven to 13 years of age were interviewed. The researchers concluded that sibling relationships are both complex and diverse and that children are active in constructing them. The researchers also noted that the number of siblings, their position in the age hierarchy, the age gap between them, and the gender balance of sibling groups are a focus of much research. Studies in this area are overwhelmingly concerned with the resulting effects on child development, behavior, and educational outcomes. However, there is a need for more research studies similar to the one by Gilbert and Morawski (2005) that address children's own interpretations of their sibling relationships and the social context in which they take place. For these reasons, the current study on family members' experiences incorporates siblings' perceptions of the relationships that existed in their family. Therefore, by employing both the family systems theory and the ecological theory, the current study was able to further explore these complex and dynamic relationships. To that end, this researcher collected sibling's stories of their experiences of having a brother or sister with IBD.

Children's Family Experiences Expressed through Drawing

The aim of the current research was to investigate the experiences of families of a child with IBD. One method of collecting the experiences during one-on-one interviews is by listening to families' stories. Not only can these stories be collected from individual interviews, they can also be obtained from sibling drawings. Further, to listening to siblings' experiences, the children were also provided with a supplementary way to communicate by drawing. For children, drawing can be perceived as an enjoyable way for them to express their views, thoughts, and experiences. Therefore, drawing can provide children with another way to communicate which is non-verbal. This method of expressing themselves may help them to feel much more comfortable and avoid their need to maintain eye contact with the adult interviewer which they may find distracting or intimidating (Dockett & Perry, 2005). Moreover, drawings have been used by a number of researchers in interview situations (Einarsdottir, 2007; Einarsdottir, et al., 2009; Wiltz & Klein, 2001; Leonard, 2006) with both the image and the child's accompanying comments used as data. For example, Wiltz and Klein (2001) used the phrase 'picture stories' to prompt children to draw and tell the stories that they associated with the pictures. Until recently, researchers focused exclusively on what they assumed the child's drawing meant rather than asking for the child to explain what he or she had drawn. Now, the focus has shifted 'from what the children draw to what the children say about what they draw' (Driessnack, 2005).

The rationale for using young children's drawings in research is that by asking them to draw, may assist in establishing rapport with the interviewer. This may also act as a prompt, or a trigger that elicits discussion, and may aid in organizing their own narratives (Miles, 2000). Drawing may also enable children to gain more control over the interview, since it gives them an

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

opportunity to draw as much, or as little as they like. This provides them time to reflect on their thoughts and ideas (Miles, 2000). Drawing has also been described as a useful and rather quick way to gain considerable amounts of information in a relatively short period of time (Miles, 2000).

There are a number of limitations in using drawing as a technique with children. For example, not all children consider drawing to be an enjoyable activity and some children may be inhibited about their drawing capabilities (Einarsdottir, et al., 2009). In short, drawing may not suit all children and according to Leonard (2006), some children may choose simply to “illustrate socially constructed rather than individual ideas.” (p.55). Children may draw what they find easy to portray or what they think would please the researcher rather than what they truly think and feel (Dockett & Perry, 2005). Finally, researchers using this method can be uncertain about how to analyze this kind of data (Backett-Milburn & McKie, 1999). In this multi-method qualitative study, this issue was resolved by allowing the pictures to speak for themselves. This meant that the siblings’ drawings were presented descriptively and were supported by the children’s words. The drawings were not analyzed for meaning or interpretation.

Chapter 4-Methodology

Introduction

The purpose of this study was to understand the educational experiences of children with IBD from the “point of view of the participants” (Denzin & Lincoln, p. 225, 2011). Hence, this qualitative research followed a case study design. It is unique because it incorporates the perspectives of children with IBD and their families.

Within the field of social science, some researchers have begun to explore children’s own perceptions of relationships (Edwards et al., 2005). Study findings have acknowledged that children have varied abilities and interests, and as such, there is no one uniformed technique to carrying out research with them (Christensen & James, 2000). Thus, some studies recommend a flexible multi-method approach (Punch, 2001; Clark, 2004), or the use of multiple techniques within one key method, such as employing a range of tools during interviewing (Hadfield et al., 2005). For this reason, this study used a modified version of Seidman’s (2006) interviewing technique supplemented with the use of a sibling’s family drawing. In general, the current qualitative study used a case study design that provided a systematic approach in which children with IBD and their family members’ views could be heard. The stories that were collected recounted their experiences in general education classrooms in Québec and their relationships at home, in their community, and society.

Case Study Design

A case study method was used since the study is an empirical inquiry that investigated a contemporary event within real-life context (Yin, 2011). Simply put, a case study is a problem to be examined, that will reveal an in-depth understanding of a *case* or bounded system, and involves understanding an event, activity, process, or one or more individuals (Creswell, 2007).

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

In this research, the problem under investigation was the school experiences of children with IBD and members of their family. The intention was to gain an in-depth understanding of these experiences from individual family member's (parents, child with IBD and sibling) perspectives. By listening to the family members as they narrated their stories, the researcher was able to collect their points of view of their school experiences in general education classrooms.

The Use of Narratives

Carter (1993) suggests that narrative has become an increasingly popular focus of conducting research. She states that it has "caught on with considerable enthusiasm throughout the intellectual world and is beginning to appear in widely different contexts" (p. 5). For example, in the field of education, scholars such as Clandinin (2007), Elbaz (2010), Huber, Murphy and Clandinin (2011) have made story, or narrative, a central element in their analyses of teachers' knowledge and students' lived experiences.

Carter (1993) further suggests that "stories are not merely raw data from which to construct interpretations, but are products of a fundamentally interpretive process that is shaped by the moralistic impulses of the author and by narrative forces or requirements. And these interpret elements operate regardless of who the author is" (p. 9). Such a perspective underscores the centrality of interpretation in the study of children with IBD and their families, while at the same time it calls to question any pretensions of special agenda in this area.

In supporting the use of narrative as a means of inquiry in research, Engel (2005), Huber, Murphy, and Clandinin (2011) and Maybin (2008) emphasized the importance of using this method to conduct research with children.

Children's Narratives

As Grover (2004) argues, there is a need for a research method where children can communicate their experiences without having their meaning transformed or manipulated by the adult researcher. Noting the premature imposition of categories of analysis, she warns of the need to preserve the “authentic voice of the child,” adding that “it is time that children are regarded as experts on their own subjective experience” (p. 91). Children's narratives are valued for the insight they offer into the experiences of their worlds (Engel, 2005). Jean Piaget (1954) showed us that children not only had thoughts and experiences worth knowing, but that these thoughts and experiences were different from those of adults.

To collect the participants' perspectives of their lived experiences, Seidman's (2006) in-depth phenomenological interviewing technique was employed. The interviewing process was complemented with one sibling drawing per family. This approach was useful to the study, because it encouraged siblings to create drawings of themselves and members of their families and to talk freely about them.

Therefore, in this study, family members' stories or narratives were of great importance, especially those of the children with IBD and their siblings. Narrative inquiry provided the researcher the opportunity to view children's experiences from their own perspectives, acknowledging children as experts in their own lives (Clark & Moss, 2001) and, in particular, in their educational lives (Levin, 2000).

Children as Research Participants

In the last three years more research has been published from children's perspectives. Although the literature in this area is thin, it is growing and beginning to reflect an increasing

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

interest in childhood research and in particular research into children's perspectives and children's agency (Lewis & Lindsay, 2000).

Increased emphasis on children's "voices" and their rights to be involved in events and decisions that affect them, has motivated a move towards children becoming participants and co-researchers in exploratory studies about their lives, rather than passive "objects" of research. This movement has prompted a further step towards enabling children to become "active" co-researchers in their own right (Kellett, 2005). Lambert (2003) writes that, there has been a shift in the focus of this area of research, due largely to greater use of the qualitative paradigms. Thus, being very cognizant of the importance of incorporating children's perspectives in qualitative research, the present study used siblings' family drawings as a supplementary communicative instrument in addition to their individual one-on-one interview.

While the use of children's spoken and written narratives in research is widely documented, the concept of using their drawings as a form of narrative is infrequently addressed. The children's drawings were a useful tool that provided a familiar and nonthreatening activity. By being asked to draw, the children were able to depict family members as they saw fit and, as drawings often take time, a quick response was not demanded of them (Einarsdóttir, 2007).

Children's Drawings

Children naturally draw as part of their developmental process (Hammer, 1997). Through their drawings, the children in this study were able to express their ideas and perceptions of the world they lived in, as well as the ways with which they dealt with it (Moschini, 2005). At an early age (about 12 months), some children are already exposed to the use of paper and crayons and begin to scribble (Einarsdóttir, 2007). From that age, they use drawings as their own language, an alternative language that enables them, before they acquire

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

complete fluency in verbal language, to express their inner world, feelings and thoughts (Moschini, 2005). As a result, the children's drawings were crucial as a supplementary tool to the research that served as a medium for accessing the siblings' inner thoughts, feelings and experiences. Sometimes when children tell stories, they may not be able to articulate a memory or experience, but if drawings are included in the process, the stories may be revealed.

Children's artistic expressions represent their impressions of their inner worlds, responses to their environments, and individual stories (Malchiodi, 1998). The drawings do not just represent situations; they represent a narrative (Malchiodi, 1998) and my aim was to gather all of this information in my sessions with them.

Wright (2007) found that the process of "drawing-telling" gave students an opportunity to create and share meaning in two modes. Asking the children to tell me about their drawing proved to be far more informative than the drawing on its own. It can be easy for researchers to interpret drawings according to their particular research agenda, but this, however, may not necessarily relate to the intentions of the drawer (Dockett & Perry, 2005a). Children will often tell stories to accompany their drawing, but sometimes, while they may not be able to articulate a memory or experience, the story is often revealed through the process of drawing.

An emphasis on "listening" to children while drawing, rather than trying to analyze their completed pictures, was an important factor in this method. This was because children's narratives and interpretations of their drawings may provide a better explanation than the adults' interpretations of the drawings (Clark, 2005; Einarsdóttir, 2007; Veale, 2005).

Individual Interviews

Each family member was interviewed individually. The interviews followed a modified version of Seidman's (2006) three-phased phenomenological in-depth interview structure. The

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

purpose of conducting one-on-one, in-depth interviews was not to obtain answers to questions, test hypotheses, nor to *evaluate* as the term is normally used (Seidman 1991, p. 3), but rather, to find out the experiences of families and what the experiences meant to them. This format also allowed participants to speak freely and set the tone for a relaxed atmosphere with me during the interviewing process.

In this approach, interviewers use mainly open-ended questions in order to explore and build upon participants' responses. In so doing, Seidman (2006) claims that the in-depth interviewing approach permits the participants to reconstruct their experiences within the topic being investigated. The main feature of this method is to conduct three separate interviews with each participant. During the process, the first interview, *life history* establishes the context of the participants' experience. The second interview, *contemporary experience* permits the participants to recreate the details of their experiences, and the third interview, *reflection on meaning*; is a point at which the participants are encouraged to examine the meaning attributed to their experience from their perspective (Seidman, 2006).

Seidman (2006) informs us that each interview within the series of prescribed structure serves a purpose by itself. Each interview is conducted over the course of a few days or a week apart and provides a foundation of detail that helps illuminate the next. The logic to the prescribed sequence is to provide a beginning, middle, and an end.

The final modification that was made was that the period of time for the interviews was reduced from three days to two days. The pilot family found that having to be interviewed for three days was taxing for both the parents and their children. The parents reported that spreading the interviews over three days interfered and took time away from their families' extra-curricular activities and daily routines. Most importantly, the reduced time was necessary to accommodate

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

the children because of their illness. Working with children who have a chronic illness over a longer period of time, meant that the illness would likely interfere with the research process. As a result of the parents' request during the pilot study, all subsequent interviews were conducted in two days to accommodate the needs of the families and the sick children. Therefore, it was for these reasons that Seidman's (2006) original interviewing approach was modified to accommodate the needs of these participants. Minimal data were gathered from the pilot study and as a result it was not incorporated in the final analysis of the study.

Research Instruments

Following Seidman's (2006) interview process, three sets of open-ended interview questions that reflected Turnbull and Turnbull's family systems theory (2001) and Bronfenbrenner's (1979) ecological theory for parents and children with IBD were developed (See Appendices A and B). In addition, a single set of open-ended questions was prepared for the siblings (See Appendix C). Only one sibling (per family) was asked to draw a picture of his or her family.

The first interview consisted of open-ended questions that were intended to explore the participants' past experience (life history)—including areas of family, school, classrooms, community and for the children with IBD, the impact of living with the disease (See Appendices A, B, and C). Next, the second interview asked participants about their present experiences. The questions about the present related to the same areas as the past, but within a contemporary context. In the final interview participants were required to reflect upon their past experiences. The reflective questions dealt with the participants' belief system, personal values, and their views of the future from their perspective. The siblings were interviewed only once. They were asked open-ended questions that dealt with their experiences in the past and present. Each

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

sibling was also invited to reflect on his or her experiences. Only one brother or sister was interviewed in each family except in the case of Family 2 where both siblings (Squirtle and Daniel) wanted to participate and as such both of them were interviewed. Following the one-on-one interviews, a sibling in each of the five families was asked to draw a family portrait.

All of the interview questions were first piloted with a trial family. Their feedback and comments resulted in minor adjustments made to two questions (#1 and #19) of the sibling interview (See Appendix D). These two questions were re-phrased for clarity.

Recruitment of Family Participants

In keeping with the ethical requirements of the University of Ottawa for conducting research, approval from the Research Ethics Board was sought and received in May 2010. This opened the way for me to contact the Montreal Chapter of the Crohn's and Colitis Foundation of Canada. Once the Foundation received the faxed copy of the ethics approval letter, I submitted a copy of the recruitment notice to their office. The recruitment notice for children with IBD and their families was posted on the association's website and published online in their monthly newsletter. Members were informed of the proposed study and how interested families could contact the researcher (See Appendix E).

The recruitment of the five participating families took place from June 2010 to March 2011. Initially, the recruitment phase was planned to last no longer than four months; however, it became a lengthy process that was unforeseen and resulted in taking nine months to complete. The reason for the extensive recruitment process was mainly due to the rigidity of the exclusion criteria that yielded few family participants (See Table 1). Using the first set of study criteria resulted in the recruitment of only two families out of a sample of approximately seven possible family participants over the course of four months. Therefore, the decision was made to modify

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

the research criteria in order to increase the probability of recruiting three more families into the study. The modifications to the exclusion criteria were the following:

1. The age of all child participants was increased from 13 to 18.
2. Children attending private or public schools were permitted to participate.
3. Single and two parent families were permitted to participate. Within the nine months, multiple approaches were employed in order to acquire the five families that met the designated research criteria. The following recruitment strategies were utilized over the nine months:

- Recruitment table set-up at the Crohn's and Colitis Foundation (CCF) Montreal Chapter's annual Heel 'n' Wheel-a-Thon,
- Researcher contacted friends, family members and university professors asking for referrals,
- Researcher contacted staff at the Montreal Children's Hospital's Department of Gastroenterology and asked for referrals,
- Recruitment posters and flyers placed at Concordia University, the Montreal General Hospital, the Montreal Children's Hospital and the SMBD-Jewish General Hospital,
- Referrals were sought from family members that were participating in the study,
- A one month paid advertisement about the study was placed in the Montreal Families newspaper,
- Researcher interviewed by the Montreal Families newspaper for special issue devoted to IBD ,
- Researcher made a presentation on IBD research at monthly CCF information evening for Ottawa and Gatineau Chapter members,
- Recruitment notices posted on the following internet sites:

-CCF Canada Facebook group, <http://www.facebook.com>

-Canadian Interdisciplinary Network for Complementary & Alternative Medicine Research (IN-CAM), <http://www.incamresearch.ca>

-Canadian Psychological Association <http://cpa.ca/>

-Alternative Medicine College of Canada, <http://alternativemedicinecollege.com>

- Recruitment notices were posted in the following newsletters:
 - CCF Montreal Chapter
 - Canadian Intestinal Research newsletter titled, 'Bad Gut'
- Researcher made a presentation on IBD research at IN-CAM 4th annual symposium
- Three previous IBD family study participants contacted.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

As such, over a nine month period five families were recruited through the use of the above multiple recruitment methods.

Study Criteria of Selected Family Participants

As noted previously, a family is viewed as more than individuals bound by a biological relationship. Hence, for the purpose of this qualitative inquiry, "family" was defined rather broadly as a group of people who thought of themselves as part of a family unit. Whether they are related by blood or marriage or not, but as long as they support and care for one another on a regular basis.

As a result, a purposive sample of five families comprised at least one parent, a child diagnosed with IBD, and at least one sibling was recruited into the study. In order to participate the families had to meet the following criteria:

- families had to agree to be interviewed over the course of two sessions (any two days),
- families had to have a child with IBD that was enrolled in a general education classroom in a Québec elementary or high school (public or private), and
- the child with IBD had to be between 7 to 18 years of age and have at least one sibling aged 7 years or more.

This younger age group was selected because at present, IBD research in this area has been focused mainly on late adolescence and adult populations. There is limited research and public awareness on the impact of the disease, especially among young children (Mamula, 2002).

Furthermore, research on sibling relationships is thin. Hence, it was anticipated that this study would add much information to these under researched populations. To maintain participants'

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

confidentiality, family surnames used in this study were pseudonyms and in the case of Family 2 the members chose their own pseudonyms.

Participant Family Demographics

Beyond the established study criteria noted above, the five participant families interestingly shared some similar family characteristics, such as all participants were Caucasian. All of the families had a mother who played a central role in the household, and they all had a child diagnosed with Crohn's disease. All five mothers had participated in an IBD Association and had been active in their children's school activities.

There were also many differences among the five families. Although all the participants were Caucasian, they were from different ethnic backgrounds and represented diverse family structures. Only one family had a child attending a faith-based school and all children were enrolled in general education classrooms. Two of the families were managed by a single parent (mother). One mother of Jewish heritage was in the process of divorce and had a son with severe IBD. He was enrolled in a private high school and had a healthy sister attending CEGEP. While in the other family, the mother of Italian heritage had become a widow due to her husband's death from Crohn's disease. She had four children of which a son and daughter were non-identical twins. Her twin daughter was healthy and went to a private high school while her twin son with IBD had a learning disability requiring the use of an IEP. He attended a public high school and trailed a grade behind his twin sister. The remaining three families were composed of two parents (mother and father). Two of the families were of Jewish heritage and coincidentally both families had endured the death of a grandmother at the time of the study. Four of the five families had enrolled at least one child into a private school. Additionally, one of these families had a father with ulcerative colitis, a son with Crohn's disease that attended a private high school

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

and two step-sisters, one of which had IBD and chronic asthma. Lastly, there was a French Canadian family who had two daughters in public schools. One daughter had Crohn's disease and Juvenile Rheumatoid Arthritis. A full description of the five participating families and their characteristics is shown in Table 2.

Data Collection Process

The family interviews were conducted during the summer of 2010 and continued until March 2011 (See Appendix F). Parent(s) were interviewed individually or together. Siblings and children with IBD were interviewed individually. The interviews were tape recorded and conducted at the families' homes on a day and time that was convenient for them. The families often chose to have the interviews held in either their kitchen or living rooms. Each participant's interview took approximately 90 minutes. Therefore, it took approximately six hours to complete one interview session with a family. Consequently, participating families committed to partake in a total of two interview sessions for this study. Interviews were conducted over a two day period.

In addition to the one-on-one interviews, a sibling in each family was asked to draw a picture of his or her family. The drawing process involved first providing the sibling with a variety of assorted coloured paper, crayons, markers, pencils, and pens (See Figure 3). Next, the siblings were invited to select the type of paper and art materials they wanted to use.



Figure 3 Art supplies presented to the siblings for their use to create their family portraits.

Then, they were free to express themselves by drawing on the paper they had selected. While drawing, the siblings shared different sentiments about their experiences within their family and the roles different members played. On average, it took 20 minutes for the siblings to finish their drawings. When they were finished drawing, they were asked to verbally share the story embedded in their drawings with me. As mentioned earlier, the advantage of using drawings in this way provided me the opportunity to gather the siblings' self-reports without some of the limitations imposed by the use of questionnaires or interviews (Pianta, Longmaid, & Ferguson, 1999).

Data Analysis

All data generated from the interviews and children's drawings were used to conduct the analysis. The analysis was done by hand to facilitate engagement of the data (Charmaz, 2000). According to Seidman (2006), "profiles [of the family] are one way to solve the problem the interviewer has of how to share what he or she has learned from the interviews" (p. 120). Therefore, each of the five families' taped recorded interviews was first transcribed verbatim. Hence, each family member's transcript served as a profile to represent a specific individual. Profiles for each family member (parents, child with IBD, and a sibling) were created. The narrative form of a profile allowed me to transform these data into a story (Seidman, 2006, p. 120). While closely reading through the family members' transcripts the data were reviewed for any information that was pertinent to answering the three research questions and supporting the literature review. After the content analysis was performed, I highlighted quotes and passages that signified ideas that were mentioned more frequently and these became the basis for codes and categories.

Coding is a process of reducing the data into smaller groupings so that they are more manageable (Gibbs, 2006). By creating codes, the data can then be categorized. In so doing, this process assisted the researcher in uncovering the types of relationships that existed between the categories, as well as revealing patterns of interactions. The purpose of engaging in coding was primarily to gain an understanding of how the family participants perceived their experiences and the nature and types of relationships that were involved. Some of the codes that were developed were based on the literature, while other codes emerged from the data. Any new observations and insights were also ascribed codes.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

The emergent codes were those that became apparent as the data were reviewed.

Seidman (2006) notes that, the researcher searches for connecting threads and patterns among the excerpts within those categories and connections between categories that might be called themes. Emergent themes and statements thought to be associated with family systems theory and ecological theory were highlighted. Once identified, the labels were placed in a table and codes were created for each. This type of coding allowed for the emergence of central themes and previously uncovered issues and connections. In addition, analytic memos were written as I proceeded with the coding. The memos provided an opportunity to reflect on the initial ideas and to examine them in relation to new information, and developing relationships and patterns.

At times, I discovered that some of the initial codes were occasionally too broad in scope. Consequently, subcategories were created as needed. This resulted in the creation of a two column table that listed the anticipated categories and the codes that were going to be assigned for that category (See Table 3).

Once the codes were listed in the tables, the constant comparison method was used (Gibbs, 2006). Consistencies between codes meant searching for similarity in meanings or ideas (Gibbs, 2006). Once again, written memos were created on these comparisons and the emerging categories until a point at which there was category saturation or no new codes were found. Eventually, certain categories were established to be more of a central focus and became core categories (See Table 4). With the data coded and summarized, I was then able to examine the information across the various summaries and synthesize the final findings. By performing multiple case studies, each case was analyzed separately then, all the cases were compared and contrasted in the final cross-case analysis.

Sibling Drawings

The purpose of the siblings' drawings was to provide them with another way to voice their experiences. As a result, each drawing stands alone and is appreciated for the descriptive nature of the work and the child's words spoken while drawing. It should be noted that when the children drew their pictures, they wrote the names of family members on them. To protect anonymity, some of the names of family members have been covered (removed) in the pictures that are placed at the beginning of each of the five family profiles.

Trustworthiness

The goal of trustworthiness in a qualitative inquiry is to support the argument that the inquiry's findings are "worth paying attention to" (Lincoln & Guba, 1985, p. 290). According to Lincoln and Guba (1985), in any qualitative research project, three issues of trustworthiness demand attention: *credibility*, *confirmability*, and *transferability*. Credibility refers to the degree to which the data accurately reflect the multiple realities of the phenomenon (Seidman, 2006). In order to ensure that credibility has been met, I employed Seidman's (2006) three-phased interview approach. The objective was to generate three layers of data from each participant (except siblings in which only one interview and a drawing was completed) in order to provide a richer, multilayered, and credible data set. One way of ensuring credibility is through *member checks* of the data (Marshall & Rossman, 2010). I conducted member checks in which participants were given the opportunity to review their interview transcripts and edit them to ensure that their thoughts were accurately presented.

Confirmability refers to the degree to which the results could be confirmed or corroborated by others (Marshall & Rossman, 2010). Confirmability is sometimes enhanced by using *audit trails* (e.g., a "residue of records stemming from inquiry", Lincoln & Guba, 1985, p.

319). According to Denzin (1994), "confirmability builds on audit trails...and involves the use of written field notes, memos, a field diary, process and personal notes, and a reflexive journal "(p. 513) to ensure that the analysis can be traced back to the original data. In order to conduct the audit trail, I relied on an independent audit of my research methods by a recent PhD graduate in the Faculty of Education at Concordia University. After I completed the data analysis and wrote the bulk of my findings, the auditor thoroughly examined my audit trail consisting of the original transcripts, data analysis documents, field notes, comments from the member checking, and the text of the dissertation itself. She assessed both the dependability and confirmability of the project, as well as the completeness and availability of all auditable documents.

According to Seidman (2006), transferability involves demonstrating the applicability of the results of the study from one context to other contexts. In qualitative research, the notion of generalizability found in quantitative studies appears to be similar to transferability, but it is different. Lincoln and Guba (1985) demonstrate the clear distinction between the two terms by stating that, "If there is a "true" generalization, it is that there can be no generalization" (p. 124). Instead the authors offer transferability as an alternative that extends beyond the limitations imposed by assumptions of predictability and replicability that bind generalizability.

Transferability can be enhanced by providing what is often referred to as *thick description* (For example, creating descriptive family profiles for each member and noting many of their quotes). In this way, families and people with the disease will be able to relate and benefit from the study of the participants' stories.

Chapter Summary

In chapter four the methodology used in the study was presented. The steps used to recruit the family participants and the inclusion criteria were outlined and discussed. The

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

rationale for using a qualitative research design and incorporating children as research participants was explained. The use of children's drawings as a research instrument was explored and discussed. The method of analysis of the interview transcripts, instruments, and gathered data was described and explained.

Chapter 5-Family Case Studies

Introduction

This chapter consists of case studies of five families. The common thread that binds these families together is that they each have a child with IBD. Families of children with IBD have used the platform provided here to voice their positive and negative experiences with the schools that their children attend. This is the first time an opportunity has been provided for siblings to tell their stories of what it is like to live with a brother or sister who has IBD. The siblings were able to share their experiences both verbally and through drawings.

The following profiles are the stories from the individual voices in each family. Each voice tells his or her own story, depicting his or her lived experiences. The case studies are poignant as they reveal the thoughts and feelings of children with IBD. The stories also give some insights into the lives of children living with IBD and their experiences in school. Children with IBD clearly expressed the reasons they do not do well in school for the most part, and their view of the help they need to receive so that they can achieve success in school—and by extension in life. They share with us their despair of the past—when they were diagnosed, and fear of the future—as they continue to live with the disease. But, they also speak to us of their hopes and aspirations for future life with or without IBD. Moreover, in their stories, members of each family speak to us about their feelings of sadness, fear, weariness, resignation, and hope for a good future for the child within the family, who has IBD.

Case Study 1–The Anderson Family: At Home in the Daycare



Family Introduction

I met the Anderson family on a Friday evening in June and was welcomed warmly into their home. There are two children in the family—13 year old Claire and 10 year old Lisa. Claire is diagnosed with Crohn's disease and Juvenile Rheumatoid Arthritis (JRA). The family is of French Canadian heritage and interestingly, their house doubles as a daycare centre during the week. The centre has been in operation for two years. Being able to work at home allows Mr. and Mrs. Anderson to attend to Claire's needs without the worry of having an employer who may not allow them to miss many days of work.

Microsystem from the Perspective of the Parent

Mrs. Anderson's Past, Present and Reflection: Experiences of IBD at Home

Mrs. Anderson recalled the exact date of Claire's diagnosis. "It was December 8, 2004," she said. In incredible detail, she described how Claire's disease progressed. She said, "In the beginning, she really only had stomach pain, her stomach hurt all the time-day, night, week-ends and holidays the cramps were there. Then she began to have diarrhea more and more, then mucus, then blood in her stool, and then the fatigue; the energy just wasn't there." What ensued was a lengthy process of frequent hospital visits and meetings with multiple doctors, until Claire was referred to a hospital's department of Gastroenterology. The gastroenterologist advised Mr. and Mrs. Anderson to monitor Claire's symptoms over the summer months and if the symptoms persisted then they were to return to the hospital in the fall. Claire did not fare any better over the summer. Mr. and Mrs. Anderson contacted the hospital in September but were only able to receive an appointment for October. According to Mrs. Anderson, "By November we had the colonoscopy [then] by December we had the diagnosis and I knew that was it [referring to Crohn's disease]. When you don't know [what's wrong with your child] you wonder is it this? [or] is it that? You're fixated on knowing what disease it is."

Upon receiving the diagnosis, the doctor provided the family with a small pamphlet prepared and published by an IBD Association. Mrs. Anderson also noted that the only other information they had received was supplied when, "We saw the dietician once who gave us a little guide of what to eat and what not to eat and it wasn't until she [Claire] had a real crisis that we saw the dietician." As soon as Mrs. Anderson had been informed about Claire's diagnosis, she made arrangements to inform her daughter's elementary school personnel.

Microsystem from the Perspective of the Child with IBD

Claire's Past, Present and Reflection: Experiences of IBD at Home

As far as Claire knows, she is the only member of her family who has IBD. She was diagnosed when she was seven years old and could only remember that at the time a doctor had given her minimal information about the disease she had. In contrast to her mother, Claire did not remember much about the process of obtaining a diagnosis. Although she had a lot of medical appointments, and received multiple drug prescriptions, those events all seem a distant memory to her now.

What did come to her mind; however, was that her life had been changed following her diagnosis. For example, her daily activities were limited and food restrictions were placed on her. She was not allowed to eat fruits and other foods high in fiber. Currently though, it appears that the family is not following any particular food regime.

Claire does not participate in any after school activities, and she is usually at home playing video games, using the internet, or spending time with her family. At the time of our interviews, she was excitedly anticipating going away for a week to a summer camp for children with Juvenile Rheumatoid Arthritis, followed by a fashion camp for teenage girls two weeks later.

Microsystem from the Perspective of the Sibling

Lisa's Past, Present and Reflection: Experiences of IBD at Home

Lisa had just completed Grade 4 when I met her. She seemed small for her age and much younger than 10 years. Although the girls are only three years apart in age, there appears to be a wide gap between them cognitively and behaviourally. Lisa's body, behaviour, and language skills seem to be underdeveloped for her age. Lisa would often dance about whimsically,

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

interrupt conversations by shrieking and mumbling inaudible words, and make inappropriate random sounds and noises; while Claire would sit and converse appropriately. Sometimes Lisa's behaviour seemed to annoy Claire because she constantly scolded Lisa and would angrily tell her to, "Stop it" or "Be quiet." The dynamic between the two sisters was interesting to observe as Claire demonstrated much anger, frustration, and annoyance towards her younger sister's behaviour and presence. Occasionally Mrs. Anderson would also scold Lisa, but she would use a much gentler tone of voice than Claire did.

When Lisa was asked how she learned about Claire's disease, she explained that her parents told her about her sister's illness. Lisa was four years old when Claire was diagnosed and although she was quite young, she tried to help her sister. For example, she shared that one thing she does frequently, is to heat up a "magic bag" [heating pad] in the microwave to help with Claire's stomach cramps.

At one point, the sisters attended the same elementary school. During the times when Claire was unable to be in school, Lisa would help by taking Claire's assignments home for her. Additionally, Lisa accompanied her parents to many of her sister's medical appointments because she was too young to stay-at-home alone. Lisa would find those appointments to be in her words, "Very, very, very, long and boring."

Similar to Claire, Lisa liked her school, especially music and art classes. Recently, she had missed some days of school because of colds, flu and, occasional stomach pains. The complaints of stomach pain began at about age seven and have continued sporadically since. These symptoms have raised the concerns of Lisa's parents, for they appear to be similar to those of Crohn's disease. Therefore, to satisfy their concerns, Lisa's parents had a colonoscopy performed on her. The test results did not reveal any signs of IBD, confirming that she did not

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

have the disease at that time. However, this year over Christmas she started having stomach pains again, but there are still no physical signs of the disease.



Figure 4 Multi-coloured family drawing using markers and crayons by 10 year old Lisa. All family members are depicted (mother, father, and two sisters).

Lisa's Family Drawing

I presented Lisa with an assortment of coloured paper, pens, pencils and markers and informed her that she may choose to use any of these that she liked to create a picture of her family. She took a moment and seemed to be thinking, and then scanned the table with the art supplies. She began slowly at first selecting a yellow sheet of construction paper. Then she chose her markers and the pace increased as she began to draw. Occasionally, she would giggle

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

to herself and make a short sound, or I could hear her utter a word, like, “Oh!”, “MMM!”, “Aha!” or “Look!”

In the end, she was very excited about the colourful picture she produced and was eager to show everyone what she had created. She drew a picture of a happy, smiling family. Each family member was represented. Lisa drew her parents standing close together and Claire stood close to her. The family was surrounded with what looks like an outdoor scene with flowers and a buzzing bee. When I asked, why she had written “konichyoi” which meant “hello” in Japanese (correct spelling is “konnichiwa”), Lisa explained that she had learned that in school. Her picture appears warm and inviting as each family member is drawn saying “hello” in English, French, or Japanese.

Family Relationships

Mr. and Mrs. Anderson each play a role in Claire’s care. However, Mrs. Anderson often acts as the primary care giver when it comes to spending nights in the hospital with Claire, attending all of her medical appointments, seeking sources of financial assistance, and conducting internet searches about Claire’s diseases. She is regularly in contact with her daughter’s teachers and advocates strongly on Claire’s behalf at school when it is necessary.

Mr. Anderson also plays a vital role in his family. He is typically responsible for doing the grocery shopping and caring for Lisa, especially when Mrs. Anderson is away at medical appointments with Claire. If Claire is feeling unwell at school, he is the parent who she calls to pick her up. Furthermore, he maintains the daycare during the week so that Mrs. Anderson can devote time to Claire’s care.

The two sisters do spend a lot of time together, but Claire tends to scold Lisa often. During our interviews Claire appeared to disapprove of much of Lisa’s behavior and regularly

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

told her so. Overall, family members appear to be in constant interaction with one another. Each person had a role and that was important to the functioning of the family because they relied on one another.

Mesosystem from the Perspective of the Parent

Mrs. Anderson's Past, Present and Reflection: School Experiences

In regards to Claire's school experiences after she had been diagnosed, Mrs. Anderson recalled meeting with Claire's first and second grade teachers. She explained the disease and informed them about Claire's IBD symptoms and possible difficulties such as incontinence. Following their meeting Mrs. Anderson found that the teachers, "really understood Claire. They were more sociable with her; they helped her with her studies."

At the outset, Mrs. Anderson's experience with Claire's public Catholic elementary school teachers and principal (a priest) was positive. The educators were supportive, sympathetic, and empathetic. However, all of this ended when her family moved to another city and Claire was enrolled in a new elementary school in Grade 4. Each September Mrs. Anderson would meet with Claire's homeroom teacher and explain Claire's IBD symptoms. Mrs. Anderson remembered that each school year always began well and then would gradually take a turn for the worse following the Christmas holidays. Upon Claire's return to school in January, Mrs. Anderson discovered that Claire's teachers and school administrators ceased being empathetic and understanding. The school personnel began to question the reasons for Claire's multiple absences and began to speculate that perhaps Claire simply was using her disease as an excuse to avoid completing her school work. Mrs. Anderson spoke of her anger and frustration in having, "To re-visit them [teachers and school administrators] and say listen, I know when

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

she's home she goes to bed. I know that when she's home she's not home to play Nintendo, to have fun and play outside. She'll go to bed, watch a little television, but she's not well."

Mrs. Anderson found that the suggestion that her daughter could possibly be inventing her symptoms or choosing that as a way to avoid her schoolwork was extremely frustrating. This was her major complaint and challenge with her daughter's high school staff. She felt a sense of injustice since everything that she was experiencing with her daughter's chronic disease day and night was not only very real but dire. Mrs. Anderson explained,

"When she's in crisis she can't concentrate. If the teachers could understand that if she's not well in the evening it's not because she hasn't done her homework or doesn't want to, she's just not able to do more than that. Once the pain starts she'll have stomach pain all night and in the morning she can't go to school. You wouldn't be able to learn anything, because you can't concentrate."

She thought that the school staff invariably failed to be understanding and accommodating. This often left Mrs. Anderson feeling exasperated, "I don't know what can be done. Each time, that's the question we ask because Claire has arthritis and a lot of muscular pain everywhere, everywhere, everywhere!" She added jokingly, "Hands, ankles, fingers, toes, wrist, hips, it would have been easier to say what places didn't have [arthritis]."

Mrs. Anderson has sought ways to improve the relationship with the school personnel, but her advocacy attempts have been unsuccessful thus far. Now she is unsure about other options. She shared her concerns by stating that, "I don't know, one year we asked the social worker that was assigned to us from [the hospital] to come with us to school it goes well just until after Christmas. She's not well [but] they [school personnel] don't see it [IBD] that's what's difficult."

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Upon reflection, Mrs. Anderson said that she was aware that teachers also have challenges to face in their classroom. She stated that these additional factors, made it difficult for teachers to attend to all the varied special needs of students in their classrooms, as well as having to teach the school curriculum. For example, Mrs. Anderson suggests that large class sizes impact teachers' work and thereby contribute to the complexity of the challenge of inclusive classrooms. Mrs. Anderson maintained this point of view as she said, "The thing, is they have large classes of 25, 27, 29 students. That's a lot of people all with little problems."

Unfortunately, the end result is that Claire and her mother are left feeling unsupported by the high school personnel, "They're [the teachers] not very strong when it comes to understanding that Claire needs time to recuperate and [the teachers never say] we're going to help you, or you need to stay in during lunch time, but she never received that kind of [support]," she complained.

The Andersons do not only have a perception of lack of support from the personnel in Claire's high school, but they feel that they are often blamed without cause and misunderstood by the teachers and school staff. Mrs. Anderson recounted two specific instances in which she thought her daughter was blamed unfairly by her teachers. Additionally, she explained that, on several occasions Claire had to be absent from school because she was hospitalized. Invariably, on her return to school, she would notice that numerous articles, such as books and pencils were missing from her desk.

Mrs. Anderson protested that, "When Claire's not at school, her things go missing!" However, her protest seemed to have gone unnoticed by the school personnel. Claire's teachers blamed her for being careless, claiming that it was her fault that her school materials were lost. Mrs. Anderson disagreed with that evaluation of the situation and argued that, "When Claire

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

comes home she takes out her things, we use it and they go directly back into her bag. She doesn't do homework in her bedroom; she does her homework in the basement. There's nothing that can be misplaced; it's either in her bag or at school. It's all a bit, annoying, all the time."

Mrs. Anderson is disturbed by these situations, because her daughter usually has to borrow more textbooks from her teachers when she cannot find the ones that are assigned to her. According to Mrs. Anderson, borrowing other books for classes is also a troubling factor, as it usually results in embarrassment for Claire. When Claire asks to have the lost books replaced, some teachers say, "Listen you're the one who lost it [textbook], you're the one who forgot it [the book]," before handing her another book. Mrs. Anderson explained that each time Claire's textbooks went missing from her desk Claire would have difficulty in completing her homework because her teacher would not allow her to take home the books that were borrowed in class – only assigned books were permitted to leave the classroom.

Mrs. Anderson recounted another incident that occurred one day in June when Claire was in Grade 5. When she asked permission from her teacher to use the bathroom, she was forbidden to leave the classroom. She viewed Claire as being difficult at the time. Despite being prohibited to use the washroom, it was urgent for Claire to leave the classroom quickly, and she ran to the washroom. That evening Claire explained to her parents what had transpired at school. The following day, Mrs. Anderson spoke to her teacher and explained that, "Claire needs to go to the bathroom immediately she has the urge to do so. Sometimes she can't go just at lunch time. She has to go to the bathroom when she wants to go."

A few days later, some of Claire's classmates were treated to cups of hot chocolate as a reward for their hard work throughout the school year. But Claire was not offered any hot chocolate because her teacher explained that she had been disobedient by leaving the classroom

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

to go to the bathroom when she was told not to do so. Therefore, she was deprived of a reward—not because of her work, but because of her illness. This incident had a lasting impact on Claire as she reflected on it during our conversation.

Mesosystem from the Perspective of the Child with IBD

Claire's Past, Present and Reflection: School Experiences

When I met Claire she had just completed her first year of high school (Secondary One). During our conversation, one of the topics she talked about was her experiences with taking her prescribed medications at school. She explained that she did not mind taking the medication, but her frustration with the disease rests with the frequency she was required to take the drugs. Another irritant in her school life, was the constant answering of questions from teachers and peers because, “They [the students] asked me why I had to take them [the medications]. It’s because I have a disease, but I didn’t really know how to explain my disease when I was younger,” she said.

Although Claire acknowledges that she finds it difficult to explain her disease to her teachers, she continues to try with the hope that she will be better able to advocate for herself in different instances. She states that she is now making more effort to speak up for herself when she is in school. When she is attacked by symptoms of her illness in school, she takes the responsibility to decide whether she is able to cope with school or she needs to go home. If she decides that she needs to be home, then she informs her teachers and contacts her father to drive her home. At this point, she relies on friends to take her homework to her after school. Claire also shared that she is using some of her friends to advocate on her behalf on some school matters. Sometimes her friends help her to explain her illness to teachers. Her reason for encouraging peer advocacy is that she frequently faces challenges in her relationship with certain

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

teachers. For example, she assumes that her gym teacher lacks empathy for her illness since the symptoms of the disease are invisible and unpredictable. Claire believes that her physical education teacher thinks that children who want to avoid their school work often complain of stomach aches and headaches. Except, this was not the case for Claire, her physical symptoms were real and associated with her chronic health condition.

Apart from having her peers advocating on her behalf, she has taken further steps to try and build a better understanding and strengthen the relationship between herself and her teachers. In so doing, Claire chooses to do presentations in her school about IBD. She stated, “I did an oral presentation to explain what I have. I did it every year. I explain what the disease is and I use posters.” Nevertheless, these annual presentations do not always create a lasting impression on all Claire’s teachers.

Claire shared that the teachers that were empathetic were especially helpful since they would take the time to further explain her disease to the students in her classes and permit her to go to the washroom whenever she needed to do so. On reflection, she mentioned that her physical education teachers presented the greatest obstacles for her, as she found that they were persistent in their lack of empathy towards her disease. She reflected, “It was usually my gym teachers. They were usually the ones who had the problem in understanding, and even when I knew I was unable to [perform the activity], the teacher told me to continue, in front of everybody.”

Claire’s other challenge lies in her desire to keep up with her assignments. Claire lamented,

“When you’re absent for a long time like a week and a half you’re missing like three classes at the same time, and when I receive a pile of papers as homework I try to get

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

information, but they [teachers] don't always want to help me. When I say I don't understand they say well it's because you were absent. But you can't catch up on everything [assignments] by yourself and when I go to them [the teachers] they [the teachers] don't really like to explain to me."

Claire is struggling to find a solution to this problem.

Another of Claire's challenges is trying to cope with the physical location of the school's bathroom facilities. Having access to washroom facilities that are in close proximity to classrooms is crucial for a student with IBD. However, in Claire's situation, the bathrooms are located three floors below her classroom. This presents a great challenge for her, as she finds it difficult to walk down three flights of stairs, when she urgently needs to use the toilet.

A final concern that Claire shared is that she finds the plastic chairs in her classroom too hard and uncomfortable for her to sit on for lengthy periods of time. The problem however, is exacerbated by her swollen and sore buttocks caused by frequent diarrhea. Surprisingly, despite all of these challenges and seemingly negative school experiences, Claire stated that she is definitely fond of her high school.

Exosystem from the Perspective of the Parent

Mrs. Anderson's Past, Present and Reflection: Experiences in her Community and Beliefs

In order for Mrs. Anderson to be informed about the services available to her family, she continually sought information from various resources. For example, after speaking with a mother of a child with another health challenge, Mrs. Anderson learned that the Québec government offered a subsidy for handicapped children. Although Claire was not handicapped, Mrs. Anderson learned that they did qualify for the assistance because of Claire's chronic arthritis. Mrs. Anderson explained that, "Because of the arthritis we were at the hospital almost

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

every week for treatments and the subsidy helped with transportation and lodging costs.” An example of the type of transportation assistance was reimbursements for gas mileage to and from Claire’s medical appointments. She also revealed that she really values the opportunity to meet with other parents with sick children that are experiencing similar life challenges. She finds that by meeting with other parents she learns so much about available resources and feels the group provides her with support. Mrs. Anderson stated that when Claire was first diagnosed she had actively participated in an IBD Association. However, Mrs. Anderson ceased attending because she did not feel included since the activities and information were mainly provided in English, and although she understood and was able to communicate, she preferred participating in her mother tongue which is French. Mrs. Anderson complained that there were not enough organizations and support groups for families with children with JRA and IBD especially for French speaking families.

Two years ago, the family moved into their current home which as noted earlier also doubles as a daycare centre. The parents made the decision to work at home based on Claire’s chronic health conditions and the realization that they would need to provide her with constant care and support. Both parents had had difficulty in their previous places of employment with managers who were unable or unwilling to accommodate their need to take time off work. By having their workplace located in their home, the parents were able to divide their tasks and always have a parent available to attend to Claire’s special needs. Although Mrs. Anderson discussed the benefits of having her workplace and home in the same location, this situation also presented many challenges as well. Mrs. Anderson mentioned that running a business was challenging; it required a lot of time and energy and caring for the needs of other people’s young children was exhausting. Also, their work week ran from Monday to Saturday and even with this

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

long work week, she did not find that they were benefiting financially. Mrs. Anderson believed that not only was it a lot of work for little pay, but also their work never seemed to end. She felt constantly surrounded by work both at the daycare and inside her home. Mrs. Anderson also mentioned that working from home made it difficult to plan and take time for family vacations because they had to work long hours. Mrs. Anderson said that they were going to operate their daycare for about another two years while considering other employment options which would include the possibility of Mrs. Anderson remaining home on a full-time basis and Mr. Anderson working full-time outside the home. This would allow Mrs. Anderson to have more time to spend with her daughters and attend to Claire's JRA and IBD symptoms.

Mrs. Anderson mentioned that there are times when she is overwhelmed with the position in which she finds herself. This is especially true for Mrs. Anderson when she has to deal with Claire's teachers. She said that during difficult periods, she wants to remain quiet and cease her efforts to advocate on her daughter's behalf. However, she has not done so, but continues to persevere in her struggles to get the services and accommodations which the family so desperately desires to have from Claire's teachers. In so doing, she has made further attempts to gain access to school services by contacting the school board's Student Ombudsman, who in turn contacted the principal. The result of this new development is yet unknown, but it is hoped that it will work in Claire's favour.

Macrosystem from the Perspective of the Parent

Mrs. Anderson's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD

Mrs. Anderson suggested that it would be beneficial if someone would create a small pamphlet that “explains the reality of children with Crohn’s, and the reality of the stomach pains. This would validate the children—especially when they are in school.” As a result, it would help the public to understand the realities of the disease, and then people would be more empathetic. She would also like teachers to comprehend and:

“...to validate the pains, they are indescribable pains that you can’t even imagine, but I don’t think we’re believed a hundred percent. We started asking the principal to be present when I explained [Claire’s disease] so when it wasn’t going well in class, I would call the principal and she would have a meeting with the teacher but it was always creating friction because she [the teacher] didn’t want to do it.”

Upon reflection of this issue, Mrs. Anderson believes that teachers and school administrators need to concentrate on behaving empathetically. She commented that they should also demonstrate a “level of understanding of what it’s really like for a child, it’s really hard to have Crohn’s.”

Macrosystem from the Perspective of the Child with IBD

Claire's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD

Although Claire constantly experiences school challenges, she voiced the opinion that her main desire is simply to have, “teachers understand that I’m not always feeling well. I’m just like everybody else, I’m no different.” Rather than be misunderstood, Claire wants to be treated the

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

same way as her classmates and to be a valued member of her class. She believes that she is entitled to receive respect, as well as having the same basic rights as her classmates.

Macrosystem from the Perspective of the Sibling

Lisa's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD

In our final interview, Lisa took some time to reflect on how she thought her life would be if she had Crohn's disease and how people would perceive her. Surprisingly, this interview was the most interesting conversation we had shared during the time we spent together. Lisa articulated her thoughts and feelings and said, "Life would be different [if I had Crohn's] a little different. I don't know (she said in a sing song voice). I would be absent a lot. It's not fun, you don't see your friends often. You're always at the hospital." Like her mother, Lisa noted the realities of living with the disease.

Summary of Family 1: The Andersons

Claire has Crohn's disease, but her health is further complicated by Juvenile Rheumatoid Arthritis (JRA). Her parents live and work at home and this facilitates the care of both of their daughters. In particular, the Anderson family had moved to a new house in order to open a daycare centre. The purpose of owning a daycare was to allow Mr. and Mrs. Anderson the flexibility to work at home and care for their daughters, especially Claire who required continual care due to her IBD and JRA. The daycare centre has been in operation for two years and although there are some positive benefits to being self-employed and working at home Mrs. Anderson and her husband are considering other employment options. The daycare centre is not meeting their needs financially. It is also challenging and tiring to care for other people's children when you have a sick child. Mrs. Anderson explained that having a child with two chronic diseases is financially very costly. There are several expenses, such as: transportation,

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

medical tests and lodging. Therefore, Mrs. Anderson takes the initiative to find government subsidies and other sources for financial assistance. She credits meeting with other parents who also have a sick child as being very helpful for learning about different resources that she can access for help. However, she noted that there are not enough of these groups to serve members of the French community. Although she can speak and understand English she said that she is French Canadian and prefers to be served in French. It was for this reason that she stopped attending the events and meetings held by the IBD Association.

Claire's early elementary school teachers and principal were empathetic to her special accommodations and this made for a pleasant school experience. Claire is now in high school and although she is fond of her school she is facing challenges in dealing with some of her teachers. Claire and her mother believe that teachers have difficulty understanding IBD. The invisibility of IBD symptoms and a lack of awareness and comprehension about the disease may be reasons why it is challenging for teachers to express empathy. Furthermore, IBD symptoms such as headaches and stomach aches are common complaints that healthy students may use as an excuse to avoid participating in school activities. It then becomes hard for teachers to distinguish which students are lying from those who are truly experiencing pain. Mrs. Anderson also suggests that teachers may lack empathy because of the large classes of students that they must teach. With so many different students having differing needs create a challenge for some teachers to adequately attend to each one. For these reasons, Mrs. Anderson has to advocate frequently on her daughter's behalf, but in her role as parent advocate, she has often met with resistance from teachers and the school principal. Mrs. Anderson has found some support however, from meeting and communicating with other parents with sick children. In this way, Mrs. Anderson has gained access to vital information and services.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

In terms of the family relationships, Lisa has complained of IBD symptoms but test results have not manifested any signs of the disease. In the meantime, she finds ways to help her older sister, and the parents continue to play an active role in both of their daughters' lives and school experiences.

Mrs. Anderson recalled that Claire's experiences attending public elementary school were positive. They had teachers and a principal that were empathetic and understanding to Claire's illness and accommodated her needs. However, all of this changed when the Anderson's made the decision to move to another city and Claire was enrolled in a new public elementary school in Grade 4. It was at this point that Mrs. Anderson remembered Claire's school experiences as turned negative. They complained that they were frequently confronted with problems and described several challenges. As a result, Mrs. Anderson continually met with teachers and the school principal to discuss Claire's illnesses and instances of ill-treatment in class. Claire said that she was often accused of using her IBD symptoms as an excuse to avoid having to do her homework, or to miss school. She suggested that her physical education teacher was the most unsympathetic of all of her teachers.

Lack of knowledge about IBD and ill-treatment continued when Claire graduated from elementary school and began attending public high school. Claire and Mrs. Anderson stated that they simply wished that school personnel would believe the complaints of headaches and stomach aches were real, and that they would grasp the severity of Claire's pain. Mrs. Anderson suggests that a reason for the teachers' lack of empathy and support may be due to having to teach large classes. She said that, she is sympathetic to the fact that teachers have to meet the needs of many students in their classrooms, which they may find overwhelming. Nonetheless, she does not feel that Claire should be punished for any of her behaviors that are

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

related to IBD. Not only does Mrs. Anderson believe that Claire is ill-treated at school, but she too feels mistreated as a parent by the teachers and principal. Mrs. Anderson has pursued many different advocacy options including using a social worker and contacting the school board's Student Ombudsman. In spite of these efforts, no positive and lasting changes to Claire's relationship with her teachers have developed. Claire also tries to educate her teachers and peers about IBD each year in a classroom presentation. Additionally, at times Claire's friends try to help by explaining IBD to teachers too. Despite these advocacy efforts, each year following the Christmas holidays, Claire is continually ill-treated by her teachers.

The Andersons talked about the public's lack of knowledge about the disease. They said that, if more information was provided about the realities of living with the disease, then people would be more understanding. Mrs. Anderson emphasized that the current available literature on IBD does not paint a picture that people (especially teachers) can fully understand. She suggests that pamphlets should be created that describe all of the symptoms and how they affect a child's behaviour. In turn, this would help teachers to believe that the symptoms that Claire experiences are real. Claire would like people to know that although she has chronic illnesses, she is a regular teenager and believes that she deserves to be treated with respect. Lisa said that people should know that it is not enjoyable living with the IBD and the disease does impose some restrictions to your life.

Case Study 2-The Clarkson Family: A Cohesive and Active Family of Five



Family Introduction

The Clarksons are a family of Jewish heritage. Their home was bursting with energy when I arrived for the interviewing session with the family. There were three boisterous boys, talking in unison, running in and out of rooms and jumping up and down the hall staircase. They exuded boundless energy and exuberance as they welcomed me into their new home. They had recently moved to their new house in the suburbs to escape the hustle and bustle of the city core. The 11 year old son recalls that, “In the first three months of being in this [new] house we actually had trouble sleeping; it was so quiet. We were used to cars and people screaming.” And the 14 year old son with Crohn’s remarked that, “You can actually play ball hockey on the street without having a car interfere.” The Clarksons seemed to all agree that the move was a good one and that their new neighborhood was much calmer.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

When Mr. Clarkson appeared, we agreed to conduct the interviews in the living room. During the explanation of the interviewing process, I indicated that their real names would not be used in the study, and that I would be assigning a pseudonym to each family member. The 14 year old son with Crohn's, immediately piped up and asked, "Can I pick my name?" "Of course," I responded.

After that, each family member eagerly chose a pseudonym. Interestingly, Mr. and Mrs. Clarkson chose to be named after superheroes. Mrs. Clarkson chose to be called 'She-Rah' who is a fictional female cartoon superhero from the 1980s; while Mr. Clarkson chose to be named 'He-Man' who is also a fictional male cartoon superhero from the 1980s. The 14 year old chose to be named 'Geddy Lee' who is the lead vocalist, bass guitarist and keyboardist of the Canadian rock band, Rush. The middle son, aged 11, asked to be named Daniel. Daniel is a common name and that is exactly the way the eleven year old wanted it; he did not want his pseudonym to refer to anyone or any character in particular. It was just a name that he happened to like. The youngest son, aged seven, chose to be named 'Squirtle,' who is a fictional cartoon character that resembles a turtle from the Japanese Pokemon game which is part of the Nintendo video game series.

Microsystem from the Perspective of the Parent

He-Man and She-Rah's Past, Present and Reflection: Experiences of IBD at Home

She-Rah and He-Man first learned that something was wrong with their eldest son after he suffered for five months from violent stomach cramps and diarrhea. During that period, he also experienced a gradual ten pound weight loss. He-Man described the occasion when he found out about Geddy Lee's illness saying, "I found out when She-Rah called me at the office. She was pretty broken up on the phone. She had to prepare me, "Like He-Man, are you sitting

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

down? This was a big thing you know!” He explained that his wife attempted to calm his fears by saying, “I remember her telling me, well it’s not like he has cancer.” He-Man understood from the telephone call that his eldest son, Geddy Lee, was diagnosed with Crohn’s disease. That conversation with his wife took place two years ago.

In reflection, the turbulent events that beset his family over the past two years still ignite feelings of great sadness for He-Man who shared that, “[When] I think back to it [those years], I almost cry.” Both parents expressed their feelings of guilt and helplessness about the situation in which they found themselves. He-Man recalled, “Even though I know there’s no way we could have known, I remember walking into his [Geddy Lee’s] bedroom [and saying] let me rub your stomach, maybe it’s something you ate? I just felt awful. He kept telling us [that he was sick] and we had a generic parental response. We thought it was left over mono [mononucleosis] and then a month and a half later he was diagnosed [with Crohn’s disease].” She-Rah expressed similar sentiments as she lamented, “I don’t know, perhaps I should have pursued it [Geddy Lee’s symptoms] more aggressively.”

When he started high school Geddy Lee was also enrolled in a Counsellor in Training Program, (CIT) at a day camp. She-Rah explained that students who completed the training were hired to work at the camp in the summer months. Sounding disappointed, she shared that, “He could have had a job the summer, had he been well and completed the program, but he had to drop out because of his illness. He was so exhausted, and we thought he was just being lazy or, maybe it was puberty. Then he started high school and every other day he was in the nurse’s office. Finally, the nurse called and said something is really wrong with your kid.” At the same time, Geddy Lee’s physical symptoms were also impacting his high school experience. She-Rah

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

recalled that, “As [high] school started the demands being made on him just made him drop physically and in terms of strength as well.”

Not only was their eldest son experiencing severe physical symptoms that were beginning to interfere with his first year of high school, but his energy level was fading fast. Therefore, it was necessary for him to have more physical tests done. He-Man said that the doctors sent Geddy Lee for blood tests, but he was terrified of needles and refused to have them done in a hospital. Since it was imperative for these tests to be done, the parents came up with a strategy to solve the problem. He-Man credits his wife for finding a private company that sent a blood technician to their home to have Geddy Lee’s blood drawn.

Having the tests done at home rather than in the hospital made it a more comfortable experience for Geddy Lee. He-Man added that this also worked well because they found the experience of having tests done at the hospital a negative one. This way, they no longer had to endure long waits and impatient medical staff. The blood technician alerted the parents to the possibility of IBD and suggested that they asked Geddy Lee’s doctor to perform a complete investigation of Geddy Lee’s blood results. The result of those investigations ended with the diagnosis of IBD.

He-Man and She-Rah were fortunate to have He-Man’s parents actively involved in their lives. The grandparents assisted with their grandsons’ child care needs and the multiple Crohn’s related medical appointments. During our interviews, both parents frequently acknowledged their gratitude to the grandparents for having helped their family to overcome the many obstacles and challenges presented over the years. The assistance the family received from the boys’ grandparents enabled She-Rah to return to school to pursue a career after being at home and

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

caring for her sons for many years. According to He-Man, “This was the best summer and fall for us.”

Unfortunately, shortly after Geddy Lee’s diagnosis, He-Man’s mother, died. The death of the children’s grandmother, who was an integral part of the family who had played a major role in their lives, had a deep impact on each member of the family. The grandmother’s death also meant that She-Rah had to withdraw from her studies and put plans for a new career on hold. Of necessity, she had to return to being a full time mother at home where she could care for her two healthy sons and her ailing first child.

Microsystem from the Perspective of the Child with IBD

Geddy Lee’s Past, Present and Reflection: Experiences of IBD at Home

Geddy Lee acknowledges his brother’s constant help, especially when he is unwell. For example, there are times when Daniel made him chicken soup or stayed home to help him when he has a day off from school (on pedagogical days—when teachers attend professional development workshops).

In reflecting on his position within his family, Geddy Lee revealed that at one point his disease had a negative impact on Daniel. He remembered that during the initial phase of his diagnosis, Daniel complained to his parents that he was being ignored and neglected. The complaint arose from the situation that existed in his home. At that time, He-Man and She-Rah were spending a great deal of time at the hospital with Geddy Lee. Fortunately, he seems to be more understanding now. “But life was not easy for me either,” Geddy Lee admitted. He claimed that he once believed that he could do anything despite his disease, but he now concedes that there are some real limitations. His short stature seemed to be an issue for him at times, especially when he is talking about playing competitive sports against his taller and bigger male

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

peers. Geddy Lee explained, “I wanted to play football, I’m a pretty fast runner, pretty agile and I can beat people pretty well, but the thing is, I’m really small, so if I get tackled, I’ll really be tackled.” Geddy Lee’s height was even a topic addressed by his youngest brother, Squirtle in his drawing of the family portrait.

Microsystem from the Perspective of the Sibling

Daniel’s Past, Present and Reflection: Experiences of IBD at Home

Sitting and talking with 11 year old Daniel was enlightening. Known as the “shy one” in the family, seems to be a misnomer. Daniel is highly articulate, and expresses his thoughts and feelings clearly and without hesitation. While reflecting on his family experiences, Daniel shared how he felt during the early months of Geddy Lee’s diagnosis. He said that, “When I first found out, in the first few months, I wouldn’t say I was neglected, I would say I had a small window of attention because most of it [the attention] would have been concentrated on Geddy Lee and his Crohn’s in the hospital and everything.” He further explained that one parent was usually with Geddy Lee at the hospital while the other was at home, but, “I help, we help. I help depending what needs to be done.”

Daniel is aware that IBD is an “inflammatory bowel disease.” He had learned that piece of information, as well as other key factors about the disease, by attending presentations his brother gave about IBD. He had excitedly mentioned that during a lecture he was asked a question from a nurse in the audience. This seemingly small gesture was important to him because it gave him a sense of inclusion. The nurse had asked, “What do you want to be when you grow up?” To which he responded, “I want to be maybe a naturalist and I’m hoping to go into Air Cadets next year, I want to be in the Air Force.” In this way, he had felt acknowledged and he was pleased to receive some of the attention.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

According to Daniel, a major change occurred within the family shortly after Geddy Lee's diagnosis. He noticed that there was a great shift in the types of foods that were purchased for the family. Daniel remembered, for example, that previous to the diagnosis his parents would argue over whether they should buy whole wheat or white bread. But, following Geddy Lee's diagnosis of Crohn's disease, white bread became the only type of bread available in their home. Currently, Geddy Lee's parents have their son following a "low residue diet," where high fiber foods such as vegetables must be cooked before he eats them. Furthermore, they have him abstaining from foods such as kiwis and corn.

Daniel vividly described the feelings of discomfort he was experiencing in school. He voiced the opinion that he was mistreated by peers at school. Daniel recalled being bullied at school at various times, beginning in Grade 1. He explained that, "In Grade 1, there was a group of girls who would pick on me and my friends." Daniel named these children the "Mean Girls." The unkindness resumed this year when a fellow student created an unpleasant Facebook page about him. He mentioned it to his mother, and at this point, she contacted Daniel's school principal. The principal and vice-Principal attended swiftly to the matter by involving the police. Daniel thought that the police had a positive effect on those students and helped to stop the cyber bullying.



Figure 5 Multi-coloured family drawing using water coloured pencils and markers by 7 year old Squirtle. All family members are illustrated including deceased family goldfish named “Penguin”.

Squirtle’s Family Drawing

Squirtle created a colorful picture of his happy family with all members present. Although, he was a rather quiet boy, he was eager to draw a picture for me. He spoke very little as he drew and seemed to be focused and concentrating on what he was creating. Once he was finished, we talked about what he had drawn. I asked Squirtle to tell me about the fish in the fishbowl that he drew. He responded sadly, “That’s Penguin. He’s my fish. That’s Penguin, but he’s dead.” His parents later informed me that Penguin had died two years ago and they were

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

surprised that Squirtle had thought to include his deceased pet fish in the family portrait.

However, his grandmother who had died more recently was not depicted. Squirtle also explained that “he’s (Geddy Lee) small.” And that was his reason why he had drawn his brother significantly smaller in height than the other family members. In reality, Squirtle’s drawing was accurate as Geedy Lee’s growth was notably stunted for his age due to a symptom of his IBD.

Family Relationships

The Clarkson family is an active family who seems to have a positive and close relationship with each other. The family members often spend time together and can be found doing activities together such as bowling. The strong family bond also extended to include He-Man’s parents. The grandparents, especially their grandmother had been a primary care giver. This allowed She-Rah to begin studies that would lead to a new career after many years of staying at home and raising her children.

What was evident was that the presence of a child with IBD impacted the family in many ways. Although He-Man and She-Rah both care for their children, they assume responsibility for different tasks. In the division of labour Mrs. Clarkson plays a central role in searching for services to meet all of Geddy Lee’s medical and educational needs. Consequently, Daniel felt that he received less attention from his parents while they cared for Geddy Lee. Daniel dealt with this by talking to his parents and telling them about his feelings of inattention. He was pleasantly surprised at how receptive they were to his feelings and he was glad that he had approached them with his concerns. Despite his feelings of neglect, Daniel was active in assisting Geddy Lee whenever he was feeling unwell. Daniel helped by doing certain tasks, such as cooking for Geddy Lee and his family. His care giving skills were particularly helpful to his parents since He-Man’s mother had died shortly after Geddy Lees’ diagnosis. She had been an

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

integral part of the family and had provided substantial assistance to the children in the home. Her death was acknowledged with great sadness from all family members except Squirtle. Interestingly, in speaking about death of a family member Squirtle referred to his pet fish that had died two years ago. He even drew a picture of the deceased fish in his drawing of the family portrait but his deceased grandmother was not represented or mentioned in any way.

Mesosystem from the Perspective of the Parent

He-Man and She-Rah's Past, Present and Reflection: School Experiences

On reflection of their experiences at Geddy Lee's school, the parents have felt incredibly supported by the public school's administration and teachers through the years. For example, He-Man explained that the public school's administration agreed to circulate a letter to inform their son's teachers about his chronic disease. In the circular, the principal included the factor of the frequent and perhaps lengthy periods of absences that could occur. From then, all Geddy Lee's needs and accommodations were met and he was well treated. As such, there was little need for the parents to advocate on their son's behalf because the school was accommodating his needs.

However, due to his low grades the principal asked Geddy Lee to leave the public school and his parents had to enroll him in a new public high school. She-Rah and He-Man have concerns that Geddy Lee may not be as well accommodated in a new public high school in September. At this time, they are unsure about the available resources to address their son's needs and wonder about the outcomes of possible reduced support.

Mesosystem at the Level of Child with IBD

Geddy Lee's Past, Present and Reflection: School Experiences

Geddy Lee recalled with clarity and in great detail the time of his diagnosis, "I was 12 when I found out I had Crohn's. It was October, I was in Grade 7 and that was a really rough three month start to high school because the first month I missed tons of starting up stuff. I tried to go as much as I could [but] my stomach would hurt and I couldn't sleep. Also, our grandmother died like the same month I was diagnosed or the month before. We were all like sad about all of that and then I got diagnosed with IBD."

He was first hospitalized a week and a half before his Christmas vacation. His medications at that time were not working and he was experiencing major flare-ups. Therefore, Geddy Lee missed all of his exams at the end of the fall term. Upon further reflection, by the end of that school year, his report card for Secondary One had a note of 'not-applicable' for three of his nine courses. He had missed too many classes, and his teachers were unable to evaluate his progress and assign him a grade for them. In response, Geddy Lee exclaimed happily, "I was really surprised that I passed Secondary One, failing only math, and I passed the year with a 79 average. I was like, what? How is that possible?"

In order for Geddy Lee to keep up with his studies while he is in hospital, he accessed a few different resources. He relied on one of his friends who lived two blocks away from his house to bring him his missed homework assignments. In addition, his teachers would gather all of his missed assignments and would grant him extra time to complete the pile of schoolwork. However, Geddy Lee found the teachers' way of dealing with his assignments particularly challenging. In his description of the problem this presents, he says, "My mom had picked up a package from the school for me. It was this thick of basically homework. I had to take two days

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

to work my butt off to finish the work. It was a project and a few assignments. I basically understood [the assignments, but] what I did not understand, I [just] did not understand it!”

This meant that there were sections of the homework that Geddy Lee did not comprehend, given that he was absent when the teacher had taught that specific lesson. At that time, he was unable to receive the teacher’s explanations of the concepts and expectations of the assignments. To compensate somewhat for the lack of a teacher’s presence, Geddy Lee was able to receive remedial assistance when he was hospitalized. He explained that there are teachers in the hospital who offer tutorials every day in math. He said, “Whatever they were doing in school I was doing there [at the hospital] so I got help in math and that was all I needed help in really, but the core subjects were supported in the hospital which were English, French, math, and I think history.”

When Geddy Lee is able to attend school he enjoys everything. Specifically, his favorite class this year is drama and he believes that he is particularly good at it. His father agrees with him on this point, and stated, “Geddy Lee is very dramatic! [He has] a great memory for remembering lines.”

Geddy Lee finds his present school environment supportive of his illness. He points out that there are washrooms on every floor and that they are easily accessible. In his classrooms, the chairs are connected to the desk. They were flat on top with a frontal opening which allows room for storage. However, he does not use the storage space in the desks because, “We change classes all the time so there’s no point in leaving your stuff in any classroom,” he explained. At this time, he continues to revel in the positive experiences at his present school because he does not know what to expect when he attends his new school in the September.

Exosystem from the Perspective of the Parent

He-Man and She-Rah's Past, Present and Reflection: Experiences in their Community and Beliefs

In reflecting on their experiences in their community, both parents expressed conflicting feelings of guilt surrounding the issue of maintaining employment outside the home. She-Rah had to return to work although she had stopped for a short while after the death of He-Man's mother. He-Man explained that due to the economic down turn and the fear of losing their jobs, they had both become really conscious of how much time they were taking off work. They had to scale back on how involved they were with Geddy Lee's doctors' appointments. It was a decision that added more stress since their son had been placed on a new medication (Remicade) and now had frequent morning medical appointments. However, according to She-Rah, "I always feel like I have to work because there's the pragmatic element; if I don't work I don't get paid."

The parents also emphasized that they believe their parenting skills are being criticized by co-workers. For example, She-Rah works full-time in administration mainly among women, most of whom are also mothers. She often senses that her female colleagues are judging her for deciding to work rather than staying home with her sick child. She recalled a female co-worker frequently asking, "Why aren't you home with your kid?" She-Rah finds these types of questions painful to answer since she desperately wants to be able to take the time off work to be with her son. But, that is not always possible, and she often has to choose to work in order to earn an income to help support her family. She-Rah also finds that her work performance suffers whenever her son is hospitalized. She shared that, "It's hard because I'm losing my focus, I'm

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

not really there at work. I've thought many times of quitting, but financially that's not an option."

In order to help with the finances, the Clarkson's discovered how to apply for receive government disability for Geddy Lee. She-Rah recalled that it was her husband who filled out the complicated application form. She-Rah explained that the government financial support is necessary to assist with the cost of things such as: "For days off work, paying out for tutors, paying for food that we don't normally buy, paying for medications and if they're not covered then we have to pay for them, paying for parking, it's crazy! We live very comfortably but we do live within a budget and those little things like if you're dishing out an extra \$150 dollars a month for parking then you feel it!"

Macrosystem from the Perspective of the Parent

He-Man and She-Rah's Past, Present and Reflections: Beliefs Regarding Societal Perceptions of IBD

She-Rah believes that society has paid little attention to IBD. She suggests that the reason for this is, "Because it's not a sexy disease, because by nature it involves the bowels." Therefore, to increase awareness of this disease, She-Rah spearheads the IBD initiatives for her family. She is also the primary person who seeks out the information that will support her sons through their various difficulties with their health or schooling.

Macrosystem from the Perspective of the Child with IBD

Geddy Lee's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD

Geddy Lee also believes that there is a lack of awareness about IBD. He thinks that it is important for people to understand that although the disease may hinder some social activities because of the need for people who are affected to spend a lot of time in the washroom and they

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

are usually in pain, it doesn't make them any different. He still enjoys singing, skateboarding and playing sports, acting in school plays, socializing with friends, attending summer camp, and going bowling with his family. He thinks that as long as children with IBD are more aware of the foods they eat and carry an extra set of clothes in case of accidents (caused by incontinence), they should do just fine. Geddy Lee contends that, children with IBD have the same interests and dreams like any other teenager. Geddy Lee is confident that a cure will be found and that one day the disease will be finally eradicated. That's why he deems it important to participate in IBD fundraising events in which he raised \$2,500 this year.

Macrosystem from the Perspective of the Sibling

Daniel's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD

Daniel believes that the public holds some misconceptions about people with IBD because there is a lack of awareness about the disease. Daniel feels that people assume that having IBD imposes many restrictions and prevents his brother from leading a normal life. However, Daniel would like people to understand that his brother is an active teenager who is passionate about skate boarding and wants to live as normal a life as possible.

Summary of Family 2: The Clarksons

Despite the death of a beloved grandparent who played an integral role in this family's system of coping, this energetic family of five has remained proactive in the face of adversity. They have, like the superheroes whose names they took, continued to advocate on behalf of the member of their family and others with IBD.

Daniel serves as an example of how a child can be impacted by having a sibling with a chronic illness. He was able to verbalize his feelings of receiving less attention from his parents when his brother was first diagnosed with the disease. Also, from this case we are provided for

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

the first time with insight into some of the possible issues that siblings are confronted with while at school. Daniel's problems of being bullied at school are additional difficulties that these parents have had to address, as well as, having to cope with the challenges presented by Geddy Lee's disease. The family credits access to resources such as extended family, government subsidies, supportive school staff, and availability of community resources as key to their means of coping with the stresses that accompany having a child with Crohn's disease.

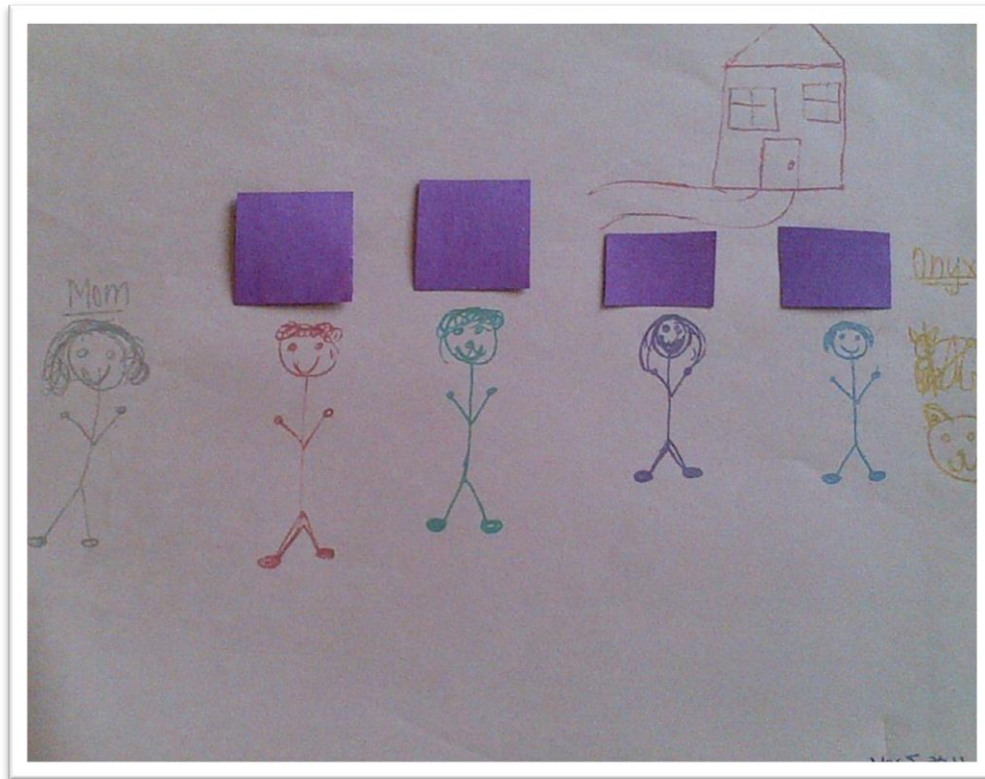
Having a child with IBD has had an impact on She-Rah and He-Man's careers and workplaces. The parents said that, they often suspect that their parenting skills are scrutinized by their work colleagues. She-Rah said that, she is treated as though she is a bad mother because she is financially unable to always take time off work and stay home with Geddy Lee when he is sick. The family's finances are also affected by the expenses associated with having a child with IBD. Ensuring that Geddy Lee receives the necessary medical care for his disease means that the family must always be prepared to pay for the additional expenses such as healthier foods, some medication costs, and parking fees. She-Rah assumes responsibility for actively searching for ways to subsidize those health-related costs by accessing services provided by the government for children with disabilities.

She-Rah believes that society has given little attention to IBD because it is a disease that involves a dysfunction of the bowels and there is still a stigma around anything involving incontinence. Geddy Lee acknowledges that having IBD does restrict him in some ways however, he believes that people should understand that as long as he is prepared with an extra set of clothing (in case he should become incontinent), he can engage in almost any activity. Geddy Lee thinks that the public needs to be informed that although he has Crohn's disease, he is an active teenager who enjoys playing many sports. He also believes it is important to support

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

fundraising campaigns in search of a cure for the disease and he actively raises money for that cause. Daniel would like society to have a more positive perception of people with IBD. He would like society to become more informed about the disease his brother has, and to view others with IBD as active people wanting to live a productive life.

Case Study 3-The Campbell Family: Widowed Mother of Four Re-visited by IBD in the Family



Family Introduction

This family of Italian heritage is known to the researcher; they were participants in a previous study she conducted in 2004. At that time, Mr. Campbell had been diagnosed with IBD, but sadly, he died from the disease shortly after the completion of the previous research. The Campbell family now comprises Mrs. Campbell, William (now 13 years old), and his twin sister, Nancy. There are also two older children in the family: Chris 18 years of age and Ryan the eldest is 23 years old. All the children live at home and their mother supports them by working full-time in a bank.

Microsystem from the Perspective of the Parent

Mrs. Campbell's Past, Present and Reflection: Experiences of IBD at Home

Thinking back to the time of the diagnosis, William's mother recalls having a deep sense of fear that something was wrong with her youngest son. It was a feeling reminiscent of her past experiences with her late husband when he had IBD, "I had a strong feeling because of his [Williams's] father's occurrences. I had a strong feeling when he was not well at all and he had lost weight and he had a lot of bloody diarrhea and it just brought back a flash from the past." As a result, she rushed William to the pediatric hospital's emergency department on two separate occasions.

However, on both trips the doctors were unable to find anything wrong with him. After battling the symptoms of IBD for some time, William was referred to the hospital's IBD clinic, and that is where he was formally diagnosed with the disease. He was six years old at the time of the diagnosis.

On the day of William's appointment at the IBD clinic, Mrs. Campbell remembers being very nervous and had her brother-in-law accompany her to the appointment so that she could:

"...have a second pair of ears and I was nervous because the doctor was talking about dysplasia [lesions or tumors that appear on the colon lining that can be cancerous] and that it [cancer] can happen. I was very much like, uh I'm sure it's going to be fine but then the other side [of me] says but what if? "

In spite of the possibilities of having cancer, William's final diagnosis ended up being Crohn's disease with no further complications. Since then, Mrs. Campbell has become more aware and sensitive to any manifestation of IBD symptoms.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Consequently, she asks her children to let her know immediately if they see or sense anything unusual happening to them physically. Recently, Chris has begun talking about experiencing stomach cramps and loose stools. So far, he has completed a few medical tests and doctors have yet to find anything wrong with him. Nevertheless, she lives in constant fear of the prospect of Chris also being diagnosed with IBD, and with the possibility of it leading to death just as it had in her husband's case.

Mrs. Campbell noted that her daughter dreams of becoming a teacher to children with special needs. As such, she hopes that Nancy will become, "An advocate, if she doesn't get to teach, she would do well in her advocacy role for kids, either [within] the law [or] the legal aspects of it." Mrs. Campbell foresees Nancy as serving as an excellent future advocate, working to ensure that children get what they need to succeed in school and within society.

Microsystem from the Perspective of the Child with IBD

William's Past, Present and Reflection: Experiences of IBD at Home

When William was asked about his early memories of being diagnosed with IBD, he responded that he didn't remember anything about the initial diagnosis or about who had told him that he had the disease. It appears that the events relating to that period of his life have now faded in his memory.

William appears to miss school only when he is not careful about what he eats (e.g., too much candy). Generally, when he is feeling sick his mother advises him to drink a lot of water, take an Advil, or use a hot water bottle for his stomach cramps. He finds that these techniques regularly help him to alleviate the pain and discomfort that he might be experiencing at those times. According to William, his disease seems to be stable at the moment and he doesn't have

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

the urge to go to the toilet as frequently as he did in elementary school. Now, he typically uses the toilet when he arrives home from school.

In referring to his sister, William stated that Nancy, unlike his mother does not assist him in any way. She does not pick up his missed homework assignments from school or help in any particular way when he is unwell. He shared that this does not bother him.

In explaining his medication routine, William said that, he takes Sulfasalazine pills in the morning. He describes his routine this way, “I brush my teeth most of the time, come upstairs take my pills, and go to the bus.” He takes two pills every morning and another two tablets every night. His mother usually has to remind him to take his medication in the mornings. He does not mind having to take his medication because he has become accustomed to it. At times, he does not take his medication on sleepovers at friends’ houses, ski, or school trips. If he needs them, then he’ll take two pills the following morning.

Microsystem from the Perspective of the Sibling

Nancy’s Past, Present and Reflection: Experiences of IBD at Home

Unlike William, Nancy attends a private high school which she enjoys. She is in Grade 8 and is one grade ahead of William. Similar to William, she likes many of the activities offered at her school such as soccer, golf, and hockey.

Nancy remembers that William was six years old when he was diagnosed with Crohn’s disease, and she was present at the hospital when he received his diagnosis. But, like William, she cannot recall any other details about the events of the early period of his diagnosis. She admits that she occasionally gets along with William, and that they do engage in some activities with one another. For example, they ski together about four or five times a season and have been doing so since they were five years old.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

In terms of Nancy's relationship with older brothers Chris and Ryan, she says that she does not look to them for advice. They tease her sometimes and that annoys her, but other than that, she did not speak further of their relationship.

In discussing her aspirations of becoming a special education teacher, Nancy explains that her experience with working with students who have special needs has heightened her desire to teach. Her school offers her the opportunity to volunteer at a center for students with sensory and physical disabilities. This centre operates some classes under what it calls a "reverse integration program" because it also offers students without disabilities the opportunity to attend classes there. Nancy has a two year placement at the centre, and this experience has had a profound impact on her. So much so, she intends to make working with special needs children her life's profession.

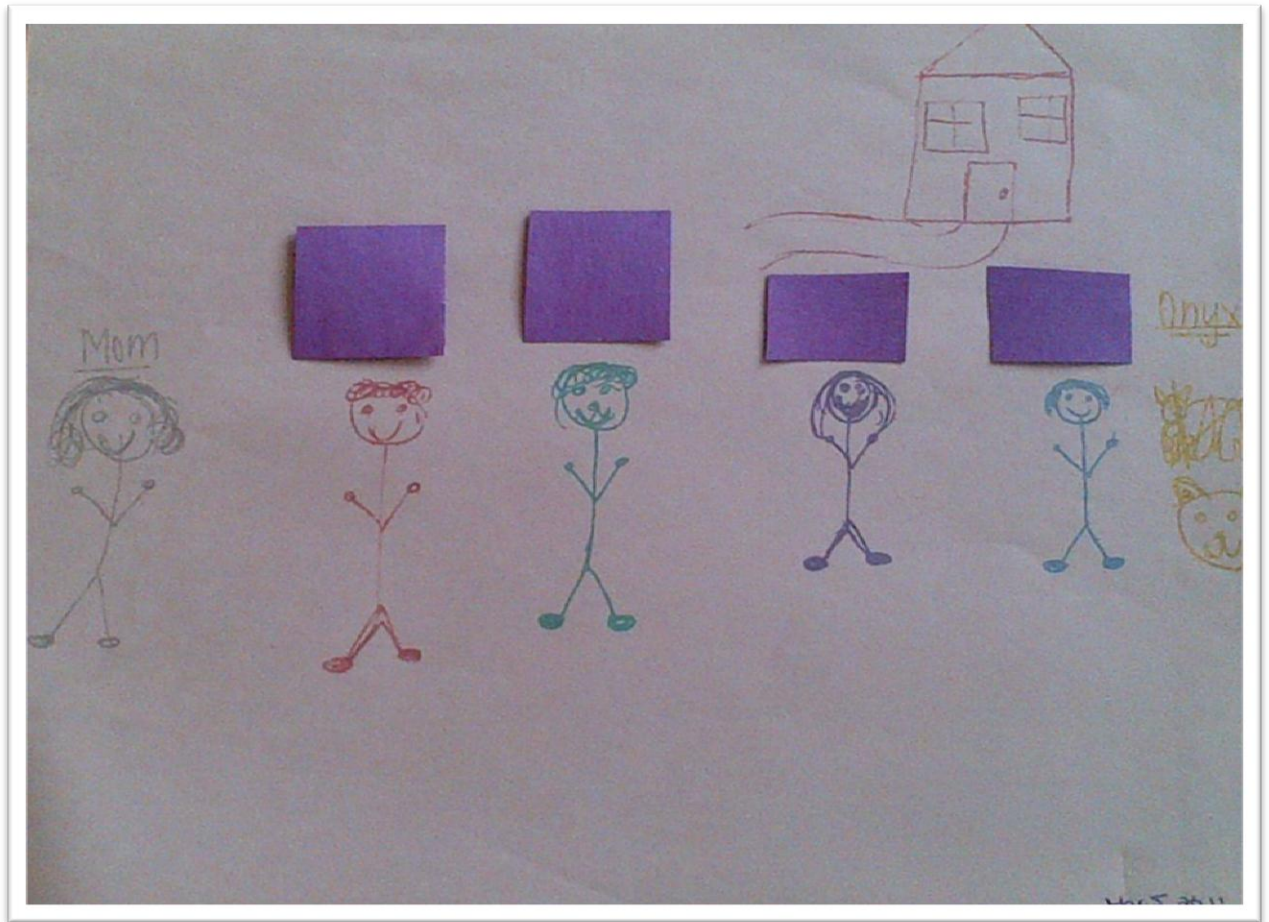


Figure 6 Multi-coloured pen drawing by 13 year old Nancy. All family members are drawn including the family pet a cat named “Onyx”.

Nancy’s Family Drawing

Nancy had expressed a fondness for art, especially drawing, and she took to drawing a picture of her family with some interest. She sat drawing at the kitchen table and spoke only if she was questioned. Nancy drew each family member as a smiling stick figure and represented each person by a different colour. Surprisingly, her drawing was not very detailed. However, she did include their pet cat named “Onyx”, who was drawn first in a side profile then crossed out and replaced with a drawing of only its face. Although, their cat in reality is a solid black color, he was drawn a yellowish gold color. Nancy anchored her drawing with a picture of a

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

house and all family members were depicted and there were no indications or representations of her deceased father who had succumbed to IBD.

Family Relationships

Occasionally, Mrs. Campbell has asked Nancy to lend William a hand in completing some homework tasks. But Mrs. Campbell is careful to point out that these infrequent requests that she makes of Nancy are only made if she is sure that Nancy has already offered to help her brother. The reason as she explained is, “Nancy tends to be very maternal and will commonly say something like, ‘Here let me help you with this’.” The problem with Nancy assisting her brother stems from William’s resentment of being placed in a position of needing his sister’s help. This factor has become a sore point between the two siblings.

Their mother believes that the underpinning of this sibling rivalry rests with differences in gender and ability. She suggests that it is understandable that William is unhappy about his situation, for Nancy who is the same age as him, does not require any special help. Mrs. Campbell believes that William perceives Nancy was excelling in many ways: she is a grade ahead of him, is able to perform at a high academic level in her private school, is musically and creatively inclined, does not have a learning disability, is sporty, and lastly does not have a chronic disease. He resents his comparative inability to achieve as much and questions, “Why me?”

Mrs. Campbell senses that this has led to feelings of inadequacy and frustration in William, which in turn, could be responsible for some of his unacceptable behaviors in school. William spent five years attending public elementary school with Nancy which gave him ample time to note the differences between them. While his early elementary school days were met with many challenges, Nancy was able to surge ahead without difficulty or illness. It is for these

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

reasons that Mrs. Campbell believes that William prefers to seek Chris' help because he is older than he and Nancy and their personalities appear to be similar. Both of them tend to be introverts and prefer to be quiet, while Nancy is more out-going. William however, is not the only child with a learning disability in the family. His mother mentioned that Ryan, "Is very slow in his process but he's in university"

Mrs. Campbell confirmed that William's prescription for IBD medication had increased over the years due to his age and weight. Nevertheless, she is pleased that William is growing and progressing well. Sometimes, she would frequent the Crohn's Association website to seek out the latest in dietary information, but she says that William eats everything and she does not place any food restrictions on him. Although, she acknowledges that perhaps she should impose some restrictions because, "the only food that seems to have an adverse effect on him is chocolate." She found that their grandmother often provides the children with chocolates and when William eats them he has stomach cramps.

Mesosystem from the Perspective of the Parent

Mrs. Campbell's Past, Present and Reflection: Experiences at William's Schools

When William was first diagnosed with IBD, he was frequently absent from public elementary school. Hence, he lagged behind in his school work and had to take extra time to catch up. When the teachers were firm about having William complete his assignments, his mother would argue that they were insensitive to his illness and not particularly sympathetic to his situation.

When he was in Grade 1, William had access to the Resource Centre in his school and the educators there helped him to catch up on some of the work which he had missed during his absences. It was through the assistance of the Resource Centre at his elementary school that he

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

had received the most help. However, Mrs. Campbell mentioned that she observed a decline in William's willingness to do his school work shortly after she disclosed to the school that he had Crohn's disease, and he continues still to lag behind.

William was also diagnosed with a mild learning disability in Grade 3 that affected his long term memory. Therefore, it took him longer to process some school material. He was classified as having IEP codes zero, two. Now, Mrs. Campbell realizes that his learning disability causes him to be bored, frustrated, and he tunes out during his classes. She also finds his behaviour problematic sometimes because it leads to a defeatist attitude that hinders his school progress. She says that his view is, "If he can't get it [school work] I'm not going to bother trying."

Mrs. Campbell never met with William's elementary school principals but she regularly met with his teachers. She informed his teachers that he had Crohn's disease to ensure that William's bathroom needs were accommodated. In spite of this, Mrs. Campbell said that, William might have accidents in his pants after returning to school from a prolonged absence. Mrs. Campbell remarked that, "I think it happened in the beginning a couple of times. I was nervous when he went back after being off sick for a month after Christmas, from October to December—he was absent." Mrs. Campbell emphasized that it is important for parents of children with IBD to remind school personnel about their children's illness at the beginning of each school term.

Although Mrs. Campbell is not currently involved in William's high school, she had been very active in the past. She said, "I met the high school guidance counselor, she was my go-to-person when I have issues with his learning and why he's not doing this, not doing that. So she was the go-to-person, more than the principal, more than anybody else." She further explained

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

that, “In high school the IEP was created by the coordinator of the STEP (Students Tutorial Educational Program). We made the IEP together.” STEP is an educational clinic within some public schools. It is designed to help students with tracking their homework, and other remedial requirements. Even though William was not present when the IEP was created, Mrs. Campbell finds that having an IEP is very helpful. It allows for certain accommodations in school, such as having someone reading the questions for him during exams, not because he can’t read, but because it takes him time to process the information. In such cases, members of staff from STEP are available to help. This year Mrs. Campbell requested that an accommodation was added to his IEP. She requested that William be permitted to use a calculator at school. However, Mrs. Campbell does not think that all of his teachers were informed. She believes that the, “Old die hards [teachers] don’t get it.” She said, “One of them made a negative comment about how the parental demands were too great.” This negative statement was made by William’s music teacher and was another reason why William was going to be switched from music to art classes next year. Interestingly, she has only had to meet with teachers regarding William’s learning disability not his Crohn’s disease. Due to William’s difficulties in math Mrs. Campbell has arranged for him to be tutored once a week. So far, the tutorial and Chris’ help seem to be enough assistance to keep him from failing his class.

Overall, Mrs. Campbell considers her relationship with her children’s school staff to be quite good because she says, “I have been in their face in every way. I’ve been involved in school committees so they’ve always known who I was. They always knew that I was William and Chris and Nancy and Ryan’s Mom. I have always been involved in their schools.”

At the time of the interview, Mrs. Campbell proudly announced that William hardly missed days from school. His absences have been sporadic and at most he had missed a

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

maximum of four to five days since September. Some of his absences have been due to Crohn's related symptoms, such as head and stomach aches.

William attends a public high school while Chris and Nancy have attended competitive private high schools. Although Mrs. Campbell acknowledges that Nancy enjoys her school, she is aware that the private school curriculum is academically demanding. She spoke at some length about the differences she had experienced in sending her children to private and public schools. "It would be nice if there wasn't such a difference between public and private school. If the public school money was able to come up a notch, it sounds bizarre but if the physical school environment were cleaner and nicer, a reflection of the private school physical environment, I think that would make a difference." Mrs. Campbell thinks that, the physical environment of private schools is tidier than that of the public schools. She said that, "In some public schools as it was in his [William's] elementary school, the principal there, kept the school neat and tidy and clean. It was quiet. High school is a little different, there's a lot of freedom but with that freedom they're [the students] everywhere and it's also a larger school it's 800 kids." This suggests that a few changes initiated by school principals, such as improving the appearance of the school and reducing the noise, albeit small changes, would, perhaps, make for an improvement in the learning environment.

Regarding the matter of family situations and the composition of families, Mrs. Campbell deems it the responsibility of teachers to take a little more time to learn about their individual students. At this point, she mentions seeing pictures of small town teachers in movies and books, and wishes that schooling could return to the days when teachers in small towns knew all about the lives of their students and the students' families.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

She believes that in those “old days” teachers knew all of the problems and issues that each of their students faced. She believes that those teachers were proactive and said that they, “would have been on the phone with the parent saying, ‘You know, Mrs. Smith, Johnny hasn’t been doing his homework, has he been coming to school or does he get breakfast in the morning? Is there something wrong?’” In this way, her belief is that those teachers took a genuine interest in the lives of their students and were fully engaged in advocating on behalf of the students, unlike her present experiences.

She acknowledges that it is not only the teacher’s responsibility to see to the welfare of students, it necessitates the participation of parents as well. She emphasized her point by saying, “I’ve used that statement, what can ‘we’ do? Because this kid needs to succeed, what can we do? You’re the teacher you have your training as a teacher, well I don’t know what to do. I’m in your face but you’re the teacher, you have the teacher training so let’s find a way so that this kid succeeds.”

Mesosystem from the Perspective of the Child with IBD

William’s Past, Present and Reflection: School Experiences

William said that he could not remember much regarding his early school days other than he didn’t enjoy going to elementary school. He spent Kindergarten to Grade 4 in one school and his later years (Grades 4 to 6) in another school. Apparently, he did not like either school. He found Grades 5 and 6 boring. He said, “You had to sit there for the whole day, no sports, just free time outside during the winter [playing games such as] King on the Hill and during the summer months playing with a soccer ball, basketball, or tether ball in the school yard.” Other reasons given for not liking elementary school were that he felt his French teacher was unkind to him. He explained, “She wasn’t nice all the time, she wouldn’t yell, just her attitude.” William also

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

experienced problems with his physical education teacher in his later years. He said, “I didn’t really participate, so he’d always yell at me and so that’s what I didn’t like.” This was just two of many teachers from both schools that he recalled not liking.

However, one positive experience was his relationship with his Grade 5 homeroom teacher Miss. P. Of all his teachers, he seemed to have cared for her because he told me that, “She was pretty nice. She would do work and then activities and that was pretty much the fun part about it. She wasn’t that strict, she was kind of laid back most of the time.” Miss P. sometimes allowed her students to create their own assignments and William seemed to appreciate the freedom and the opportunity to have his input in the curriculum. When William was questioned about how he coped with missed homework, he stated that he couldn’t remember how he had dealt with that either.

Although William had attended two different elementary schools it seems that he made friends easily in both schools. He stated that, “It’s always been pretty easy to make friends.” He still has two of the friends he had made in elementary school and they are all attending the same public high school now.

William had just started high school and was in Grade 7 at the time of our interview. Similar to his elementary school experiences he was not enjoying high school. In the beginning, William said that he was nervous about starting high school because it was a “big school with a lot of people and then I just got the hang of it. It’s hard learning how to go from one class to another class, in elementary you just pull out your books from your desk.” William explained his reasons for disliking high school. He expressed that, “[At times] I hate high school because I’m in a bad mood.” Yet he feels that his ‘bad mood’ was unrelated to his IBD symptoms. When he was asked if he found high school stressful, his response was, “I didn’t find high

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

school stressful simply because some classes have a lot of work and some days there isn't a lot of work." In addition, he mentioned that there wasn't a single course that he liked.

Currently, he finds his hardest subjects to be math and French. In French class he struggled because he did not always understand what the teacher was saying. It is mandatory that he studies French, English, math, science, history, geography, music, and physical education. He explained that he dislikes his music class because all the students had to learn to play the guitar and he would rather learn to play the drums. It was his teacher who decided which instrument the class would learn to play. As a result, he will not be taking a music class next year. Instead, he will be taking an art course because he likes art and tries to draw. In the end, it turns out that he does have a course that he enjoys after all. Another positive thing for him is that he also likes his male homeroom teacher.

There have been times when William has been sick in school. Despite feeling sick, if he is able to tolerate the pain, he will simply ask his teacher's permission to leave the classroom and get a drink of water, and then he will remain in school. Usually, he said that, his stomach growls when he is feeling really sick then he would call his mother. Then his mother would telephone the school and grant her son permission to be dismissed early. Only then, was he able to take a bus and return home.

William described some of his teachers as being helpful whenever he was absent. On the other hand, he also said that he had teachers who were less empathetic who would say, "Oh, you should have been responsible to get the homework," if he was absent from school and did not get the assignments. In those instances, he would rely on his friends to get the work for him, but if his friends were unable to inform him about missed assignments he would forget about it. He mentioned that he would merely sit in class and participated as much as possible with whatever

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

knowledge he had. Later, he would ask Chris to assist him with the homework and the following day, William would hand in his late assignment with the excuse that he had somehow forgotten to hand it in on time.

As a rule, William does not tell his teachers about his illness; however, he has told a few of his friends. William discovered that his friends do not think that having the disease changes him in anyway. When he describes the disease to his friends he explains that he gets stomach pains and then has to take pills for his colon because his, “colon is not strong.” He has come to realize that some of his friends are really quite sympathetic, often because they already have aunts and uncles with Crohn’s disease. Therefore, they are fairly familiar with the disease and its effects.

William is an active teenager, who likes to go skiing with his family. He also enjoys soccer which he began playing at the age of six and once belonged to a soccer team while he was in elementary school. Currently, he is not a member of any team, even though his high school offers basketball, soccer, and volleyball. He had also tried to play football and baseball, and at some point he would like to try hockey because he thinks it would be fun.

Mrs. Campbell openly shared that, “William’s friends up until last year, let’s say school buddies, did not know that he didn’t have a father. He didn’t broadcast it. They [his classmates] went on a retreat and they had to write about each other. One of the friends wrote to William, he said I’m so sorry, I just thought you were weird. He didn’t realize that he had no father. [William’s] very much a private introvert.” And Nancy had a similar situation, “A lot of her friends don’t know that she has no father.”

Exosystem from the Perspective of the Parent

Mrs. Campbell's Past, Present and Reflection: Experiences in her Community and Beliefs

Being a single mother, Mrs. Campbell stated that she has to work full-time and her employment at the bank does not allow her to take an extended period of time off work. Therefore, through the years she has relied on her parents and relatives to help in caring for her four children while she worked. In this way, she has been able to provide financially for her family. This has meant being able to finance private schooling for her daughter, afford the medical expenses associated with having a child with IBD, meet her children's needs, and maintain the running of her household. She also mentioned that because she does not have a university education, she believed that her career choices were limited and had she earned a university degree then she would have had better career prospects that afforded a greater salary than she is presently earning. But she cites her Italian heritage as the reason for not pursuing higher education. She claimed that in her culture, she was raised to believe that the role of a woman was to be a wife and mother and to care for her children. Therefore, it was her husband's responsibility to be the sole income earner. However, all of this changed when he died and she had to become the sole income earner. When her husband passed away, Mrs. Campbell's priority was to be employed as quickly as possible and she was hired by the bank where she has remained for about six years.

Despite having to work full-time, Mrs. Campbell has maintained an active role in her children's schools through the years serving on various committees, and helping out at a variety of school events. She has also been an active volunteer in her community. For example, when the twins were six months old she volunteered and enrolled them into a longitudinal twin study on IBD in which she continues to participate. Although she noted that as the children matured,

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

she spends less time volunteering. When she does have some free time, she continues to volunteer in activities hosted by the IBD Association, such as assisting at their annual fundraising BBQ event.

Macrosystem from the Perspective of the Parent

Mrs. Campbell's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD

When it comes to discussing how she feels about William and how he is treated within the family, she voiced her opinion strongly saying,

“I think it’s a combination. I’m more of the type, yeah, yeah, he has Crohn’s ok.

Whereas, my parents’ generation is, oh be careful with him you have to watch what he eats because he has this and he has that. But I’m more of the type, he has Crohn’s and it’s no biggie. He’s on medication. He’s good now, things are good.” She was adamant that she did not want to concentrate on his illness, “We don’t want to focus on the label.

It’s interesting a kid that has Crohn’s is already labeled as different,” she said.

She has concerns that the label is restrictive and that “the label is coming from not understanding what Crohn’s is.” Being seen simply as a person with IBD leads her son to question, “Why do I have to have Crohn’s? Why do I have to have a learning difficulty? Why do I have to be sick when my sister doesn’t, she does this, she does that, she doesn’t have trouble learning, she doesn’t have Crohn’s.” She claims that focusing on his challenges does not help in building William’s sense of self-confidence and self-worth. In general, Mrs. Campbell does not want to coddle her son due to his illness. She remarked that, “We don’t want to walk around on eggshells.” She concluded by saying that she has a philosophy which is shared by other parents in similar circumstances—that, “This is what we’ve got [IBD], so today’s Saturday and we have

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

to look at what needs to be done, not does your tummy hurt?” In her view, children may have challenges, but this should not hinder whatever daily tasks need to be accomplished. Her belief is that daily living needs to continue as usual despite their children’s obstacles.

All in all, Mrs. Campbell would like to see more connection and awareness to different types of needs for children with IBD. She hopes to see more accommodations made by teachers and more knowledge promoted to the larger society because, “a lot of people don’t even know what it [IBD] is.” In addition, she would like teachers to be aware that “family” takes on many different shapes, for example some families comprise a single parent such as in her situation. Furthermore, she believes that teachers need to know about their students’ home lives. Only then can teachers truly comprehend who their students are and where they are coming from. This idea links to her deep-seated belief that, “It takes a village to raise a child.”

Macrosystem from the Perspective of the Child with IBD

William’s Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD

William does not think that having IBD prevents him from doing anything that he wants to do. While he is at school, he is able to play sports and does not get too tired. He believes that because he has Crohn’s disease, it does not make him any different from other children without the disease. He sees himself comparable to other teenagers. He said, “I’ll still do what I want to do. I’ll still bike and if my stomach’s hurting then I’ll stop’ cause that’s what I want to do.” Finally, William aspires to be a movie director when he grows up.

Macrosystem from the Perspective of the Sibling

Nancy’s Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD

Although Nancy has a friend whose sister has Crohn’s there have been times that she has had to explain the disease to her friends by stating that, “IBD is when your bowels inflamed.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

You have to watch what you eat. There are some things [foods] that bother your colon so, like chocolate, red meat, spicy food.” Furthermore, she explained that William has to take medication for his Crohn’s disease. Up to this point, she has found that after providing people with information about the disease that they exhibit very little reaction. When people understand what the disease is, then they are empathetic and do not treat William differently.

Summary of Family 3: The Campbells

This family did not have long to mourn their father who died from IBD before having to cope with another family member being diagnosed with the disease. Mr. Campbell’s death remained an unspoken topic among the children and their friends.

Mrs. Campbell is the primary caregiver who worked full-time, maintained connections to her community and her children’s schools. Although she is fearful for her children, she does not let them believe that having Crohn’s disease or a learning disability are labels that define who they are as individuals. Her message to her children is that Crohn’s is simply a disease and learning challenges should not prevent them from pursuing any of their interests, dreams, or becoming successful. This is a message that she not only verbalizes, but also puts into action when she believes that her children are not receiving the school accommodations to which they are entitled. She makes sure that she is known by all of her children’s teachers. She remains tenacious in her pursuits and efforts to stay well informed and to work for the good of her children. While her family remains active, vigilant, and proactive.

Although Nancy and William are twins and have many interests in common, such as sports and a love of art, there are large differences between them. Nancy is active both in and outside of her school and is academically a year ahead of William. Her achievements place a strain on their relationship, and at times create animosity between them.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Being a single parent for Mrs. Campbell has meant that she has had to work full-time in order to support her family. In particular, the costs associated with IBD are high and Mrs. Campbell has chosen to maintain full employment in order to be able to pay for William's health needs, as well as her daughter's private schooling, all the needs of her children, and the running of her household. Mrs. Campbell felt disadvantaged by not obtaining a university degree and believed that had it not been for her upbringing she would have pursued higher education and would have been able to have a more lucrative career. Mrs. Campbell also highlighted the importance of having a strong relationship with extended family members. It would appear that her relatives assume an important role in caring and supporting her, and her four children whenever needed. Although her situation may be challenging, she finds time to help others by volunteering at her children's schools and the IBD Association.

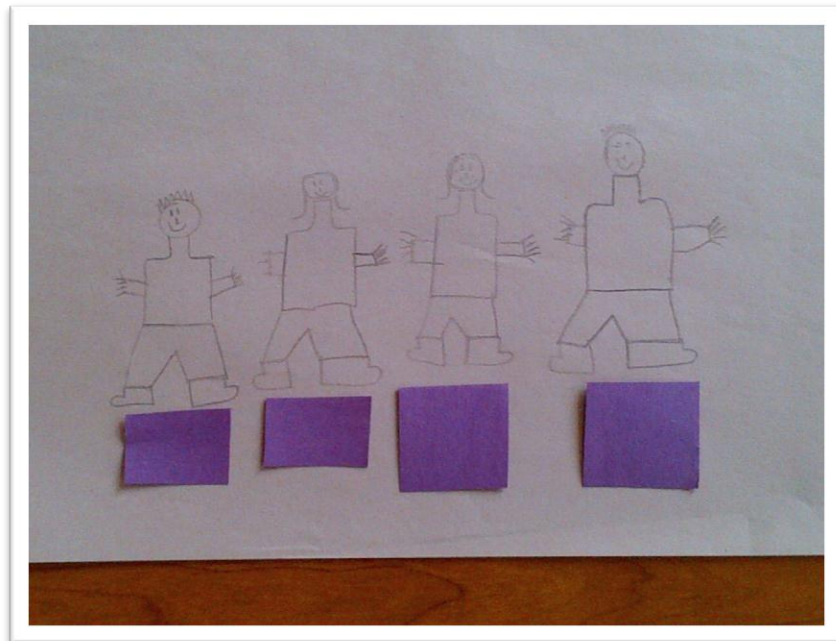
William was diagnosed with IBD while he was attending public elementary school. Mrs. Campbell believes that having Crohn's disease has had a negative impact on William's schooling because initially he had to miss many days of school. In addition to IBD, William has a learning disability and he has an IEP that stipulates how some of his special needs are accommodated. Mrs. Campbell thinks that William's learning disability and IBD affect his self-esteem and may be the reason why he has never enjoyed attending elementary or high school. While William struggles academically, his twin sister excels and is enrolled in a competitive private school. She is in a grade above him. Mrs. Campbell notices significant differences between public and private schools. For example, she maintains that private schools have cleaner and quieter environments. However, she asserts that public schools can also have much better environments but it all depends on the priorities of the principal. She finds that a good principal can really make the difference to any school. Currently William is completing Grade 7 and is not enjoying

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

his first year of high school. He claims that the problem is unrelated to IBD and has more to do with trying to adjust to the fast pace of high school, and having to take classes that he does not like, such as French, music, and math. During his absence from school, some of his teachers were helpful. In addition, he relies on his friends and older brother Chris to tutor him. Mrs. Campbell has always played an active role in all her children's schooling. This includes participating in events, serving on committees, and ensuring that William's school needs are met. For example, she made sure that an accommodation such as the use of a calculator was added to William's IEP. Now he is permitted to use a calculator at all times in math class. Mrs. Campbell believes that William's school experience would improve if teachers would take more personal interest in their students. She understands that teachers may be overwhelmed with the large class sizes that they are responsible for teaching. Nonetheless, she feels that it should be their responsibility as professionals to engage more with their students. In turn, this would improve the child-teacher relationship.

Family members believe that society may have erroneous perceptions about IBD, such as believing that a child with the disease may be restricted in the things that he or she are able to do and achieve and in Mrs. Campbell's words, the child may be "coddled". In turn, these views can negatively impact a child with IBD, for example by lowering the child's self-esteem.

Case Study 4-The Keller Family: A Critical Case of Crohn's Disease and a Family in Transition



Family Introduction

A family of Jewish heritage, the Keller family continues to reside in the same neighborhood and occupy the same house in which I first met them in 2004. However, seven years later, much had changed within their home. According to Mrs. Keller, the family had progressed well, until last year. It was at that time, the family experienced a period of great transition due to two major life changing events. The key events significantly impacted each member and have forever changed their lives.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

The first dramatic event was the separation of the parents. Consequently, Mrs. Keller became a single mother and the primary caregiver of her two children: Sophia aged 17 and 15 year old son Michael. In addition, the separation necessitated the children to make travel arrangements to visit their father who had moved to the United States. The second major change was that Michael's Crohn's disease symptoms worsened and reached a critical stage. This resulted in his doctors doubling the dosage of his medications including his vitamin supplements. The doctors also informed his parents that if Michael's disease continued to progress, then he would require a liver transplant in the next few years. These two major life altering events, and the impact that they had on the family's relationships within their home, school and community environments are explored further from their perspective in the following profile.

Microsystem from the Perspective of the Parent

Mrs. Keller's: Past, Present and Reflection: Experiences of IBD at Home

In talking about her recognition of the onset of her son's illness, Mrs. Keller said, "I first noticed that something was wrong with Michael when he began running to the bathroom often and having stomach cramps frequently." Then she explained that a colonoscopy performed by a gastroenterologist revealed that Michael, who was seven years of age at the time, had Crohn's disease. Mrs. Keller recalled that she was not entirely shocked by the diagnosis because she already knew of some adults with the chronic disease.

Since his initial diagnosis, Mrs. Keller explained that Michael's disease has been well controlled by the use of immunosuppressant drugs, which he has been taking for the past seven years. Mrs. Keller shared that it was not until last year that Michael's disease symptoms worsened. She said that the deterioration is due to, "Associated complications from the Crohn's, like a mass on his pancreas, except in the end, it turned out to be a part of a liver disease and he

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

will probably require a liver transplant and have a lot of other health problems.” In talking about the progression of the disease, Mrs. Keller mentioned that it, “puts stress on the family, but the hospital staff has been somewhat helpful.”

In reflecting on her family, Mrs. Keller spoke freely about her relationship with her children. She said, “I find Michael to be a positive kid who doesn’t complain very much. Although, when he’s not feeling well, it’s like having my baby all over again.” She continued this thought by saying, “He usually sleeps with me when he is not well.”

Mrs. Keller also shared that, especially when Michael is unwell, she prepares foods for him, such as fruits and vegetables because she knows that they will be easy for him to digest. At this juncture, she expressed her persistent concern about Michael’s small stature and low weight. Therefore, she tries to offer as much support as possible to Michael by maintaining an active role in his life. By so doing, she makes every effort to be home when he arrives from school and have a snack prepared for him, hoping that he will gain weight.

Regarding the sibling relationship, Mrs. Keller pointed out that Michael and Sophie have a close and loving relationship. She mentioned that Sophie had always been rather protective of Michael and that it had been difficult for her to watch him suffer, especially during this past year. Sophie spent a lot of time visiting Michael while he was sick in hospital and worries about her brother constantly. Mrs. Keller finds it troubling that her daughter spends a lot of her time worrying. Not only does Sophie worry about having a brother that has a progressive chronic disease, but also having to observe her parents go through their marital separation. Mrs. Keller believes that the past year has been especially difficult for Sophie since she no longer has her father at home. Mrs. Keller said that she literally finds it painful to listen to her daughter when she talks about her longing to have, “things [the family] return to normal.”

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Mrs. Keller also had concerns, particularly about her children's future. As she shared these concerns, she explained that as her children grew she worried about how to balance caring for them while teaching them at the same time to be empowered and independent. Although she had these fears, she stated that she felt unable to think too far ahead into the future. She never knew what to expect each day with Michael's fluctuating Crohn's disease symptoms. At present, she believes that Michael's severe case of Crohn's disease is very different and unique from other children with the same disease. She explained her position this way, "He is not the same as other kids with the same disease and those factors will influence his future." These issues heighten her insecurity about her son's future. She's unsure for example, "If he'll ever be able to become a doctor and pull an all-nighter for med. [medical] school and doing a residency does affect your life, but luckily he has a very positive attitude." Therefore, at the moment she chooses to live life minute by minute and day by day.

Microsystem from the Perspective of the Child with IBD

Michael's Past, Present and Reflection: Experiences of IBD at Home

Michael is a bright, inquisitive teenager who is short in stature and wears glasses. During our interview he laid on his living room sofa and was connected to an intravenous drip that his mother had prepared for him. The intravenous drip was necessary to supply the antibiotics needed to treat his blood infection. He explained to me that he was required to remain on the antibiotics for another week.

In talking with him, he recalled being diagnosed at the age of seven, but could not remember who had informed him about the disease. Aside from himself, he was unaware of anyone else in his family with that disease. Following his parents' separation, Michael found it difficult to visit his father in the United States as often as he would have liked because of his

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

frequent bouts of illness. For that reason, he felt that his IBD had greatly limited their interactions and affected their relationship.

When feeling well, Michael shared that he enjoyed socializing with his friends. Some of his closest friends were also neighbours. He regularly went to their homes to play video games and they often carpooled to school. On the other hand, when feeling unwell or suffering from cramping stomach pain, his only recourse was to take Tylenol and sleep. It appears that Michael frequently needs to take time out of his day to rest, even after performing seemingly basic tasks such as having to walk up and down the staircase in his home. It was apparent that he found these simple movements to be taxing, so much so, that at the end of our interviews, he had to go to his bedroom to rest.

Being inquisitive, Michael decided to learn more about the disease from which he suffers. He informed me that he spends a considerable amount of time learning everything he can about IBD from the internet. Once his blood infection was cured, his doctors wanted to prescribe Remicade for him. He mentioned that he had begun to question his doctors concerning his prescribed medications and their side-effects. From his research, he believes that he has gained a deeper understanding of IBD and now does not fear the possible side-effects from any of the medications. Michael credits the internet as being an invaluable source of information. He especially likes the way the information is presented on the internet because he finds it easy to understand. I was surprised to learn that although Michael spoke of spending lengthy amounts of time conducting online research about IBD, he was unfamiliar with the Crohn's Association's website specifically for teenagers.

In reflecting on his family, he described his relationship with his sister. He spoke fondly of Sophia and acknowledged that she played a big role in helping him whenever he was not well,

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

especially when he was hospitalized. He shared that when his sister was in high school with him, he could depend on her to always collect his homework for him when he was absent from school. Michael regretted that he no longer had the opportunity to spend time together with Sophia and his father, now that Mr. Keller lives in the United States. The siblings usually visited him separately, at different times in the year. Regarding the issue of visiting his father, Michael appeared sad as he spoke about how he had missed Sophia's presence when she is with their father in the United States.

Microsystem from the Perspective of the Sibling

Sophia's Past, Present and Reflection: Experiences of with IBD at Home

At the time of the interview, Sophia was almost 17 years of age. She recalled the few high school years that she spent with Michael. During those years she did her best to help him whenever she could and in whatever way she could. There were times when Michael was too sick to go to school and she would approach his teachers to find out about his school work and take home his missed assignments. It seemed as though she was experiencing difficulty in talking to me about her brother and his illness. It was clearly a topic that evoked a lot of emotion for her. However, difficult as it was, she did talk about it, and she explained her feelings of guilt. Sophia did not understand why her brother should be stricken with such an illness and she was spared.

Sophia graduated from high school and is currently enrolled in Collège d'Enseignement Général et Professionnel (CEGEP). While she dealt with this part of her life, she spoke sadly of her sense of being unable to assist Michael as much now, since they were no longer attending the same school. Sophia mentioned that her brother was overall an active boy but that since the

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

progression of his disease, she found it very difficult to watch him suffer. “It is tough to see him lying in bed for hours in the hospital. It makes me feel bad for him,” she said.

Sophia expressed wishes that their father were present to help their mother during Michael’s bouts of illness. Although, she was enjoying her CEGEP experience, Sophia said that she often felt that she should remain home to be with her mother and brother. At the time of our interview, she was preparing to travel to the United States to visit her father, and she showed an eagerness to see him. However, she was concerned that she would not be present if something were to happen to Michael. She was constantly concerned that Michael could relapse and would have to be rushed to hospital because of liver failure. Sophia also discussed that she felt tired of having to travel back and forth to the US in order to spend time with her father. She missed the days when they used to be together as a family.

Sophia also talked about her joy in seeing her father, but at the same time not having Michael around took some of the fun out of it. Since Michael’s disease progressed, they have not been able to travel and visit with their father at the same time. All in all, “I simply wish that things would return to normal, the way they used to be; with everyone together, but I know it won’t, so that’s it. It’s just the way it is, I guess,” she said.

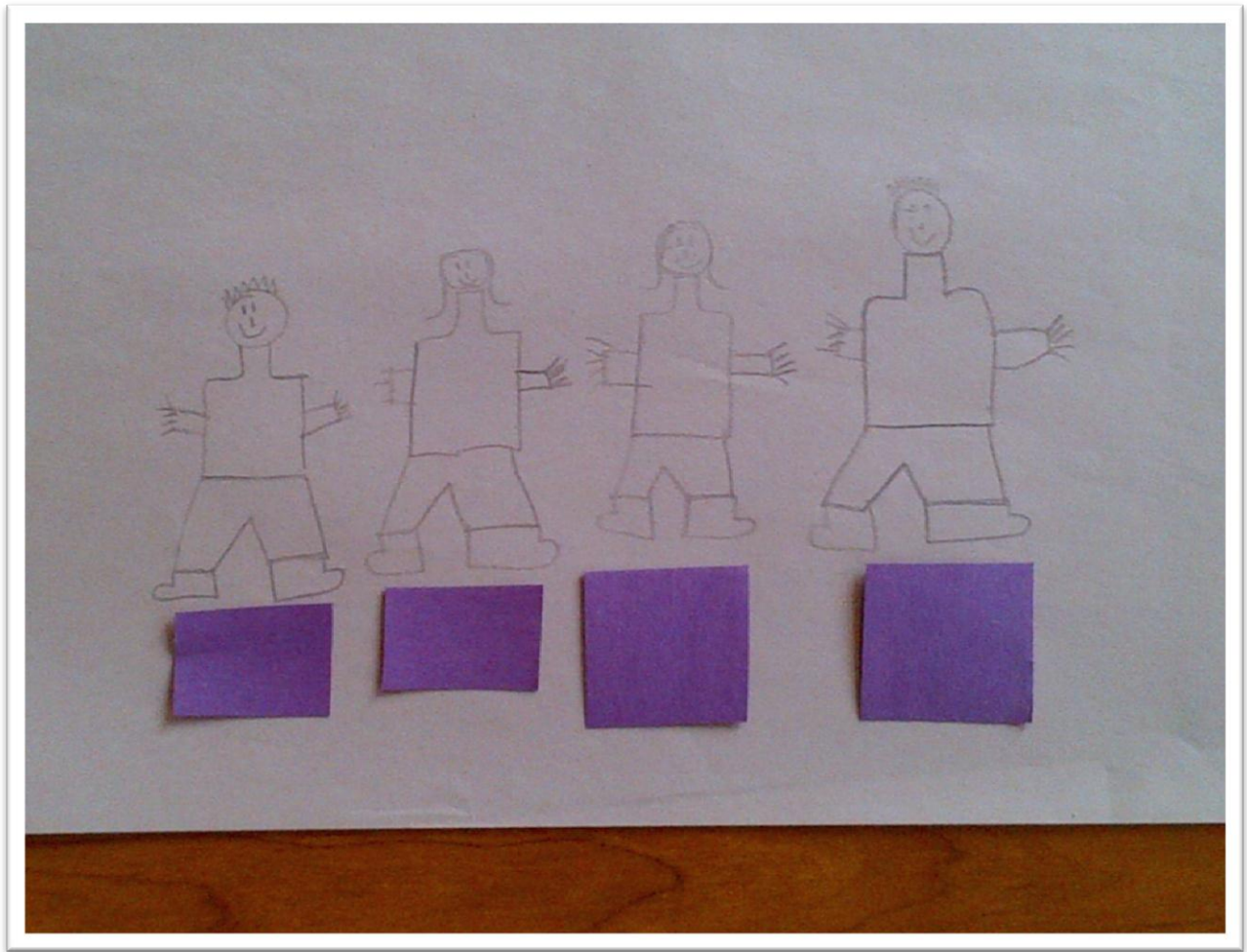


Figure 7 Family drawing in pencil by 17 year old Sophia. All family members are drawn.

Sophia's Family Drawing

Sophia produced this picture of her family. Initially, she was reluctant to draw stating, "I'm bad at drawing, do I have to?" I explained that she did not have to draw a picture of her family if she did not want to and reassured her that the choice was hers. As with all the other siblings, I made available an assortment of art supplies and Sophia chose to draw at the living room table. Mrs. Keller called for me and I left Sophia to talk to Mrs. Keller who was in the kitchen. Upon my return to the living room, I observed Sophia in the midst of drawing. She drew in silence and completed the picture within about 15 minutes. Sophia asked "Is that all

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

right?” I responded by thanking her for taking the time to create the picture for me.

Interestingly, unlike the other siblings Sophia’s drawing of her family was void of colour and had very few details. Each family member was drawn as if they were simply an outline without specific characteristics or personalities.

Family Relationships

In terms of family relationships, Mrs. Keller believes that as a parent, school decisions, such as which classes a child can afford to miss and those classes that a child must attend, are all decisions that need to be made together as a family, and in collaboration with the school staff. “This is something that parents and kids need to know how to do together. And that’s why I think the school has to be involved, so that Michael attends the classes that he really needs,” she explained. When I asked about special accommodations, Mrs. Keller remembered that the only accommodation that she requested from the school had to do with food. She shared one example where, upon Michael’s return to school following the Christmas vacation period, the cafeteria was only offering whole wheat bread. Subsequently, Michael had been prohibited from consuming foods high in fiber in his diet. Therefore, Mrs. Keller had to contact the school and ask if they could provide him with sandwiches made of white bread. She claimed that the school staff was receptive to her request and supplied the bread without objection.

Mesosystem from the Perspective of the Parent

Mrs. Keller’s Past, Present and Reflection: Experiences at Michael’s Schools

In reflecting upon Michael’s private Jewish elementary school experiences, Mrs. Keller recalled that despite having Crohn’s disease, Michael was able to keep up with his studies and did not require an IEP, or need any special accommodations. At that time, she played an active role at Michael’s elementary school and served on the school’s Parents Committee. She felt that

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

she had a positive relationship with Michael's teachers and was well supported by the school's administrators. "He was in a private school, so there was kindness and much more understanding," she said. As such, during the early years of Michael's diagnosis with Crohn's disease, Mrs. Keller stated that no special effort had to be made on her part to meet with the school staff to discuss Michael's illness because his needs were being met.

It was only this past year that Mrs. Keller encountered some resistance from some of the teachers at Michael's private high school. "He's missed a lot this year at school, even the first semester even though he wasn't all that sick, but there were things that he couldn't do like gym, and so he was taking off from certain subjects and returning home to sleep," she said. Mrs. Keller further explained that it was at this point that some of Michael's teachers began to disapprove of his behaviour and began to challenge his poor attendance in some of their classes. For the first time, Mrs. Keller felt compelled to meet with Michael's high school principal. In that meeting, she asked, "Them [the teachers] not to yell at him if he has to put his head on the desk while in class. If that's what he needs then let him be! I don't want to bring him to school for two hours and have the other teachers harassing him because he was not there for their classes." She also mentioned that, "It was important to me that his teachers understood that if he has to stop because he's not feeling amazing and if you see him in school and he's not in your class, I don't want you saying something to him."

At that meeting, she found that the principal was receptive to her concerns and assured her that he would attend to the matter. Although she claimed that this was not necessarily her reason for choosing to enroll Michael in private schools, nevertheless she said, "They [private schools] can be accommodating, like when Michael misses a few weeks of school, his school sends a tutor to our house." Since meeting with the principal, Mrs. Keller is satisfied with the

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

results and found that the teachers ceased confronting Michael. She mentions that she is pleased with the open lines of communication that she has had with the high school staff, and is reassured that the staff listened to all of her concerns and responded accordingly.

Mesosystem from the Perspective of the Child with IBD

Michael's Past, Present and Reflection: School Experiences

When I first met Michael, he was attending a private Jewish elementary school. In reflecting upon his school experiences, he recalled while attending his public elementary school he had experienced a prolonged absence in 2001 when he had to have surgery. He had memories of receiving a great deal of assistance from his teachers and friends while in hospital, which permitted him to stay abreast of his missed assignments. Despite receiving help from friends and teachers, Michael remembered that he did not enjoy his elementary school experience. He expressed that there were many reasons for his dislike of school, such as lack of cleanliness of the school environment, particularly the washrooms, lack of challenging academic course material, teachers that were not accommodating to his IBD needs and large class sizes.

Michael is currently in Grade 10 and contrary to his elementary school experience he has been enjoying his private high school immensely. He described the physical structure of his high school as being small with classes of approximately 15 to 20 students and washrooms that were readily accessible. Interestingly, he had maintained many of the friendships that he had formed in public elementary school to private high school. He also said that he loved everything about high school including the friendships and his supportive relationship with some of his teachers. Although, he complained that some subjects were “boring”, he claimed that some teachers were able to make their classes interesting.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Michael is taking English, French, physical education, and math classes, and he also participated in an Outreach program. The purpose of the outreach program is to have students placed as volunteers in their community for a semester. The program was organized and led by his homeroom teacher. The students were given an opportunity to list a total of three locations in which they would like to volunteer (e.g., veteran hospitals or senior residences).

Of all of his classes, math was his favorite, while French and history were his least favorites. When I inquired why he did not enjoy these classes, he responded that he was unable to have input in the course material. Everything was pre-determined by the teachers and he did not find that the ways in which those teachers presented their course material was interesting.

In discussing his illness, Michael described in vivid detail, the way in which his symptoms of Crohn's disease had dramatically progressed last year. He explained that, during the Christmas vacation he was visiting his father when he became extremely ill. His father rushed him to the hospital, but the doctors were unable to determine what was wrong with him. His symptoms appeared to be more severe than a typical IBD flare-up, because he experienced frequent blood infections, repeated vomiting of all foods he consumed, use of the toilet every five minutes, and had insomnia. Ultimately, the doctors prescribed antibiotics and this helped him to feel well enough to return home to Montreal. Once the course of antibiotics ended, he began to develop fevers. Mrs. Keller rushed Michael to the hospital where blood cultures revealed that he had contracted a second blood infection and required hospitalization for a week.

Unfortunately, two weeks following his hospital release, the blood infection returned for a third time. Michael was then required to remain on antibiotics for an extended period. In spite of having to take medications intravenously and experiencing recurrent fatigue, he was resilient. When his hospitalization period ended, Michael returned to school. At this point, he said that he

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

didn't find it difficult to return to his studies because some of his friends had helped him by collecting his homework assignments while he was in hospital. Although he had the help of his friends, he relied mainly on his teachers, many of whom had made his assignments accessible on the school's website. In this way, he had been able to log on from any computer and receive his assignments. He then worked on them at home, and when he was hospitalized.

Upon returning to school he felt comfortable taking his medications during lunchtime and did not experience any side-effects from any of the drugs. However, what did become a challenge was the way in which some of his teachers began to treat him. For example, his math teacher began to limit the frequency in which he was able to access the bathroom. Michael was restricted from being able to leave the classroom and go to the washroom whenever he needed. He claimed that his math teacher's reason for prohibiting him to leave was that he would miss important information that was being taught if he left the class.

Michael disclosed that he had experienced similar situations of being prevented from going to the washroom while in elementary school. When I asked Michael if he had ever explained to his teachers the reasons why he needed to use the toilet often, he responded by saying that he did not feel that it was necessary to inform his teachers that he had Crohn's disease because his mother had already notified his principal. It seemed that he did not see the need to advocate on his own behalf because the principal sent a note to all his teachers at the start of each school year to inform them about his disease. Michael confirmed that this past year his mother was proactive in contacting his principal to ensure that he gained free access to the washroom as needed. Nonetheless, Michael spoke of supportive teachers like his physical education teacher who was always accommodating, and permitted him to sit out of activities when he wasn't feeling well.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

In physical education, last semester, the students were taught karate, but Michael was not permitted to participate because karate is a contact sport. Consequently, he would return home during his physical education classes. As a result, Michael missed most of the scheduled physical education classes that semester. Remarkably, he was not given any assignments or additional course work to replace his missed physical education classes. Equally surprising, Michael earned a credit last semester in physical education.

Michael disclosed that his school does not have a nurse, and his parents provided him with a cell phone. This allows him the ability to call his mother immediately if he feels unwell, and it speeds up the process of getting home. He did divulge though, that if his mother sensed that his symptoms were not severe enough, she would instruct him to remain in school and continue attending his classes.

When I questioned if there was anything at all that he did not like about his school, he seemed to have great difficulty in arriving at an answer. After much thought, and a lengthy pause, he merely responded that the only thing that he disliked were the green school uniforms. He hated the colour green, but other than that, he was seemingly quite content with his high school experiences thus far.

Exosystem from the Perspective of the Parent

Mrs. Keller`s Past, Present and Reflection: Experiences in her Community and Beliefs

Mrs. Keller worked part-time in a store located five minutes away from Michael`s high school. Due to Michael`s illness, she found it impossible to accept full-time employment. She did try to work full-time in the past, but it was difficult to work when she had to be absent often to care for Michael. Therefore, she appreciated her current job since her employer was sympathetic to her leaving work to attend to her son whenever she needed to do so.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Initially, Mrs. Keller was very involved in her community as a committee member of the IBD Association. Mrs. Keller admitted with regret that in the last few years she had to leave the association because her husband frequently travelled for work purposes, and she did not want to leave Michael at home alone while he was sick. Since the progression of Michael's illness, she no longer participates in community associations or their events. Sadly, she stated that she found it too difficult, "To commit to them [associations] under the circumstances. If he's [Michael] sick like in the past year, it's been rough on all of them." Therefore, she spends as much time as possible at home with her children. While at home, she spends little time seeking out information about IBD on the internet. She believes that over the years she has learned all that she needs to know about the disease.

Macrosystem from the Perspective of the Parent

Mrs. Keller's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD

Unlike some of the other parents interviewed, Mrs. Keller did not believe that Crohn's disease necessarily needed a 'face' because she believed that many people already knew about IBD. Her major issue with her son's illness rests with the fact that she thinks there is still a stigma attached to the disease. Upon further reflection, her thoughts were that the stigma emanated from the fact that Crohn's is an invisible disease. She explained her concerns by saying, "You can't see it and it's not like a broken arm that you fix it and then it's gone." This common theme was echoed by some of parents who were interviewed in the study. It appears then, that IBD is perceived as a complicated disease that is difficult to comprehend mainly because of the invisibility and stigma associated with the factors of the disease and its symptoms.

Macrosystem from the Perspective of the Child with IBD

Michael's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD

When Michael and I talked about how he thought people perceived him and IBD, he seemed self-assured and stated that he would like people to know that, "I'm no different than any other kid and people need to know that." Upon further reflection, Michael believed that it was important that people understand that although he may feel tired at times and frequently needed to rest, he still enjoyed and participated in similar activities as other teenagers without IBD. He would like people to know that when he is feeling well, he is a very active teenager and can play many sports. He is a member of a competitive community non-contact hockey team and he is able to travel to tournaments and typically spend two nights away from home. He always makes sure that he has his medications with him. In fact, Michael informed me that he had learned from his mother that there were two other boys on his hockey team with Crohn's disease. He claimed that his mother had uncovered this information through some common acquaintances while attending a Crohn's fundraiser. Besides hockey, Michael plays golf, baseball, and tennis and thoroughly enjoys them.

Macrosystem from the Perspective of the Sibling

Sophia's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD

Sophia would like people to know that having Crohn's disease is not easy to live with: "It's hard to watch my brother going through everything that he has to." In reflecting further, she believes that people should know that "it's really hard." It is a painful disease and she wishes that a cure can be found very quickly so that children like her brother could benefit readily.

Summary of Family 4: The Kellers

When I last visited the Keller family seven years ago, they were a harmonious and flourishing family unit. Now the members of the Keller family have to cope with the challenges of a marital separation and a severe case of IBD. These two significant events have drastically changed the way in which this family functions. Presently, each member has been experiencing some level of anxiety and uncertainty due to the advancement of Michael's IBD and the associated illnesses that have accompanied his Crohn's disease. Consequently, the parents' separation meant not only the disintegration of a marriage, but also a slightly severed relationship between a father and his two children.

For years, Mr. Keller spent a great deal of time away from his family because he constantly travelled for work. However, Mr. Keller's permanent move to the United States last year seems to have left Michael and Sophia in a state of grief at their loss of the original family structure. Both children speak of their father as being absent and express missing him. In turn, Mr. Keller's absence impacts the way in which the family functions, as Mrs. Keller has to assume the primary responsibility for the children and has to be readily available to be with Michael at all times. This added responsibility interferes with the possibility of her gaining full-time employment. In addition, the members of the family have had to reduce their participation in the community. Similarly, Michael's experience with the progression of Crohn's disease has further limited the family's participation in community events, as well as limited the frequency with which Michael can visit his father.

Mrs. Keller's choice of employment has been impacted by having a son who has IBD. Due to the severity the disease she has been unable to assume full-time employment. Rather she has chosen to spend more time at home caring for her son and working part-time in a store that is

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

in close proximity. The progression of her son's disease has also restricted her opportunities for social interaction in her community. She expresses sadness that she is no longer an active volunteer in the IBD Association as her priority is attending to her son. The unpredictability of his health condition makes it difficult for Mrs. Keller to commit to social events.

Although she has had an amicable relationship over the years with the school staff at Michael's private schools, the relationship had not assured her that Michael's needs would always be accommodated by his teachers. There were instances when Mrs. Keller still had to advocate on Michael's behalf at school.

In her son's case, attending private schools did not exclude him from being ill-treated by his teachers particularly-when he was in elementary school. However, Mrs. Keller stated that, having him attend a private school made a difference and she felt that the school personnel were kind and understanding. Now that he is in high school, Michael's special needs are being more accommodated, but his disease has greatly progressed. Michael credits his school needs being met to his mother's advocacy efforts and the support of a few understanding teachers, such as his physical education teacher. Mrs. Keller is proactive and attends immediately to the few problems that arise at school. In turn, Michael depends on her and when he becomes sick at school he calls his mother. At that point, Mrs. Keller decides whether the symptoms Michael is describing are severe enough for him to leave school. She considers the school events that are occurring before advising Michael how to proceed. Mrs. Keller also believes that it is important for parents to engage in these decisions with their child.

As with some of the siblings interviewed for this study, Sophia was instrumental in providing support for her brother throughout his illness. Having a brother with Crohn's disease has impacted her tremendously and has helped to strengthen the bonds that bind them. It is no

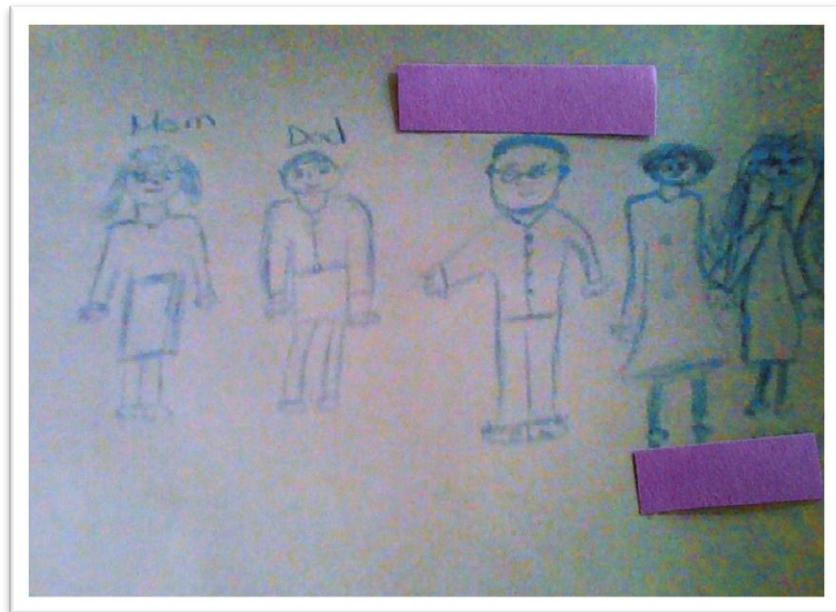
EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

wonder then, that Sophia experiences moments of sadness when she sees her brother or thinks about him.

Mrs. Keller believes that people do have knowledge about IBD, but lack empathy because of the stigma that surrounds the disease and the problem of the invisibility of the symptoms. Michael would like people to know that when he is feeling well he is just like any other active teenager and is usually engaged in multiple sports. He is a member of a non-contact hockey team and participates in tournaments in different cities. Michael mentioned that he makes sure to take his medication with him when he travels. He noted that he was not unique because he knows of two other players on his team who also have Crohn's disease. Sophia suggests that, it is important for people to understand that Crohn's disease is a difficult and a painful disease with which to live. She finds it hard to watch her brother in pain. She can only hope that a cure will be found soon.

The lasting message that the Keller family would like the public to know is that each case of IBD is unique. Yet, children with IBD want to be treated like children without IBD because they do not perceive themselves as any different from them.

Case Study 5-The Lévesque Family: Making School Success a Family Affair despite a Legacy of IBD



Family Introduction

The Lévesque family is also of Jewish heritage. When I first met Alex, he was nine years old, and was already very active in his public Jewish elementary school. At that time, he had been elected class ambassador. His first initiative in that position was to implement a major clean-up campaign of all the schools' bathrooms. I now looked forward to re-connecting with Alex and hearing how he and his family were doing. I also wanted to find out how Alex was coping with his IBD symptoms, as well as his experiences in school. Additionally, the meetings

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

for this study allowed me the opportunity to meet with Mr. and Mrs. Lévesque who were absent the first time I interviewed Alex.

In talking with the parents during the interviewing process for this research, I learned that Alex's grandmother had died the day before, but that the family decided to continue with the scheduled meeting with me. At that time, I was informed that both parents always played an active role in Alex's life and placed major emphasis on high academic achievement. The parents reported that they have continued to provide Alex with all the resources necessary for him to be successful. Both parents attend all of Alex's doctors' appointments together. Although they both show a keen desire to support their son, but there are instances where Mr. Lévesque plays a more prominent role.

Mr. Lévesque appeared to prefer to take charge in meetings with healthcare professionals and his son's disease management. The reason for his preference is that he has first-hand knowledge of IBD, because he has waged his own tumultuous battle with ulcerative colitis for years. He also suffers from chronic asthma. Hence, Mr. Lévesque has attempted to use his IBD experiences to guide his son with his health challenges.

Alex is now a tall 16 year old boy who has been struggling with his IBD symptoms for the past seven years. Presently, he is enjoying being an energetic student enrolled in a private high school. He revealed that he had a close relationship with his two older step-sisters, Paige (age 18) and Emma (age 34), even though they had never lived with him. Alex talked frequently to his step-sisters, especially Paige who interestingly also has IBD and, like her father (Mr. Lévesque), is diagnosed with chronic asthma.

Having a parent and a child with IBD as well as examining the impact of having a step-sibling that also has the disease creates a unique family dynamic. The ways in which the family

members mobilize and assist each other in order to cope with three family members experiencing chronic illness are explored below. From their points of view, their family relationships with one another while at home, school and within their community are investigated in the family profiles that follow.

Microsystem from the Perspective of the Parent

Mrs. and Mr. Lévesque's Past, Present and Reflection: Experiences of IBD at Home

Mrs. and Mr. Lévesque explained that Alex was nine years old when he had his first colonoscopy. They recalled that following the test, a nurse and a doctor informed them that Alex had Crohn's disease. Mrs. Lévesque mentioned that when she received Alex's diagnosis her greatest concern at that time was actually not of Alex's illness, but rather the problem of Alex taking his medication. Mrs. Lévesque explained it this way,

“Because I was familiar with the disease since my husband has ulcerative colitis, I was not too alarmed when Alex was diagnosed with Crohn's disease. But my main worry in the early years of Alex's diagnosis was that he refused to take his prescription of sulfasalazine because it was in pill form. I became very anxious because it was critical for Alex to take his medications in order to reduce his intestinal inflammation.”

Alex was extremely afraid of swallowing pills and refused to take the medication. Mrs. Lévesque said, “This went on for years and it was scary for me.” Mr. Lévesque remembered experiencing feelings of frustration at that time about his son's lack of cooperation in taking his medication. He said, “It was frustrating, we tried everything you can imagine, even a famous hypnotist, he was very well known.” His wife agreed and added that not only would Alex resist taking his medication, but that he would also refuse to have any medical tests done. This further behaviour complicated the situation for Mrs. and Mr. Lévesque because Alex had to have blood

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

tests done at the hospital every two months. During those hospital visits, Mrs. Lévesque explained that the only thing that she could do was sit there with him while he screamed, fought, and cried until the tests were done. Mr. Lévesque distinctly remembered those difficult years and now marvels with pride that Alex has been able to overcome his fears in his teenage years.

Microsystem from the Perspective of the Child with IBD

Alex's Past, Present and Reflection: Experiences of IBD at Home

Alex remembered being diagnosed with Crohn's disease when he was in Grade 4 or 5. As an active child, he was always spending a great deal of time away from home because of his sports, studies, time at the tutoring center, visits with his step-sisters, and travel.

He is of the opinion that he is not treated differently at school or at home and his reason for that rests with his belief that whenever he gets angry he snaps. He claims that family members and friends have seen him angry, and as such, he thinks that people are afraid to treat him differently. Consequently, while he was in elementary school, when he was not feeling well, he would often visit the nurse's office complaining of stomach pain. The nurse would then call his mother to inquire if he had permission to be excused from class and go home. Alex revealed that his mother usually says, "Let Alex return to class and tough it out." Rarely, did his mother allow him to miss class simply because he was having stomach pain.

Alex mentioned that when he is at home, he monitors his own food choices as he does not think that food has an impact on his disease. Therefore, he tends to eat most foods that his mother prepares with his medical needs in mind. He tries for the most part to eat a balanced and a healthy diet. To enhance physical wellness, he also engages in an exercise program with a trainer at a local gym.

Microsystem from the Perspective of the Sibling

Paige's Past, Present and Reflection: Experiences of IBD at Home

Paige did not grow up in the same house as her brother. She lives with her mother, a younger brother and her step-father. Although she does not live with Alex, she likes to think that she knows him quite well and that she has a good relationship with him. She continued by saying, "We are able to talk about our school experiences, challenges with IBD, friends and family." She also mentioned that Alex likes to talk about his travels and his love of being in a private school. Paige says that, Alex had confided in her about his unhappiness in the public elementary school that he attended. Now that he is attending a private high school, she is pleased that he is finally happy at school. "Even though he had to make sacrifices," she said.

Paige seemed to have understood her brother's sense of contentment in being placed in a private school because she too, attended a private school, but this was only for her elementary education. Paige remembered that by moving from the public school Alex had to leave many of his friends behind in his graduating year and develop friendships at his new school.

Although Alex and Paige are diagnosed with Crohn's disease, they did not always agree on the best medical approach to help with the symptoms of their IBD. Paige thinks that there may be a difference in the way in which they experience IBD symptoms because her disease is further complicated by chronic asthma.



Figure 8 Family drawing by Paige using a water coloured pencil. All family members were illustrated.

Paige's Family Drawing

Paige took her time in composing her picture. When she had finished with her drawing, she explained that she was unsure which family members to draw. Paige was unclear if she should sketch her own family which would then include her brother, mother and step-father or if she should depict Alex's family (her step-brother). I left this decision up to her and was interested to see how she perceived "family." Paige explained further that she had chosen to show the family from Alex's perspective since the study was about Alex and his IBD. If not, in her view, the picture would be too big and have to include too many family members. Therefore,

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

she drew Mrs. and Mr. Keller, Alex, herself and Emma. In talking with Paige, she made sure to emphasize that her drawing was not a representation of her family, rather it depicted everyone in Alex's family. Her sketch was made with a black colored pencil that included details in the appearance of each member. Each family member depicted has a rather sober face with small smiles.

Family Relationships

Mr. Lévesque was employed full-time in the importing business while Mrs. Lévesque remained at home to care for her family. This made it possible for Mrs. Lévesque to meet with Alex's elementary school teachers and principal to discuss her son's disease and advocate for the use of the bathroom whenever he needed to use it. Mrs. Lévesque made sure to stress that this was the only school accommodation that she sought for Alex because his teachers had not believed him. Mrs. Lévesque also mentioned that Alex would not have wanted to receive any special accommodations, as he was adamant that he did not want to be treated differently from the other students.

In some ways, Alex has been raised as an only child. He has always lived with his parents alone, since his step-sisters grew-up in another household. Although they live apart, Alex described his relationship with his step-sisters as being close and explains that they communicate often by phone. Alex also stated that the families get together for celebrations, such as birthdays and religious holidays.

When Alex talked about his relationship with Paige, he mentioned that they are especially close because they are roughly the same age and both of them have IBD. However, Alex does not depend on Paige for information about IBD; he usually conducts his own internet searches

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

and forms his own opinions. Still, he appreciates the opportunity he has to talk to her about his daily experiences and more importantly he believes that she understands.

The feeling of being understood by someone with the disease was also expressed by Mr. Lévesque. He explained that he too had IBD. He said,

“It’s an internal disease and the only person that can understand it is someone with the disease or someone who works with it. Because you look at him [Alex] some mornings and he looks fine; there’s nothing wrong with him. This is something internal and people don’t see what’s going on. Sadly, my daughter, she has it; she has IBD and asthma too.”

Despite having IBD, Alex has remained active and does not appear to spend a lot of his time at home. He spoke often about his travels with his classmates to many places including Alaska, Arizona, Calgary, and Australia. Mrs. Lévesque is usually the parent who organizes and packs his medications for his trips. She mentioned that Alex would be heading off on another trip shortly to Poland. She had concerns that the trip would be emotional given that he would be touring concentration camps. She said that, “Because of the high emotional context of such visits, they may act on his stomach.” On the other hand, she said, “Ever since Alex switched to Remicade he has not been experiencing painful IBD symptoms.”

The parents played essential roles in Alex’s IBD treatments, and also supervising his school life. Mrs. Lévesque describes how they deal with Alex’s school life by saying, “Throughout his entire education we have given him [Alex] extra tutoring to give him whatever he needed to get him to that next level. For a few years I was helping him and that wasn’t so great.” Therefore, as parents the Lévesques have made a large financial investment in Alex’s schooling by paying for tutors, school trips, sports activities, and private school tuition.

Mesosystem from the Perspective of the Parent

Mr. and Mrs. Lévesque's Past, Present and Reflection: School Experiences

Mrs. Lévesque expressed her disappointment with Alex's public Jewish elementary school. "It was just not a healthy environment for him; the work was not challenging for him at all," she complained. Similarly, Mr. Lévesque recalled that Alex had mentioned once or twice that his teachers were not supportive because they would not allow him to visit the bathroom when he needed to go. Alex claimed that his teachers did not believe that he was suffering from a chronic illness, and in response to this concern his father took up his cause and advocated for special accommodations to be made at school. Mr. Lévesque said,

"Although in the beginning when they didn't take his need to frequent the washroom seriously, I made it clear, and I did go to the principal, and I did talk to the principal, and I did tell the principal that this is what he [Alex] has and he must be allowed to go to the washroom. But as far as coming home and having to leave school because of it was difficult. It wasn't easy for me but I felt that [staying in school] was important and that he just push through it."

Mrs. Lévesque remembered that she had also informed teachers about Alex's disease, but she prefers to instruct Alex on how to conduct himself and to instill confidence in him. She therefore, reminds Alex constantly that, "You are not the disease, that's not who you are and there are going to be tough times and it's going to be difficult, but you know you just have to push through it." She confirmed that there were many times that she received calls from school nurses about Alex's illness and she would tell them that he should stay in school for he would be all right.

Mrs. Lévesque spoke glowingly about the principal at Alex's public elementary school

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

when he was there. She said, “The principal who Alex was close to at the time was a very, very wonderful woman. She liked him [Alex] and she was really the nucleus of all of the whole conversations I ever had about what he had [Crohn’s disease]. Whenever he became frustrated he knew that he could go and see her [school principal].” Despite Mrs. Lévesque’s satisfaction with the principal, both parents spoke in earnest about their displeasure with Alex’s public elementary school education. Mrs. Lévesque stressed that, “They [teachers] had not taught him how to organize, how to study, how to do homework, how to apply himself, and the academic level was not the same as the private school.”

Therefore, while in elementary school, Alex was frequently attending interviews in the hopes of being admitted to a private school. However, Mrs. Lévesque remarked that Alex had not been accepted due to a lack of space in the various private schools. In spite of that, Mr. Lévesque proudly declared that he was impressed that Alex never ceased trying to be admitted because he was determined to leave his public school as soon as possible.

At the start of Grade 6, the Lévesque family was informed that a new class was being formed and a place had finally become available at a private school. Mr. Lévesque stated that, “This was not an easy decision because he [Alex] had to leave all of his friends. It was supposed to be his graduating year, but he wanted to start over. I was proud of him for that, it wasn’t easy.” Consequently, rather than graduating from his elementary school, Alex enrolled in the private school and began Grade 6 there.

Mr. Lévesque provided a detailed description of the differences he experienced between the public and private schools. He described walking down the halls of the private school one day and there was complete silence unlike the public school where the students were loud,

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

shrieking, and yelling. He said, “I often pondered how learning could take place in that institution [public school] when students seemed unruly and the noise level was deafening.”

Mr. Lévesque recalled that he was impressed when he saw that even when students were changing classes there was order, quiet, and respect when they spoke in the private school. He was also impressed that, “The school taught ethics which is beyond the academics and sports.

They are taught how to respect others even in sports rather than just go out and win.” Mrs.

Lévesque expressed her view of the difference between the public and private school by stating that, “The teachers [in the private school] know that the kids are serious. The kids in his [Alex’s] grade are going to be very, very, serious about the work in their grade, for them it’s about getting high achievement. It’s not about trying to dodge the homework or the work in the program.”

She further added, “That’s why there’s such a hard application process. There’s a lot of kids that want to go to that school and a very few get accepted. The private school offered a wealth of opportunities and Alex has taken advantage of some of them. For example, he became head of human services which took him on a trip to Alaska.”

In Alex’s first year of private school, Mrs. Lévesque explained with dismay that her son was unprepared because the public school had lower academic standards than his new private high school. The parents had to provide their son with a lot of extra tutoring after school. Mrs. Lévesque added that Alex’s need for remedial assistance continues as, “sometimes he goes to a study center where he does his homework twice, three times, four times a week depending on what he needs.” Mr. Lévesque added that, “The support and encouragement from his [Alex’s] tutor has helped him tremendously.

Mesosystem from the Perspective of the Child with IBD

Alex's Past, Present and Reflection: School Experiences

Alex expressed much gratitude in having had a special bond with his public elementary school principal that started in pre-Kindergarten. He remembered that on his first day of school, “My mom left me and I was not impressed with the whole situation. I spent two hours with her [the principal] in her office just playing games with her.” Nevertheless, Alex claimed that it was in elementary school that he began developing poor study habits in subjects like math. He said, “It was like a joke to me. I didn’t feel like my teachers cared about my math homework in Grade 5. We were still doing $1-5 = -4$ and $2-4 = 2$ instead of -2 .” Now Alex is in Grade 11 and he has been attending private school since he was in Grade 6. He said that Grade 6 flew by because it was such a tremendous change from the public school and he had no problems at all in his new school.

In Grade 6, he participated in every sport the private school offered. Alex mentioned that he played on a basketball team and won the award for Most Valuable Player. He also played on teams that he did not particularly enjoy. For example, he was on the soccer team but said, “I didn’t really like soccer, I just played because everyone else played.” His sports activities took place during and after school hours. Alex mentioned that sometimes there were competitions held in other cities and provinces, but those events were not usually far from his home.

Upon reflecting on his school experiences, the only time Alex could remember having an overnight trip was when he attended a four-day snowboarding trip. The point of that trip was for all the students graduating that year to share in a special activity that allowed them to bond over the four days. Alex fondly recalled that it was a very active trip. “It was a lot of fun. We did cross country skiing, played hockey, had hot chocolate in the woods, and built snow forts,” he

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

said. On class trips Alex would take his medications with him and this included his syringe. He stated that he never had a problem taking his medications because he never took them in front of his friends, classmates, and teachers. Also, since his Grade 5 days, he always takes a toothbrush with him so that he can brush his teeth after eating and taking his medications. This is important to him because his medication is a very thick yellow liquid that would coat and stain his teeth. He acknowledges that it was his mother who prepared and organized his medications for him.

Other than that, Alex claimed that he usually took on the responsibility of advocating on his own behalf and would inform his teachers after the first two classes about his disease. Alex revealed that his teachers have never told any of his classmates about his IBD, but he has personally told most of his close friends about his disease. However, there are some peers that are still unaware of his condition. Alex said that in the beginning, “Some friends thought that IBD meant that I just ran to the bathroom a lot but as friends from school started to see me getting sick they started asking what is the actual disease? They’re not really aware of what it [IBD] is until I throw it down on them, then they’re like woah!”

Alex recalled that some of his elementary school teachers were more supportive than others, “I remember some of them [teachers] very open and willing to help but some-I don’t think they believed I had it [IBD].” Since leaving public school Alex now loves going to school and is really enjoying attending private high school. “They’ve [teachers and school staff] been really good with me, I’ve had some hard times with my stomach. The school has really catered to me and helped me out whenever I needed it,” he said. Alex provided an example of an instance where he remembered being supported by a teacher when he was in Grade 8. He had been elected by his class to go on a school trip to California and his teacher was helpful and supportive allowing him to sit out of activities as needed.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Alex started taking a new medication called Remicade when he began Grade 10. At that time, he was concerned about the side-effects of the medication (e.g., lymphoma, fatigue, and muscle pain) because he had read about it in his internet searches. While he was on a class trip that involved traveling by bus from Calgary to Arizona, he stopped taking the medication. During that trip, he concluded that he had not felt any worse for not taking the medication. Alex exclaimed, "I loved that trip and had zero stomach problems while I was away from home!" He stopped taking the medication for about a year. Then he had a relapse and became very sick, and he resumed taking the Remicade, which stabilized his disease symptoms.

In talking about his school environment, Alex described his private school as having small classes of between 10 and 21 students. There were many specialized courses for him to choose from, such as physics and broadcast journalism. Currently, he is in the following classes: English, math, French, chemistry, global issues, drama, physics, and gym. His favorite class is gym because it has a community service component where the students from his school assist children with disabilities in learning how to skate. Alex appears to be excited about the part of the course that involves working with the children. He exclaimed, "It is so much fun and every two weeks we go on the ice with kids from the center [for children with disabilities]. It's inspiring." In addition, Alex benefits from the way in which homework is structured. He explained that there is flexibility in the homework. The teachers expect the work to be submitted in a timely fashion; however, it is possible to have an extension on assignments because their primary interest is that students hand in quality work. This type of flexibility has made things easier for Alex as it facilitates his special needs.

Exosystem from the Perspective of the Parent

Mr. and Mrs. Levesque's Past, Present and Reflection: Experiences in their Community and Beliefs

Mrs. Lévesque is not employed outside of her home, and she has always been available to care for Alex's health needs, participate in his elementary school activities and volunteer in the IBD Association and in the Jewish community. Although Mr. Lévesque does work full-time, he plays an instrumental role in attending almost all of Alex's medical appointments and school meetings. As such, both parents devote a lot of attention to Alex and meeting his health and educational needs. Mrs. Lévesque notes that it is financially taxing on the family to maintain their son's expensive private school, tutors, personal trainer, travel, and medical costs. However, they continue to fund all of Alex's needs to the best of their abilities with little help from government subsidies.

Macrosystem from the Perspective of the Parent

Mr. and Mrs. Levesque's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD

Mr. Lévesque had clear thoughts on how he perceived IBD was viewed by others. He explained that, "Nobody knows what the future is like. It's a hard disease for them [doctors] to understand and how it affects the system. But I believe they've come a long way. You know, there could be a cure and people should always believe that things are possible in life that's what gets them through."

Somewhat teary eyed, he complained that he did not appreciate how one doctor had responded to Alex's question. Then he told the story of the time when Alex was first diagnosed with the disease and he asked the doctor if he would have the disease for the rest of his life. The

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

doctor responded, “Yes, you would!” Mr. Lévesque expressed his disappointment with the doctor’s response because he viewed it as negative and devoid of hope. However, now he seems to have developed a better relationship with the doctor as he said, “The relationship I have with Alex’s doctor is a million times better now because of everything we’ve been through with him.”

He believes that people in the society need to be positive and optimistic about the disease including those affected with it. “No one knows what type of cure might be discovered in the future”, he said. Then he continued to express his views by saying, “Every day they’re coming up with new things; hopefully there will be a cure. Furthermore, the person with IBD has to also believe within himself that he will get better.” He returned the topic of the conversation to his son where he credited him for paying attention to his health. “He works out, he does everything, no one eats 100 percent perfect, but he’s come a long way and that helps him.” At this point, he reflected on the experiences of his life; the disease that has affected him and two of his children; and his belief, and expressed his views this way, “You have to look at it that there’s always worse things out there in life. Therefore, having IBD is not the worst thing that can happen to someone. There are greater life challenges and obstacles to be overcome.”

Macrosystem from the Perspective of the Child with IBD

Alex’s Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD

Alex firmly stated that he believed that his IBD symptoms were stable because of Remicade and had very little to do with what he ate. He was adamant that any information to the contrary was unfounded and he felt that his doctor would agree with him completely. He arrived at this conclusion recently after being on Remicade which yielded excellent results. Also, it is imperative to Alex that he be perceived as a regular person and never be placed in special

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

education classes because of his Crohn's disease. Throughout his education, he has only attended enriched and advanced classes.

Macrosystem from the Perspective of the Sibling

Paige's Past, Present and Reflection: Beliefs Regarding Societal Perceptions of IBD

Paige believed that it would be helpful if perhaps more people knew about the disease. She found it difficult and sometimes uncomfortable to describe the disease to people. Like her step-brother, she only informs some of her closest friends about IBD. She can only speculate that more awareness might also bring forth a cure sooner.

Summary of Family 5: The Lévesques

Mr. and Mrs. Lévesque have devoted a lot of their time and money to their son Alex through the years. They have focused on helping him to achieve a high level of academics, as well as inspire a desire to serve his community. The parents' expectation is that IBD should not limit Alex nor prevent him from achieving in all aspects of his life. As such, Alex has always sought academic excellence, as well as a commitment to all sports and opportunities offered by his private school. Therefore, Alex frequently travels to go on school trips.

Alex is surrounded by family members who are equally busy and also have IBD and serve as models for him to follow. Paige remains close to her step-brother even though they do not live in the same house. They are able to talk about their experiences of IBD and share possible ways of coping, although they only see each other on special family occasions.

Although, Mr. Lévesque has always been involved in the lives of his children, it appears that Mrs. Lévesque has been the primary caregiver for Alex. Mrs. Lévesque is a stay-at-home mother and is able to attend to all of Alex's health and educational needs. She has typically been the parent who prepares the food and medications, and she deals directly with the school whenever

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

problems rise. Mr. Lévesque is the only income earner in the family and is employed full-time. Despite this, he is very involved in most of his son's medical appointments and school meetings. However, relying on only one salary to pay for all of Alex's needs is a great burden that his parents manage with very little financial government assistance.

Alex was enrolled in a public Jewish elementary school when he was diagnosed with Crohn's disease. His parents informed his school about his disease and stressed the importance of allowing Alex to use the washroom as frequently as needed to because of his incontinence. The Lévesque's acknowledge that it was a caring and empathetic principal who played a significant role in ensuring that Alex's special needs were met at school. Mr. and Mrs. Lévesque value education highly and made sure that Alex was always enrolled in advanced classes. Although Mr. and Mrs. Lévesque were pleased with Alex's school principal, they felt that the education the public school was providing was at a lower academic standard. Hence, it came as a relief to be accepted by the private school to complete Grade 6.

Despite his close relationship with his school principal and his friends, Alex did not enjoy his elementary school experience. However, he is thoroughly enjoying his school life in his private high school. He finds the school curriculum much more challenging and engaging. He also finds that the school readily accommodates his needs and provides many opportunities for him to travel and play sports. In order to keep up with the high academic demands of his private school, Alex continues to use the support and assistance of tutors outside of the school.

Chapter 6-Cross-Case Analysis

Introduction

This study examined the school experiences of families with a child with IBD. In this chapter, only the family members' one-on-one interviews were analyzed using a cross-case analysis. Each of Bronfenbrenner's ecological systems were analyzed and presented in this chapter except the siblings responses at the Mesosystem. The data reflecting the school experiences of the five siblings within the Mesosystem was thin and were therefore omitted from the final analysis. Additionally, sibling drawings were not analyzed using a cross-case analysis. Rather, all five family drawings were left in a descriptive form in Chapter 5 and the data remain open to the readers' own interpretations. All final study results are included in this chapter and summaries of the outcomes are discussed in detail for each of the systems.

Microsystem

Parents' past experiences of diagnosis of a child with IBD

When asked about their past experiences regarding their child's diagnosis, all parents recalled in vivid detail the events that led up to the day of diagnosis, as well as all that transpired on the actual day of the diagnosis. Parents were first alerted to the disease when they noticed that something was wrong with their children as their behaviour had changed dramatically. They all noted that some of the early symptoms exhibited by their children were fatigue, followed by repeated complaints of stomach cramps. The parents later observed that their children began experiencing frequent diarrhea, bloody stools, and significant weight loss. These symptoms are consistent with those reported in a study by Hill and colleagues (2010) with children with Crohn's Disease.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

The symptoms were said to occur typically, on an average of a year, and were painful enough to interfere with their children's schooling. During this early phase of the illness, the children had multiple school absences. Parents explained that their children's high rate of school absenteeism was attributed to their undergoing feelings of malaise, exhaustion, having multiple emergency hospital visits, and medical appointments. Similar research outcomes were found in the IBD studies described in Chapter 2 by Akobeng and colleagues (1999), a study by Mackner, Bickmeier and Crandall (2012) and another by Kilroy and colleagues (2011).

At that time, the parents expressed feelings of fear, worry, and sadness in not knowing what was wrong with their children, and sought a diagnosis. In Family 3, the father's death was caused by chronic IBD symptoms and in Family 5, the father had experienced a painful physical and emotional battle with IBD for years. The unfamiliarity of the symptoms impacted negatively on all parents except in those two families because the fathers had some form of IBD, and family members already had an awareness of IBD symptoms.

In all cases, the parents waited a long period of time before receiving an official diagnosis of IBD (either Crohn's disease or ulcerative colitis). The process involved numerous hospital visits, often initially to the emergency department and many appointments with a pediatric gastroenterologist. These experiences by parents of a lengthy process to obtain a diagnosis are consistent with the findings reported in research by Avdi, Griffin and Brough (2000). The process often induced feelings of guilt, worry, fear, and frustration in parents. For example, in an attempt to ease some of her feelings of anxiety, Mrs. Campbell (Family 3) brought her brother-in law with her for support on the day she received her child's diagnosis.

Following numerous tests that usually included blood tests and colonoscopies, a diagnosis was provided. When the diagnosis was established, parents mentioned that other than

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

a pamphlet they received very little information from the health practitioners. The pamphlet was presented as a resource to provide answers to any questions they had about IBD. More resources and information were usually only offered with the progression of the child's disease. Parents also made a point of finding out more information about IBD through internet searches and discussions with other parents.

Having a child with IBD is financially very costly to the families. The parents spent a lot of money and time being proactive in having their child diagnosed, for example taking time off work, frequently paying parking and transportation costs, attending many doctor's appointments, and paying to have blood tests done privately. After the diagnosis was made, further financial costs were incurred for more medical tests and to find ways of having their children take their prescribed medications. For example, in Family 2 She-Rah dealt with Geddy Lee's fear of needles by finding a company that provided technicians to perform blood tests in the comfort of their home. In Family 5, the parents went to great lengths and costs to rid their son Alex of his fear of needles and medical tests, including hiring a world renowned hypnotist. Fortunately, in both cases, the boys accepted having the needles as they matured. Similarly, parents of children with special needs also experience financial burden to ensure that all of the children's health needs are met (Jackson, Traub, & Turnbull, 2008).

Parent's Present Experiences of Child with IBD

When the parents were asked about their feelings with regards to having a child with IBD, they all stated emphatically that the label did not define their child. They were conscious of their child's disease and were very sensitive to the problems he or she faced but they said that they were constantly encouraging the child to be undaunted by the disease. They stood firmly on

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

the position that the disease should not handicap any child. Children should not only aspire to do something that they enjoy, but they should not allow IBD to prevent them from doing it.

In this way, parents advised their children to learn to “just get on with it!” especially when it came to the matter of their schooling. Despite the physical pain from IBD symptoms, the parents wanted their children to be resilient and cope with the experience as best they can. For example, in Family 5, Mrs. Lévesque frequently told her son Alex, that, “You just have to push through it.”

Following the diagnosis, each family experienced changes in the ways in which the family functioned. All parents spent more time with hospital appointments. In some cases having to be away from home impacted the relationship that the parents had with their other children. For example, in Family 2, spending more time attending to Geddy Lee resulted in the two other siblings frequently having to be cared for by their grandparents. Also, the parents in Families 2 and 3 expressed that they experienced feelings of guilt because they could not always financially afford to stay home with their sick child. These findings of parental guilt are similar to those found in the study by Dyson (2010) with parents of children with a learning disability. Furthermore, in Families 1 and 3 the parents lived in constant fear and became vigilant in looking for any evidence of IBD symptoms in any of their other children, since they had had other immediate members with the disease. Lastly, Family 4 experienced a major change in the family structure as the parents were in the process of a divorce and the father had moved to the United States. I cannot speculate if the parents’ separation was in any way due to the challenges of their son’s IBD. However, it was made apparent that the separation did have an impact on each family member in many ways, as the children were now being cared for by a single parent, and they saw their father infrequently. Mrs. Keller expressed the difficulties she is experiencing

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

in being a single parent, and the primary caregiver of her two children. Her situation proved to be even more difficult because she had the added challenge of caring for a child with a severe case of IBD on her own.

Not surprisingly, all the parents viewed their role as being the caregiver of their children (with and without IBD). The ways in which IBD extends this role for parents is by being at home as much as possible for them. While at home parents monitor their child's symptoms, prepare their food, and administer their medication. Providing their child with emotional and physical support as well as attending their medical appointments are other duties. Furthermore, parents seek out the latest IBD information, and resources while making time to participate in their children's activities. These tasks are an attempt to provide as "normal" a life as possible for all family members.

The parents shared the same concerns about the future of their children with IBD. Their principal concerns pertained to:

1. being able to maintain their child's current state of health and not incur additional chronic health conditions (e.g., the possibility of developing cancer, or in the case of Family 1, Juvenile Rheumatoid Arthritis, or in Family 4, liver malfunction).
2. contending with the side-effects from new medications. All except families 2, 3 and 4 were prescribed Remicade at the time of this study. However, the remaining families were in the process of being switched to Remicade. All parents and children had concerns about Remicade as it is a fairly new drug on the market, with many warnings from Health Canada of potential side-effects such as lymphoma. Furthermore, the drug had only been used and researched in adult populations, but are now prescribed for

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

children. This posed great concerns for parents over the effects of its long term use among their children.

Child with IBD's Past Experiences of Diagnosis

When exploring the past experiences with IBD, the children all recalled that it was either a nurse or a doctor, who informed them that they had IBD. Unfortunately, the children could not remember how they or their parents had reacted at that time. Interestingly, they all commented that there were very few changes made in their lives after they found out that they had IBD. The primary change noted was the regular use of medication which, for the most part, they disliked taking.

Child with IBD's Present Experiences

While at home, all five children noted that there was little they could do when they were suffering from the physical symptoms of their disease. The children listed their few coping strategies, such as lying down, sleeping, taking Tylenol or Advil, using heating pads, playing video games, or watching TV. All of the children (except William in Family 3) acknowledged that they had a sibling who would help them when they were unwell at home. The ways in which the siblings did help and provide support are listed and discussed in the following sections.

Siblings' Past Experiences of Brother or Sister's Diagnosis

Four of the five siblings recalled being present at the time of their brother or sister's diagnosis. However, they were all too young to remember how they had behaved when they heard about their sibling's illness. Lisa from Family 1 was only four years old when her sister Claire was diagnosed, thus she had no recollection of the events. Some siblings experienced feelings of resentment. Daniel, from Family 2, voiced feelings of neglect by his parents during

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

that period. He thought that his parents were giving too much time and attention to his brother, Geddy Lee. But Paige from Family 5 had a different reaction. Unlike Daniel, she was sympathetic to her step-brother's experiences because she also had IBD.

Siblings' Present Experiences of Brother or Sister's Diagnosis

In discussing how the IBD impacted the siblings, it was found that brothers and sisters were affected in two important ways. Firstly, all siblings noted ways in which they assisted their brother or sister with IBD when he or she was sick. Lisa explained that she would heat Claire's heating pad in the microwave for her. Other ways of helping that siblings listed were cooking meals, collecting missed homework from school, staying home with them on pedagogical days, and explaining assignments to them. Secondly, feelings of resentment resurfaced, as was the case in Family 2. In that family, Daniel expressed feeling neglected by his parents while they frequently attended to his brother with IBD.

Moreover, siblings had to cope with their own challenges. In Family 5, Paige had IBD and chronic asthma. Sophia in Family 4 was experiencing a sense of loss due to the separation from her father while the parents were going through the process of divorce, as well as feelings of worry over the decline in her brother's health. In Family 2, Daniel had been frequently bullied at school to the point at which the police had to be involved.

Summary of Findings in Family Relationships

The family units differed in a variety of ways (Two parent, single-parent and step-family) and their interactions within the home environment were complex and multifaceted. However, each member's role in the family unit and the relationship to one another was summarized in the following three ways:

1. Parent and Child with IBD Family Relationships

After the diagnosis of IBD there were changes in the role of the parents and siblings. Although fathers usually played important supportive roles in the lives of their children, mothers emerged as the primary caregivers. They were usually the ones who spent the most time on medical appointments, seeking out IBD information and resources, and being involved in their children's schools. Three of the five mothers were either stay-at-home mothers or worked part-time to allow them to devote the time needed to attend to the health and educational needs of their child with IBD. Since they now had to spend a great amount of time with their child with IBD, they relied on their other children to assist them in caring for the child with IBD. In addition, parents played a vital role in advocating for a diagnosis for their child and specific IBD treatments.

These data showed that having a child with IBD in the family did affect and change the role of family members. This finding is one that is also supported by Turnbull and Turnbull's family systems theory (2001) and Bronfenbrenner's ecological theory (1979).

Overall, in the home environment, there was a strong relationship between the parents and their child. After the diagnosis, the parents cared for the child with IBD by attending to many of their needs and by providing systems of support. In turn, the child with IBD relied on their parents for specific health-related needs.

2. Parent-Sibling-Family Relationships

In the parent-sibling relationship, the parent relied on the sibling to help to care for his or her brother or sister with IBD. In turn, the siblings found ways to help their family members. However, at the same time, siblings are often experiencing their own challenges and sometimes they were resentful that their needs were not being met, as illustrated in Families 2 and 3. As a

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

result, the siblings sometimes had to care for themselves or advocate for themselves. Similar findings were reported in a study by Dyson (2007) with siblings of children with learning disabilities.

3. Sibling-Family Relationship

In the sibling relationship, the brothers and sisters were made a part of the early stage of diagnosis by being present at many of the medical appointments. Consequently, they had an awareness of the disease and expressed feelings of worry or sympathy for their brother or sister. The siblings had their own friends, but they also socialized with their brother or sister, usually, while engaged in sports such as skiing, bowling or in various activities when they were on family vacations. The siblings have unique personalities, interests, and needs. Occasionally, they experienced feelings of guilt, sadness, worry, jealousy, and resentment because of the situation in which they found themselves. Despite their individuality, whenever a crisis would occur in the family, they found ways to assist-especially if the crisis involved their brother or sister with IBD.

Mesosystem

Parents' Past School Experiences with their Children with IBD

In talking to the parents regarding their children with IBD's past school experiences, the interview questions focused on examining the classroom setting. All the children were educated in general education classroom settings and in the case of Family 5, Alex was the only child with IBD who was enrolled in advanced courses. All of the parents mentioned not needing, nor wanting their children with IBD to be placed in special educational classes. They also wanted their children's school experience to be as 'normal' as possible, meaning resembling the school experiences of their peers who did not have IBD.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

All five children with IBD had to miss several days of school in the early stages of their diagnosis. Only William in Family 4 had an IEP because in addition to having a health problem he had a learning disability. The IEP permitted him to have his needs accommodated, such as the use of a calculator during exams, and a “Reader” (a person hired to read aloud all the information written on his exams). The other four children with IBD did not have an IEP because they did not have a learning disability. It may also have been that their parents were unaware that IBD is listed as an IEP category under handicaps or they might have found that talking to the principal and teachers was sufficient. Moreover, it is not mandated by the Québec Education Act (2010) for children with health conditions to have one. Consequently, parents took it upon themselves to inform teachers and school administrators regularly about their child’s required accommodations (unconditional access to the washroom). The parents informed teachers and school administrators about their children’s disease. Additionally, Families 1 and 2 circulated a letter with the child’s photograph at the start of every school year to all their children’s teachers. With a view to preparing the teachers to help the child, the letter explained the child’s illness and the service delivery he or she would need to have in the classes. However, educators were not required to implement the accommodations listed by parents because there was no IEP. Requiring access to the washroom may seem an unusual accommodation to be written on an IEP, especially if it is the *only* item on an IEP. Therefore, without an IEP, teachers were not obliged to grant unconditional permission to the bathroom.

In this study, all of the parents were proactive in contacting teachers and school administrators to advise them of their child’s IBD, school absences, and the need to accommodate their child’s frequent bathroom requests. Despite communicating with school personnel in the public schools, problems seemed to occur around the month of January. After

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

the holidays, parents found that the public school teachers reverted to unempathetic behaviours towards the children with IBD. Therefore, teachers would become less accommodating and impose restrictions on matters like bathroom access. Whenever these events occurred, the child with IBD would tell his or her parents, and the parents would immediately telephone either the teacher or school principal to have the issue resolved.

All mothers played active roles at school at different points in time. The roles that mothers assumed at school have also been examined in research by Shatkin and Gershberg, (2007). Parents advocated for their children's school services and spoke out against their ill treatment. These outcomes are similar to those found in research studies on families of children with disabilities by Duquette (2007); Nowell and Salem (2007); Wang, Manning, and colleagues (2004); and Lake and Billingsley (2000). The five families reported that the lack of empathy seemed to occur most when their children entered high school. Parents reported having to meet more frequently with their children's high school teachers who were much less accommodating than their elementary colleagues.

Parents' Present School Experiences

Following elementary school, the parents continued to advocate on their children's behalf at the high school level. Parents listed the ways in which they continued to be active participants: meeting with teachers and school personnel to request accommodations, informing school personnel about school absences, collecting missed homework assignments, and providing access to all resources found in their community (discussed in the exosystem) to ensure the child's school success. Parents spoke freely of their expectations for their child. They believed that failure in any sphere of their child's life is not an option and being successful is expected. In their view, IBD is not an excuse for failure. Parental expectations of high academic

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

school success for children with disabilities have also been cited in studies by Epstein, 1995; Hoge, Smit and Crist (1997); and Mau, (1997). Consequently, the children with IBD attempted to meet these high expectations, but in some cases they found them stressful. This was indicated by Paige in Family 5, in relation to her step-brother Alex and the high expectations imposed on him by his parents and educators at his private high school.

When parents were asked if there was anything that they would like to change about their children's school environment, they listed three specific areas. Firstly, all of the parents wanted teachers and school personnel to be empathetic to their child's IBD symptoms and to accommodate their child's special needs. Secondly, parents hoped for more awareness among teachers about IBD and wanted them to understand that although their children's symptoms were internal, they believe that the physical suffering of the symptoms were real. Lastly, two sets of parents (Families 4 and 5) wanted their children to be able to attend schools that were clean and run in an orderly fashion.

Parents as Advocates

The findings from this study demonstrated that parents have become their children's advocates in an attempt to secure washroom privileges, teacher awareness of IBD, and their children's educational success. For the purpose of monitoring, the parents were dependent on their children to provide them with the details of the events of their school day. When unpleasant situations were revealed the parents contacted the schools to have them addressed. In this way, the parents could attend swiftly to any contentious issue on their child's behalf. Therefore, it was imperative for the child with IBD to have a close relationship with his or her parents so that this component of advocacy could occur.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

There appeared to be a difference in the amount of advocacy required in public versus private schools. Whether at the elementary or high school level, it became evident that parents and their children enrolled in public schools had to exert a greater amount of effort to have their needs met. This was the situation for both the Anderson and the Campbell families. These findings are consistent with the review of the literature presented in Chapter Two regarding the experiences of Canadian students in private schools (Boerema, 2009). It seems that having to pay for education yields certain benefits. Parents who pay to have their children attend private schools are more likely to have their needs met because they are paying directly for the services. Parallel outcomes were reported in studies by Caputo (2007) and Duquette et al. (2007).

In conclusion, most parents seemed to agree that it was their obligation to provide their children with a home and school environment that made allowances for their children's diseases. They also voiced the opinion that within the school environment:

1. Having a good relationship with the principal was important to securing accommodations.
2. Overall, teachers lacked empathy, due in part, to the "invisibility" of the disease. Children with IBD identified music, and French teachers as those who usually lacked the most empathy.
3. The teachers' lack of empathy may also be due, in part, to a general lack of knowledge and awareness about IBD.
4. By January, parents found that they had to re-visit the issue of their child's illness and needs with teachers.
5. In order to catch up with assignments and in an attempt to have their child achieve academic success, all parents accessed a variety of resources.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Child with IBD's Past School Experiences

Subsequent to the diagnosis, the children reported that the main accommodation that they required in school was to be able to go to the bathroom whenever the need arose. Not all teachers were willing to accommodate this request. Nonetheless, all five children did recall at least one teacher in elementary and high school who had been kind to them and supportive whenever they were feeling unwell.

Although the parents would typically inform teachers about their children's disease at the beginning of every school year, the children also found ways to inform their teachers and friends. Claire in Family 1, would do a class presentation on IBD each year to teach her peers and teachers about her disease. In most cases, the children took their time to tell their friends about their illness; but they talked about not knowing how to explain the complexity of the disease, or about the issue of having frequent bowel movements. Three families (2, 3, and 5) found it helpful to have had friends, neighbours, and acquaintances who also had the disease.

Whenever they were in discomfort, the children had an established system with their parents. The process in the five families was very similar. First, when the child became sick in school, he or she would notify his or her teacher and then proceed to either the school nurse's office or to the principal's office. At that point, the parent would be contacted and would either pick up the child, have the child take the bus home, or tell the child to return to class. The decision of the parent was usually based on that day's school activities and the severity of their child's IBD symptoms.

Child with IBD's Present School Experiences

All of the children noted that there was not a particular resource they needed at school to help them manage their IBD symptoms. Overall, the children were content with their school

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

environment. However, similar to their parents' views, they discussed at length their desire to have teachers who were more empathetic to their needs and challenges, especially their gym, French, and music teachers. Children with IBD often had to struggle to keep abreast of missed instruction and homework assignments. Some teachers were said to make it difficult for the child to catch up, while only a few were helpful. As a result, some of the children began taking on the advocacy role. Essentially, they wanted teachers to have an awareness of IBD. The children resoundingly spoke of just wanting their teachers to believe them when they describe the physical symptoms they are suffering and to have a better understanding of the disease. The children explained that this would make their school experience easier to manage.

Claire and Geddy Lee recommended some changes at their school. Claire in Family 1, wanted to have washroom facilities closer to her classroom. While Geddy Lee in Family 2 expressed concerns about the classroom furniture. He saw the need to replace the hard plastic classroom chairs with wooden ones.

Summary of Findings at the Mesosystem

In this study, the mesosystem included the relationship between home and school. The findings revealed that parents play an integral role in the relationship with teachers and school administrators. It was their responsibility to inform the school personnel regularly about their child's needed school accommodations. However, despite these efforts, teachers did not always lend their support. Families reported that they experienced a lack of empathy more frequently from school personnel at the high school level.

Children with IBD attempt to fit into the pre-existing structure set in the general education classrooms. In order to integrate into general education classrooms, children with IBD depend on their parents and siblings to advocate for them when they experience challenges at

school. The level of advocacy and support needed appeared to depend largely on whether or not the child with IBD attended public or private school. Families reported receiving greater support from private school personnel than public school education. Similar results were found in the study by Duquette et al. (2007) among families of adolescents with Foetal Alcohol Spectrum Disorder.

Exosystem

Parents' Past Experiences in their Community

Parents talked about the roles that they played in their communities. All of the parents had been at some time active volunteers in their IBD Association. However, as their children matured, they noted that they had less time to devote to volunteering. While the mothers generally undertook a large portion of the work of caring for their children, this role was often expanded and extended over a longer period of time. One of the consequences of taking on the “caring” role was that mothers were often limited in pursuing other roles separate from that of caring for their child. Research by Traustadottir (1991) and Caputo (2007) reported similar findings regarding mothers as maintaining the primary caregiver role in the lives of their children.

Three of the five sets of parents (Families 1, 2, and 3) spoke of the difficulty in having to balance their employment with having to care for their child with IBD. The mothers and the father in Family 2 expressed that their employment created four major challenges:

1. Their inability to work full time adds to the financial burden,
2. Feelings of guilt at having to spend time away from their child who was sick,
3. Lack of concentration and focus at work, and
4. Being negatively perceived by colleagues as being poor parents for working rather than

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

staying home with their child who was sick.

Although all the fathers in this study were employed outside of their homes (except for Mr. Anderson in Family 1), they were still actively involved with their children when they were home. Research results by Caputo (2007) support that there is “evidence of fathers’ roles having undergone positive changes in Canada over the past decade with regard to childrearing and other family responsibilities” (p. 175). In the current study, fathers were found to support their wives’ advocacy activities by assuming childcare responsibilities, except in Family 4, where Mr. Keller lived in the United States and was divorcing his wife; and in Family 3, where the husband had died. The fathers also proudly reported on the advocacy efforts of their wives.

Parents’ Present Experiences in their Community

The internet proved to be an invaluable tool to all the parents in this study. It provided a source of information about IBD, a place to connect with other parents of children with IBD, and a reference for information on services and funding for children with disabilities. A similar finding about the use of the internet was reported by Duquette et al. (2007). Parents also talked about the interactions they had with doctors and nurses who provided them with information concerning different government funding programs. Subsequently, they were able to receive financial assistance to defray some of the costs associated with having a child with IBD.

In addition, parents continued to participate in some way with IBD related activities as a means of giving back to others. For example, Family 2 gave lectures to health care professionals, engaged in fund raising for their IBD Association, and strove to spread awareness about IBD. There were many ways in which all the families made serving others in their community a priority. The parents believed that it was important that their children also maintain ties to their community.

Summary of Findings at the Exosystem

Despite having a child with IBD, parents played an active role in their communities. All families made an effort to participate in activities as a volunteer, typically in an IBD Association. Additionally, having a child with IBD required that parents direct a portion of the family budget to the needs of that child. Although acknowledged as a burden, the parents did their best to ensure a “normal” life for all family members. In terms of employment, it proved challenging for them to strike a balance between being a caring parent, attending to their child with IBD, and earning a salary to provide sufficient financial support. Parents voiced their concerns of having limited access to funding, and they constantly had to seek out supplementary sources. The challenge of the limited availability of support services for parents of a child with a disability was also highlighted in the study by Jackson, Traub, and Turnbull (2008).

Macrosystem

Parents’ Past and Present: Beliefs Regarding Societal Perceptions of IBD

Overwhelmingly, parents believed that society lacked awareness about IBD. As a result, IBD was perceived negatively because it is a disease associated with issues related to going to the bathroom and as She-Rah said, “IBD is not a sexy disease.” Parents hoped that increased medical research would improve awareness and a possible cure may be found. They also wanted people to know that their children can achieve anything despite having IBD, because in their view, the disease is just a label. On this note, Mrs. Lévesque from Family 5, often reminded her son: “You are not the disease, that’s not who you are.” Also, parents believed that one of the biggest barriers in gaining understanding and support for their child’s disease was related to the invisibility of IBD.

Child with IBD's Past and Present: Beliefs Regarding Societal Perceptions of IBD

All the children with IBD repeatedly said that they view themselves as regular teenagers and want others to perceive them the same way. They echoed the same sentiments as their parents in their belief that they can achieve anything to which they set their mind. Therefore, the parents' expectations were accepted by the children with IBD. Interestingly though, unlike the parents the children often acknowledged that having IBD did limit them in some ways, such as playing sports like karate or football. But they believed that they would find ways to overcome those challenges.

Sibling's Past and Present: Beliefs Regarding Societal Perceptions of IBD

At some point in their lives, the siblings had to explain their brother or sister's disease to friends. The siblings tended to explain the disease in simple terms. Nancy in Family 3, explained that, "IBD is when your bowel's inflamed, you have to watch what you eat, there are some things [foods] that bother your colon so, like chocolate, red meat, spicy food." All siblings said that their friends did not respond or act differently towards them after learning about their brother or sister's disease.

The siblings all acknowledge that having IBD was not enjoyable and it imposed some restrictions on the lives of their brother or sister. But they also felt that people need to know that although some limitations are placed on children with IBD, they are still regular children. Despite having IBD, they are active teenagers and have the same wants as their peers. Similar to the children with IBD, siblings also had clear ideas of their hopes and future career aspirations. For example, Nancy (Family 3) would like to be a special education teacher, and Daniel (Family 2) would like to become a naturalist.

Chapter 7-Discussion

In this chapter, the study findings and the family members' recommendations are described. The contributions of this research to the areas of IBD, family, school research, and systems theory are described.

Summary of the Study

Interviews with families with a child with IBD were conducted to explore the participants' views of their lives and experiences at school. The findings indicate overwhelmingly that children with IBD and their family members want the support and empathy of school personnel and the society at large. This researcher concluded that despite the differences in family structures (single parents, two parents, and a step-family) there were common experiences among them. The areas of commonality that emerged were that all the parents had experienced challenges in coping with their child's education, the family's finances, and societal perceptions of IBD.

Education

All the parents in this study chose general education classrooms as the most appropriate place to educate their children. In Québec, these classroom settings are regulated by a system of integration, whereby students with disabilities are educated alongside students without special needs. It means that each student is an integral part of the class in which he or she is placed. Although the system of school integration has been in place since the 1970s, the law did not allow for schools to adjust their programmes to accommodate students with special needs. However, the law was changed in 1996 by former Minister Marois so that students with disabilities were no longer expected to adapt to the pre-existing school structure and the

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

conditions that existed in general education classrooms. Rather, the revised version of the Education Act (2010) mandated school boards to provide adequate educational services for students with disabilities. Therefore, in the new model of integration, it was the school's responsibility to accommodate the specific needs of students with disabilities (Education Act, 2010). Nevertheless, what is blatantly missing from the Education Act is the mention of educators having to accommodate students' physical "health" needs at school.

Although (Bowe, 2005) has been demonstrated that integration can be advantageous for all children, the findings of this study showed that problems arise when accommodations are not made available to students with disabilities. It would appear that while the onus is on schools to meet the needs of students with special needs it does not always occur. Therefore, there were differences in the ways in which schools implemented the revisions to Québec's Education Act. Here then lies the problem, and as a result three of the five families in the current study chose to enroll their children in private schools because they had experienced inadequate service delivery within the integration system. Although the parents had to incur additional expenses by having their child schooled privately, parents reported that less advocacy effort was required. Parents in this study experienced support and accommodations for their child's needs at private schools and stated that they rarely had to advocate on their child's behalf. These findings are further supported by research studies on private school services in Canada by (Boerema, 2009) and another by Caputo (2007). These results were contrary to the experiences in public schools whereby the parents had to exert constant advocacy efforts on their child's behalf. Similar study outcomes were found in research on parents of children with disabilities by Duquette et al. (2007); Nowell and Salem (2007); Wang, Hasheem and colleagues (2004); and Lake and Billingsley (2000).

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

As a result of this situation, some of the students with IBD in this study experienced difficulties in functioning well in public general education classrooms in Québec. However, due to the persistent advocacy by their parents and adolescents themselves, some accommodations were made and awareness of this invisible disease gradual increased at school.

Answers to Research Questions

In order, to understand the relationship between families of children with IBD and their school environment, this study sought to answer three central research questions and the findings are described in this section.

Research Question 1: What are the Experiences of Children with IBD Enrolled in General Education Classrooms?

The children with IBD reported that although they generally enjoyed their classroom experiences, each child had at some point perceived being treated unkindly by a teacher who was insensitive to the problems associated with his or her chronic illness. The unkind behaviours mentioned included teachers' lack of empathy towards their problem of incontinence and insufficient assistance with missed homework assignments.

When the children were asked if there was anything that they would like to change about their classroom experiences, they mentioned that there were subjects with which they struggled and for which they often required remedial assistance (most had at least one tutor for subjects such as math and French). Only one of the five adolescents with IBD was diagnosed with a learning disability and he was provided with an IEP. One child complained that the plastic chairs in his classroom were too hard and should be changed, while another noted that the physical location of the bathroom was too far from the classrooms. Close proximity to

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

bathrooms is crucial for youth with IBD when they are in school because one of the symptoms of the disease is incontinence.

Overall, adolescents with IBD perceived their general education classroom experiences to be tolerable. Their views were largely due to a dichotomy of their experiences at school. On one hand, the youth had negative experiences with an unkind teacher. This was offset by positive social connections they had with their friends and peers, whom they felt did not treat them differently because of their IBD. Despite having IBD, the teenagers enjoyed participating in sports and other extra-curricular activities offered by the schools. This finding is contrary to research outcomes reported in a Globe and Mail newspaper article regarding a Canadian study conducted by Anne Snowdon (article in press.). Her study results revealed that 53% of youth with disabilities had no friends. Even more alarming was that the few youth with disabilities that did have friends had very limited contact with their peers, spending on an average only an hour of interaction per day (Picard, 2012).

It is also important to acknowledge that although the adolescents with IBD had reported negative experiences with some of their teachers, there were some positive teacher interactions. The children mentioned teachers and school staff who had shown them kindness and empathy, which contributed to some positive experiences in school.

Research question 2: What are the Experiences of Parents of Children with IBD Enrolled in General Education Classrooms?

The findings from this study, regarding the school experiences of parents of adolescents with IBD, substantiates a growing body of research that points to the positive effect that parental involvement has on school outcomes and on the well-being of youths (Hartas, 2008). Therefore,

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

understanding parent–teacher interactions has important implications for the education and care of teenagers with IBD.

Adolescents with IBD require specific accommodations when placed in general education classrooms, but not all teachers in the study provided them. Consequently, parents become actively involved in advocating for the rights of their children. To obtain those rights in Québec, they exercised agency and engaged in an active relationship with teachers and school administration (Bailey, et. al., 1998; Duquette, et. al; 2007; Lake & Billingsley, 2000; Nachshen & Jamieson, 2000; Nowell & Salem, 2007; Turnbull & Turnbull, 1996).

The parents in this study were proactive, as they took the initiative to advocate for their teenager’s right to accommodations in school, as soon as they were diagnosed with IBD. In addition to advocating for special accommodations for their children, they viewed the nature of the involvement in their education, to include informing teachers and school staff about IBD. Although the parents acknowledged that teachers have educational expertise, they realized that teachers’ awareness of IBD was minimal. Therefore, they viewed the home-school relationship as a crucial one that should be collaborative (Dauber & Epstein, 1993; Epstein, 1992; Kalanpur, et al., 2000).

Not only did parents provide educational support at home (Hoge, Smit, & Crist,1997; Mau, 1997), but it was incumbent on them to provide emotional support as well. It was the parents who served as sounding boards for their children while they listened to their daily school experiences. This daily exercise in communication between youths and their parents was important because it kept parents informed and helped them to monitor the provision of accommodations. In this way, parents were able to make informed decisions in order to address inadequacies that may exist in school.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

In conclusion, it appears that from the parents' and children's perspectives a successful relationship between home and school can only be achieved if both parties share responsibility in relation to the child's health and educational needs. Also, teachers would need to acknowledge and embrace parental advocacy efforts. The parents' school-related experiences were layered and complex because they involved relationships that extended beyond their child's classroom to the school, community and their home environment.

Research Question 3: What are the Experiences of a Brother or Sister of a Child with IBD?

Some siblings in this study were experiencing difficulties in school, others had a chronic disease(s) or were showing possible symptoms of IBD, and some were neglected and jealous because of the lack of parental attention. These outcomes are similar to the experiences of siblings of children with cancer (Alderfer, Long, Lown, Marsland, Ostrowski, Hock, and Ewing, 2010). Despite the siblings' personal struggles, they all revealed feelings of empathy towards their brother or sister with IBD. Additionally, siblings often performed caregiving activities for their brother or sister (e.g., heating magic bags or cooking a meal) and frequently provided assistance with missed homework assignments (e.g., tutoring or bringing home the work). In this way, the relationships between siblings appeared close and supportive overall, despite tensions caused by IBD.

As shown in the findings, the sibling relationship focused on a number of factors and behaviours that characterized the quality of the relationship between the children. The siblings thought that they had a shared responsibility with their parents to protect and defend their brother or sister with IBD. In addition, they readily offered assistance to their brother or sister with IBD. In this way, the siblings followed the example of their parents and felt that they were contributing to the comfort of their brother or sister. Furthermore, most siblings demonstrated a

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

great amount of affection for their brother or sister with IBD. They seemed empathic when they saw their brother or sister in pain. However, for all siblings in this research it was not surprising that an integral part of living together involved rivalry. Some of the negative behaviors that the siblings demonstrated in their relationships with their brother or sister were teasing and irritating each other. Also, it appeared that siblings played a major role in assisting with the education of the children with IBD. As such, most siblings did not hesitate to offer their brother or sister help in teaching, or tutoring.

Study Findings in Terms of Systems Theory

Microsystem

Bronfenbrenner's Ecological Theory

This study demonstrated that Bronfenbrenner's ecological theory (1979) was a useful framework for uncovering the multi-directional relationships between family members and their environments. At the level of the microsystem, having a child with IBD did impact the home environment and the ways in which family members perceived their functioning.

The parents' perceived their primary role to be their children's care-giver. Among married couples the labour was usually divided by gender. For example, mothers more frequently attended medical and school appointments, monitored IBD symptoms, sought out IBD information, located resources, and participated in their children's activities. Meanwhile, fathers were usually the primary income earners and spent a great amount of time away from home. Similar findings have been found in studies that mothers and fathers maintain different parenting roles with regard to children with disabilities (Barnett, Deng, Mills-Koonce, Willoughby, & Cox, 2008, Dyson, 2010; Traustadoltir, 1991).

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Parents also played an active role in the education of their children with IBD. Similar to the findings on adolescents with Foetal Alcohol Spectrum Disorder by Duquette et al. (2007), it was shown in this study that parents played an instrumental role in assisting their child with IBD with the academic demands of school. Assistance took many forms such as helping with homework assignments, picking up missed assignments from school, hiring tutors, or advocating for specific accommodations at school. Additionally, parents voiced high academic expectations for their child with IBD.

Another outcome from the current study is that less time spent at home led to feelings of guilt among some of the parents (Families 2 and 3). This finding is consistent with the research results presented by Dyson (2010), in which she examined the impact of children with learning disabilities and their families. Parental guilt was further compounded by parents' increased dependency on siblings and extended family for assistance with care-giving tasks associated with their child with IBD. This finding is also supported by Lussier, Deater-Deckard, Dunn, and Davies (2002), who state that "the closeness of children's relationships with their grandparents seem to be related to their adjustment and well-being (p. 366)."

Furthermore, the research findings also showed that siblings of children with IBD may experience an increase in responsibilities and negative feelings as a consequence of their brother's or sister's disease. Changes in family routines and roles due to increased trips to the hospital and the doctor's office may disrupt day-to-day functioning of siblings, with some siblings assuming more household chores and responsibilities. Siblings also witnessed physical changes in their brother or sister and worried that he or she could die (Alderfer, Long, Lown, Marsland, Ostrowski, Hock, and Ewing, 2010).

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

In spite of their concerns and personal challenges, the siblings played an important positive role in the lives of their brother or sister with IBD. This study found that no matter the gender, the siblings played a nurturing role. This finding supports the idea of a dichotomous relationship of warmth and resentment that characterizes the sibling relationships (Dyson, 2010; Levitt et al. 2007).

Both parental support and sibling relationship qualities are strongly related to children's well-being, social development, and self-esteem (Kim et al. 2007; Yeh & Lempers 2004). Hence, the siblings' emotions had an impact on the family dynamics both positively and negatively.

Turnbull and Turnbull's Family Systems Theory

Parents in this study appeared to have a close, loving relationship with their children. Mothers generally had the most intimate connection with their children. It was the mothers who occupied the role of nurturer, advocate, educator, and in most cases, income earner as well (Traustadottir, 1991). The bond that the children shared with their father was also strong. When that relationship was fragmented, as was the case with the family in the process of divorce, then the loss of that strong parental bond threatened the family cohesion. In this case, the children experienced feelings of sadness, worry, and loss at not being able to spend time with their father as they did previously. In turn, it placed additional stress on each member of the family. Research suggests that an invisible chronic disease in children is associated with various negative outcomes in children, including anxiety and depression (Kilroy, Nolan, and Sarma, 2011). The children with IBD in the current study were dependent on their family members for many of their needs, but did not exhibit any signs of experiencing a diminished family bond, except in the case of the Keller family who were in the process of divorce. Generally, the data

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

showed that parents strove to ensure as much normalcy as possible. Despite the changes in family dynamic due to a diagnosis of IBD, the families presented as being happy units.

The sibling-child with IBD relationship differed in some ways from the parent-child with IBD relationship. The effects of the close sibling relationship can be both uniquely positive and uniquely negative (Jenkins & Dunn, 2009). In this study, siblings seemed to carry the worries and concerns of their brother or sister with IBD on their shoulders. Their parents had made them an integral part of their brother or sister's life. They had been present at medical appointments and attended most of the events that concerned their brother or sister's illness. Turnbull et al. (2004), note that, there is often an overriding focus on the child with a disability by the primary care-giver, perhaps to the detriment of other family members. The current study substantiates this notion, and for this reason, the sibling relationship at times became charged with feelings of resentment, jealousy, and guilt.

Mesosystem

Parent-School Relationship

The importance and benefit of parental involvement in the education of all children, regardless of their diagnoses, have been well documented (Ainge, Colvin, & Baker, 1998; Lambie, 2000; Mahoney & Kaiser, 1999; Mundschenk & Foley, 1994; Sheridan & Kratochwill, 1992; Snodgrass, 1991; Turnbull, Turnbull, Erwin, & Soodak, 2006). Additionally, the literature has demonstrated that parents' involvement in the education of their child positively affects academic achievement in both elementary and secondary school (Epstein, 1995; Heyman & Earle, 2000). Despite this large body of research evidence that affirms the importance of parent-school partnerships (McKnight, 1995; Adelman & Taylor, 1997; Roberts et al., 1998), the current study found that at the level of the mesosystem, parents felt that they had experienced a

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

negative relationship with their child's teachers and school staff. It would appear that an IBD diagnosis requires parents to develop a dependent relationship with school personnel. At times, the relationship can be tenuous and conflictual rather than supportive and mutually beneficial. Parents seemed to be engaged in a constant battle with school personnel for accommodations to meet their children's needs. Therefore, in the face of poor understanding and inaction by the schools, the parents were forced to become strong advocates for their child with IBD. As a result, all of the mothers in this study participated in some form of advocacy and assumed the responsibility of communicating the child's needed accommodations to teachers and school administrators (Blum, 2007). Fathers were not as active as direct advocates with their child's school, but they supported their wives' advocacy efforts. The parents who had children in public schools desired and sought a better collaboration with the school staff.

If the integration approach to education is to be successful, and students with special needs are to experience school success, it is incumbent on teachers and all school personnel to know about the different exceptionalities that are present in general education classrooms. It should also be recognized by teachers that parents are experts of their child (Duquette & Stodel, 2005) and that teachers need to work towards developing positive partnerships with parents (Kalyanpur et al., 2000).

Child with IBD-School Relationship

Children with IBD frequently experienced a negative relationship with their teachers and school personnel. This resulted in the children maintaining a positive relationship with their parents, primarily, because the children needed them to advocate for their needs and rights at school. Hence, children with IBD communicated openly and frequently about their school experiences and needs with their parents who advocated as required.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Additionally, at the level of the mesosystem, the issue of lack of knowledge about various chronic diseases by school personnel was another factor that needed to be addressed. The children with IBD spoke consistently of the teachers' unawareness of their disease, which precipitated some of the discomforts they experienced in the classroom. Another factor that emerged from the study was the behaviours of the adolescents with IBD. They exhibited behaviours of resilience, determination, and strength in the face of their challenges.

Peers also played a vital role in the school experiences of adolescents with IBD. The children reported that they enjoyed the time spent socializing with their friends and this formed a major motivation for their perseverance at school. Although in a different context, a similar conclusion was also found in a study conducted by Duquette et al. (2007). Teenagers with IBD relied on their friends' assistance with missed homework assignments and tutoring in order to complete their studies. Unlike the experiences of Canadian youth with other disabilities (Globe and Mail, January 2010), adolescents with IBD maintained many friendships both inside and outside their classroom setting.

Exosystem

Family Finances

The parents spoke openly about their struggles with maintaining employment and finding sources of supplementary income to support the additional medical and educational needs incurred by having a child with IBD. This situation negatively impacted the family by increasing the financial demand placed on them, which in turn created additional stress and hardship for parents and siblings. Similarly these financial burdens associated with having a child with a disability were also found in a study by Jackson, Traub and Turnbull (2008). Parents had to make difficult decisions about the type of employment options available to them that would meet

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

their financial and family needs. The five mothers in this study preferred to stay home and care for their sick child rather than having to accept full-time employment. Nevertheless, for most parents in this research this was impossible and only one mother was able to stay-at-home on a full-time basis because her husband's income was sufficient.

In this study, most parents were employed full-time in order to afford the medical, educational, and recreational services their children needed. Medical expenses included frequently having to pay for specialty foods, medical tests, parking, and medications. The educational expenses incurred for most of the families were in the form of tutors hired to assist their children with IBD with subjects with which they were having difficulty. Additionally, in three families the children were enrolled in expensive private schools. Furthermore, parents incurred costs to place their children in extra-curricular activities such as sports teams, music lessons, personal trainer, and summer camps. In addition to extra expenses, the parents reported disruptions to their careers and reduced employment options due to having a teenager with IBD at home, which affected the amount of money the parents could earn.

Parents felt the need to choose occupations that offered shift work, allowed them to miss days of work, and had an empathetic employer. Thus, their occupations were generally low paying and mothers reported having to put their career aspirations on hold. In addition, parents often experienced negative emotions while working, noting factors such as low concentration, feelings of guilt, or being judged by their colleagues. Moreover, by choosing to work, parents had less time available to spend at home with their children. As a result, parents had to depend on siblings and extended family, especially grandparents, to assist with caregiving tasks. In an attempt to solve this dilemma, the Anderson family chose to work at home. Unfortunately, the solution to have their home doubled as a day care centre did not resolve the problem because the

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

income generated, was insufficient. Therefore, finding a balance between home, work, and income to support all family members remains a great challenge for parents.

Besides employment, parents participated in their community in other ways. For the most part, it was mothers who volunteered at their children's schools, community events, and were usually members of their local IBD Association. Similarly, these findings were found in the study by Shatkin & Gershberg (2007). All mothers reported that as their children grew, their participation as volunteers waned. Instead, their time was spent searching the internet for information on sources of financial assistance to cover their considerable medical costs.

Macrosystem

Societal Perceptions of IBD

All the parents expressed the belief that society still lacked awareness of IBD. As a result, they thought that their children were negatively perceived because of the stigma associated with the disease. The parents believed that society stigmatized the disease because IBD is associated with incontinence, diarrhea, and feces. They believed that through continued medical research, awareness would increase and most importantly a cure would be found. In the meantime, the parents held high expectations for their children and had confidence that they could achieve anything. They emphasized their belief that having IBD was not a disability for their child and pushed to ensure that their children with IBD would graduate and achieve their career aspirations.

Both siblings and children with IBD shared the belief that having the disease did not make someone abnormal. Rather, these children had similar wants, desires, and interests as their healthy peers. For a summary of all study outcomes and findings see Figure 9.

Contributions to Theory and Practice

Contributions to Theory

This study is the first to explore siblings, parents and children with IBD in relation to education. The study findings have made contributions to Bronfenbrenner's ecological theory (1979). Specifically, the current research provides information about the interconnectedness of family members' experiences to their environments from their perspectives. Previous research on children's responses to family transitions has been based on adults' reports (Dunn, 2004). However, this study complements Bronfenbrenner's theory (1979), by including children's experiences with their environments from *their* point of view. This perspective was previously missing from the ecological theory, especially regarding the role of siblings and the ways they shape their environments and how the environment affects them. Furthermore, this study provides support for the use of Bronfenbrenner's ecological theory as a useful framework for understanding the multi-directional relationship of family members within their environments.

The use of Turnbull and Turnbull's family system theory (2001) was also shown to be a valuable framework, as it provided an effective lens from which to understand the complex interactions that occur in families. Also, the theory is valuable for illustrating how a child with a chronic disease, such as IBD, can impact the family dynamics. The current study corroborates many of Turnbull and Turnbull's previous findings and adds the child's perspective rather than solely the adults' perspective to the data. For a summary of all new contributions made to theories see Figure 10.

Contributions to Data Collection Strategy

The current research found that the siblings' drawings, although interesting, failed to yield much data that informed this study. The drawings depicted happy, smiling families with

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

individuals who stood in close proximity to each other. Pets both alive and deceased were also drawn indicating that they were also considered as members of the family. However, deceased family members who had assumed a care-giver role in the siblings' lives were not depicted in the drawings. Beyond these data, no other real information could be extracted, and hence this strategy contributed little to the pool of data.

Contributions to Practice

The data showed that having an IEP was a double edged sword. On one hand, having the accommodation documented would guarantee access to washrooms. However, it would also ensure that a label was placed on the children which may have the effect of making them appear less capable. The parents in this study did not press for an IEP for IBD because they either did not know about the possibility of having one or wanted to ensure that teachers viewed their children as "normal".

Recommendations made by Parents

The parents reported recommendations that may have benefits for other parents of children with IBD as well as educators. These parents urged others to support their children with IBD through advocacy for accommodations. Parents were mindful of the limitations that labeling could place on their children. They were also concerned that labeling their children as only, "children with IBD" could have adverse effects on each child. Therefore, they recommended that parents should encourage their children to move beyond the label and work to achieve their fullest potential. They further recommended that all parents should assist in increasing awareness about IBD particularly at their child's school.

Recommendations made by Children with IBD

The children with IBD would like their teachers to believe them when they say that they are tired or sick while they are in class. They would also like to be permitted to go to the washroom whenever it is required. As well, the children also recommended that a summer camp be created specifically for children with IBD, so that they can socialize, share, and exchange information about their disease with their peers. Furthermore, the camp would meet their specific needs, unlike camps for children without IBD.

Recommendations made by Siblings

The siblings recommended that society should view children with IBD as normal and active. They want the general public to see individuals with IBD as having similar goals and aspirations as their peers without IBD. Essentially, siblings would like others to understand that their brother or sister may have limitations imposed on them by their disease, but they are often able to overcome many life challenges and persevere.

Recommendations to Québec educational system

In 2010, the Ministry of Education appeared to have been cognizant of the weaknesses in the system and revisited the Act on Integration (1996). The revision was expanded to include adaptation of services in general education classrooms for students with some specific special needs. Since then, the onus is no longer on students with disabilities to “fit in” to pre-existing structures. The responsibility is placed on all school boards to provide adequate educational services for them within general education classrooms.

Unfortunately, the present Education Act (2010) has not resolved the problem of accommodating students with special needs in general education classrooms as was evidenced in

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

the schools where the students with IBD attended. In those schools, the needs of students with IBD were not consistently being met. Consequently, their parents had to advocate for their children's needs that they were entitled to as stipulated by the Education Act (Québec Education Act, 2010).

In order to correct some of these problems, it may be beneficial to move from a system of integration towards an inclusive model. In this later approach, the services and accommodations are included in the daily routines of classroom structure, environment, curriculum and strategies. With inclusion, it is recognized that the environment must be adapted to meet the needs of all students. Inclusion is about the students' right to participate, academically and socially and the schools' duty to accept them as they are. All students should have access to a curriculum that plays to their strengths, as well as provides meaningful and challenging learning opportunities for them (Bucalos & Lingo, 2005; Burnstein, Sears, Wilcoxon, Cabello, & Spagna, 2004; Idol, 2006; Voltz, Sims, Nelson, & Bivens, 2005). In this way, it is incumbent on the school to have all the policies and practices in place, so as to offer the best educational service delivery possible to students with disabilities. By moving in this direction, Québec's model of schooling its students with visible and invisible disabilities would fall in line with the other provinces, since it is the only one that still uses the model of integration education.

Limitations of the Research

Given the particular focus of this study, there were four potentially influential factors that were not assessed. The first factor resulted from time constraints. Unfortunately, the researcher was unable to have more than two opportunities to interview the families in their home, and there was not enough time to include interviews with extended family members (e.g., grandparents) who often played important roles in the functioning of each family.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Secondly, the researcher was unable to hear from all of the fathers in this study. The fathers mentioned that their spouse as the primary care-giver was more able to talk about their child with IBD and the family situation. In two cases, it was not possible to speak with those fathers because one had died from complications of IBD and the other lived in the United States. The development of father-child relationships (and stepfather-stepchild relationships) over time may have contributed to our understanding of changes in family dynamics and to our knowledge of the role fathers and stepfathers play in children's development, when a child in the family has IBD. Thirdly, teachers and school administrators were not interviewed and their perspectives on families with a child with IBD might have made some contributions to this research.

Lastly, there was a selection bias as three of the families recruited in this study had previously participated in the researcher's 2004 IBD study. Therefore, these families were already used to participating in research studies. In addition, Family 3 was enrolled in another study (longitudinal study on twins) at the time they were recruited into the current study. Even though there were so few families who were available to participate, their involvement was appreciated and the focus of this study was different from other studies about children with IBD.

Implications for Practice and Future Research

The implications for parents and schools are many. As accurate information is critical to making informed decisions, parents need to be familiar with the community services and educational programs offered by local schools. For example, all the parents in this study chose to have their child with IBD placed in general education classrooms. In general education classrooms students with special needs are always educated alongside students without special needs, while policies and practices are put in place to maintain supports and services for them. Here, the goal of integration for these students was hindered because either the parents did not

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

know that the required accommodation could be attained by acquiring an IEP, or they did not want their child to be labeled as requiring a special accommodation. These children are incontinent and as such, they need to have easy access to washrooms at all times. This was a problem for all the children with IBD in all the schools that were mentioned in the study, and they suggested that the situation be remedied.

The parents in this study also recognized that a successful school experience and positive outcomes could enhance their children's life experiences. Therefore, the parents established open lines of communication with their children and the personnel of their children's school. Parents ensured that IEPs were developed and followed and they attempted to maintain a positive home-school relationship.

Although substantial evidence supports the importance of fathers in children's development (Lamb & Tamis-LaMonda, 2004), many questions remain about the specific ways through which fathering contributes to children's relationships in families, particularly in the early school years. Children are known to be affected by fathering in the context of the marital relationships among adolescents. For example, deficits in the inter-parental relationship are known to cause strain on the father-child relationship and negatively affect children's emotional security about the stability of the family (Cowan & Cowan, 2009; Cummings, Goeke-Morey & Cummings, 2007). The current study reported findings for only two out of the five fathers. Nonetheless, the data provide a starting point for understanding the possible impact of fathers in the family context. The literature on fathering discussed above suggests that in addition to these indirect processes, fathers also impact children directly, but more research and exploration in this area is needed.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Furthermore, this study determined that siblings also experienced challenges of their own with their health, learning disabilities, and lack of adult attention at home and school. Additional research is needed to examine the quality of the sibling relationships in families with a child with IBD. Research should focus on the nature of the relationship between a child and his or her sibling with IBD since little has been written about the impact of IBD on a sibling's development. Also, more information needs to be gathered about their life experiences from their perspective since most of the research on IBD usually focuses on the child who has been diagnosed with the disease and not his or her family members. Although a growing body of research examines sibling relationships during adolescence, little is known about the longitudinal and multiple linkages between sibling relationships and parental support in families with a child with IBD.

Lastly, further research is needed to investigate teacher training and practice. In the general education classrooms, teachers are expected to teach all children, but this researcher cannot help but wonder if teachers have the training and willingness to do so. This study demonstrated that the teachers of the students with IBD had little to no knowledge of the disease before they were informed of it by the children's parents. If teachers are unaware of the problems that exist among their students, then it may be difficult for them to be effective teachers if they are not properly prepared. Moreover, information and training may increase willingness to give accommodations to students with IBD. In the future, it is hoped that this research may affect teacher training programs and policies regarding how students with chronic illnesses, particularly those that are invisible, are treated so that they are provided with the empathy and accommodations they need.

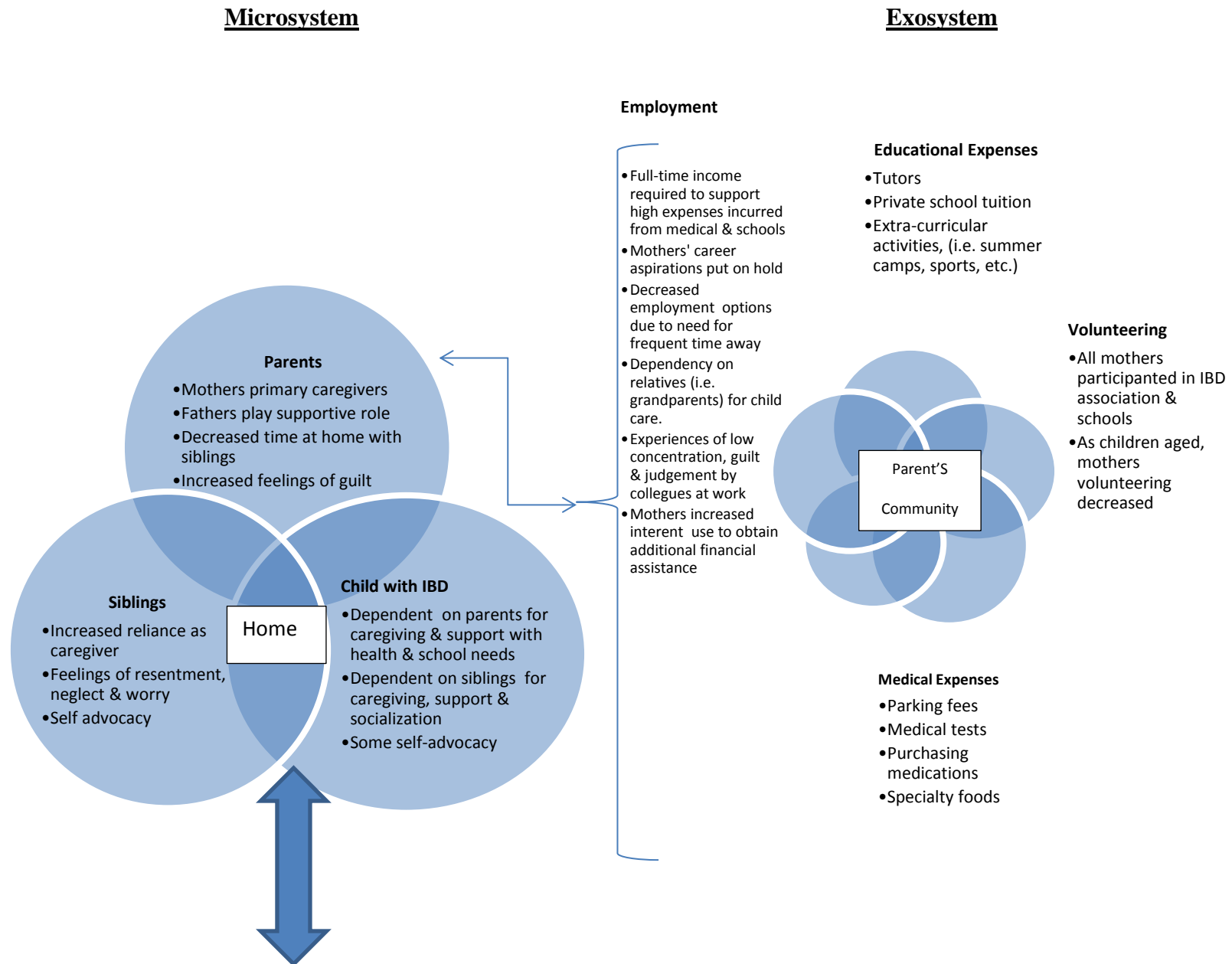
Conclusion

This study examined the relationship between family members in families with a child with IBD. The research examined each family member's connection to environments extending outside the home including: the school, community, and society. These relationships are not uni-directional, but rather multi-directional because whatever affects one member is directed to each of the other members in the family. Therefore, understanding the impact of these relationships and the effect they have on the family and school is vital not only to school success, but success in all areas of the lives of children with IBD. Within the family, school organization, and community, each person with whom the child with IBD interacts plays a role in his or her experiences. This research also brought attention to the need for adequate preparation of teachers and the implementation of accommodations for students with disabilities in general education classrooms. These factors are important to school success of students with disabilities within general education classrooms.

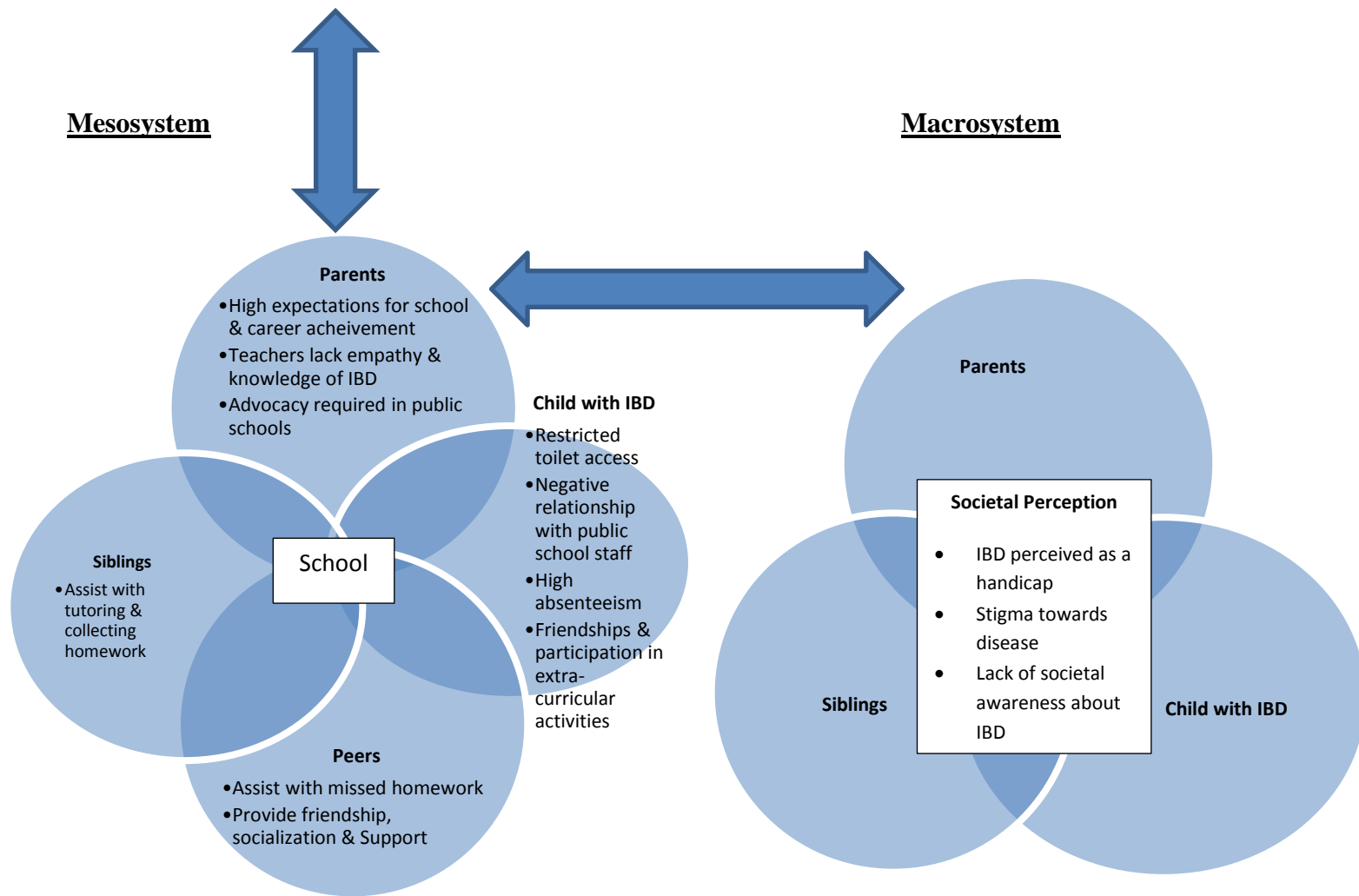
While children with IBD and their families have to deal with many challenges, their interviews and family portraits revealed that they are functioning well in spite of the problems they face. These results are contrary to much of the available research on families of a child with special needs. The findings demonstrate that although IBD can have negative effects on the individual and family members, the family unit can be resilient, attain happiness, and thrive.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Figure 9 Study Outcomes and Findings

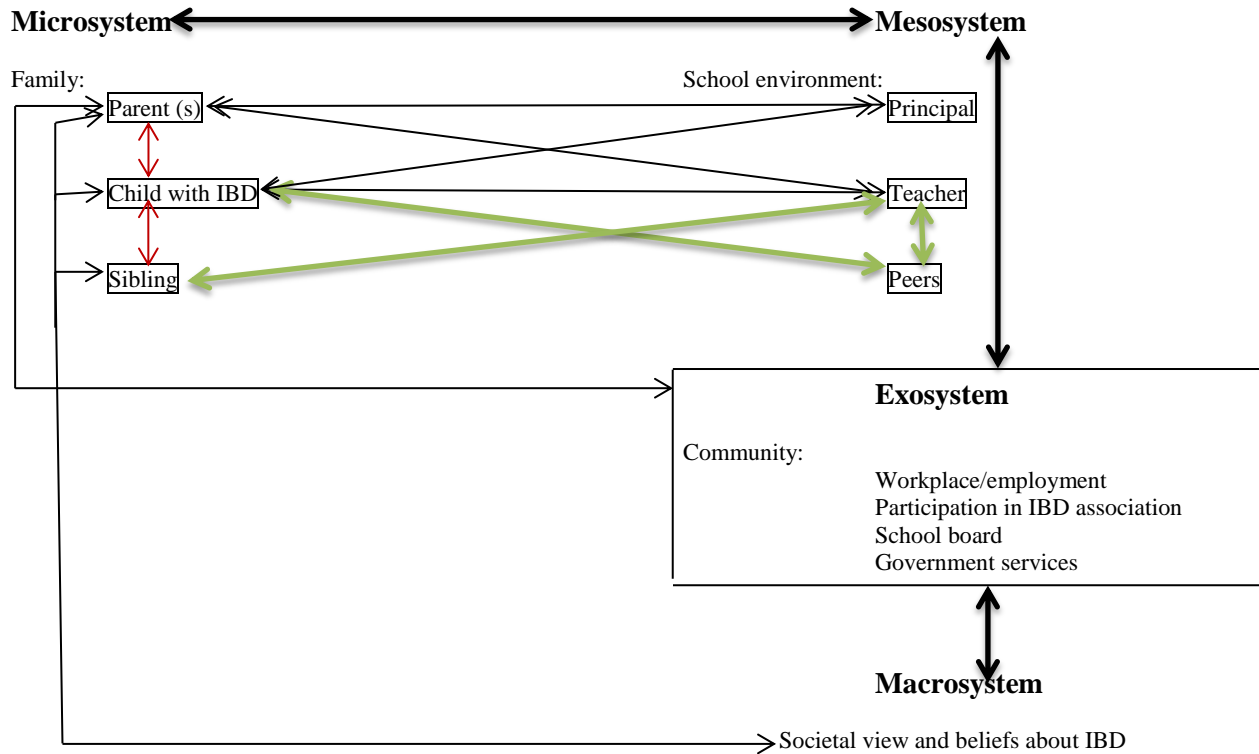


EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE



EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Figure 10 New Findings and Contributions to Bronfenbrenner and Turnbull and Turnbull’s Systems Theories



The diagram displays all the environments and family relationships examined in this study. Green lines indicate new findings and unexpected study outcomes. Siblings interacted with teachers in order to collect missed assignments and tutor their brother or sister with IBD. Unlike many children with disabilities and chronic diseases, the children with IBD maintained friendships and also depended on peers to receive help with missed homework.

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Appendix A

Parent/Guardian Interview (Past)

Demographics

- Can you please tell me your first and last name? (Name will be converted to a pseudonym for confidentiality purposes)
- What is your date of birth?
- Are you currently employed outside of the home? If yes, what is your employment? Is it full or part-time often? If part-time, how often do you work?
- How many children do you have?
- What school(s) do your children attend? What grade(s) are your children in?
- When was your child diagnosed with IBD? (Date)
- What type of IBD does your child have?
- Does anyone else in the immediate family have IBD? If yes, who and what type?

Diagnosis

1. How did you first become aware that your child had IBD? How did you feel about this diagnosis? (Microsystem)
2. Tell me the process to obtain a diagnosis for your child? (Microsystem)
3. How did this information make you feel? How did you react, family members, etc.? (Microsystem/Family systems)
4. Tell me about how you informed the school about the diagnosis? (Mesosystem)

School and Community

5. Where was your child placed, was it in a general education classroom? (Mesosystem)
6. Does your child have an IEP? If yes, what accommodations and services are listed? Did the school provide them? If yes, why? If no, how did you obtain them? (Mesosystem)
7. Did you have any interaction at the school or school board level? (Mesosystem/Exosystem)
8. What role(s) did you play at home, school and in your community? (Each system examined)
9. What were the services sought from the community? (Exosystem)

Parent Interview (Present)

Diagnosis

1. How do you feel now about your child's IBD diagnosis? (Microsystem)
2. How do you help your child manage his/her IBD symptoms at home, school and in the community? (Each system examined)
3. What role do the siblings play in helping your child with IBD at home? (Microsystem/Family systems)

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

School and Community

4. What accommodations have been made for your child at school, home and in your community? (Each system examined)
5. What is your current relationship like with your child's teachers and administrators? (Mesosystem)

Appendix A

6. When your child is feeling sick at school, what have you instructed him/her to do? (Mesosystem)
7. How many days of school has your child missed? How does that affect you and the family members? (Mesosystem/Family systems)
8. What school activities do you participate in (i.e. sports, lunch program, arts and crafts etc.)? Why did you choose to take part in these activities? (Mesosystem)
9. What extra curricular activities (home, school, and community) do your children participate in? (Each system examined)
10. When you have questions or need support for your child with IBD what resources do you use? (Exosystem)
11. What role do the siblings play in helping your child with IBD at school? (Mesosystem/Family Systems)

Parent Interview (Reflection)

Diagnosis

1. Were there any changes in how your family functioned after the diagnosis? (Microsystem/Family systems)
2. What impact has the IBD diagnosis had on your relationship with your spouse/partner and siblings? (Microsystem/Family systems)
3. Was there a change in your relationship with other family members as a result of your child's IBD diagnosis? (Microsystem/Family systems)
4. How do you manage your child's medication and hospital visits and family responsibilities? (Mesosystem/Family systems)
5. How do you think society views people with IBD? (Macrosystem)

School, Family and Community

6. Is there anything that you would like to change about the services and supports provided at your child's school? (Mesosystem)
7. What message do you have for teachers? (Mesosystem)
8. How do you balance outside employment and caring for your children? (Exosystem/Family systems)
9. What dreams do you have for your children? How do you think IBD will impact those dreams? (All systems examined)
10. What advice do you have for other parents of children with IBD? (Exosystem)

Appendix B

Child with IBD Interview (Past)

Demographics

- Can you please tell me your first and last name? (Name will be converted to a pseudonym for confidentiality purposes)
- What is your date of birth?
- How many brothers and sisters do you have?
- What is the name of your school? What grade are you in?
- Does anyone else in your family have IBD? If yes, who?

Diagnosis

1. What did the doctors/nurses tell you about your IBD (first diagnosed)? How did this make you feel? (Microsystem)
2. How did family, friends, neighbors, etc. react? (Each system examined)
3. Did you have to visit the doctor/hospital often? How did that make you feel? (Microsystem/Mesosystem)
4. What did you have to change after learning about your IBD (e.g., foods, activities, etc.)? (Each system examined)

School

5. After the diagnosis, what was it like for you at school? How did kids treat you? How did teachers treat you? (Mesosystem)
6. What medications were prescribed? How did you feel about that and having to take medication at school? (Mesosystem)
7. What services or accommodations did you need at your school? (Mesosystem)
8. Did your teachers help you (what accommodations)? (Mesosystem)
9. Who did you tell about your IBD at school? (Mesosystem)
10. What did your parents tell you to do if you felt sick at school? (Mesosystem/Family systems)

Child with IBD Interview (Present)

School

1. What do you like to do for fun at school? (Mesosystem)
2. Let's talk about your classroom, could you describe the room to me? (Mesosystem)
3. What do you do if you feel the need to rush to the bathroom while in class? (Mesosystem)
4. What do you tell your friends and teachers about your IBD? (Mesosystem)
5. Who do you like/enjoy talking to at school? When you're not feeling well who do you go to? (Mesosystem)
6. How many days of school have you missed? Why were you absent? What role(s) did your family play overall to help with school? (Mesosystem/Family systems)

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

7. How do your parents help you when you are not feeling well at school? (Mesosystem/Family systems)

Appendix B

Family

8. What do you presently do at home to manage your IBD? (Microsystem/Family systems)
9. How do your sister or brother and parents, help you manage your IBD at home and school? (All systems examined)
10. What do you like to do for fun after school and with family? (Microsystem/Family systems)
11. We all have good and bad days, describe what a good day would be like. Describe a bad day. (Mesosystem)
12. Which medication(s) are you taking for your IBD? What accommodations do you need to take your medications? (Microsystem & Mesosystem)

Child with IBD (Reflection)

Diagnosis

1. How has having IBD affected your participation in school and other activities? (All systems examined)
2. How has having IBD affected your friendships? (Microsystem/Mesosystem)
3. How do you think your diagnosis has affected your family? (Microsystem/Family systems)

School, Family and Community

4. What would help you to manage your IBD symptoms while at school and home? (Microsystem/Mesosystem)
5. If you could change one thing about your classroom and school_what would it be? (Mesosystem)
6. How has your IBD affected your relationship with your sister or brother? (Microsystem/Family systems)
7. What advice do you have for other kids with IBD? (Macrosystem)
8. What message do you have for teachers? (Mesosystem)
9. Do you think your friends and family understand what IBD is? (Microsystem/Family systems)
10. What are your future hopes and dreams? How can you reach them? What do your parents think of these ideas? (Microsystem/Family systems)

Other:

1. How do you see yourself (e.g. a child with IBD; a regular kid)?
2. When do you feel like a regular kid?

Appendix C

Sibling Interview (Past, Present and Reflection)

Demographics

- Can you please tell me your first and last name? (Name will be converted to a pseudonym for confidentiality purposes)
- What is your date of birth?
- How many brothers and sisters do you have?
- What is the name of your school? What grade are you in?
- Does anyone else in your family have IBD? If yes, who?

Diagnosis

1. How did you feel when you learned about your sister or brother's IBD diagnosis? (Microsystem/Family systems)
2. How did your family members react? (Microsystem/Family systems)
3. What changes (accommodations) had to be made at home due to your sister or brother having IBD? How did these changes affect you? (Microsystem/Family systems)
4. How do you help your sister or brother with IBD at home? How does this make you feel? (Microsystem/Family systems)
5. How do you help when your sister or brother with IBD misses school? When they have doctors/hospital visits? (Mesosystem/Microsystem/Family systems)

School

6. Does your brother/sister attend the same school as you? How do you feel about that? (Mesosystem)
7. What is school like for you (i.e., challenges, concerns, achievements, etc.)? (Mesosystem)
8. What do you like doing at school? What do you not like? (Mesosystem)
9. How do you help your sister or brother with IBD with their schooling? How does this make you feel? (Mesosystem)
10. How do your parents help your sister or brother with IBD with their schooling? How does this make you feel? (Microsystem/Family systems/Mesosystem)
11. When you feel sick what do you do (home and school), who helps you (parents, siblings, teachers, friends)? (Examine all systems)

Family and Community

12. What do you think it is like to have IBD? (Microsystem)
13. What things do you and your sister or brother with IBD do together? (Microsystem/Family systems)
14. What things do you do as a family? (Microsystem/Family systems)
15. What do you think friends, family, and neighbours think about IBD? (Examine all systems)
16. How does your sister or brother with IBD help you? (Microsystem/Family systems)
17. What do your friends know about your sister or brother with IBD? (Microsystem)

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

18. What is it like having a sister or brother with IBD? (Microsystem)
19. What are your hopes and future dreams? What do your parents think? (Microsystem)
20. What advice do you have for other kids whose brothers or sisters have IBD? (Exosystem)

Appendix C

21. What would you like your parents to know about you and how you feel?
(Microsystem/Family systems)

Appendix D

Modified Interview Questions

1. How did you feel when you learned about your sister or brothers IBD diagnosis?
(Microsystem/Family systems)

Question was rephrased for clarity to:

How did you feel or what did you think when you were first told that your brother or sister was diagnosed with IBD?

19. What are your hopes and future dreams? What do your parents think? (Microsystem)

Question was rephrased for clarity to:

What would you like to be (or do) when you grow up? What do your parents think/feel about your decision(s).

Appendix E

Recruitment Notices

Pages 223-226

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

CROHN'S AND COLITIS FOUNDATION OF CANADA



HEEL 'N' WHEEL-A-THON

[Invite People to Join](#)

Information

Category:

[Organizations - General](#)

Description:

This June, I'll be participating in the 12th Annual Heel 'n' Wheel-a-Thon in order to raise money for the Crohn's and Colitis Foundation of Canada (CCFC). The CCFC is a national not-for-profit voluntary medical research Foundation, whose mission is to find the cure for inflammatory bowel disease.

For all of you that have joined this group and don't now what it's about and why I am doing this.

I was diagnosed with ulcerative colitis in June 2004. It is an inflammatory bowel disease which has... [\(read more\)](#)

Privacy Type:

Open: All content is public.

Families with IBD

Hello! Do you have a child with IBD? Do you have a brother or sister with IBD? Then I invite you to participate in a study on families and their experiences of IBD and going to school. This study involves doing interviews with me to talk about what your life is like in.

See More

July 5, 2010 at 10:33am · [Participate](#)

Invitation to Participate in a Study about Children with Inflammatory Bowel Disease

Location: Québec

Do you have a child with IBD? Do they also have a brother or a sister? If so, then I would like to talk to all of you to hear about your family's experiences of living with IBD and life at school for your child.

Currently, a study is underway to investigate what life is like for families that have a child with IBD and the ways they navigate the Québec educational system. Participation in this study involves each family member (parents/guardians, child with IBD, and at least one sibling) doing audio taped interviews.

Participation is completely voluntary and you may choose to discontinue your participation at any time. All interviews will take place on a day and time that is convenient for you and your family. There are no risks and no benefits associated with participating in this study.

Parents/guardians and the child with IBD will do a total of three interviews. Siblings will only do one, and all information is strictly confidential.

This study hopes to bring awareness to the topic of IBD and the information learned might be helpful in the future for school personnel and others involved in children's learning, so they may be in a better position to assist children who have IBD with their education, and provide much needed services to their families.

The Crohn's and Colitis Foundation of Canada (CCFC) Annual Conference

This year's annual conference will be held in Toronto in mid-October. The CCFC charter authorizes one delegate voter by chapter for the general assembly held on Sunday. This delegate will have all related expenses paid and must be elected by the members of the chapter. **To propose a member or to vote, send your vote by e-mail at: montreal@ccfc.ca.** Don't miss out an exciting chance to meet with researchers, sharing tips and ideas with members like you across Canada!

Invitation to Participate in a Study about Children with Inflammatory Bowel Disease

Do you have a child with IBD? Are they between 7 to 13 years old? Do they also have a brother or sister that is also between 7 to 13 years old? If so, then **I would like to talk to all of you and hear about your family's experiences of living with IBD and life at public school.**

Currently, a study is underway to investigate what life is like for families that have a child with IBD and the ways they navigate through the public education system in Quebec. Participation in this study involves each family member (parents/guardians, child with IBD and at least one sibling) doing audio taped interviews with me. Participation is completely voluntary and you may choose to discontinue your participation at any time. All interviews will take place on a day and time that is convenient for you and your family and there are no risks and no benefits associated with participating in this study. Parents/guardians and the child with IBD will do a total of three interviews, while siblings will only do one. All information is strictly confidential.

This study hopes to bring awareness to the topic of IBD and the information learned may in the future be helpful to school personnel and others involved in children's schooling to better assist children with IBD with their education and provide much needed services to their families. For

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

IN-CAM News FLASH (2010/07/16)

Please read on for more information about:

1. Abstract Submission Deadline - 6th IN-CAM Research Symposium, Vancouver, BC
2. Participants Needed for a Pediatric Inflammatory Bowel Disease Study - Quebec
3. Education Session - Statisticians Working on Complementary and Alternative Medicine (CAM) Studies - Vancouver, BC

1) Abstract Submission Deadline - 6th IN-CAM Research Symposium, Vancouver, BC

The 6th IN-CAM Research Symposium, *Complementary and Integrative Health Care: Methodological, Theoretical and Practical Issues*, will take place Nov. 19 - 21, 2010 at the Sutton Place Hotel, Vancouver, BC. The abstract submission deadline is fast approaching! Abstracts must be submitted by midnight EDT on **July 30th, 2010**. In addition to oral and poster abstracts, we also welcome workshop abstracts. Please note that workshops are 1.5 hours in length and are scheduled to be held on Saturday, Nov. 20th.

For more information or to submit an abstract, please go to www.incamresearch.ca.

2) Participants Needed for a Pediatric Inflammatory Bowel Disease Study - Quebec

A Natural Health Consultant and doctoral student in the Faculty of Education at the University of Ottawa is currently conducting interview based research on families with a child with Inflammatory Bowel Disease (IBD). Families living in the Province of Quebec who are interested in participating in this research can contact the study investigator by email or telephone.

3) Education Session - Statisticians Working on Complementary and Alternative Medicine Studies, Vancouver, BC

A session entitled "Statisticians Working on Complementary and Alternative Medicine (CAM) will take place on **August 4th, 2010** from 7 - 8:30 pm at the Fairmont Waterfront Hotel, Vancouver, BC. This session is being offered as part of the 2010 Joint Statistical Meetings (www.amstat.org/meetings/jsm/2010).

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Best regards,

Canadian Interdisciplinary Network for Complementary and Alternative Medicine (IN-CAM)

Visit us online at: www.incamresearch.ca

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Appendix F

Interview Timeline 2010-2011

May 2010	University ethics approval received and recruitment notice appears in IBD association newsletter.
June 2010	Family 1 interviews conducted (2 day period) and recruitment notice appears in IBD association newsletter.
July 2010	Family 2 interviews (2 day period) and recruitment notice appears in IN-CAM online newsletter.
August 2010	No interviews conducted.
September 2010	Paid advertisement placed to recruit families through the Montreal Families newspaper.
October 2010	No interviews conducted.
November 2010	No interviews conducted, recruitment notice appears in Montreal Families newspaper.
December 2010	No interviews conducted.
January 2010	No interviews conducted.
February 2011	Family 3 interviews conducted (2 day period).
March 2011	Family 4 and 5 interviews conducted (2 day period for each family).

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Assent Form *(Minors aged 7-13)*

Title of the study: Experiences of Children with IBD and their Families within Inclusive Public Educational Settings

Invitation to Participate: I am invited to participate in the above mentioned research study.

Purpose of the Study: The purpose of the study is to hear the experiences of families with a child with IBD and to understand their experiences within inclusive public school settings.

Participation: My participation will consist essentially of one taped interview in which I will be encouraged to answer questions about my family and my experiences of having a brother or sister that has IBD. The interview will last no more than 90 minutes and will happen on a day and time that is good for me and my family. The interview will take place at my home or at a place that I feel is more comfortable for me.

Risks: My participation in this study means that I will voluntarily answer questions and share personal information about myself and my family's experiences, and this may cause me to feel emotional at times. I have received assurance from the researcher that every effort will be made to minimize these risks by being permitted to refuse to answer or to take a break and resume the interview at another time or to withdraw completely from the study.

Benefits: My participation in this study will help to add much needed information to the under research area of IBD from the child's point of view. Information gained may help to improve services within public schools for families of children and with exceptionalities like IBD.

Confidentiality and anonymity: I have received assurance from the researcher that the information I will share will remain strictly confidential. I understand that the contents will be used only for the purposes of a doctoral thesis and publication within IBD associations and academic journals and that my confidentiality will be protected by being given a pseudonym (real name won't be used, a different name will be created instead) and no personal contact information will ever appear such as telephone number, or personal address or email.

Anonymity will be protected in the following manner by never using participants real names in any publications nor any of their personal contact information will be disclosed including the name of your school. This sensitive information will never be disclosed publicly.

Conservation of data: The data collected including all hard copies, notes and audio tapes will be kept in a secure manner for 5 years. All research and collected data will be kept in a locked storage box in which only the researcher will have the 2 keys. On the fifth year, the data will be shredded in a paper shredder by the researcher and the audio tapes will be erased.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can stop the study at any time and/or refuse to answer any questions, without suffering any negative consequences. If I choose to stop, all data gathered until the time of withdrawal will be shredded and any audio files will be erased.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Consent Form *(Parent/Guardian)*

Title of the study: Experiences of Children with IBD and their Families within Inclusive Public Educational Settings

Invitation to Participate: I am invited to participate in the above mentioned research study.

Purpose of the Study: The purpose of the study is to hear the experiences of families with a child with IBD and to understand their experiences within inclusive public school settings.

Participation: My participation will consist essentially of three audio taped interviews in which you will be encouraged to answer questions about you and your family's experiences of having a child with IBD and your encounters within their school setting. Each of the three interviews will last no more than 90 minutes and will occur over a period of a few days on a day and time that is convenient for you. Interviews will be held at your home or at a location that you feel is more comfortable and convenient for you.

I will also be asked to have my child/children and spouse/partner participate in audio taped interviews in which they will be asked similar questions regarding their thoughts, feelings and experiences of having a family member with IBD. All interviews will take place concurrently.

Risks: My participation in this study will entail that I voluntarily answer questions and share personal information about myself and my family's experiences, and this may cause me to feel emotional at times. I have received assurance from the researcher that every effort will be made to minimize these risks by being permitted to refuse to answer or to take a break and resume the interview at another time or to withdraw completely from the study.

Benefits: My participation in this study will help to add much needed information to the under research area of IBD from the family's perspective. Information gained may help to improve services within public schools for families of children and with exceptionalities like IBD.

Confidentiality and anonymity: I have received assurance from the researcher that the information I will share will remain strictly confidential. I understand that the contents will be used only for the purposes for a doctoral thesis and publication within IBD associations and academic journals and that my confidentiality will be protected by being given a pseudonym (real name won't be used, a different name will be created instead) and no personal contact information will ever appear such as telephone number, or personal address or email.

Anonymity will be protected in the following manner by never using participants real names in any publications nor any of their personal contact information will be disclosed including the name of the children's schools. This sensitive information will never be disclosed publicly.

Conservation of data: The data collected including all hard copies, notes and audio tapes will be kept in a secure manner for 5years. All research and collected data will be kept in a locked storage box in which only the research will have the 2 keys. On the fifth year, the data will be shredded in a paper shredder by the researcher and the audio tapes will be erased.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Table 1 Initial Study Criteria

1. The participating family has to reside in the province of Québec
2. The child with IBD must be aged 7-13.
3. The child with IBD must have at least one sibling.
4. Siblings must also be aged 7-13.
5. Participating families had to be able to communicate in English.
6. Families that had a two parent structure could participate.
7. The child with IBD had to attend a general education classroom at a public school.
8. Family members must be available for one-on-one interviews over the course of three days.
9. The child with IBD must be diagnosed with either Crohn's disease or ulcerative colitis.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Table 2 Participant Family Demographics

Family 1

Andersons French Canadian	Marital Status	Occupation	Age (Years)	IBD Dx	Other Dx	Type of School	Public or Private	Grade Level	IEP	School Met IBD Needs	Deceased Relative
Mother	Married	Daycare (full-time)									
Father	Married	Daycare (full-time)									
Claire (Sister)			13	Crohn's Disease	Juvenile Arthritis	High School	Public	Secondary One	None	No	
Lisa (Sister)			10			Catholic Elementary	Public	4	None		

Family 2

Clarksons Jewish Heritage	Marital Status	Occupation	Age (Years)	IBD Dx	Other Dx	Type of School	Public or Private	Grade Level	IEP	School Met IBD Needs	Deceased Relative
Mother	Married	Administrator (full-time)									
Father	Married	Manager (full-time)									
Geddy Lee (Brother)			14	Crohn's Disease	Stunted Growth	High School	Public	Secondary Two	None	Yes	
Daniel (Brother)			11			Elementary	Public	6	None		
Squirtle (Brother)			7			Elementary	Public	1	None		
Grandparents											

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Family 3

Campbells Italian Heritage	Marital Status	Occupation	Age (Years)	IBD Dx	Other Dx	Type of School	Public or Private	Grade Level	IEP	School Met IBD Needs	Deceased Relative
Mother	Widow	Bank (full-time)									
	Deceased			Crohn's Disease							Yes
Father											
William (Twin)			13	Crohn's Disease	Learning Disability	High School	Public	Secondary One	Yes	No	
Nancy (Twin)			13			High School	Private	Secondary Two	None		
Chris (Brother)			18			CEGEP	Public	1 st year			
Ryan (Brother)		Restaurant (part-time)	23		Learning Disability	University	Public	1 st year	None		

Family 4

Kellers Jewish Heritage	Marital Status	Occupation	Age (Years)	IBD Dx	Other Dx	Type of School	Public or Private	Grade Level	IEP	School Met IBD Needs	Deceased Relative
Mother	Separated	Retail (part-time)									
Father	Separated	Business (full-time)									
Michael (Brother)			15	Chronic Crohn's Disease	Frequent Blood Infections	High School	Private	Secondary Four	None	Yes	
Sophia (Sister)			17			CEGEP	Public	1 st year	None		

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Family 5

Lévesques Jewish Heritage	Marital Status	Occupation	Age (Years)	IBD Dx	Other Dx	Type of School	Public or Private	Grade Level	IEP	School Met IBD Needs	Deceased Relative
Mother	Married	Homemaker (full-time)									
Father	Married	Importer (full-time)		UC*							
Alex (Brother)			16	Crohn's Disease		High School	Private	Advanced Secondary Four	None	Yes	
Paige (Step-Sister)			18	Croh's Disease	Chronic Asthma	High School	Public		None		
Emma (Step-Sister)			34								
Grandparents											Grandmother

*UC: Abbreviation for ulcerative colitis

Table 3 Anticipated Categories and Codes

Child with IBD-(Past, Present & Reflection Experiences)

Category	Sub-categories
<p>Microsystem (Family relationships)</p>	<ul style="list-style-type: none"> - Relationship between child with IBD and parent(s): <ul style="list-style-type: none"> • Close relationship. • Child talks openly and frequently with parents about their feelings, IBD symptoms and how things are going at school including relationship with teachers as well as academic path. • Child relies particularly on their mother for many of their needs such as comfort, daily care, food preparation, coping strategies when feeling unwell, pick-ups to and from school and various activities, drug preparations or reminders to take medications. - Relationship between child with IBD and sibling(s): - How IBD affects the relationship <p><u>The experiences of child with IBD within their family was:</u></p> <ol style="list-style-type: none"> 1. All children with IBD spoke of the difficulty in recalling their experiences of early diagnosis. They felt that on overall they were too young to remember. The initial diagnosis occurred when they were on average less than 10 years of age. They recalled their parents taking them frequently to doctor’s appointments at that time. 2. Although they were sick, all the children spoke of an awareness that they were expected to attend school, be active, involved and to achieve just as any other child. 3. They had an awareness of their limitations brought on by the disease but did not feel that this prevented them from pursuing their interests and goals. 4. They were expected to perform their roles in the family just as their siblings were. 5. Siblings helped by tutoring, picking up homework, lending support, socializing and playing with their brother or sister.
<p>Mesosystem (School Experiences)</p>	<ul style="list-style-type: none"> - Experiences at school– related to IBD, achievement, other disabilities.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

	<p><u>Relations with teachers:</u></p> <ul style="list-style-type: none"> • Negative experiences with teachers who lacked empathy, restricted toilet access and would not assist with missed homework. There seemed to be a lack of awareness about IBD. Children did not feel that their teachers believed them when they were sick due to invisible nature of symptoms. There were only a few teachers that were helpful and understanding. • Besides having some teachers with negative attitudes, children with IBD enjoyed school because of their friendships. <p><u>Relations with other kids – friends? Extra-curricular activities?</u></p> <ul style="list-style-type: none"> • Despite disease child with IBD very physically active. They have many friends and long term friendships. They participate on sports teams or play sports with friends and siblings. There are some sports that they are unable to play such as contact football and karate. • Their friends help by picking up missed homework, advocating on child with IBD’s behalf at school, providing support and socializing. • They didn’t have difficulty taking their medications at school.
Macrosystem	<p>- Society’s values?</p> <ul style="list-style-type: none"> • Perception that IBD is a handicap and lower expectations for child with IBD. Perception that there are many things they are unable to do. Lack of societal awareness about the disease. They feel just like any other child their age.

Parent (Past, Present & Reflection Experiences)

Category	Sub-categories
Microsystem	<ul style="list-style-type: none"> - The relationship between child with IBD and parent. - The relationship between parent and siblings. - How IBD affects the relationship (these 3 points cover Family Systems Theory) -
Mesosystem	<ul style="list-style-type: none"> - Experiences at school–related to IBD, achievement, other disabilities. - Advocacy-more efforts required in public schools. - IEP for 1 child with learning disabilities. - No IEP for IBD symptoms. - Difference between public and private school setting/

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

	environment.
Exosystem	<ul style="list-style-type: none"> • Workplace: colleagues are judgmental, parental guilt, few employment options since parents need to take a lot of time off work for medical appointments. • Parents have to work full-time to afford medical expenses, private school and extra-curricular expenses • Reliance on relatives, i.e. grandparents, aunts, uncles to provide caregiving and support. • Many additional expenses such as parking fees, medications (Remicade) and medical tests that are not covered by medical insurance, etc. • Mothers were all active volunteers especially in IBD association, school boards and at school events. Their participation decreased as their children aged. • All mothers wanted to stay home and care for their child but four of the five mothers had to work to finance the family. • Mothers spent time conducting internet searches for additional financial support especially from government.
Macrosystem	<p>- Society's values?</p> <ul style="list-style-type: none"> • Stigma towards IBD because of symptoms (incontinence). • Stigma is due to lack of public knowledge about the disease. • Hope that a cure will be found soon. • They want their child & people to know that they can aspire & achieve anything despite having IBD.

Sibling (Past, Present & Reflection Experiences)

Category	Sub-categories
Microsystem	<ul style="list-style-type: none"> - The relationship between sibling and parent. Siblings felt they received less attention at times and had to self-advocate. - The relationship between child with IBD and siblings – jealousy, guilt, worry etc. Siblings were also caregivers, making meals, heating magic bag, and supporting their brother or sister with IBD. - How IBD affects the relationship (these 3 points cover Family Systems Theory). <p>There is some sibling rivalry but overall a great deal of care and support.</p>

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Mesosystem	<ul style="list-style-type: none">- Experiences at school – general description of sibling’s experiences:<ul style="list-style-type: none">• Some siblings experienced their own challenges at school such as bullying or also having IBD symptoms.• Siblings did not receive as much attention from parents and advocated for themselves.• Despite having their own challenges siblings were helpful and would tutor or pick up missed homework.
Macrosystem	<p>- Society’s values? Perception that child with IBD is different and has many limitations but they believed their brother or sister with IBD was just like any other child and enjoyed many of the same activities despite their disease.</p>

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Table 4 Central Themes and Study Categories

Microsystem (Parent)

1. Mother as primary care giver
2. Mother as primary advocate
3. Employment/Finances

Microsystem (Sibling)

1. How the diagnosis impacts the sibling
2. Siblings as helpers and caregivers
3. How sibling views IBD

Microsystem (IBD Child)

1. How their diagnosis impacts them
2. How medication impacts them
3. Role of family members as caregivers

Mesosystem (Parents)

1. Teachers lack empathy
2. No accommodations (i.e., no bathroom access)
3. Challenges

-Parents seek out resources

-Parents advocate

Mesosystem (IBD child)

1. Teachers lack empathy (i.e., Gym)
2. No accommodations
3. Challenges (i.e., Child with IBD ill-treated by teachers)

Exosystem (Parents and IBD child) – Community involvement

1. Parents: Active in IBD associations, especially mothers, internet use; also parents work experiences and how that impacts them, family, school and community.
2. IBD kids: Active in community as volunteers, sports, camps, and internet use.
3. Siblings: Active as volunteers, in sports, camps, and friends.

Macrosystem: (Parents)

1. Parents believe society views IBD as: Children with IBD are labelled but they should not be because the child is **not** the disease. High expectations for academic success; they can achieve anything.
2. Parents believe that society needs more awareness about the disease.

EXPERIENCES OF CHILDREN WITH INFLAMMATORY BOWEL DISEASE

Macrosystem: (Child with IBD)

1. Not different, just like any other child.

Macrosystem: (Sibling)

1. Not fun having IBD and they are limited in some ways by the disease symptoms.