

ADOLESCENT PERCEPTIONS OF LIVING WITH CROHN'S DISEASE

by

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DALHOUSIE UNIVERSITY  
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## **DEDICATION**

In memory of my brother, Robert Gerard Haas

And

For Stacy Tifford Kaufman... Thank you for your love and encouragement.

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## **Abstract**

In Canada, 3,300 children under the age of 20 are living with Crohn's Disease (CD) (Crohn's and Colitis Foundation of Canada, 2008). When an illness such as CD occurs in adolescence, the challenges associated with it are further compounded by the developmental tasks associated with this life stage. The purpose of this study was to understand how adolescents experience living with CD; to explore the impact of disease activity on their quality of life (QOL) and the strategies utilized to maintain and improve their QOL. Using a resiliency framework and narrative inquiry as a research methodology, seven adolescents were interviewed. The results include seven individual stories exemplifying their experiences, and from the stories shared, four patterns emerged: (1) Unconditional Support, (2) Embracing and Accepting Differences, (3) Attitudes and Personal Beliefs and (4) Daily Coping Strategies. These findings may have relevance for health professionals and families and adolescents with CD.

## **LIST OF ABBREVIATIONS USED**

IBD	Inflammatory Bowel Disease
CD	Crohn's Disease
UC	Ulcerative Colitis
HRQOL	Health Related Quality of Life
QOL	Quality of Life

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## **Chapter One**

### **Introduction**

#### *Background to the Study*

Crohn's Disease and Ulcerative Colitis, two idiopathic inflammatory bowel diseases (IBD), are chronic illnesses with no known cure (Crohn's and Colitis Foundation of Canada, 2008; Engstrom, 1992; Porth, 1998). The clinical course is often unpredictable, with intermittent exacerbations and periods of remission, and as many as half of those with IBD relapse annually (Cunningham, Drotar, Palermo, McGowan & Arendt, 2007; Engstrom, 1992; Porth, 1998; Sewitch, Abrahamowicz, Bittton, Daly, Wild, Cohen, Katz, Szego & Dobkin, 2001). Of the 200,500 individuals living with IBD, it has been reported that 3,300 children under the age of 20 are living with CD and 1,600 children under the age of 20 are living with UC (Crohn's and Colitis Foundation of Canada, 2008).

Adolescents are the least researched of all age groups. According to Wong, Hockenberry-Eaton, Winkelstein and Ahmann, (1999), it is often difficult to recruit adolescents into research studies, as other things are more pressing in the adolescent's life such as interacting with their peer group. Another reason given for the lack of recruitment and lack of adolescent research is adolescents often do not want to talk to and do not trust individuals (research nurses/research physicians) they perceive in positions of authority (Kyngas, Hentinen & Barlow, 1998).

The literature related to exploring adolescent perceptions of living with Crohn's Disease (CD) is scarce. Most of the existing research literature focuses on the pathophysiology and treatment of CD. In addition, in the literature, most research studies

that do offer some insight into the daily life of adolescents with CD have sample populations that include not only CD adolescents but Ulcerative Colitis (UC) adolescents as well. These two conditions occur as two separate clinical entities but since they share some similar clinical characteristics, they are typically grouped and studied together under the condition known as Inflammatory Bowel Disease (IBD). Because of this, IBD literature and UC literature will be integrated into this study, with the awareness that although CD and UC share many similar characteristics, they differ from a pathophysiology perspective and therefore may experience their illnesses differently.

In addition to the above, the sample populations in the majority of IBD, UC, and CD studies consist of adolescents being grouped in with their young adult counterparts. The interpretation and generalizability of findings from these studies is difficult for this reason since adolescents developmentally and cognitively are quite different from their young adult counterparts.

Most of the research literature exploring the client's subjective experience of living with CD, UC, or IBD has been conducted within the adult population. This literature is focused not so much on the everyday experiences of adults living with these conditions, but the deficits or problems, concerns, and worries it brings to one's life. In addition, a large amount of the research about CD and IBD is based on quantitative methodologies using questionnaires such as The Rating Form of Inflammatory Bowel Disease Concerns to determine the concerns, worries, and issues this population presents (Drossman, Patrick, Mitchell, Edwina, Zagami & Appelbaum, 1989). While the questionnaires have proven to be reliable in adult patients (Guyatt, Mitchell, Irvine, Singer, Williams, Goodacre & Thompkins, 1989), their applicability in children and



youth, including age appropriateness of questions asked, the selection of respondents, the optimal mode of administration, and comprehensibility of the instrument, remains a point of debate (Koot & Bootman, 1999; Joachim & Milne, 1987).

Truly understanding the experiences of adolescents with CD places nurses and health care professionals in a better position to be able to provide more comprehensive, holistic health care to this particular group of clients. In addition, adolescents are more likely to adhere to their treatment regime if they feel their concerns are being addressed and their experiences with their condition are being understood (Kyngas & Duffy, 2000; Kyngas, Hentinen, & Barlow, 1998). Finally, providing a venue for adolescents to voice their concerns and express how they cope with these concerns will create an environment in which the adolescent is seen as a partner in care thus creating more of a collaborative partnership, an approach that is supported in all health care institutions (Kyngas & Duffy, 2000; Kyngas, Hentinen, & Barlow, 1998).

### Conceptual Framework

For several decades, clinical practice within the health professions including nursing has been dominated by a deficit, problem-solving approach (Feeley & Gottlieb, 2000; McAllister, 2003). The twentieth century, with an emphasis on science and technology, has provided the right atmosphere for this dominant ideology to take hold (McAllister, 2003). Health care has benefited from the advances in science and technology particularly in diagnostic and illness treatment, but this ideology has revealed certain drawbacks (McAllister, 2003). First of all, technological, scientific solutions to some of the social issues healthcare clients encounter have been only partially successful (McAllister, 2003). In addition, the deficit, problem-solving approach tends to focus on

what is wrong, missing, or abnormal within a family/individual and how health professionals can fix this problem (Feeley & Gottlieb, 2000; McAllister, 2003). This approach to interacting with clients is both pessimistic and paternalistic, and supports the notion that the health care provider is both omnipotent and omniscient (Feeley & Gottlieb, 2000; McAllister, 2003). As a result, the client/health care professional interaction is neither liberating nor empowering to the client and can produce passivity and docility on the part of the client (Feeley & Gottlieb, 2000; McAllister, 2003).

A different ideology, one that focuses on client strengths and is both solution and resiliency oriented, began to take hold in the health care arena in the early eighties and nineties (McAllister, 2003). As early as 1950, Hill studied families' responses to dealing with stressors, especially the stressor of having a family member diagnosed with a chronic illness (McCubbin et al., 1998). Hill proposed that the adaptation of families to these stressors is influenced by the resources available to them (McCubbin et al., 1998). These resources would determine how the family would meet and manage the demands they might face (McCubbin et al., 1998). Other nursing researchers such as McCubbin and McCubbin (1993), Boss, Lavee and Olson (1988), Dunst, Trivette and Deal (1988), and Lazarus and Folkman (1984) have built upon Hill's initial work. These researchers have examined individual, family, and community strengths/resources present during times of adversity and how these strengths and resources have led to successful outcomes for families and individuals facing difficult challenges (McCubbin & McCubbin, 1993; McCubbin et al., 1998). In addition, these researchers have explored the concepts of hope, family/individual adjustment, and adaptation especially during times of extreme stress (McCubbin et al., 1998).

The discipline of psychology, in which researchers have focused much of its research attention on studying the “characteristics of people who survive, overcome and endure stressful situations” (McAllister, 2003, p. 531), has also contributed greatly to the evolution of this resiliency/strengths base approach. Nursing and psychology are inextricably linked, due to both of their emphasis on studying the human condition and as a result psychological research into the concepts of resiliency and client strengths has been integrated into the nursing resiliency literature.

A resiliency approach that is both strengths base and solutions orientated helps resolve some of the inherent flaws that exist in the deficit approach, especially with respect to the issues of passivity, paternalism and disempowerment of clients (McAllister, 2003). This approach changes the way in which health care professionals and clients interact with one another; identifying and maximizing family/individual strengths, achievements, capacities, competencies, and resources (Feeley & Gottlieb, 2000; McAllister, 2003). This approach is grounded in the belief that all families/individuals possess the abilities and strengths to manage effectively a stressor/health care issue (Feeley & Gottlieb, 2000; McAllister, 2003).

This approach to health care delivery has been in existence for several decades, but within the nursing arena much of the literature that exists on this topic is still theoretical in nature (McAllister, 2003). In undergraduate nursing programs and in clinical practice settings, identifying nursing problems and writing nursing diagnoses and nursing action plans is still the dominant approach being used to guide nursing care (McAllister, 2003). This approach to health care delivery is in keeping with the deficit, problem-solving approach described above and does not support the nursing philosophy

of providing holistic, partnered care to its clients - care that focuses on empowering clients to use the resources available to them to help them cope with their health issues (McAllister, 2003). As a result, this study will utilize a strengths/resiliency-based perspective with the goal of integrating existing theoretical knowledge on this topic into nursing practice. In other words, adolescent perceptions of living daily with CD will be explored through examination of strengths, capacities, competencies, and resources that adolescents utilize to cope with their chronic condition. In the studies that do exist in the adolescent literature on this topic, researchers have shown that the majority of adolescents cope and show resilience in the face of adversity, especially the adversity they encounter when living with a chronic illness (Brydolf & Segesten, 1996; Brydolf & Segesten, 1996; Meijer et al., 2002).

Resiliency has no single definition but in examining the concept of resiliency some common themes emerge (Steinhaurer, 1998). Two of the most common themes are the emphasis on coping and utilization of resources in the face of adversity/stress (Steinhaurer, 1998; Stewart, Reid & Mangham, 1997; Ungar, 2004). Steinhaurer (1998) integrates the above themes into his definition of resiliency and he defines resiliency as “unusually good adaptation in the face of extreme stress” (p. 51). Unusually good adaptation means that the resilient individual has developed the resources needed to cope with and overcome difficult conditions. Several sources of resiliency allow an individual to transcend adversity, including genetic make-up and health, goodness of fit between child and parent, parental capacity to support the optimal development of their child, the level of chronic stress experienced by the family/child, and the perspectives of the parents and child when confronted with stress (Steinhaurer, 1998).

Other authors have emphasized these two central themes, but have integrated other themes into their definition of resiliency. For example, Stewart, Reid and Mangham (1997) believe resiliency is achieved through creating a balance between risk and protective factors. Risk factors typically stem from multiple life stressors, a traumatic event, or cumulative stress often referred to as a pile up of stressors from a variety of personal and environmental factors (Stewart et al., 1997). Examples of risk factors include being diagnosed with a chronic illness, difficult temperament, poverty, parental pathology, developmental transitioning, and losing a family member (Stewart et al., 1997). Protective factors, which will be discussed in-depth in the upcoming paragraphs, minimize the negative influences that risk factors may have on an individual; enhancing the likelihood of a positive outcome (Stewart et al., 1997).

Resiliency is also defined differently depending on one's philosophical approach. An ecological and constructivists approach to resiliency will be discussed to highlight this point (Ungar, 2004). Traditionally, an ecological approach, which has been described above, emphasizes the predictable relationships that exist between risk and protective factors, where protective factors interact with risk factors to reduce the potential for negative outcomes (Ungar, 2004). This approach supports the theory that health outcomes are predetermined, and resilience is defined as health despite adversity.

Resiliency within a constructionist's approach is defined as the outcome that results from successful negotiations between individuals and their environment for the resources that would allow them to define themselves as healthy amidst conditions collectively viewed as adverse (Ungar, 2004). One of the aims of this approach is to illustrate that resilience and health can be achieved through alternative pathways typically

thought to indicate vulnerability or risk (Ungar, 2004). For example, youth who decide to live on the streets to escape an abusive home life are often labelled by society as delinquent or disordered. According to the ecological approach, these youth are at risk for a poor outcome. However, in keeping with the constructionist definition of resilience, these youth often label themselves as incredibly resilient and healthy.

In exploring the concept of resiliency, researchers have shown that resiliency factors are multidimensional in nature, and as a result different categories are often used to classify them (Steinhauer, 1998; Ungar, 2004). When these factors are utilized effectively, they enhance the likelihood of a positive outcome (Steinhauer, 1998; Ungar, 2004). The first category, personal protective factors, includes: 1) optimism in the face of adversity; 2) autonomy; and 3) a sense of hope, meaning; and purpose in life (Steinhauer, 1998; Stewart et al., 1997). Resilient individuals may possess the will to overcome, display high levels of self-confidence and self-esteem, and have a sense of connectedness with others, nature and God (Haase, 2004; Haase et al., 1992; Mandleco & Peery, 2000; Steinhauer, 1998; Stewart et al., 1997). They report a sense of well-being, enhanced feelings of self-worth, feelings of being healed, an ability to move beyond one's own self-interest, and acceptance of an inescapable situation (Haase et al., 1992). Other positive personal protective characteristics present in resilient individuals include: 1) high levels of motivation; 2) strong sense of control over one's life; 3) self-awareness; 4) self-reliance; and 5) self-efficiency (Haase et al., 1992; Mandleco & Peery, 2000; Meijer et al., 2002; Steinhauer, 1998; Stewart et al., 1997).

One of the most effective coping strategies utilized by resilient individuals is their ability to recruit social support, especially during difficult times (Mandleco & Peery,

2000; Meijer et al., 2002; Ryan-Wenger, 1996; Steinhaurer, 1998; Stewart et al., 1997).

Other coping strategies include their ability to endure, to problem-solve, and to seek appropriate information that would allow them to successfully adapt to some of the challenges they may encounter in life (Mandleco & Peery, 2000; Meijer et al., 2002; Ryan-Wenger, 1996; Steinhaurer, 1998; Stewart et al., 1997).

The second category, family protective factors, also fosters resilience in families and individuals (Mandleco & Peery, 2000; Steinhaurer, 1998; Stewart et al., 1997).

These include: 1) a caring, cohesive, and supportive family with good parent-child attachment; 2) high but achievable expectations for family members; 3) the opportunity for all family member to participate in decision-making; 4) shared facilitative beliefs such as religious beliefs; 5) optimistic outlook in the face of adversity; and 6) financial and economic resources such as extended family and health insurance (Mandleco & Peery, 2000; Steinhauer, 1998; Stewart, et al., 1997; Walsh, 2003).

The final category is community protective factors. These include such things as safe neighbourhoods free of violence and crime and the formation of positive relationships with other adults (ministers, youth leaders, teachers, or adult family friends) within that neighbourhood (Mandleco & Peery, 2000; Stewart et al., 1997; Walsh, 2003). Community protective factors also encompass supportive schools that foster and support its members and sets achievable expectations (Mandleco & Peery, 2000; Stewart et al., 1997 Walsh, 2003). In addition, resiliency is enhanced in communities where its members have access to health care and social services resources (Mandleco & Peery, 2000; Ungar, 2004). And lastly, community resources such as youth organizations, including after school programs or church groups, are also significant as they provide a

venue for individuals to become connected with caring, supportive, competent adults, a factor that is important in fostering resiliency in individuals (Mandleco & Peery, 2000; Stewart et al., 1997; Walsh, 2003).

Very little research to date has been conducted using the resiliency model on adolescents with CD. In this research study, the following definition of resiliency by Mandelco and Peery (2000) will be used, “Resilience typically refers to the tendency to spring back, rebound, or recoil and involves the capacity to respond and endure, or develop and master in spite of life stressors or adversity” (p. 99). In addition, an ecological approach will be employed and resiliency will be viewed as an outcome that results when individual/family/community protective factors (strengths, capacities, competencies and resources) are utilized successfully and allows an adolescent to successfully integrate a chronic illness into his or her daily life (Feeley & Gottlieb, 2000; McAllister, 2003). This research study will place particular emphasis on exploring the personal protective factors that adolescents utilize to help them cope daily with their illness. Research into the concept of resiliency has placed enormous emphasis on personal protective factors and the role they play in allowing individuals to transcend adversity and successfully integrate a chronic illness into their everyday life. However, to date, no such research has been conducted with adolescents who have IBD.

#### *Purpose of the Study*

The purpose of this study is to understand how adolescents experience living with Crohn’s Disease (CD) using a narrative inquiry approach.

#### *Research Objectives:*



- To provide adolescents with an opportunity to share stories exploring the impact of disease activity on their QOL.
- To identify social, emotional or management related strategies adolescents utilize during the active phases and non-active phases of their CD to maintain and improve their QOL.

#### *Research Questions*

- (a) What do adolescents describe as the impact of the disease on their QOL?
- (b) What are some of the social, emotional or management related strategies adolescents utilize during the active and non-active phases of their CD to maintain and improve their QOL.

#### *Summary*

Adolescents are the least researched of all age groups, and although some research has accumulated in the area of adolescents living with CD, this research is limited in its focus. Most of the research that is present focuses on three things: the pathophysiology of the CD, the treatments available, and the worries and concerns individuals with CD face daily. There is very little research to date that focuses on exploring the adolescent experience of living daily with CD from a resiliency perspective. It has been noted in the literature that individuals, including adolescents with chronic illnesses, are more likely to achieve a positive outcome in the face of extreme adversity when certain protective factors, such as peer support, are present in their lives. This study approaches the topic from a resiliency perspective with the aim of exploring the emotional, social and management related strategies adolescents utilize to successfully integrate their chronic illness into their everyday lives.

### *Definition of Terms*

For the purpose of this research, the following definitions are used.

#### *Inflammatory Bowel Disease (IBD)*

IBD is used to designate two inflammatory bowel conditions: Crohn's Disease (CD) and Ulcerative Colitis (UC) (Porth, 1998).

#### *Crohn's Disease (CD)*

CD is a recurrent granulomatous type of inflammatory response that can affect any area of the gastrointestinal tract from the mouth to the anus. CD is often accompanied by the formation of fistulas which may develop between the bowel and other sites including the bladder, vagina, urethra, and skin. The principal symptoms include intermittent diarrhea, colicky pain, weight loss, electrolyte disorders, malaise, and low grade fever (Porth, 1998).

#### *Ulcerative Colitis (UC)*

UC is a nonspecific inflammatory condition confined to the rectum and colon. UC usually follows a course of remissions and exacerbations, and some of the common characteristics are diarrhea and stool that typically contains blood and mucus. Other symptoms include fever, acute abdominal pain, cramping, fecal incontinence, anorexia, weakness and fatigue (Porth, 1998).

#### *Resiliency Terms*

(a) *Hope* is defined as an energizing force; with the individual orientated towards achieving desirable future outcomes (Philips-Salimi, Haase, Kinter, Monahan & Azzouz, 2007).

(b) *Optimism* is defined as the propensity to expect positive outcomes (Mannix, Feldman & Moody, 2008; Weber, Rose-Puskar, & Ren, 2010).

c) *Sense of meaning* refers to the realization there is meaning to be found in hardship, suffering, and adverse circumstances such as having to live with a chronic illness (Kim & Kang, 2003). This meaning is often realized overtime and as one becomes use to living under adverse circumstances (Kim & Kang, 2003). When a sense of meaning is found, individuals are often able to endure adverse circumstances and continue to remain hopeful of living a purposeful life (Kim& Kang, 2003). Individuals who find a sense of meaning are less likely to lower their expectations for their lives and are more likely to respond to problems caused by a stressor with a more positive attitude (Kim & Kang, 2003).

d) *QOL/Health Related Quality of Life (HRQOL)*: It describes the overall impact the IBD/CD is having on the life of the affected individual (Otley, Smith, Nicholas, Munk, Avolio, Sherman & Griffiths, 2002). Specifically, it looks at the physical, emotional, and social functioning of the individual with IBD and explores the behaviours, perceptions and attitudes of this individual in relation to their heath status (Cunningham et al., 2007; Dorrain, Dempster & Adari, 2009).

## **Chapter Two**

### **Literature Review**

Studies conducted on adolescents with CD are scarce in the research literature, and the majority of research studies consists of both CD and UC participants. Both of these conditions fall under the umbrella of IBD. As a result, this literature review will present findings from CD, UC and IBD studies. In addition, since the vast majority of these studies focus on IBD, a thorough discussion around IBD and its impact on adolescents will be presented.

CD and IBD necessitates that the affected individuals become accustomed to and integrate the illness and its treatment into their daily lives. During adolescence, the challenges of living with CD or IBD are compounded by the developmental issues also associated with this stage in their lives. The following literature review will explore the conditions known as IBD and CD - how these conditions are managed and a discussion around how IBD/CD disease activity and disease severity impacts the adolescent's quality of life (QOL). It will also include an exploration of the physical, social, and psychological impact IBD and CD has on the lives of adolescents, and the gaps in adolescent IBD and CD research.

#### *Inflammatory Bowel Disease (IBD)*

IBD is equally distributed among males and females, it occurs more in individuals living in urban areas, and is more prevalent among Caucasians, especially in the Jewish population (Baron, 2002; Rayhorn, 2001). It has been noted that the incidence of IBD is increasing globally, especially in the pediatric population (Cunningham et al., 2007; Lynch & Spence, 2007). IBD affects 90 to 300 of every 100,000 people, and in 15-20%

of cases the disease manifests itself before the age of twenty, with the majority of individuals diagnosed during adolescence (Cunningham et., 2007; Engstrom, 1992; Daniel, 2002; Giese & Terrell, 1996; Szigethy, 2005).

CD, in particular, affects 3.1 to 14.6 per 100,000 persons in North America, and although CD can occur at any age, cases cluster around two age ranges: 15-25 years and 50-80 years (Crohn's and Colitis Foundation of Canada, 2008; Goldfarb, Pizzi, Fuhr, Salvador, Sikirica, Kornbluth, & Livis, 2004). In addition, CD is more common in Caucasians, women, and individuals of Jewish descent (Cunningham et al., 2007; Crohn's and Colitis Foundation of Canada, 2008; Knutson, Greenberg, & Cronau, 2004).

It has been noted in the research literature that Canada has the highest frequency of UC and CD in the world (Cunningham et al., 2007; Crohn's and Colitis Foundation of Canada, 2008). In 2008, it was estimated that 200,500 individuals were living with IBD in Canada - 112,000 had been diagnosed with CD, while 88,500 individuals were living with UC (Crohn's and Colitis Foundation of Canada, 2008).

Although UC and CD occur as separate clinical entities, they share many similar clinical characteristics including frequent and often uncontrollable episodes of diarrhea, abdominal pain, gastrointestinal bleeding, anorexia and growth failure (Crohn's and Colitis Foundation of Canada, 2008; Cunningham et al., 2007; Decker, 2002; Drossman, Leserman, Zhiming, Mitchell, Zagami & Patrick, 1991; Engstrom, 1992; Giese & Terrell, 1996; Kirschner, 1998; Koot & Bouman, 1999; Rayhorn, 2001). UC is limited to the mucosa in the colon, with rectal bleeding, abdominal pain, and the urge to defecate being the most prominent symptoms (Crohn's and Colitis Foundation of Canada, 2008; Engstrom, 1992; Daniel, 2002; Giese & Terrell, 1996; Porth, 1998). CD, on the other

hand, can affect any part of the gastrointestinal tract with pain in the right lower quadrant, cramping, flatulence, nausea, fever, diarrhea, and weight loss present as the most common symptoms (Crohn's and Colitis Foundation of Canada, 2008; Engstrom, 1992; Giese & Terrell, 1996; Porth, 1998). CD is often more acute in nature but is likely to progress more slowly and less aggressively than UC (Daniel, 2002). The etiology of these diseases is unknown but immunological and genetically determined processes and environmental factors appear to be involved (Crohn's and Colitis Foundation of Canada, 2008; Engstrom, 1992; Merchant, 2007; Porth, 1998; Szigethy, 2005; Rayhorn, 2001).

#### *Management of IBD and CD*

Since there is no cure for IBD/CD, the goal of treatment is to bring about symptom relief and slow the progression of the disease (Crohn's and Colitis Foundation of Canada, 2008; Merchant, 2007).

Management of IBD often entails dietary modification that may include the introduction of intensive nutritional therapy via feeding tubes or total parental nutrition (TPN) to provide adequate intake and reverse impaired weight and growth velocity (Baron, 2002; Brydolf & Segesten, 1994; Crohn's and Colitis Foundation of Canada, 2008; Decker, 2000; Drossman et al., 1991; Hommel, Shannon, Sander, & Baldassano, 2011; Kirschner, 1998; Peterson 2008). When medical management fails and depending on the severity and extent of IBD, surgery may be required to treat complications such as perforations, hemorrhages, obstructions, toxic megacolons, abscesses, fistulas and intractability (Baron, 2002; Brydolf & Segesten, 1994; Crohn's and Colitis Foundation of Canada, 2008; Decker, 2000; Drossman et al., 1991; Hommel et al., 2011; Kirschner, 1998; Merchant, 2007; Porth, 1998). Over 50-70% of children with CD will require

surgical intervention to help resolve intestinal obstructions and fistulizing disease and to remove diseased portions of the bowel (Crohn's and Colitis Foundation of Canada, 2008; Merchant, 2007; Skinner, 2002). Surgical intervention may also include colectomy, colostomy, or bowel resection (Crohn's and Colitis Foundation of Canada, 2008; Merchant, 2007; Skinner, 2002).

A daily medication regimen may also be required. The primary goal of pharmacological treatment in IBD and CD is to bring the inflammation in the gastrointestinal tract under control and to bring the symptoms associated with IBD and CD under control (Baron, 2002; Brydolf & Segesten, 1994; Crohn's and Colitis Foundation of Canada, 2008; Cunningham et al., 2007; Daniel, 2002; Decker, 2000; Drossman et al., 1991; Hommel et al., 2011; Merchant, 2007; Skinner, 2002).

#### *Adolescence and CD/IBD*

Adolescence, as a developmental stage, is a time of great physical, social, and psychological change (Brydolf & Segesten, 1996; Decker, 2000; Peterson, 2008; Wong et al., 1999). For adolescents with health problems such as IBD, the adaptation to the normal developmental changes of adolescence is made even more complicated. The UC or CD can either hamper and/or exaggerate the developmental changes, thus making the transition through this period very difficult (Brydolf & Segesten, 1996; Decker, 2000; Peterson, 2008). The following discussion will include a general overview of how IBD/CD affects the adolescent's overall QOL and how disease activity and disease severity impacts the adolescent. It will also include an exploration of the physical, social, and psychological impact IBD and/or UC/CD can have on the daily life of an adolescent. Finally, gaps in the adolescent IBD and CD literature will be identified. The majority of

this discussion will revolve around IBD, as there is very little research completed in the area of exploring the impact of just the condition CD on the daily life of an adolescent.

### *Quality of Life (QOL) and IBD*

QOL or health related quality of life (HRQOL) is now a term more popularly used in adolescent IBD/CD literature. It describes the overall impact the IBD/CD is having on the life of the affected individual (Otley, Smith, Nicholas, Munk, Avolio, Sherman & Griffiths, 2002). Specifically, it looks at the physical, emotional and social functioning of the individual with IBD and explores the behaviours, perceptions and attitudes of this individual in relation to their health status (Cunningham et al., 2007; Dorrain, Dempster & Adari, 2009). It is felt this approach provides a more global measure of the IBD individual's health status rather than just disease parameters alone (Otley, Smith, Nicholas, Munk, Avolio, Sherman & Griffiths, 2002).

Studies exploring the experiences and impact of the IBD/CD on the individuals QOL/HRQOL seem to be approached mostly from a deficit perspective. The results of these studies are varied. Yi et al. (2009) reported poorer physical functioning and poorer general health perceptions in adolescents with IBD/CD but emotional, social and school functioning scores were not significant. In other studies, children and adolescents reported lower HRQOL in the areas of physical functioning, psychological functioning and autonomy (Grootenhuis et al., et al., 2009; Herzer et al., 2011). Dorrian et al. (2009) determined that individual personal beliefs about IBD play a more significant role on QOL than things like physical functioning. Finally, families with adolescents with CD, who had a high degree of family dysfunction, reported lower overall QOL scores, especially in the areas of general well-being and social functioning (Herzer et al., 2011).



In comparing UC and CD, lower QOL scores were found in individuals with CD (Herzer et al., 2011; Koot & Bouman, 1999; Sewitch et al., 2001). The difference was attributed to the fact that CD individuals seem to experience more severe disease than UC individuals (Herzer et al., 2011; Koot & Bouman, 1999; Sewitch et al., 2001).

On a more positive note, less frequent occurrence of symptoms, longer disease duration, higher level of education, symptom inactivity and less frequent hospitalizations have been found to predict better QOL in children and adolescents living with IBD (Dorrain et al., 2009; Herzer et al., 2011).

It should also be noted that other research studies on adolescents with IBD have shown that the impact of IBD on everyday life in relation to nutritional intake, elimination activities, recreational activities and sexual function is minimal (Brydolf & Segesten, 1994; Joachim & Miline, 1987; Koot & Bouman, 1999). In another study, it was indicated that IBD has little impact on adolescents' relationships and ability to attend school. Moreover, it has very little impact on their emotional and psychology well-being (Joachim & Miline, 1987).

#### Active vs. Non-Active Disease

Current adolescent IBD literature is now slowly beginning to explore the impact of active and non-active IBD on adolescents' QOL. The few research studies that do exist in this area reveal that disease activity and disease severity have the most negative impact on children's/adolescents' QOL. Herzer et al. (2011) reported that disease activity and disease severity were associated with lower HRQOL scores in the following domains: general well-being, emotional functioning, social functioning, and body image. Cunningham et al. (2007) showed that adolescents who experience more active disease

and more steroid treatment related symptoms perceived their general health status as less adequate than their healthy peers. All other QOL domains' scores were not statistically significant (Cunnigham et al., 2007). In the same study, however, parents reported the impact of IBD on their children's or adolescent's QOL as quite significant. They perceived their child/adolescent as having more limited physical functioning and general health and experiencing more role and activity limitations, more bodily pain, and more depression and anxiety (Cunnigham et al., 2007).

The literature indicates a significant relationship between increased disease activity and disease severity and poor adolescent adherence to oral IBD meds (Hommel, et al., 2011). It is estimated that 65-75% of adolescents show non-adherence to their oral IBD regime (Hommel et al., 2011). Some barriers to adherence include: the complexity of the IBD treatment routine, forgetting to get medication refills, forgetting to take medications due to being engaged in other activities, and not being at home during the time in which their meds are to be taken (Hommel et al., 2011). Adolescents are also less likely to adhere to medication and therapy regimes when these regimes cause them to look physically different from their peers (Kyngas & Rissanen, 2000; Taylor et al., 2008).

### *Physical Impact*

Adolescents with IBD experience frequent and often uncontrollable episodes of diarrhea, abdominal pain, gastrointestinal/rectal bleeding, anorexia, delayed growth, puberty and sexual maturation, nausea, flatulence and physical exhaustion (Crohn's and Colitis Foundation of Canada, 2008; Danile, 2002; Decker, 2002; Drossman et al., 1991; Engstrom, 1992; Giese & Terrell, 1996; Kirschner, 1998; Koot & Bouman, 1999; Lynch & Spence, 2007; Merchant, 2007; Mayo Clinic, 2010; Porth, 1998; Rayhorn, 2001).

Panic over these uncontrollable physical symptoms, especially when around peers, is often reported by adolescents (Lynch & Spence, 2007). These symptoms often require the adolescent to stay close to home because of the constant need to be near bathroom facilities. As a result, the adolescent may miss out on activities such as sports, shopping and “hanging out” with friends (Brydolf & Segesten, 1996; Daniel, 2002; Decker, 2000; Loonen, Derkx, & Griffiths, 2002; Peterson, 2008). Given the importance of peer support and peer bonding to the adolescent, IBD could have significant social and psychological implications for them. These implications will be summarized in the subsequent paragraphs.

#### *Medications Side Effects and Physical Impact*

The medications required to keep the IBD under control have visible side effects including weight gain, mood changes, loss of energy, puffiness, being too thin, weight loss, reduced height, delayed puberty, delayed sexual maturation, retarded bone development, and acne (Brydolf & Segesten, 1994; Brydolf & Segesten, 1996; Daniel, 2002; Decker, 2000; Drossman et al., 1991; Koot & Bouman, 1999; Hommel et al., 2011; Peterson, 2008; Rayhorn, 2001). In addition, diarrhea, urgency to defecate, fecal incontinence, and surgical ostomies can lead to the formation of painful fistulas and foul smelling, draining abscesses on the buttocks or the perianal area (Gazzard et al., 1987; Giese & Terrell, 1996; Peterson, 2008; Salter, 1992; Wong et al., 1999). These side effects can have a significant impact on body image, and often lead to the one thing adolescents are trying to avoid: looking physically different from their peers (Brydolf & Segesten, 1996; Brydolf & Segesten, 1994; Calsbeek, Rijken, Bekkers, Dekker, & Van Berge Henegouwen, 2006; Cotton, Kudel, Roberts, Pallerla, Tsevat, Succop & Yi, 2009;

Daniel, 2002; Decker, 2000; Koot & Bouman, 1999; Lynch & Spence, 2007; Peterson, 2008; Rayhorn, 2001). Poor body image, combined with the sense of feeling different, have been associated with feelings of loss, powerlessness, guilt, embarrassment, depression, and low self-esteem (Brydolf & Segesten, 1996; Calsbeek et al., 2006; Cotton et al., 2009; Decker, 2000; Loonen, Derkx, & Griffiths, 2002; Lynch & Spence, 2007; Peterson, 2008; Rayhorn, 2001; Szigethy, 2005).

### *Pain and IBD*

Pain associated with IBD and its impact on the adolescent is an area now receiving a little more attention in IBD/CD literature. The types of pain mentioned include pain from eating, especially abdominal pain; pain from various procedures and surgeries; and pain from stoma formation (Lynch & Spencer, 2007; Merchant, 2007). An increase in the amount of physical pain during times of stress has also been noted in the literature (Merchant, 2007). In one study, an adolescent used the following brief but powerful statement to show the negative impact pain has had on her life: It is a “living hell...have to lie on the couch in agony with pain in my stomach” (Lynch & Spencer, 2007, p. 226). More attention is now also being paid to the extra-intestinal manifestations of IBD, especially the sacroiliitis, ankylosing spondylitis, and arthritic peripheral joint pain experienced by children and adolescents with IBD (Evans, P & Pardi, D, 2007; Merchant, 2007) Both the abdominal pain mentioned above and the extra-intestinal pain of the IBD have been shown to negatively impact the adolescent’s ability to attend school regularly, to concentrate in school, and to achieve academic success (Britto, DeVillis, Hornung, DeFriese, Atherton, & Slap, 2004; Calsbeek et al.,

2006; Cunningham et al., 2007; Crohn's and Colitis Foundation of Canada, 2008; Lynch & Spence, 2007; Mayo Clinic 2010; Peterson, 2008; Sinclair, 2009).

### *Social Impact*

The chronic nature of IBD and its daily burden, which include the physical complaints, severe treatment side effects, the disability it causes in endurance, the adherence to a dietary regime, the need to always be near a washroom, and the presence of an ostomy, often result in frequent hospitalizations and absences in leisure and school activities, with one study reporting 20-40 missed days of school over 1 year (Brydolf & Segesten, 1996; Calsbeek et al., 2006; Cotton et al., 2009; Daniel, 2002; Decker, 2000; Groothenuis, Maurice-Stam, Derkx & Last, 2009; Koot & Bouman, 1999; Lynch & Spence, 2007; Peterson, 2008).

IBD/CD often interferes with the adolescent's ability to socialize with friends and develop supportive peer group relations, which is one of the developmental milestones of adolescence (Brydolf & Segesten, 1996; Daniel, 2002; Decker, 2000; Groothenuis et al., 2009; Koot & Bouman, 1999; Loonen, Derkx, & Griffiths, 2002; Lynch & Spence, 2007; Peterson, 2008; Sinclair, 2009). One of the reasons for decreased socialization with peers may be due to the IBD related changes in physical appearance (Brydolf & Segesten, 1996; Calsbeek et al., 2006; Cotton et al., 2009; Decker, 2000; Groothenuis et al., 2009; Lynch & Spence, 2007; Peterson, 2008). Due to these changes, adolescents often withdraw from interacting with their peers out of fears of rejection, or they may be ostracized from their peer group for looking different (Brydolf & Segesten, 1996; Decker, 2000; Groothenuis et al., 2009; Lynch & Spence, 2007; Peterson, 2008). This has translated into accounts by adolescents of feelings of loneliness, isolation, a sense of

feeling different from their peers, and a sense of failure over not being able to participate in activities (Brydolf & Segesten, 1996; Calsbeek et al., 2006; Cotton et al., 2009; Groothenuis et al., 2009; Lynch & Spence, 2007; Peterson, 2008; Salter, 1992).

Another milestone of adolescence is the development of social skills, especially the skill of learning to interact with others (Brydolf & Segesten, 1996; Decker, 2000; Loonen, Derkx, & Griffiths, 2002; Groothenuis et al., 2009; Lynch & Spence, 2007). It has been shown that IBD can interfere with normal social development, which can negatively impact the adolescents' self-confidence and self-esteem as well as affect their ability to feel a sense of control and independence over their lives (Brydolf & Segesten, 1996; Decker, 2000; Loonen, Derkx, & Griffiths, 2002; Groothenuis et al., 2009; Lynch & Spence, 2007).

#### *Holidays and Social Impact*

In a phenomenological study by Daniels (2002), participants, who were between 18-24 years of age, reported that disease activity and imposed food restrictions related to their disease made it difficult for them to participate in holiday celebrations such as Christmas and Thanksgiving. They also felt they had a disease that they could not talk about socially and as a result, they reported feelings of alienation from their friends and family (Daniels, 2002).

#### *Psychological Impact*

The delayed biological/physical development and illness state of the adolescent with IBD impacts the parent-child relationship in very dramatic ways (Brydolf & Segesten, 1996; Decker, 2000; Fishman, Barendse, Hait, Burdick & Arnold, 2010; Reichenberg, Lindfrey & Salman, 2007). Parents of adolescents with IBD have a

tendency to overprotect the chronically ill child (Brydolf & Segesten, 1996; Decker, 2000; Fishman et al., 2010; Herzer et al., 2011; Rayhorn, 2001), and that overprotection frequently manifests itself in the form of parents taking on a lot of the responsibility for IBD management. This includes taking the adolescent to clinic appointments, getting prescriptions refilled, and reminding the adolescent to take his/her medications (Fishman et al., 2010; Herzer et al., 2011). As a result of this, parents often start to view their son or daughter in a child-like fashion and leave them out of IBD information gathering and health care decision-making (Brydolf & Segesten, 1996; Brydolf & Segesten, 1994; Daniel, 2004; Decker, 2000; Koot & Bootman, 1999; Rayhorn, 2001). All of the above parental actions have been associated with cultivating increased dependency and passivity in the adolescent, thus preventing them from achieving the adolescent developmental milestone of increased independence (Brydolf & Segesten, 1996; Decker, 2000; Fishman et al., 2010; Herzer et al., 2011; Reichenberg et al., 2007). It has also translated into accounts by adolescents of feelings of ambivalence toward their parents' concern for them. This ambivalence is expressed as an oscillation between the adolescent seeking parental help with IBD management to refusing any of their help (Reichenberg et al., 2007). Lastly, adolescents often perceive these actions by their parents as unsupportive. This lack of support has been associated with feelings of isolation, alienation, low self-confidence, low self-esteem, anger, and fear in social situations (Brydolf & Segesten, 1996; Brydolf & Segesten, 1996; Calsbeek et al., 2002; Decker, 2000; Lynch & Spence, 2007).

On the other hand, when parents encourage their child to be part of their IBD management, including IBD medical decision-making, it has led to reports by adolescents

of feelings of increased self-confidence, a heightened sense of personal maturity, increased self-esteem, and a belief they have the capacity to manage their IBD (Brydolf & Segesten, 1996; Brydolf & Segesten, 1996). Family support, good parent-child relationships, and open communication among family members have also translated into better health outcomes for adolescents living with IBD (Hommel et al., 2011).

The uncertainty of living with IBD, especially during active disease states, has also resulted in adolescents describing their life as a roller coaster ride of emotions - fearing for one's life one day to hoping for a response to a new treatment the next day (Lynch and Spence, 2007). Uncertainty also arises when the adolescent is faced with having to go through a new round of medical tests and procedures. The uncertainty results from fearing the unknown, that is, what the test results will mean for the adolescent and their future, causing great psychological distress in the CD youth (Grootenhuis et al., 2009; Lynch & Spence, 2007, Yi, Britto, Sherman, Moyer, Cotton, Kotagal, Canfield, Putman, Carlton-Ford, & Tsevat, 2009). It has also been suggested that this uncertainty can potentially have a negative impact on the adolescent's QOL and affect their ability to navigate successfully through adolescence (Brydolf & Segesten, 1996; Decker, 2000; Loonen, Derkx, & Griffiths, 2002; Rayhorn, 2001).

#### *IBD and Psychiatric Illness*

According to Cotton et al. (2009), individuals with IBD are at greater risk for behavioural and emotional difficulties, including episodes of anxiety, depression, and low self-esteem. Other studies have alluded to the same finding. For example, Helzer, Chammas, Norland, Stillings & Alpers (1984) compared a group of young adults with CD (n=50) with a control group consisting of subjects with various chronic medical



illnesses, such as diabetes and cardiac diseases (n=50). This study found that a significantly greater number of patients with CD in comparison to the controls met criteria for some psychiatric disorder (Helzer et al., 1984). Other researchers have shown that CD patients, in comparison to other chronically ill groups and control groups, were more likely to receive a diagnosis of depression and report a greater number of obsessive compulsive and phobic symptoms (Bennett, 1994; Helzer et al., 1984; Koot & Bouman, 1999). Despite these results, the authors were unable to state conclusively that there was evidence of a casual link between psychiatric disorders and CD (Helzer et al., 1984; Talal & Drossman, 1995).

In contrast, Engstrom (1992) found a correlation between psychiatric disorders and IBD when comparing children and adolescent subjects with IBD (n=24) against a headache (n=20), diabetic (n=20) and healthy control group (n=20). Findings revealed that the highest levels of psychiatric disturbance, emotional maladjustment, and behavioural problems occurred in the IBD group (Engstrom, 1992). In addition, participants in the IBD group were found to be less socially competent than other groups. This was attributed to the fact that the symptoms of IBD were embarrassing, humiliating, and difficult for the children/adolescents to discuss (Engstrom, 1992). Lower self-esteem and higher rates of depression were found among participants in the IBD and headache group; this was attributed to the embarrassing nature of the illness (Engstrom, 1992).

### *Sexual Impact*

Active IBD can also lead to amenorrhea in females and preterm delivery and low birth rates for pregnant women, while IBD drugs can inhibit sperm production in males (Cunningham et al., 2007; Giese & Terrell, 1996; Salter, 1992). The medications used to

treat IBD/CD can also lead to delayed sexual maturation and can have potential teratogenic effects on a developing fetus (Cunningham et al., 2007; Peterson, 2008).

These issues could be significant for those individuals in adolescence who are becoming sexually active and for those in late adolescence who are looking forward to developing intimate relationships and becoming parents.

### *Ostomy and Its Impact*

Depending on the severity of the IBD and the degree of loss of bodily functions, especially the ability of the adolescent to control defecation, a recommended treatment option may be the formation of an ostomy/colostomy (Barnabe & Dell'Acqua, 2008; Daniel, 2002). It is estimated that one million people in the United States and one hundred thousand people in Canada live with an ostomy (Sinclair, 2009). Within five years of diagnosis, 50% of individuals with Crohn's will most likely have undergone ostomy surgery resulting in the formation of a temporary or permanent ostomy (Sinclair, 2009).

Living with an ostomy and the issues that arise from it has led to reports by adolescents of feelings of embarrassment, isolation, mutilation, unattractiveness, fear, loss of self-confidence and dignity, anger, hate, disgust, and repulsion (Barnabe & Dell'Acqua, 2008; Brydolf & Segesten, 1996; Gazzard, Price, Libby & Dawson, 1978, Giese & Terrell, 1996; Salter, 1992; Sinclair 2009). In one study, an adolescent stated, "the stoma is ugly and I am damaged goods" (Sinclair, 2009, p. 311). It has also been reported in the literature that the above feelings may result in the adolescent abstaining from socializing, dating, and developing close intimate relationships, leading to future issues around intimacy and commitment (Barnabe & Dell'Acqua, 2008; Brydolf &

Segesten, 1996; Gazzard et al., 1987; Giese & Terrell, 1996; Salter, 1992; Sinclair, 2009; Wong et al., 1999).

Conversely, there are some studies showing the positive impact of having an ostomy. In a study by Brydolf and Segesten (1994), participants between the ages of 14-31 reported a high degree of life satisfaction with the ostomy. Sinclair (2009) reported that having an ostomy resulted in an overall improvement in life and a resumption of normal everyday activities and education. As one individual stated, “the best part of having an ileostomy is you live again” (Sinclair, 2009, p. 311).

### *Spirituality and IBD*

There exist only a few studies exploring adolescent spirituality and IBD. Those studies reveal that the spiritual well-being of adolescents with IBD is similar to the spiritual well-being of their healthy peers (Cotton et al., 2009; Yi et al., 2007). Spiritual well-being was also associated with less depressive symptoms in adolescents with IBD (Yi et al., 2007). And finally, it was shown that meaning and purpose in life, rather than a connectedness to a higher power, had the more positive impact on the IBD adolescents emotional functioning (Cotton et al., 2009).

### *Gaps in Adolescent IBD/CD Research*

Three gaps in adolescent IBD/CD research exist. There is minimal research focused on: (a) comparing the concerns and worries of CD adolescents versus UC adolescents; (b) exploring IBD/CD disease severity/disease activity and its impact on the adolescents QOL; and (c) exploring the experiences of CD adolescents from a resiliency perspective.

### *Summary of the Literature*

This literature review outlines the conditions known as IBD and CD. The review includes discussion related to how these conditions are managed and the impact of IBD/CD disease activity and disease severity on adolescents' QOL. It also includes a discussion around the physical, social, and psychological impact of the IBD and CD on the lives of the adolescents.

The studies results included in this review have to be interpreted with caution for a number of reasons. First of all, in most studies, adolescents with IBD have been grouped in with their young adult counterparts. From a developmental perspective, it could be argued that the experiences of these two age groups may be quite different since they are coping with different challenges and different developmental milestones.

Adolescents with CD and UC have also been grouped together in the majority of these studies; the number of adolescents with CD to UC is very disproportionate, with CD adolescents being less represented. Considering the differing pathophysiology of these diseases, the experiences of these two groups may not be comparable at all. Comparing the experiences of these two groups separately would provide more insight into whether or not these two groups share very similar experiences.

Literature pertaining to exploring the daily experiences of adolescents with IBD/CD is scarce; only two such studies exist (Brydolf & Segesten, 1996; Brydolf & Segesten, 1996). Instead, much of the research literature has focused on exploring the concerns, worries, and negative impact the IBD has on the daily life of the adolescent. Various questionnaires were used to determine the concerns/worries and negative impact. The validity and reliability of most of these questionnaires has yet to be determined in the adolescent IBD population. Therefore, these results must be interpreted with caution.

One study (Herzer et al., 2011) in this literature review did use a questionnaire that has actually been determined to be reliable and valid in the adolescent IBD population (Otley, Smith, Nicholas, Munk, Avolio, Sherman, & Griffiths, 2002). The self-administered questionnaire used was the Impact 111: A Quality of Life Questionnaire for Children and Adolescents with IBD (Otley et al., 2002). It is a descriptive questionnaire that focuses on exploring the impact of illness and disease activity on the adolescents' QOL (Otley et al., 2002). It contains 35 questions exploring six domains: bowel functioning, systematic functioning, emotional functioning, social functioning, body image and treatment/interventions (Otley et al., 2002). This questionnaire contains questions pertaining to both active and non-active disease states and can be a good guide for qualitative or narrative research (Otley et al., 2002)

There are very few studies that focus on exploring the impact of CD disease activity and disease severity on the adolescents' QOL. The studies that do exist on this topic have varying results. Some studies indicate that active disease and increased disease severity has a severe negative impact on the adolescents' QOL (Herzer et al., 2011; Yi et al., 2009), while others suggest the impact is minimal (Brydolf & Segesten, 1994; Joachin & Miline, 1987). Further research into this area is needed. In addition, in most of these studies, sample populations consisted of only adolescents in quiescent disease. In order to truly understand the experiences of adolescents with IBD/CD, individuals who have experienced varying degrees of disease activity and disease severity will need to be included in future studies.

There is minimal research focused on exploring the experiences of adolescents with IBD/CD from a resiliency perspective. Drawing on the conceptual model of

resiliency, a few studies focused on adolescents with various other chronic illnesses have shown that most adolescents possess the necessary tools, resources, capabilities, and competencies to live well with their illness (Decker, 2007; Jaser & White, 2010; Taylor et al., 2008). Noting the same finding in adolescents with CD is important, as it can have an impact on the care health professionals deliver to these youth and their families.

### *Significance of the Study*

There is a gap in the adolescent research literature around the exploration of perceptions of adolescents living with CD from a resiliency perspective. Awareness of how adolescents live with and overcome the challenges of this illness is important, as findings may aid with the development of new and innovative nursing interventions aimed at helping this population cope with their condition in the best way possible. In addition, by understanding what the adolescent is experiencing, a more collaborative atmosphere may evolve between nurse and adolescent, where the adolescent realizes that their concerns, issues, and experiences are being heard and addressed. It has been shown that when a more collaborative approach is taken with adolescents, they are more likely to successfully integrate their chronic condition into their everyday lives (Kyngas & Duffy, 2000; Kyngas, Hentinen, & Barlow, 1998). Taking all of this information together (the conceptual model and the details related to the lack of qualitative or descriptive experiences of adolescents with CD), this study was conducted to shed light on how adolescents experience living with CD on a daily bases. It was also conducted to give some insight into the daily CD issues these adolescents struggle with and the social, emotional and management related strategies they utilize to maintain and improve their QOL.

### *Adolescent Developmental Milestones*

The following is a short discussion around adolescent developmental milestones. The inclusion criteria, the findings, and the discussion section of this thesis were written taking into account the three distinct adolescent sub-phases: early adolescence (ages 11-14), middle adolescence (ages 15-17), and late adolescence (ages 18-20) (Wong et al. 1999).

#### *Early Adolescence (11-14 years)*

This period is marked by rapidly accelerated physical and emotional growth, the appearance of secondary sex characteristics, and wide mood swings. It is also marked by limited abstract reasoning, increased conformity to group norms, and defining of independence-dependence boundaries. There is usually no major parental-child conflict over boundaries during this time. During this phase, adolescents seek peer affiliation, especially with the same sex, and as a result, this period has been associated with limited interaction with the opposite sex and limited development of romantic relationships (Wong et al., 1999).

#### *Middle adolescence (14-17 years)*

During this stage, adolescents' stature reaches 95% of their adult height and their secondary sex-characteristics are well developed. This stage is also marked by a developing capacity for abstract reasoning and the ability to perceive future implications. In addition, this is the period when there is a major battle over independence and control, especially with parents, and typically this is the difficult point in the parent-child relationship. Acceptance by peers is extremely important and behavioural standards are set by peers. Finally, adolescents develop multiple plural relationships and there is

tentative establishment of dating relationships and feelings of being in love (Wong et al., 1999).

*Late adolescence (17-20 years)*

Structural and reproductive development is almost complete at this point. In addition, there is an established capacity for abstract thought. Adolescents can perceive and act on long range operations and view problems comprehensively. Furthermore, there is stability of self-esteem and a showing of greater concern for others. Emotional and physical separation from parents and social roles are also defined and articulated. Peer groups recede in importance in favour of individual friendships, and dating relationships evolve with an emphasis on the establishment of intimacy and commitment (Wong et al., 1999).



## Chapter 3

### Methodology and Method

Nursing is both an art and a science (Lo-Biondo-Wood & Haber, 1994).

Qualitative research combines both the scientific and artistic nature of nursing to enhance the understanding of the human health experience and gain deeper insight into complex human behaviours (Lo-Biondo-Wood & Haber, 1994). Qualitative research, often associated with naturalistic inquiry, attempts to deal with the issue of human complexity by exploring it directly (Loiselle, McGrath, Polit & Beck, 2004; Morse & Field, 1995; Polit & Beck, 2004). It also attempts to answer questions pertaining to what an experience is like, such as what is it like to live with CD on a daily basis from an adolescent perspective (Loiselle et al., 2004; Morse & Field, 1995; Polit & Beck, 2004).

Qualitative methodology offers many different methods to explore the experiences of research participants from the perspective of the participants themselves (Clandinin & Connelly, 2000). One of these methods is narrative inquiry. According to Clandinin and Connelly (2000), narrative inquiry is one of the most effective ways of representing and understanding the everyday experiences of individuals. Narrative inquiry is based on the belief that life is filled with narrative fragments, enacted in storied moments of time and space, and that using narratives is a natural impulse for individuals since it is a primary means by which individuals make sense of their experiences (McCance, McKenna & Boore, 2001).

In addition, “narrative methods are particularly appropriate for research experiences through time such as chronic illness” (Bleakley, 2005, p.536). This method is a suitable means by which to explore sequentially the impact a particular illness has

had on the life of an individual, since most individuals tend to organize their encounters that result from their illness experience into chronological, coherent stories (McClance et al., 2001; Polit & Beck, 2004). Since the purpose of this study was to describe and explore the experiences of adolescents living with CD, a qualitative narrative inquiry is suitable and was used.

The broad underlying premise of narrative research is based on the belief that most people effectively make sense of the events in their lives and assign meaning to these events through constructing and narrating stories (Bleakley, 2005; McCane et al., 2001; Overcash, 2004; Polit & Beck, 2004). Clandinin and Connelly (2000) suggest that to do research into an “experience...is to experience it simultaneously in...four ways and to ask questions pointing each way” (p. 50). These four ways or four directions into narrative inquiry are called backward, forward, inward, and outward (Clandinin & Connelly, 2000).

#### *Backward and Forward Directions into Narrative Inquiry*

Backward and forward refers to the issue of temporality. Temporality is a central feature in the narrative process and is necessary for making sense of any person, event or thing (Clandinin & Connelly, 2000). In other words, in narrative inquiry an event is seen not as something happening at a particular moment in time, but an expression of something happening over time, that is, life as it is experienced now but also with life as it is experienced on a continuum (Clandinin & Connelly, 2000). Therefore, it is important to look not only to an event or thing but to look to its past, its present and its future (Clandinin & Connelly, 2000).

#### *Inward Direction into Narrative Inquiry*

To explore an experience inwardly means to look towards the internal conditions - to explore the participant's subjective reality and the meanings they attach to that reality through examining their thoughts, feelings, behaviours, perceptions, hopes, aesthetic reactions and moral disposition (Clandinin & Connelly, 2000; Holloway & Wheeler, 2002; Polit & Beck, 2004).

#### *Outward Direction into Narrative Inquiry*

To explore an experience outwardly means to look towards existential conditions, that is, to explore the environment of the participant (Clandinin & Connelly, 2000). Narrative inquiry includes concern for the spatial and personal contexts (Clandinin & Connelly, 2000). Stories shared are given meaning in terms of their larger social context. This meaning may change as time passes, and is also influenced by the actors involved and the places in which the stories are shared and experienced (Clandinin and Connelly, 2000). Exploring the participant's environment means to examine the place in which the event occurred and the place in which the individual is recounting the event; both of these will impact the meaning the participant and the researcher assign to an event or experience (Clandinin & Connelly, 2000).

#### *Purpose of the Four Directions into Narrative Inquiry*

Exploring these four directions into narrative inquiry serves as a prelude to the development of thick, descriptive narrative data that consists of "describing the location and the people within it, giving visual pictures of the setting, events, and situations as well as verbatim narratives of individual's accounts of their perceptions and ideas in context" (Holloway & Wheeler, 2002, p. 13). This is done in attempt to represent the participant's reality as accurately as possible, to help the reader comprehend what is

going on in the life of the participant, and to assign meaning to these events (Clandinin & Connelly, 2000; Holloway & Wheeler, 2002).

In narrative inquiry it is impossible for the researcher to stay silent and present a kind of perfect, objective, and idealized inquiring self (Clandinin & Connelly, 2000). Narrative researchers work within the space of the research participants as well as their own space which means that the researcher becomes visible with their own experiences and told stories (Clandinin & Connelly, 2000). The researcher's stories can come to light as much as those of the research participants, and these stories or the researcher's responses to the participant's stories may influence what the participant shares and the amount of detail in which they share (Clandinin & Connelly, 2000). Complete objectivity and neutrality are neither pursued nor ever achieved in narrative research (Clandinin & Connelly, 2000). What in the end may appear as an objective tape-recorded interview between participant and researcher is already an interpretive and contextualized text (Clandinin & Connelly, 2000). It is interpretive because the interviews, the direction of the interviews, and the stories shared are shaped by the interpretive process of the researcher and the participant as well as their relationship (Clandinin & Connelly, 2000). It is already contextualized because of the circumstances, origins, and setting of the interviews (Clandinin & Connelly, 2000).

Finally, one of the principal interests of narrative research is to explore the growth and transformation in the life story that a participant authors (Clandinin & Connelly, 2000). The act of sharing stories and then retelling of stories by participants and by the researcher allows both parties the opportunity to explore the goals and the intentions of the human actors involved in the story (Clandinin & Connelly, 2000; Overcash, 2004).

It also affords the opportunity to explore the impact certain actions have had on the participant's illness journey and how these actions have allowed or may allow for growth and change in the lives of all individuals touched by these narratives (Clandinin & Connelly, 2000; Overcash, 2004).

Illness narratives, especially progressive and stable illness narratives, are particularly useful in helping to achieve this goal (Bleakley, 2005). Progressive illness narratives focus on seeing illness as an opportunity and a chance to harness internal and external tools to help the individual adjust to living with a chronic illness (Bleakley, 2005). Stable illness narratives focus on recounting stories where an illness is accepted stoically and integrated into the everyday life of the individual (Bleakley, 2005). In stable illness narratives, the predominant theme is accepting the illness and getting on with living everyday life as best as possible (Bleakley, 2005). Progressive and stable illness narratives also avoid the reduction of an individual's illness experience into a medical case by situating the participant in a wider psychosocial context through exploring the intellectual, spiritual, practical, emotional, and relational aspects of living with a particular illness (Bleakley, 2005). In addition, the tellers of illness narratives often construct stories about physical symptoms, diagnosis, and progression through their treatment regime in a way that allows the experience to be understood by both the listener and the teller (Overcash, 2004). The telling of illness narratives may also help repair some of the mental and physical damage the illness has done to the body of the teller (Overcash, 2004). Since this research study is based on a resiliency framework, illness narratives that focus on accepting CD, harnessing resources, integrating CD into

everyday life, and seeing CD as an opportunity for growth and change was the focus of this research.

### *Setting*

This study was conducted in a large tertiary children's hospital in Atlantic Canada. The IWK Health Centre is a 332 bed, tertiary care facility that provides quality care to women, children, youth, and families in the Maritimes. Complex clinical cases from the province of Newfoundland and other surrounding areas are often admitted to the IWK Health Centre as well. The IWK Health Centre advocates patient/family centered care and it recognizes and respects patients/families in the health care process and their cultural and personal values (IWK Health Centre, 2007). The mission statement for this institution is: (a) to make a difference in the care and well-being of women, children, youth and families; (b) to bring together care, research, teaching and advocacy - to achieve the best possible results for patients/families; and (c) to be international leaders in research and knowledge sharing (IWK Health Centre, 2007).

### Inclusion Criteria:

For the purpose of this study the following inclusion criteria were utilized:

### Participants:

- a) Must be able to understand, speak, and read English;
- b) Must be between the ages of 13-17 years and have received a confirmed diagnosis of CD for greater than one year. This particular age range was chosen because it would be inclusive of the three distinct adolescent sub-phases (early, middle, late adolescence), thus allowing for a comparison between these three different phases. Including adolescents from these three distinct sub-phases would also

allow the researcher to present a clear and accurate picture of what it is like for youth of all ages to live with CD. A confirmed diagnosis of one year was chosen because it was felt this would have been sufficient time for the adolescent to come to terms with their diagnoses and begin the process of integrating the CD into their everyday life;

- c) Must be willing to share their experiences around living with CD;
- d) Must be scheduled to receive Remicade™ therapy at the IWK Medical Day Assessment and Treatment Unit. Remicade™, also known as Infliximab™, is medication used to treat moderate to severe medically refractory and fistulising pediatric CD (Rayhorn, 2001; Veres, Baldassano & Mamula, 2007). It is a medication that is used primarily when other medications and treatments have not been effective, and it acts to decrease the inflammatory response in CD patients, often bringing active disease states into a remission (Rayhorn, 2001; Veres et al. 2007). This medication is also used to promote healing when there is fissure development (Rayhorn, 2001; Veres et al. 2007). Adolescents receiving Remicade were chosen because they are a diverse group of all ages with moderate to severe degrees of disease activity and severity, who may have undergone surgeries, hospitalizations, and ostomy formation. This particular group was also chosen because of ease of accessibility in the clinic. Remicade™ Therapy requires a four to five hour stay at the IWK Health Centre, giving the researcher ample time to conduct her 45-90 minute interviews at the convenience of the participants and their family.

#### Study Procedure

Prior to ethics approval, the student researcher met with the Chief Gastroenterologist on staff at the IWK Health Centre, and informed him of the goals of this research study. He agreed to be a collaborator in this study and wrote a letter to the IWK Ethics Committee confirming his role (Appendix A).

Study recruitment began following Dalhousie University and IWK institutional ethics approval. Adolescents with CD scheduled to receive Remicade™ therapy at the IWK Gastroenterology (GI) Clinic-Medical Day Assessment and Treatment Unit were invited to take part in this research project. The GI clinic is one of the many outpatient clinics located within the IWK Health Centre. The clinic staff includes: three gastroenterologists, three clinic nurses, two dietitians, and one social worker (IWK Health Center, 2007). The multidisciplinary team helps individuals who have significant nutritional issues or who have illnesses and disorders of the gastrointestinal system (IWK Health Center, 2007). These conditions may be congenital or acquired and include CD, UC, celiac disease, liver disease, failure to thrive, constipation and abdominal pain (IWK Health Center, 2007).

The Chief Gastroenterologist at the IWK Health Centre first approached potential research participants and their parents, inviting them to meet with the nursing student researcher to discuss their experiences around living with CD. All adolescents and parents received the same information (Appendix B). It was emphasized by the Chief Gastroenterologist that the adolescents' participation in this study was completely voluntary and that they could withdraw from the study at any time without it affecting the care they have been receiving at the IWK. When the youth and their parents showed interest in hearing more about the study, they were introduced to the student researcher



and the student researcher read a brief introduction to the study to the adolescents and their parents (Appendix C).

On that same day, once each potential participant's Remicade™ Therapy had started, the student researcher returned to the Medical Day Assessment and Treatment Unit and met once again with the adolescent and his/her parents. The main part of the Unit was an open space consisting of several lounge chairs where the youth sat while receiving therapy. The curtains were drawn around the researcher, participant, and his/her parents, and the researcher proceeded to review the Information and Parental Authorization Form (Appendix D) and the Information and Consent Form (Appendix E). The parental authorization form informed the parents about the study, while seeking their permission for the researcher to meet privately with their son or daughter. Once forms had been reviewed and questions answered by the student researcher, the youth and their parents mutually decided if the study was a good fit for them, both parties understanding fully that participation was completely voluntary.

Once consent and authorization had been attained, the interview between the student researcher and the adolescent began. On all except two occasions, the student researcher was able to secure a private room to interview the adolescents. In these cases, the adolescents were escorted by the researcher from the less private curtained-off open space at the IWK Medical Day Assessment and Treatment Unit to one of the treatment rooms located within the Unit. The treatment rooms contained a bed, several chairs, and various pieces of medical equipment and medications.

These five youth who were interviewed in a private treatment room chose to either sit or lay on the bed as they were being interviewed. The student nurse researcher

sat across from the youth as she conducted the interview. Nurses in the clinic were required to do 15-minute interval vital sign checks on the youth receiving therapy, and during each occasion the interview between the youth and nurse researcher was stopped until the nurse completed her tasks and left the room. All nurses had been previously notified of the nature of this project and the time requirements for the participants; all indicated their support for this study verbally.

Due to the lack of access to a private treatment room, the other two interviews were conducted within the actual clinic as the participants sat in their loungers. The tape-recorder was placed near each participant's chair. Despite clinic noises, chatter, and nurses having to do regular Remicade™ checks, the interviews were conducted successfully while taking every measure possible to ensure the youths' privacy, including pulling the curtains and talking in low and audible voices. These two adolescents were also informed that their interviews could be postponed until the student researcher was able to secure a private room, but both adolescents expressed they felt comfortable doing the interview in the setting they were currently in. The adolescents were also advised that if at any time they became uncomfortable in their current setting, to let the researcher know and the interview would be stopped and a more private location would be secured. This option was not pursued by either youth.

### *Data Collection*

Recruitment took 4 months, from September 2011 to December 2011. Seven adolescents agreed to participate in this study. From a qualitative perspective, this study sample is estimated to provide a sufficient amount of qualitative data that will capture in detail the meaning adolescents assign to living with CD (Polit & Beck, 2004).

Each participant was interviewed once using the same interview guide (Appendix F). The semi-structured interviews, took between 45-90 minutes. Semi-structured interviews are best suited when exploring issues of a sensitive nature (Elmir, Schmied, Jackson & Wilkes, 2011). Adolescents with CD tend to find it difficult to discuss their disease because of CD symptoms they consider to be embarrassing and humiliating (Brydolf & Segesten, 1996; Daniel, 2002; Decker, 2000; Loonen, Derkx, & Griffiths, 2002; Lynch & Spence, 2007; Rayhorn, 2001; Salter, 1992; Szigethy, 2005). The researcher remained cognizant at all times of this issue. In an attempt to avoid further embarrassment, she phrased questions pertaining to CD symptoms carefully and sensitively. For example, instead of initially naming embarrassing symptoms, the researcher alluded to them by asking such questions as, “Having any troubles with going to the washroom a lot?” The adolescents seemed to appreciate this approach, and as they became more comfortable talking about their CD, they named their own symptoms directly. This allowed the researcher an opportunity to explore more thoroughly the impact certain symptoms have had on their daily life.

Interview questions were broad based and open-ended; this format is pursued in narrative inquiry because it promotes storytelling (McCance et al., 2001) and elicits freer responses in participants, responses that truly reflect their experiences (Elmir et al., 2011). The open-ended questioning enhanced the quality of the participants’ responses as demonstrated in the findings section of this research study. Further direct questioning occurred when exploring a particular experience the adolescent had in relation to their CD. Direct questioning helped the researcher to capture as accurately as possible the reality of each participant (Polit & Beck, 2004).

As is the approach in most qualitative studies, during the initial phase of the interview the researcher tried to establish rapport, gain trust, and build the relationship between herself and the research participants (Polit & Beck, 2004). This approach enhanced the researcher's access to the interviewee's lives (Elmir et al., 2011). The success of this approach is demonstrated by the enormous amount of interview data the researcher was able to collect from each interview.

In an attempt to build rapport and trust, Field and Morse (1985) indicate that initial discussions between researcher and participants should begin at a superficial level and as the relationships grow, discussions and conversations will increase in depth. All seven interviews followed this course. During initial discussions with the adolescent, the researcher was able to draw out common interests she shared with the participants, including being a part of a choir and a love of sports. The adolescents quick to note the shared common interests began to elaborate a little more about things they had been up to socially. This naturally led them into sharing stories about their disease and how it interferes with their everyday life, especially their social life. This provided the researcher with an opportunity to ask some of the questions present in her interview guide. Many of these questions, however, did not need asking, as the youth naturally touched upon most of these areas as they started to share stories around their illness journey. A narrative inquiry approach to data collection proved invaluable to this study, as using chronological narratives was a natural impulse for these adolescents (McClance et al., 2001; Polit & Beck, 2004).

As time progressed, participants visibly noticed the researcher, too, has chronic illness issues. The youth began making statements like, "I bet you know what I'm

talking about,” or “I bet you had this procedure done,” and they seemed to take comfort in sitting across from someone who they thought really understood what they were going through daily. The researcher did convey her understanding of their situation and did express that she knows the difficulty of living with daily health struggles, all the while maintaining the focus on their journey and not hers. Reciprocity, which involves a mutual exchange of information between researcher and participant and the conveying of empathy, contributes to rapport and trust building. This leads to freer exchange of information between participant and researcher (Elmir et al., 2011; Polit & Beck, 2004). As stated previously, the success of this approach is evident in the quality of information and experiences shared by these adolescents.

And, finally, a few adolescents stopped in the middle of a few stories because they were afraid of how the researcher would perceive them. For example, one adolescent was afraid to elaborate on stories that highlighted his issues with his temper. The researcher was quick to remind him that she was not there to judge him and that she viewed him in the same way she did when she first began the interview. She also was quick to empathize with him, reminding him that being a teenager was difficult enough and chronic illness makes it even harder. And finally, she conveyed to him to be gentle on himself because his feelings were normal, since he is coping with so much. Demonstrating caring and empathy during research is essential in eliciting information from participants (Elmir et al., 20011). After this, he talked at great length about issues that were causing him anger and seemed to feel somewhat better after venting some of his frustration. According to Overcash (2004), the act of being able to share stories and in particular express frustration around some aspect of their illness journey helps repair

some of the mental damage the illness has done to the body of the teller; that was certainly the case for this participant.

The researcher used various tools to guide interview question formation. These tools included the Rating Form of IBD Patient Concerns (Drossman et al., 1991), the Inflammatory Bowel Disease Questionnaire (Drossman et al., 1991), The Sickness Impact Profile (Drossman et al., 1991), the Adolescent Resilience Model (Haase, 2004; Haase et al., 1999), the literature review, and the Impact 111: A Quality of Life Questionnaire for Children and Adolescents with IBD (Otley et al., 2002). The Impact 111 Questionnaire, developed by the GI Clinic Chief and the Pediatric Inflammatory Bowel Disease Working Group based in the study site, had the most impact on interview question development. It contains 35 questions pertaining to both active and non-active disease states and it explores the impact of illness and disease activity on the IBD children's/adolescents' QOL, which is one of the goals of this research study (Otley et al., 2002). It has been proven to be a reliable and valid tool in IBD children/adolescent populations (Otley et al., 2002). Interview question development was also influenced by the researcher's own experience. Finally, the research questions and purpose of this study, which was to elucidate the respondent's feelings around living with CD and the strategies they utilize to maintain and improve their QOL, influenced interview question development as well.

Interviews were audio-taped and transcribed verbatim to ensure accuracy of data. It is recommended in qualitative research that interviews be recorded rather than relying on the interviewer's notes, since notes tend to be incomplete. Note taking can also be distracting to the researcher and participant, interrupting the flow of the interview and

curtailing the data collection process (Polit & Beck, 2004). The behaviours (facial reactions/body language) of the research participants, the non-verbal responses of both the researcher and the participant to the stories each shared, the emotional tone of the interview, a description of interview setting, difficulties encountered in the interview, and the feelings of the researcher post-interview were all recorded as field notes (Morse & Field, 1995; Polit & Beck, 2004). The intention of these rich, descriptive field notes were to make details so vivid in the research that the reader will be able to “see, taste and smell” what is going on with the participant (Strauss & Corbin, 1998). This will enhance the study’s rigor and allow for more abstract interpretation of the data (Chiovitti & Piran, 2003; Strauss & Corbin, 1998).

#### *Protection of Human Rights*

Participation in this research study was voluntary. To minimize the travel of research participants, the researcher met with each participant during the time in which they were scheduled to receive their Remicade™ therapy at the IWK Medical Day Assessment and Treatment Unit. Remicade™ therapy typically requires a four to five hour stay at the IWK and the interview between the research participants and student researcher took between 45-90 minutes. Due to the length of the interview and the fact that it was conducted during their usual clinic time, no extra costs were incurred by the research participants and their parents. Movie vouchers were given to all adolescents, at the end of the interview process, as a way to show the researcher’s appreciation for their participation in this project. All participants were informed they could withdraw from the study at any time and they would still receive the movie vouchers. In order to avoid any exploitation of participants they were assured that they would be allowed to freely speak

of their experiences of living with CD and that receiving the movie vouchers would not be contingent upon the responses they gave to the researcher. The researcher assured all participants that confidentiality would be maintained at all times (Loiselle et al., 2004). Upon recruitment into the study, research participants were given a code number to maintain confidentiality and the participant's names were not placed in any of the researcher's notes. A list of the participants names were kept in a password-protected file on the student researcher's password protected computer, with names linked to study code numbers. The consent forms and participant's number, as well as tape-recorded files, were kept separate from one another at all times.

The interviews between the adolescents and the researcher were recorded using a tape recorder. Any private information such as the participants name was removed when the notes on the tape were transcribed. Information from the tape recorded meeting between the researcher and participant was put onto a computer disc and this disc and the interview tapes were kept in a locked filing cabinet at Dalhousie University School of Nursing, where they will remain for a minimum of five years, after which time they will be destroyed. The research findings and any publications resulting from the study will not contain any information that will identify research participants.

Due to the fact the student researcher attended the GI Clinic Medical Day Assessment and Treatment Unit and spent time with adolescents during their Remicade™ Therapy, the health professionals on staff became aware of the adolescents' participation in this study. As a result, participation in this project was not completely anonymous, and the participants were aware of this. These health professionals did not have access to any of the information the adolescents shared with the researcher.



### *Benefits/Risks of the Study*

This research did not result in any physical, social or economic harm to the study participants. The interviews did not cause the adolescents any distress, especially psychological distress from recalling a difficult experience related to CD. While conducting the interviews, the researcher was prepared to terminate the interview should the above have occurred. The researcher remained cognizant at all the times of the impact certain questions could have had on the participants. In an attempt to minimize any distress this could have caused, the researcher carefully and empathetically phrased all questions (Polit & Beck, 2004). A back-up plan for debriefing was prepared but was not required.

There was no direct benefit to participants taking part in this study. However, this study could help health care professionals more thoroughly understand the adolescent experience of living daily with CD. By understanding the adolescent experience and the meaning he/she gives to that experience, health care professionals may in the future be better able to work with these clients to develop new and innovative interventions aimed at helping this population cope with their condition in the best way possible.

### *Data Analysis*

In narrative inquiry data analysis is two-fold, consisting of constructing individual narrative accounts and performing a thematic analysis on all data collected (Polit & Beck, 2004). This process will be described in the following section.

#### Part 1

#### Narrative Accounts

This form of analysis allowed the researcher to construct summarized accounts of each adolescent's illness journey and the meaning they assign to living with their illness. The first step in this process consisted of replaying and listening repeatedly to each tape recorded interview, transcribing each interview verbatim, and reviewing field notes pertaining to each individual interview. This allowed the researcher to gain a sense of each interview as a whole and its context. Then began the process of questioning and interpreting the data collected from each individual interview (field notes) using the four directions of narrative inquiry (inward, outward, backward and forward). The goal of this process was to capture as accurately as possible the reality of each participant (Clandinin & Connelly, 2000; Holloway & Wheeler, 2002). One of the ways in which this was achieved was through arranging chronologically the descriptive data collected from each interview along a timeline continuum. This continuum included a summary of each of the phases of the participant's illness journey: (a) when they were first diagnosed and first started treatment; (b) changes in disease activity and treatments along the way; and (c) present day disease activity and treatments. It also meant taking the following six factors into consideration when writing each individual illness journey account:

(1) The environment in which the participants were retelling their stories and the environments in which certain experiences related to their CD occurred;

(2) The number of active disease phases and remissions each participant experienced along their illness journey and where they were developmentally in adolescence during each active disease phase and remission;

(3) The number of failed therapies and the severity of side effects experienced during different treatments;

- (4) The supports they had in place during each phase of their illness journey;
- (5) Where they saw themselves years from now living with CD; and
- (6) Their thoughts, perceptions and feelings about each stage of their illness journey.

Since this study was guided by a resiliency framework each written account includes a summary of the individual, family, and community protective factors-social, emotional and management related strategies that the adolescent utilized during each phase of their illness journey to maintain and improve their QOL.

The researcher followed the same procedure for each interview. The end result of this process was the development of seven narrative, descriptive, interpretative, and chronological accounts of each adolescent's illness journey and the meaning they assigned to living with their illness.

## Part 2

### Thematic Analysis

The second mode of analysis used in narrative inquiry is thematic analysis. The goal of thematic analysis is to bring meaning and identity to an experience and its variant manifestation and to capture and unify the nature or basis of an experience into a meaningful whole (Polit & Beck, 2004). In this study, this meant presenting an accurate picture of how adolescents experience living with CD, with emphasis on exploring the challenges the CD cause during active and non-active disease states and the social, emotional, and management related strategies they utilize to overcome these challenges.

As in part 1 of the data analysis, the first step in this process involved replaying each interview. The researcher listened clearly to the content, especially to the questions

the researcher asked around CD management and the participant's verbal responses (Holloway & Wheeler, 2002; Morse & Field, 1995). The field notes taken during the interview process were also reviewed during this time. As in part 1, this process allowed the researcher to gain a sense of each interview as a whole and get a clear sense of the interview's context (Holloway & Wheeler, 2002; Morse & Field, 1995).

The researcher then began the process of coding the data. The resiliency framework and the four directions of narrative inquiry guided this process as well. During the coding process, each interview was compared to every other interview. Furthermore, interviews were compared against existing adolescent CD and IBD literature, resiliency literature, the researcher's own experiences, and discussions the researcher had with one of the Gastroenterology Clinic nurses. The original transcripts were reviewed by the thesis supervisor, and themes and quotes were discussed related to relevant themes. The entirety of the data was questioned in terms of its larger psychosocial significance, which meant exploring the medical, intellectual, spiritual, practical, emotional and relational aspects of living with CD (Bleakley, 2005). Persistent words, phrases, patterns, concepts, or themes within the data were identified (Clandinin & Connelly, 2000; Holloway & Wheeler, 2002; Morse & Field, 1995).

In the final stage of analysis, the researcher endeavoured to draw out the most common themes, concepts, and patterns pertaining to the two areas described above and to weave these various thematic pieces, patterns and concepts together into an integrated whole (Polit & Beck, 2004). This resulted in an integrated description of the challenges and issues the CD brings into the daily lives of these adolescents and the emotional, social, and management related strategies they utilize during the active and non-active

phases of their disease to maintain and improve their QOL. To substantiate the work, the researcher's integrated description included relevant quotes from the participants in an attempt to show the data from which the patterns, themes, concepts and constructs arose (Holloway & Wheeler, 2002).

### *Establishing Trustworthiness*

Qualitative researchers must take steps to “demonstrate the trustworthiness of the data while in the field” (Polit & Beck, 2004, p. 57). Trustworthiness refers to the believability of the data (Crewell, 2007) and it is evaluated using four criteria: *credibility*, *confirmability*, *transferability* and *dependability* (Lincoln & Guba, 1985; Polit & Beck, 2004). The central goal of this process is to confirm that the findings from the study accurately reflect the experiences and viewpoints of the participants (Polit & Beck, 2004).

*Credibility* refers to “confidence in the truth of the data and interpretation of them” (Polit & Beck, 2004, p. 431). The researcher provided a private and safe environment for the interviews, as well as established trust and a rapport with the adolescents. In this way, she provided an environment conducive to honesty and openness from the adolescents about their experiences living with CD, in order to gain truthful, credible data.

Another way in which the researcher was able to establish credibility was by being transparent in her description of the research process. Also, since researcher bias can threaten the credibility of a study, the researcher's beliefs, feelings, and assumptions were examined throughout the research process through the use of field notes and self-reflection. This allowed the researcher to recognize the similarities and differences

between her own perspective and that of the research participants, with the intent of being transparent during data analysis, adding to the credibility of the research findings.

*Triangulation* was another method used to establish credibility. Triangulation refers to “the use of multiple referents to draw conclusions about what constitutes truth” (Polit & Beck, 2004, p. 431). In this study, the researcher provided her thesis supervisor with the interview transcripts to review, and she communicated with her regularly during data collection to discuss theme development. A clinical nurse specialist from the Gastroenterology clinic, who has worked with adolescents with CD for over ten years, was also consulted to review the themes and concepts that evolved from the data. This ensured that the links the researcher made between data collection, data analysis, and interpretation of findings were accurate (Creswell, 1998).

*Confirmability* refers to the objectivity or neutrality of the data, ensuring that the data and its interpretation is grounded in events rather than the researcher’s personal beliefs (Polit & Beck, 2004). To achieve this, the findings of this study were supported by relevant quotes from the participants in an attempt to show the data from which the patterns, themes, concepts, and constructs arose. In addition, a thorough explanation of the data collection and analysis process was given with attention paid to how patterns were identified and interpreted.

The researcher, through the act of reflection, was able to stay aware of and change behaviours, perspectives, and practices that may influence data collection and analysis. This meant staying aware of any preconceived notions the researcher had about adolescents living with CD, and not letting her personal beliefs affect the objectivity and neutrality of the data.

*Transferability* refers to the generalizability and applicability of the findings to other settings (Polit & Beck, 2004). The focus of narrative inquiry is to give meaning and insight into each participant's experiences; broad generalizations are not the main consideration. Despite generalizability not being the emphasis, the student researcher did focus on providing thick, rich, detailed descriptions of the research process. In addition, findings included narrative accounts of each adolescent's experience living with CD. Themes representing the emotional, social, and management related strategies the adolescent uses to improve and maintain their QOL are also thoroughly described. This was done so that individuals reading the data can easily evaluate the applicability of these findings to the setting they find themselves.

The researcher tried to recruit adolescents of various ages and cultural backgrounds and adolescents who were experiencing varying degrees of CD severity and disease activity to increase transferability of findings to other settings.

*Dependability* refers to the "stability of data over time and over conditions" and is demonstrated through replication (Polit & Beck, 2004). In this study, the researcher ensured dependability by asking the youth similar questions in multiple ways to assess the consistency of each participant's responses. The researcher did not find any inconsistencies within each participant's responses. Also, dependability of the data was demonstrated through the transparent identification and replication of themes throughout the data collection process, confirmed by the researcher, the GI Clinic nurse and her thesis supervisor.

The following measures were also taken to increase dependability: transcripts were re-read several times; field notes reviewed; the researcher kept abreast of any

potential bias she was feeling throughout the study; and constant comparative analysis was employed during data collection and analysis. The researcher also reviewed her findings with one of the GI clinic nurses and her thesis supervisor.

By using strategies that helped ensure credibility, conformability, transferability, and dependability, the researcher demonstrated the trustworthiness of her data.



## **Chapter Four**

### **Findings**

In this chapter the demographic data of the participants and the findings from this study will be discussed. In Part 1 of the findings section, the seven adolescents' illness narratives will be presented. In Part 2, the themes and patterns that emerged from the thematic analysis will be presented. The resiliency framework adopted in this study and the four directions of narrative inquiry guided narrative account development and the thematic analysis process.

The findings in this section will be described using existing resiliency language and resiliency terms. In this study, resiliency is defined as unusually good adaptation in the face of extreme stress and it is "the tendency to spring back, rebound, or recoil and involves the capacity to respond and endure, or develop and master in spite of life stressors or adversity" (Mandelco and Peery, 2000, p. 99). In addition, resiliency is viewed as an outcome that results when individual/family/community protective factors (strengths, capacities, competencies and resources) are utilized successfully, allowing an individual to successfully integrate a chronic illness into their daily lives (Feeley & Gottlieb, 2000; McAllister, 2003).

The results in this section were derived from analyzing each phase of the participants' illness journeys and questioning and interpreting the data using the four directions of narrative inquiry. This meant taking the following six factors into account when writing each individual's illness narrative and when coding the data: (a) the environment in which the participants were retelling their stories and the environments in which certain experiences related to their CD occurred; (b) the number of active disease

phases and remissions each participant experienced along their illness journey and where they were developmentally in adolescence during each active disease phase and remission; (c) the number of failed therapies and the severity of side effects experienced during different treatments; (d) the supports they had in place during each phase of their illness journey; (e) where they saw themselves years from now living with CD; and (f) their thoughts, perceptions and feelings about each stage of their illness journey.

This section will contain only a description of the study results: fuller discussion of these results will take place in Chapter Five.

### **Demographic Data**

Seven participants took part in this study: five male youth and 2 female youth between the ages of 13-17. They were all Caucasian and from various areas around Nova Scotia. All participants lived at least 1-3 hours away from the IWK Health Centre and were driven to their appointments by their parents. All participants in this study received Remicade™ therapy; their therapy occurred once every six to eight weeks. None of the participants had an ostomy. In this study, all participants were able to clearly articulate their own experiences with living with CD.

Demographic information was collected from each participant and displayed in Table 1, Table 2, and Table 3 below. Table 1 reveals that more than half of the participants had a nasogastric tube for nutrition at one point in their past, all had taken a steroid to control the inflammation (Prednisone™), more than half had tried Methotrexate and Imuran™, and all were receiving Remicade™ at the time of the study. Table 2 reveals that four participants have family members with CD, four had been hospitalized for their CD for an extended period during the course of their illness journey, and two

participants had fistulas develop during the course of their disease. Table 3 is an indication of the types of support the adolescents access during their illness journey; these include adolescent Web CD support groups and Camp Brigadoon.

Table 1: Treatments Experienced

Participant	Age	Yr	NG	Pred™	Metho	Imu™	Rem™
1	13	4	X	X	X	X	X
2	17	6	X	X			X
3	17	1	X	X		X	X
4	16	6		X		X	X
5	13	4		X	X		X
6	16	6	X	X	X	X	X
7	14	2		X	X		X

Table 2: Disease Course and Family Members with CD

Participant	Family	Surgery	Hospital	Fistula
1	Dad		1	
2				
3			2	X
4	Mom			
5				
6	Mom	X	1	X
7	Brother		1	

Table 3: Support Systems

Participant	Internet Support	Camp Brigadoon
1		X
2	X	
3		
4	X	X
5		X
6		
7		

Table key

Participant: Participant in Study

Age: Current Age

Yr: Years with CD

NG: Nasogastric Therapy

Pred: Prednisone™

Metho: Methotrexate

Imu: Imuran™

Rem: Remicade™  
Family: Family Members with CD  
Surgery: CD Surgery  
Hospital: Number of Prolong Hospital Stay  
Fistula: Fistula  
Camp: Camp Brigadoon  
Internet Support: CD Support Group (Facebook or Online Forums)

## **Part 1: Participant's Stories**

Part I of the findings section contains the seven participants' illness narratives. These narratives explore, describe and interpret each adolescent's experience with living with CD and the strategies they employed daily to help them cope successfully with their condition. As was mentioned above, the four directions of narrative inquiry and the studies resiliency framework guided this process.

### **Account 1**

Todd is 13 years old and was diagnosed 4 years ago with CD. He had been experiencing stomach pain, loss of fluids, and weight loss. He was hospitalized for 6 weeks and after a series of tests was told he had CD. His reaction to the news "but it wasn't that scary...my dad had it too...so we just got ready for it and when it came it was a breeze." During this time, both parents were present for every treatment and test and discussed with him "anything to do with Crohn's that might bother" him. His parents also shared with him their past experiences such as his dad's experience with having a colonoscopy and both their experiences with being put to sleep and he found this helpful.

Todd began treatment for his CD immediately. He recalls the following treatment order: Prednisone™, iron pills, Imuran™, Nasogastric tube (NG), Methotrexate and Remicade™ therapy. He is currently still receiving Remicade™ therapy, the only medication he is now on for his CD, and he travels to the IWK with his Mom once every

6 weeks for his infusion. Most of the therapies, with the exception of Remicade™, came with their own unique challenges. He spoke of how Prednisone™ affected his mood resulting in periods of “I’ll get crankier, you know, and a lot more irritable.” The Imuran™ and iron therapy had no significant impact on Todd’s everyday life.

Todd was required to do tube feedings at home and described the NG tube as one of the “funniest times because it was always strapped to my face.” The nurses and doctors at the IWK GI clinic explained and showed him the process using “this head...to show us exactly how to put it in” and this alleviated a lot of his anxiety. He was only 10 years old at the time and Todd’s mom became responsible for tube insertion and he discovered the whole process was not painful at all. The teachers at his school “explained to everybody why he had the feeding tube, what it was all about, what the disease was...and it made it a lot easier on me.”

The most difficult period Todd encountered was when he started the Methotrexate. He described it as “the worst pill ever.” It led to severe bruising of the thigh, nausea, vomiting, headaches, and flu like symptoms. Due to the severe side effects Todd states, “I was just like screaming.” “I can’t do this anymore.” He got through this treatment simply by “counting down the days until I was over with this.”

After the Methotrexate he states, “I was really down; I was like always nauseous, always tired, always sick....” In addition, Todd described experiencing bouts of insomnia, decreased appetite, more stomach pain, episodes of irritability and crankiness. He wasn’t able to keep up with school and sports - one of his favourite things to do.

During this difficult time, while playing sports, he reminded himself to slow down and regulate his breathing. When cranky he would “just stop and...say...you’re being

pretty crappy right now...like you gotta stop.” In order to keep up with school he developed an organized binder system. He used a hot water bottle for his stomach pain and if that didn’t work he would try to “sit there and stand through it.”

Todd at that time was also using the bathroom a lot more and using the bathroom at school was for him a very “disgusting...and embarrassing” experience. He avoided it as much as possible and when he did go he would pray and hope that no one would walk in. If anyone did walk in he would just sit there quietly waiting for them to leave. Due to the above issues, Todd, his parents and the doctors at the GI clinic made the decision to try Remicade™. He has experienced little to no side effects from this medication, his appetite has improved and as he happily states “I got all the weight back.” He has been in remission for about a year now.

As Todd grew older he became acutely aware that he was different from other adolescents. He stated, “I just feel sometimes that being different is really hard for them to accept of me...I subconsciously stay a little aloof from everybody else.” As a result of this, he pursued situations where this sense of difference was minimized. This past summer he attended a camp for adolescents with CD and this has benefitted him greatly. He states, “It’s really wonderful being in a place where like you are just one of the other kids...there is like no discrimination, no segregation, everybody’s equal.” Todd has stayed friends with quite a few people from this camp and keeps in contact with them regularly via email and Facebook. As he stated, “We all share... troubles... emotional and relationship issues and we all just like talk.”

Todd has settled into remission and he now finds himself thinking about how lucky he is because “a lot of kids that I met...have these, uhmmm, bad food issues...but

for me I am so happy that I can eat almost anything.” He has also taken on a new role and that is talking to kids who are new to living with CD. He states “I got to meet this young kid and, uhmm, I got to talk, explain to him about the feeding tube.”

Todd has lived with CD for 4 years and over the course of the 4 years he has learned to incorporate the disease very successfully into his everyday life. Support from his family, health professionals, teachers and other friends with CD, his perspective on the disease itself and his problem solving skills have all been important to this process.

### **Account 2**

Gal is 17 years old and was diagnosed 6 years ago with CD. She lives with her dad and sister. Gal had been experiencing stomach pain, cramps and diarrhea, delayed growth and some weight loss. After a series of tests including a colonoscopy and indium scan she received the CD diagnosis. Her reaction to the diagnosis was “a big relief to know that it had a name so that we could start doing something about it.”

Gal’s treatment for her CD began with NG therapy. That lasted for about six months, and despite gaining weight, the other CD symptoms were still present. Prednisone™ therapy was then started but once again symptoms returned. As Gal stated, “It just came a point where I was like in a lot of pain, like I couldn’t move, and that’s when I started the Remicade™...that was Jan 2007.” She began with an 8-week cycle of Remicade™, but it did not give her good control of her CD. She was switched to a 7-week cycle, but continued to have trouble. Gal and her dad now travel to the IWK once every 6 weeks for Remicade™ therapy and this is now the only medication she is on for her CD.

Throughout both NG and Prednisone™ therapy, due to still being very symptomatic, Gal was late to school almost every day. She also spent a lot of time, with the aid of her dad, travelling back and forth to school multiple times due to not feeling well.

During NG therapy Gal spent time on an adolescent CD web support group reading about other adolescents' experiences with their tubes, and she found this very helpful. The tube made her feel different from other students. This feeling decreased after explaining to her friends why she had the tube and once she realized she wasn't alone - that another girl at her school was undergoing the same therapy.

Gal experienced really bad "mood swings" and episodes of anger during her time on Prednisone™. She spoke of being hungry all the time and gaining weight. This was stressful for her and she found all of this extremely "unfair." She was referred to a psychologist and went for a short time but found it unhelpful since she felt they couldn't possibly understand what she was going through. She states she got through the Prednisone™ therapy simply by "waiting it out, like there wasn't a lot I could do."

With all of her therapies, including early on in her Remicade™ therapy, Gal was still going to the washroom frequently and sometimes she had to go at school. Some of her peers noticed this and noticed how long she was gone and made comments. She decided to ignore those comments and changed the topic immediately.

The 6-week course of Remicade™ therapy has been controlling Gal's CD quite well. Difficult side effects from the medication Gal described included severe exhaustion and picking up longer lasting colds more easily. This has made it hard for her to keep up



with school. Her teachers and guidance counsellors have been supportive of her, giving her extensions when needed.

Staying aware of how she is feeling and not pushing herself has helped her manage her fatigue. Making sleep a priority and “knowing when I am going to have to let something go” has helped when recovering from a cold. Her peers feel she should be able to work through her colds and fatigue. She tells herself “they...don’t understand.” With close friends she will “try to explain to them...I’m on immunosuppressants...and I...have to...rest and get better.” This explanation has helped.

In 2008, Gal’s mom passed away from colon cancer. Gal’s mom was a source of comfort and support to her because “like my mom...she was really sick, too, and so I kind of had her because we were both sick.” Her supportive and loving relationship with her dad has become even more important to her. Gal’s dad often prompts Gal to talk to her teacher if he notices she is starting to look unwell or feels she is getting sick. Gal states her dad also “validates...like if I’m not feeling well” to others and she has found this to be very helpful.

Gal worries the Remicade™ medication may stop working for her since it already has needed to be adjusted. She worries about potential new flare-ups and that university professors will not be as supportive of her. She thinks things will work out, however, and is “sure it will go over fine.” She feels her previous experiences will help her work through some of these issues. Gal also worries she may develop colon cancer. She plans on getting tested regularly for this.

Gal is part of a choir. In fact, the first time,

I got Remicade™ there were two girls here and they were actually in the choir that I had then joined...and like I got to talk to them and it was cool ‘cause like yeah...hey they knew like what I was going through.

She has done some travelling and in grade 9 she travelled to Banff Alberta, while last year she travelled to Florida. The CD had no impact on her trip to Alberta but last year’s trip she found very tiring and when she thinks back about it she realizes, “I definitely pushed myself more than I should have.”

Gal also spends time on the Facebook group for CD adolescents. She likes reading other people stories and it has helped her gained perspective. She states, “A lot of them is way worse...I’m...lucky.” She feels that living with CD has given her a “better understanding of things like that, like people being sick.”

Coping with fatigue and colds have been Gal’s two biggest challenges, but she has found ways to work around those things. Her dad, her teachers, and guidance counsellors have provided tremendous support to her. Despite losing her mom Gal has displayed remarkable resilience and has adapted quite well to living with CD.

### **Account 3**

Bob is 17 years old and in grade 12. He lives with his mom and dad and twin brother who is healthy. Tests show that Bob has been living with active CD since grade 7 but was only diagnosed this year.

Bob started experiencing cramping, stomach pain, nausea, pallor, diarrhea with blood and weight lost in grade 7. The cramping resulted in frequent bathroom visits. Due to the embarrassing odour from defecation, he would try to “hold everything in” and “tough through it” until he got home. He socialized very little with friends because he

was always worried about finding a washroom and also because of fatigue. He spent a lot of time at home watching TV, playing video games, and playing guitar.

He recalls embarrassingly the few times he did go over to friends' places to hang out with peers and having to use the washroom. The odour was painfully obvious not only to him but also his friends. Bob made "a joke out of it" to his friends and tried to laugh it off and they played along.

Since grade 7 Bob has been dealing with leakage from a fissure and fistula. During school he would notice stains on his pants and the chairs he sat on, and that the stains had a strong odour to them. Bob's brother often checked the behind of Bob's pants and noted any stains. Bob would go to the bathroom and "try to clean up as best as I could." He would avoid standing because he felt standing made the leakage worse plus sitting helped to hide the stains. When he was sitting down and noticed he left a stain on the chair he would "push the chair in a certain way...try to hide it kind of thing."

Bob and his parents sought medical attention for five years. They were told he had a high metabolism and to have "more fibre and water." Bob and his parents did just that but his symptoms only worsened. Bob tried convincing himself that he "felt normal, I thought everyone felt like that...I'd be thinking in my head how can these people eat...in so much pain." He would spend a lot of time trying "to tough through it pretty much, maybe try to watch TV, or like play video games." His parents were always available to talk with him, constantly validating his feelings, especially to his friends who "thought I faked being sick."

This year "the pain was so bad I was pooping all the time, puking all the time, like I could barely walk." This led to a hospital admission and the CD diagnosis came after

that. Bob and his whole family reacted with relief. While in hospital a peripherally inserted catheter (PICC) was inserted to help replenish essential nutrients. Having a PICC inserted was “pretty freaky” to Bob. He felt better once the doctors explained to him the procedure and its complications. Knowing he would receive Ativan beforehand took away a lot of his anxiety as well. Bob’s dad was present during the procedure and he spent a lot of time with Bob in hospital and they “talked and stuff about everything, like what’s going on.”

Bob was readmitted to hospital two months later due to continued weight loss. NG therapy was decided on and he found the idea of this “a little bit nerve racking.” The nurses, prior to the first insertion, discussed in detail with Bob the procedure, what it would feel like and what to expect. This decreased a lot of his uneasiness. Bob continues to do nightly tube feeding at home and inserts the tube himself most times. He uses water to aid with insertion and his mom and brother often assist him. Bob also began to meet “people who tube fed” and he found this extremely helpful.

Bob started Prednisone™ therapy immediately after the diagnosis. After that he was started on Imuran™ and Lansoprazole. He wasn’t on Imuran™ for long because it “was kind of like not really doing its job.” He was also started on Gabapentin because of the arthritic type pain he was experiencing due to the CD. He continues to be on the Gabapentin and has recently started remicade. All treatment decisions have been made with Bob’s input.

Prednisone™ did help decrease the symptoms, especially his stomach pain, but he started experiencing tremors, increased energy, ear ringing, headaches and increased heart rate. All these side effects made him want “to freak out.” He got rid of some of his

excessive energy by “mostly just playing drums in the air really hard.” Due to the side effects and his still active CD he was tapered off Prednisone™ and started on Remicade™.

Bob continued to have problems with leakage from his fissure and fistula even after treatment for his CD had started. He was given pads to wear to help catch the drainage. Despite feeling uncomfortable with the thought of having to wear a pad he was relieved to no longer have to worry about visible stains on the back of his pants. He also began having sitz baths to help aid in the healing process.

Bob worried about starting Remicade™ therapy because he had heard this drug could cause cancer. That fear quickly went away once doctors told him there was a very low chance of that happening. Bob is now experiencing very little stomach pain. When he does he takes “Tylenol or something, you know, just let it pass.” His fissure and fistula are 90% healed and he no longer has a problem with leakage. The frequency of bathroom use has decreased substantially and he is now spending more time socializing with his friends and as Bob states, “It’s awesome having to go to places and not have to worry about the bathroom. I’m loving that.”

Bob is really open about having CD and takes comfort in finding others who feel the same way, especially his cousin’s girlfriend who has been through a lot of the same stuff as him. His non-Crohn’s friends seem to have trouble relating to him but Bob never gets upset because “I just don’t think they really understand, actually.”

Bob graduates this year and has an interest in pursuing psychology because “the human mind, it sounds really interesting.” He looks optimistically towards the future and living a “normal life” with the hopes of someday getting married and having a family.

He also is quick to point out “you can get through it; things can get better” and he is living proof of that.

#### **Account 4**

Cal is quiet, shy and soft spoken. He is 16 years old and lives with his mom, dad and sister. Cal’s mom has CD and was diagnosed in 2000. 6 years ago Cal started experiencing stomach pain, fatigue, weight loss and decreased appetite. A colonoscopy was done and thereafter Cal received the diagnosis. Prior to the colonoscopy, the doctors and nurses at the IWK told him “what was going to happen, how I’d be afterwards and I’d be like ok” and he was grateful for that. Cal’s reaction to the diagnosis was “well, I really quickly realized it’s not going to go away and it’s something I have to live with.”

When Cal was first diagnosed, if he “had any questions about like the pain or if anything did happen in the washroom then I could ask mom.” Most of his questions were answered through observing what his mom went through daily. Cal’s mom also shared with him her experience with any procedure or surgery she had and he found this helpful.

Cal was unsure which therapy came first after he was diagnosed but it was either Prednisone™ or Imuran™. Cal doesn’t remember a lot about the Imuran™ especially any side effects it had. He recalls not liking Prednisone™ because “I got my eating habits back but I gained a lot of weight.” Fatigue became an issue as well but this didn’t bother him too much. Despite not liking this medication Cal felt it was something he “had to do.”

The above medications did very little to relieve his CD symptoms, especially the stomach pain. This period of time, which was from grade 4-6, was the most difficult time for him. In his words, “I was really in hard shape then.” The CD was affecting his

schooling and he would fall asleep in class due to the fatigue. Cal's mom talked to his teachers and made them aware of why he was feeling like this. Often times the teachers would see Cal asleep and just let him stay asleep, and at other times his friends would wake him before his teachers would get to him. Cal's mom also told his teachers that he may have an urgent need to use the washroom, and he was given permission to go whenever he needed.

During this time period he missed a whole year playing organized basketball because of his stomach pain. He states he "just dealt with it," accepted it and got through it. On occasion he was able to play a little leisure basketball at lunch and he enjoyed that. He spent very little time travelling anywhere because he "would...rather not sit in the car for hours on end hunched over in my seat." He did spend a lot of time at home, sitting on the couch, watching TV, and playing guitar in an attempt to take his mind off his pain. Most times, however, he would just wait it out or tough through the pain.

About four years ago, while attending a GI clinic appointment, Dr. X notified Cal that the Prednisone™ and Imuran™ would be stopped. Three new treatment options were discussed: Remicade™, Humira or NG tube feedings. Cal's parents immediately decided to go for Remicade™ therapy. Cal was open to the NG tube feedings but his parents did not want this because he would "be the only kid walking around with a thing in my nose." Cal did not share the same concern because he felt "my friends would have understood." He believes if he pushed for the NG his parents would have considered it since they always involve him in any decisions surrounding his treatment.

Cal has been in remission for four years now. He states that unless "you were talking to anyone besides my friends no one would ever know I had Crohn's" and "I

pretty much live a normal life besides coming up here every few weeks.” After the first round of Remicade™, Cal noticed quite a significant decrease in the amount of stomach pain he was having. The Remicade™, however, made him feel nauseous, and this was an issue for the first two years. He would take the next day off school and “relax,” which helped. Cal never wanted to know the specifics around how Remicade™ worked, just that it did, and should it stop working he would “deal with it.”

Cal’s dad drives him and his mom to all their treatments. Cal states his dad and sister don’t know much about CD, that he and his mom are the “authority on that.” This doesn’t bother him too much and it’s “just the way it is.”

This summer Cal attended the Brigadoon summer camp for adolescents with CD. He made a lot of new friends who he now keeps in regular contact with via phone and Facebook. During camp he spent most of his time swimming, playing sports, fishing and playing guitar. He recalls only one time during camp where he and his friends shared “hospital stuff” and “what we had to go through and stuff” with our CD. He found hearing other people’s experiences very helpful. He is also a part of a Facebook CD adolescent group and, more recently, he just goes on to see how everyone else is doing. He feels sad for some people and what they are going through.

In the past two years he has been in a few fights because he can be “a bit of a hot head.” His friends stay away from him when they sense he is in a bad mood. Cal combats this issue by taking the time and space he needs to cool down. His school is also a current source of concern because there is a drug problem. He won’t “have anything to do with” anyone who does drugs. His health is very important to him and he doesn’t



drink or smoke because he knows this will make his CD worse. He thinks about the future but only in regard to the financial aspect of living with CD “cause it’s not cheap.”

He is currently spending his time playing basketball, hanging and eating out with friends and attending a Friday youth group. He feels he is largely able to do these things because of the Remicade™ therapy. His ability to problem solve, comprehend consequences to his behaviour, as well as his attitude toward his illness have also helped him. Friendship, health professional, and parental support, especially the support of his mom, has helped as well.

### **Account 5**

Kate is 13 and lives with her mom, dad and brother. She was diagnosed with CD when she was 9. She began experiencing fatigue, decreased appetite, weight loss, increased washroom frequency, nausea and abdominal pain. She missed a half year of school due to not feeling well. She spent most of that time at home, on the couch, watching TV or playing videos games and spending time on the computer. These activities took her mind off her pain and other CD symptoms. Sticking to a vegetarian diet also helped and she continues to stick to this diet. She spent very little time socializing and out with friends.

Kate and her family sought medical attention and a series of tests were performed including a colonoscopy. Shortly thereafter, Kate received the news she had CD. She and her family felt “kind of confused” by this news because they had no idea what CD was. Afterwards, Kate asked her mom a lot of questions about CD including what it was, how it would affect her and how the medications would work. Her mom shared with her any information she had learned and this lessened the confusion she was feeling.

Kate began treatment for her CD immediately and recalls being on 2 different medications prior to starting Remicade™. The first medication she was required to take was Prednisone™, which resulted in increased appetite and weight gain. Kate was happy to be gaining weight since “I weighed like seventy pounds...and it was really bad.” The Prednisone™ controlled her CD well for about 2 months; the symptoms then returned but were slightly less severe. She remembers still struggling quite a bit with fatigue, pain in her stomach, minor weight loss and constipation. Because of this the Prednisone™ was stopped and Kate was started on Methotrexate injections. She had no problem with “needles at all” and didn’t mind going to the hospital to get her injections. Side effects from the Methotrexate were not an issue for Kate but like Prednisone™, this medication didn’t control her CD symptoms very well.

The biggest challenges to Kate, during these two therapies, were “getting my weight up...keeping up with school” and coping with fatigue. There wasn’t much she could do about her weight. With school, some of her teachers did become aware of her situation and did what they could to help. When Kate missed a test due to not feeling well, her teachers administered it to her at another time. Her teachers always filled her in on anything she missed when she was unable to attend school and immediately Kate would proceed “to study it.” Her teachers were open to receiving phone calls from her about various subjects and they would explain the things that “confused” her. She also kept up with school by staying organized which included making sure she “can find everything,” especially school worksheets. She coped with fatigue in school by choosing to not participate in activities like gym, conserving energy for studying. Her gym teacher always supported her decision.

Kate started Remicade™ 2 years ago. It has worked well and she has been in remission since starting this drug. She states, “Like I’ve got my energy back and I’m eating normally now.” She and her mom travel to the IWK once every six weeks to receive her infusion. Upon returning to school the next day, her teachers find her and catch her up on what she has missed. Her best friend also keeps her up-to-date on what she misses in class. Her friend is aware she has CD but Kate has not shared any of the specifics of the disease as she doesn’t “really feel comfortable talking about it.” She does recall how supportive her best friend has been to her on occasions like when her hamster died when she was in grade 4. She will also talk to and vent to her best friend and other close friends when other things besides CD upset her, and venting really helps her work through feelings.

Kate does not belong to any online CD support groups and “didn’t even know there were any,” but now that she is aware she is open to considering joining them. Her mother continues to be her biggest support when it comes to her CD and the one person she feels free to openly discuss her CD.

She attended Camp Brigadoon this past summer and made a few friends. She thought the camp “was amazing” and she spent time canoeing, swimming, playing games and building campfires. There was only one time during lunch where they focused on learning and talking about their CD. For her the best part was “having fun and hangout” with people who had the same condition as her. She did remain in contact with some of the people from this camp and they are now friends on her Facebook. She is planning on having one of these friends stay at her place during the upcoming March break.

She joined the school band a few months ago and plays the trumpet and guitar. She is enjoying this experience since it has allowed her to make new friends and spend more time away from home. This helps keep her mind off her CD and school.

Kate worries about the future and wonders if her CD “will...get worse,...get better, will they find a cure.” She also worries about whether or not the Remicade™ will keep working. These worries lessen when she is with her friends, walking her dog, playing her trumpet and guitar and when she reads adventure or mystery books.

Kate feels her CD has made her a stronger, caring and more compassionate person, especially towards people who are sick. And despite some worries and concerns she feels positive about the future and thinks things will work out for her.

Kate has been living with CD since she was 9 years old. She has done remarkably well despite not getting relief from her symptoms until she started Remicade™. Her mom, teachers, friends, school band, and her ability to stay organized have been paramount in helping her live as well as she has with CD.

### **Account 6**

John is 16 years old, in grade 10, and has one brother and a step-brother. His parents have been separated for 10-11 years and his father is living with his girlfriend. His mom also has CD.

John is with his mom from Sunday night until Thursday and with his dad for the remainder of the week. He has had time to get used to his parents being separated, but living in 2 different homes with 2 different set of rules has been difficult for him and it “causes friction.” He also feels like his step-mom and mom are always “trying to out-do each other.” At his mom’s house, John takes 5-6 pills for his CD. At his step-mom’s he

takes 14. The increase in pills at his step-mom's is also because she believes "in all the naturopath stuff." John "feels like he doesn't need all of it" and has expressed this to her but she is not open to any changes in his treatment regime. They have had "some falling outs" over this. When the "falling outs" happen John typically will take some time away from his step-mom either by going for a walk or going to "his mom's...and just didn't come back for a while." John's step-mom also puts "a lot of pressure on him to eat healthy" including sticking to a vegetarian diet and eating 10-12 servings of vegetables a day. John is unsure if his step-mom understands the relationship between some of his CD symptoms and having a diet filled with a lot of raw vegetables. He no longer wishes to have this discussion with her because "we're both very stubborn." When it comes to the issues between John and his step-mom his dad "will take her side one week and then my side the next week." John also feels his father "doesn't really try to connect" with him and wishes there was "more communication between them."

John was diagnosed in grade 5 when they discovered he had a fistula. The fistula required draining and he underwent surgery. Surgery required him to be out of school and when he returned his teachers asked him to do "a word search" for his class because this would help them understand his disease. Prior to this, John's mom informed his teachers as to what was going on. John's reaction to the diagnosis was "whatever, mom has it, so mom's ok, it can't be that bad. Then I realized that it was pretty bad." Things took a turn for the worse that year when he went down to "63lbs," and was experiencing vomiting and extreme fatigue that required frequent after school naps.

John was started on Prednisone™ but it didn't control his CD very well. It made him feel even more tired and he developed severe arthritic type pain that made it difficult

for him to walk. In response to these side effects he adopted the attitude, “I just went through life, not much you can do.” The Prednisone™ was stopped and he was started on Imuran™. The arthritic type pain he was experiencing continued and nothing he did decreased it. It didn’t prevent him from attending school but it did prevent him from taking part in gym. The pain stopped once he was taken off this medication and he resumed participation in this activity.

During this time John’s mom was a huge support to him, offering him advice on “how to deal with it,” “how to make it like not as big of a deal,” and “just some relaxation stuff.” She has also spent time explaining to him why he had to take various medications. He found all this very helpful. She continues to be a good resource for him and is the main reason why he is not overly interested in joining any CD support groups.

After Imuran™ John started tube-feeds and has been doing feeds for the past 4 years. They were just recently stopped. John assumed responsibility for tube insertion while his dad made a stand for the feeding pump. He used the stand quite often at home as it made it easier for him to move around during tube feedings. His mother encouraged him to name the pump and on occasion “she’d let me take a night off” feedings and he very much appreciated that. For the first 3 months the tube was in 24/7 and he was required to take it to school. At school he would keep the small, lightweight, square feeding pump apparatus in his school bag; hiding it from the view of his classmates. The pump would often beep and he found this very embarrassing. He would leave class, go to the bathroom and fix the pump. If asked by a friend “what was that” he would state “Crohn’s stuff” and “change the topic.” No longer wanting to deal with this issue, John took a can of food “with me and put a syringe in it and pumped it in like that.” John’s

friends were very supportive of him during this time and would stay with him in class while he “pushed the stuff in with a syringe.”

During the 4 years on feeds John spent a lot of time at home and didn't attend “many parties.” He didn't often stay over at friends due to the embarrassment he felt over having to put a tube in his nose and take medications. Despite the above challenges he made a lot of good friends at school. His closest friend has been one of his greatest supports, reassuring him all along the way that things would get better for him. The tube feeds helped initially, especially with weight gain, but this was short lived and he continued to have other CD symptoms.

John travelled to Cuba last year while still on tube-feeds. His CD was well controlled, but he found having to bring cases of food with him terribly inconvenient and made it “harder to move around.” When experiencing stressful situations like this he often deals with it by “I'll sit back and think about it...just why I got it, why I have all this stuff.” He feels this approach helps. He believes travel stress, home-life stress and school stress is why his CD has been hard to treat. He spends a lot of time thinking about his stress and ways to decrease it.

Last year, he underwent another colonoscopy and prior to it he became very fearful about having it done again. The doctors, nurses and his mom tried to calm his fears by sharing information with him, but John felt the less he knew the better. Afterwards things became even more uncomfortable for him since he was un-clothed and “it was kind of awkward.” He was grateful when the whole thing was over. The colonoscopy revealed another fistula and as a result, on Oct 13th, 2011, John, his mom and his dad made the decision to start Remicade™. His mom normally takes him to his

hospital appointments and he is now on an eight-week cycle of Remicade™. He was also started on Methotrexate and he is “doing good with it.” He has gained 10 lbs and his fistula has cleared up. His CD is no longer preventing him from doing the things he loves like cadets and rock climbing. He states, “If I really want to go” and do something he will and the CD won’t stop him anymore. He is hopeful things will continue to improve and he hopes one day he will be well enough to join the Armed Forces.

John has not yet experienced a complete remission and still continues to experience CD symptoms. The relationship with his step-mom and dad are problematic to him. Despite all this, he has shown remarkable resilience. He has surrounded himself with supportive friends and is very good at problem solving. The support from his mom has been paramount in helping him to live as well as he can with his CD.

#### **Account 7**

Jim is 14 years old, in grade 9, and was diagnosed with CD in 2009. Jim has very mild asthma and on rare occasions uses a puffer. He lives with his mom, dad and sister. He has one brother who has CD as well. They rarely talk about their CD because his brother no longer lives at home and they are very “different” personality-wise. His brother is now in remission and is doing very well.

Prior to being diagnosed, Jim began experiencing fatigue, fevers, vomiting and increased washroom frequency with passage of blood in the stool. He started to lose weight, and developed sores in his mouth and “stabbing” pains in his stomach that “made me cringe.” To help alleviate some of the pain, Jim took Tylenol. For the nausea, he would take Gravol and after an episode of vomiting he would get some “fresh air” to help him feel better. Jim and his parents went to see a doctor in his home community



who referred him to the IWK in Halifax where he underwent a colonoscopy. Prior to the scope, Jim's brother shared his experiences and told him that the only thing that would hurt afterwards would be his throat. The nurses described to him what was going to happen. Jim found all this information very helpful and was glad to hear "it wouldn't be that bad." The scope "found all the inflammation" and shortly thereafter Jim was given the news he had CD. He decided "it's not that big of a deal" and "it didn't matter much" to him. Upon being discharged and sent home he was started on Prednisone™ and he was required to take 15 pills all at once and that "was kind of annoying." The Prednisone™ made his "cheeks...really big" and his "appetite increased." He found it "annoying" to have to eat all the time. He also started to experience even more fatigue and "I'd have to sleep after school." Jim doesn't remember anything in particular that got him through that period other than simply tolerating the side effects and "just kept going."

The Prednisone™ was working at first but symptoms returned especially the pain. The decision was then made to start Methotrexate via needle. At first things went well but then Jim developed a "phobia" of the needle and the smell of the alcohol swab made "me sick to my stomach." Because of this and he thought he might "do it wrong" his mom administered his needle. The Methotrexate was eventually switched to an oral form, much to his relief. Jim, with the complete support of his parents, made the decision to add other therapies to the Methotrexate since he was still experiencing decreased appetite, vomiting, and blood in his stool. He decided he would come into the IWK to "clean out my bowels," to get a "PICC line in and get fed through that" for 10 days, and to start Remicade™ therapy. He did not mind having his bowels cleaned out and the

PICC line therapy went well, but after a while he just “really wanted to eat.” Jim expressed to his parents how hard it was not being able to eat and drink and venting these feelings really helped. His parents stayed by his side the whole time he was in the hospital and accompanied him to the “Teen Center” at the IWK when he became “bored” so that he could play games. His aunt and cousins also visited him and Jim states that it was his family that helped him through this difficult period. After the PICC therapy the passage of blood in the stool stopped.

While in hospital, Jim’s teachers gave him work to do so that he wouldn’t fall behind in his studies. They also sent him a get well card with all his classmates’ signatures. The teachers were also very helpful when he went back to school by giving him extra time to do his work.

During the course of all these treatments, Jim talked to his mom about how he was feeling. She offered him suggestions on how to cope, like suggesting more sleep to deal with his fatigue. When he was having trouble keeping up with school she suggested he work through his school lunch. But there were also times when she and his dad would suggest he ease up on his school work due to his over-achieving tendencies. Jim welcomed these suggestions and found them very helpful. Jim doesn’t talk much to his dad about his CD but he does feel he can if need be. During all this time he continued to have stomach pain but chose to work “through it” and resumed playing basketball, hockey and gym and he even stayed in school when not feeling well. At home he would try to sleep or play video games to deal with how he was feeling.

Jim started Remicade™ a year ago and things have improved for him. He has experienced no side effects and is “never in pain.” He is no longer vomiting and his

appetite and growth are “normal.” He is continuing to play hockey and has picked up playing the drums. He feels his life is getting back to normal and he is coping much better with school, everyday life, and his CD. His new found ability to “stay calm” and “I just don’t worry about different things” have really helped him.

The doctors and nurses at the IWK have been very supportive by explaining to him how procedures and medications work. He is currently not part of any online or local CD support groups and has no desire to be. He feels he gets all the support he needs from his family, especially his mom, and he’d rather just socialize with the friends he grew up with. He “wouldn’t wish” this disease upon anyone and he hopes at some point he will go into a complete remission and “stop treatment overall.”

Jim has done remarkably well. The support from his family, teachers, doctors, nurses, and his ability to problem-solve and work through his “pain” have allowed him to resume and continue on with the things he loves to do such as school and sports. He is living quite successfully with his CD.

## **Part 2: Themes**

In analyzing the data from all the interviews and while considering the seven individual narrative stories four themes along with subthemes emerged from the participants’ stories. The following is a list of the themes:

### **1) Unconditional Support**

**a) Parental Support**

**b) Friendship Support**

**c) Teacher Support**

**d) Health Professional Support-Customizing Care**

2) **Embracing and Accepting Differences**

3) **Attitudes/Personal Beliefs**

a) **Acceptance of Diagnosis**

b) **Sense of Hope/Meaning**

4) **Daily Coping Strategies**

a) **Distraction Activities**

b) **Handling Embarrassing Situations**

c) **Staying Aware/Being Proactive [Problem Solvers]**

d) **Waiting it Out/Toughing Through It**

**1. Unconditional Support**

Unconditional support is pivotal in helping these adolescents manage the active phases of their CD and the troublesome symptoms and treatment side effects they have to endure. This resource is accessed mostly in the early stages of their disease when the adolescents, due to their developmental level, are unable to view CD challenges comprehensively and problem solve their way through these challenges. This resource is also accessed when the youths' QOL is poorest and they feel physically incapable of managing all aspects of their care.

Four main sources of support were identified: (a) friendship; (b) teacher; (c) parental; and (d) health professional support.

**1a) Parental Support**

Parental support is the most important protective factor for these participants. It is crucial in helping the adolescents in this study successfully integrate the CD into their

everyday life. This support is especially evident in early adolescence when the participant is first diagnosed, during treatments (especially when side effects became an issue), during hospital stays, and especially during active disease when QOL is poorest. It is interesting to note that the mothers of these participants are the main source of support, especially when the adolescents need someone to talk to about their CD. As one participant stated, “Talk to my mom...just my mom...Ah, just when I am not feeling good and stuff like that” since she is “the authority on that.”

Three patterns of parental support were identified within this first subtheme. The following is a list of the parental dimensions of support:

***-Logistical Support***

***- Being a Parent***

***- Encouraging Autonomy***

***Logistical Support***

Parents offer logistical support to their son or daughter in the following ways: attending appointments and treatments, providing pickups and drop-offs to school, and helping out with various treatments. Once the CD diagnosis was given and treatment commenced, parents offered support by “she takes me up to a lot of the appointments.”

Another participant emphasized how,

My mom has been here every single treatment. My dad has to work...but my mom has a home-based business so she gets to come with me whenever she wants. And it’s really awesome because they are always here. They know everything.

During times in which these participants are admitted to hospital due to a flare-up of their CD or because they are undergoing a procedure or surgery, their parents will stay by their side all throughout their stay. One participant stated his dad, “Would just, like... like we would basically talk and stuff about everything, like what’s going on, we talk... and that’s pretty much the basis of how he supports me.” When another participant became bored during a hospital stay, his parents suggested he go to the IWK,

Teen Centre... I’m not sure... where all the games are and everything, and they’d help me with my, ah, IV or whatever line... Ah, just move the machine out of the way and unplug it from the wall and stuff like that.

One way in which one father supported his daughter with CD was,

I wasn’t sure if I was going to be feeling well, like, I might be feeling OK then, but by the time I get to school I feel sick and I just, like, go back and forth...like through elementary school I’d be, like, back and forth between school multiple times in the day sometimes... Well, he always...he works from home a lot, and so if I ever need to be picked up and stuff...

Parents also support their son or daughter by assuming some of the treatment responsibility, especially when treatments for their CD first start. For example, one participant shared,

It was really supportive of my mom...when I first got my feeding tube and they had this head...this... that was cut in half to show us exactly how to put it in. My mother learned how to put it in and I...it was really weird ‘cause I was like 9 years old and it was pretty scary for me to have to deal with that. I had seen it on TV and usually people... it was really difficult for people... like, it looked really

painful to me...when I was looking at it. But then later after my mom put it in, we found out it was really simple.

Parents also offer simple encouragement or assistance to the participants who know how to get their own NG tubes in but run into some difficulty. One parent always reminds her child to drink some water from a straw when the tube becomes stuck; another parent helps advance her child's tube as he drinks water in an attempt to get the tube down, and once the tube is down they check for placement.

### ***Being a Parent***

Being a parent to these youth with CD involves being available to talk with their child about their condition, validating their child's feelings around living with CD, helping them resolve issues that arise as a result of their illness, and sharing information and experiences around CD.

Living with CD has been challenging for many of these participants and has often resulted in some very frustrating and upsetting times for them, especially early on in their disease course when things seemed to be at their worst and their QOL was poorest. The CD symptoms, the treatments and their side effects, and comments from peers are especially difficult for these participants to cope with. Through these challenges, the parents of these participants are available to talk with and listen to their child vent their frustration. For one participant who was extremely frustrated with her CD, its symptoms, and the side effects from the Remicade™, she vented to her dad since,

My dad has been there and he has seen me go through it...I guess, like, he can validate...like if I'm not feeling well...he can understand more what it's like and

I guess he paid more attention...about how I was feeling and stuff. So he gets it...

For another participant, who lived with undiagnosed CD for five years and had to cope with numerous comments from peers inferring he was faking being sick, his parents offered support in the form of “backing me up” and sharing with his friends ““Well, “X” just puked,” and they be like, “Oh, really?” “Oh, yeah... he is really sick.””

When coping with extreme side effects from treatments or symptoms from active disease, parents will offer their son or daughter suggestions to help manage and deal with some of the issues these things present, especially when their son or daughter is incapable developmentally of resolving these issues. For example, for one adolescent who was in early adolescence at the time and was having trouble keeping up with school due to the fatigue he experienced as a result of his CD and its treatment, his parents suggested, “Go in at lunch time to keep up with school work.” He found this suggestion immensely helpful as it helped him get back on track. Another parent and older child will work together to figure out “if the feeling is too bad, are we going to go to the hospital.” One father notices,

That I’m not looking good before I notice I’m not doing well. And he’s always there, like, telling me to talk to my teachers and stuff, too. Like sometimes, I might not and I might let it go on longer and get more stressed. So he tells me when I should probably talk to my teachers sometimes... I understand, like, why he does it, and it is the right thing to do.

In helping their child understand their illness and cope with it, parents often share whatever information they have learned to help their child cope with and manage their



disease as best they can. This is especially evident during the beginning stages of treatment, just after their child is first diagnosed. For example, one participant who was 9 years old when she was diagnosed and ended up feeling extremely “confused” since “I really didn’t know what it was” was helped to feel better when her mother explained to her “just what it was and what it would do and how it would affect me.” Parents also share with their child information on, “how to manage” things “like the pain” and “anything to do with Crohn’s that might bother me they always bring it to my attention.”

Parents also share this knowledge about CD with others, such as schoolteachers, to help them understand what their child is going through. This sharing of knowledge typically takes place in the beginning stages of their child’s disease management and when QOL is poorest. By imparting this knowledge onto the schoolteachers, it makes it easier for their child to easily negotiate bathroom privileges and extensions with schoolwork. Parents are also quick to share with health professionals any information about their child’s condition. This is especially apparent when their child is first seeking medical attention for the symptoms they are experiencing. As one participant stated, his parents were always “backing up” what he was going through symptom wise.

And finally, for those youth who have parents/siblings living with CD, they offer support in the form of sharing their experiences around living with their disease. One child, who was about to undergo a colonoscopy and experience anaesthesia for the first time shared,

It was really weird because it’s the first time I ever had to be put to sleep...my parents were there the whole time...like, they had experiences because of their diseases...they both have chronic illnesses and so they just told me their

experiences - what it's going to be like... and they explained to me how they felt when they had theirs...and/or when they were put to sleep, what it's like when you wake up...It made it a lot better to be put to sleep and to be waking up later because they were right there.

These same parents with CD also offer support through answering their children's questions about similar symptoms they went through and successfully coped with. For example, one participant spoke of how "if anything did happen in the washroom, then I could ask Mom and she could tell me to the best of her abilities, like with her experiences with it and stuff."

### ***Encouraging Autonomy***

Several parents encourage their children to become part of the decision-making process, especially around treatment choices. Autonomy is especially encouraged as their child becomes more used to living with CD and more confident and developmentally able to handle the day-to-day issues that arise as a result of their CD. As one participant shares, "It is my disease, so they just realize that and they just help me make my decisions," while another states, "Well, they always bring me into any decision that has to do with my Crohn's...they ask my opinion..." "Do you think...? Do you want to...?"

### **1b) Friendship Support**

Some of the participants, who are now in junior high and high school, have remained friends with the individuals they met in elementary school. These friends have become a great source of support to them. One of the positives of these enduring friendships is that the youth are surrounded by people who "know what I am going

through.” They do not have to explain how they are feeling because “they knew me, like, when I started to get sick” and they “just get it.” These friends make them feel like they are not any different from them despite their CD. One participant spoke of how his parents didn’t want him to have a feeding tube, but, he stated, “My friends would have understood” and would not have viewed him differently. As some of these youth approached middle adolescence, when developmentally acceptance by peers becomes a central theme, they appreciated even more the accepting, close bonds they have with these healthy youth.

The youth seek out these friends, especially in times of needing extra support such as when symptoms and treatments interfere with their ability to keep up with daily life. For example, one 13-year old participant who was missing school due to her Remicade™ therapy spoke of how her best friend since grade 3 was “the one informing me of what I’m missing today” in school. For another participant, during active disease phases, his best friend, who he has known since preschool, is always available to talk and offer reassurance that things will “get better” for him.

For one participant with an NG tube, support from his friends came in the form of “at lunch time when I would push the stuff in with the syringe, they’d stay in the class room and hang out with me.” Finally, another participant experiencing extreme fatigue as a result of his CD spoke of how “sometimes friends would just nudge me before, like if the teacher was going to pass something out to the class, and they would just nudge me, you know. Get me up and stuff.”

### **1c) Teacher Support**

Teacher and guidance counsellor support have played an important role in helping these participants integrate the disease into their daily lives while maintaining their school responsibilities. Teacher support also helps minimize the potential for the CD to make these participants feel different from their school peers.

This support is especially evident when the participants are first diagnosed (pre or early – adolescence), are in active disease, are experiencing a stay in hospital due to a CD flare-up/fistula issues, or are undergoing a visible therapy while attending school - all situations in which their QOL is poorest.

For one adolescent who was just diagnosed with CD, and in grade five at the time, and returned to school after fistula surgery, the teacher offered support by encouraging and helping him do “a word search for my class” so that his classmates understood his disease and why he was absent from school.

Another older youth, who possesses strong problem solving skills when in active disease, will talk to her guidance counsellor and tell her “what’s going on and they can tell your teacher...if you go through them, usually your teacher is, like, more supportive, like really helping you to get caught up and stuff.” Also during active disease, several participants speak of how they will fall behind in their studies or miss tests and the teachers will “give you an extension” or re-administer a test “during class...or just at lunch.” Another example of teacher support during active disease involves “if I wasn’t feeling good and had to use the washroom and had to leave, they were good about that.”

For another participant in the midst of a new flare-up and admission to hospital, the teacher helped this high school participant by giving him a list of school work to complete so that he wouldn’t fall behind in his studies, while another teacher sent him a

card with his classmate's signatures. And when one of the 13-year old participants misses school due to Remicade™ Therapy, her teachers help her get caught up in her studies by allowing her to "phone" them at any time "and say, "I don't understand this. Can you explain this to me?"

And finally, when participants come to class with NG tubes and pumps, teachers offer support in the form of explaining,

To everybody why I had the feeding tube, what it was all about, what the disease was... and it made it a lot easier on me. When people know it makes it better because you don't have to explain it and it is a lot easier on you.

In addition, for one participant who experienced a lot of embarrassment due to his feeding pump "beeping" in class, the teacher would minimize this embarrassment by simply ignoring the beeping sound and "just kept talking." She also gave him advance permission to leave class and go fix the pump whenever it would go off.

#### **1d) Health Professional Support-Customizing Care**

Health professional support was commented on by a few participants but did not receive a lot of attention during the interviews. Depending on the developmental level, unique needs, desires and wishes of each youth in this study, the doctors and nurses at the IWK customize the care they offer to each of these adolescents. For one youth, this means the doctors and nurses work hard to create a fun and uplifting atmosphere during his therapies and medical appointments. They create this atmosphere through joking around with him and through making positive statements such as these medications will "help make you feel better."

For some older youth desiring to know as much as possible about their CD and therapies, customized care means the doctors and nurses providing them with information about how their medications work and what to expect when undergoing certain procedures like a colonoscopy. As one participant shared, “Like my scopes, for instance... they tell me what was going to happen, how I’d be afterwards and I’d be, like, OK.” Customized care also means health professionals providing information on therapies that will occur in their home and showing them how to carry out these therapies. For example, when one of the participants was about to start NG therapy, the doctors and nurses spent time explaining and showing him the process using “this head...to show us exactly how to put it in.”

For participants who experience procedure anxiety, the doctors and nurses try to decrease this anxiety by “give me the heads up in what I’m doin’ before I do it.” And for two participants who experienced several failed therapies and severe side effects from various treatments and desire to hear some hopeful news going forward, the doctors and nurses tailor their care through offering reassurance “that if one drug didn’t work they had literally thousands of drugs that they are able to use.”

Lastly, two participants are very happy when the doctors and nurses realize they want to know as little information as possible around treatments and procedures, since they are of the mindset that when “it comes... I will deal with it.”

In summary, one of the most effective coping strategies utilized by resilient individuals is their ability to recruit social support, especially during difficult times. All the adolescents in this study recruit social support from the four different groups listed above.

For this theme of *Unconditional Support*, four sub-themes emerged. The first sub-theme is “parental support,” where the youth outline the logistical and emotional support their parents provide them daily in regards to their CD. The second sub-theme is “friendship support,” where the youth describe the great source of support their few close friends are to them (these friendships that originated in elementary school). The third sub-theme is “teacher support,” where the youth list all the daily actions the teachers take to help incorporate their illness into everyday classroom life. The final sub-theme is “health professional support,” where the youth share examples of how health professionals customize the care they give to each adolescent.

## **2) Embracing and Accepting Differences**

Many of the participants speak of feeling different from their peers. This difference is attributed to the fact they have CD and look at times physically different from their peers, especially when undergoing visible CD therapies. This sense of difference is especially evident during middle adolescence, when the developmental themes of peer acceptance and body image are most prominent. Several strategies are incorporated to minimize this sense of difference.

The first strategy of demonstrating resilience involves accepting they are different and embracing that difference. One 13 year old participant summed this up by sharing, Like you’re different, you know... Even if they don’t know it, you know it, and that kind of keeps you away from everybody else. Like outside of that you may be really popular and you may have fun all the time but it, like, it’s really hard being different. I am ok with it; I’m perfectly fine with it, but everybody...I just feel sometimes that being different is really hard for them to accept of me...so I

don't know... Me - it's no big deal. I'm... I'm always different from other people; like everybody is different; I'm different from you and you're different from me and I'm different from the kid over there.

Another adolescent embraces her difference by acknowledging it and adopting the attitude that her non-CD peers just don't "understand, actually yeah. 'Cause you really don't understand what someone goes through if you have not gone through it yourself."

Another participant who lived with undiagnosed CD for five years normalized his life somewhat during that time by trying to convince himself that,

I...felt normal, I thought everyone felt like that. And I was thinking... "Everyone feels like this..." Like for example, everyone would eat and eat and eat. And I'll be thinking, I'll be thinking in my head, "How can these people eat and eat so much?" you know... in so much pain. These guys... I thought they'd be in pain, too, but I guess they weren't.

Another strategy employed by more confident, capable youth is fielding and answering questions from their peers and non-CD friends. For example, one participant who was undergoing NG therapy was asked,

Well first, like, people were, like, "What is that?" I explained to them what it was for, that I couldn't eat normal food. And, like, people got that and I don't think, like, my friends ever treated me differently because of that.

Another older participant, proficient in problem solving and made to feel different by her peers because they repeatedly point out her general state of un-wellness as compared to them, minimizes this sense of difference by explaining,



Like if it's a friend, I'll like try to explain to them that "[it's] because I'm on immunosuppressants. I can't just, like, push pass some things and I actually have to, like, just rest and get better." They're pretty good, like they get it, "Ohhhh... I didn't realize that.

Other participants do not actively try to minimize their sense of difference through offering explanations to their non-CD peers but rather do so by not going into a lot of detail with their friends about any aspect of their disease.

The most common strategy used during early, middle and sometimes late adolescence to reduce a sense of difference is seeking out others who have CD, even if it is from a distance or through joining a choir where other CD adolescents are present. One participant, when first diagnosed, took comfort in knowing,

There's one girl that goes to my school, like she was diagnosed, like, I think a couple months after me. So we were both on tube feeding at the same time.

Well, it was just, like, more knowing someone was going through the same thing as you, especially we both, like, had to have our tubes at school and stuff. So it wasn't like you were the only person.

The IWK Gastroenterology Clinic, which contains the Remicade™ Clinic, also has become another forum for these participants to meet and become friends with others like them. In fact, during therapies, these adolescents often spend time with each other, getting to know one another or catching up on things since they last saw one another. They typically never discuss much CD related stuff, but discuss other life issues such as school. The comfort, however, still comes from knowing that there is someone going through the same thing as them.

Another method utilized to seek out others with CD is joining online forums, especially the Facebook group for adolescents with CD. This has been extremely helpful, especially in the beginning of their disease when these participants' QOL was poorest and they were unable to socialize with friends or recruit friendship support in person as a result. This is also helpful when the youth are faced with having to undergo very visible CD therapies such as NG tube feeds that they know very little about. The following quote was shared by one adolescent,

I think when I just got diagnosed, I think I was part of, like, a web forum for people with Crohn's and... at that time it was helpful because I didn't know how I was really going to know...anything, especially...when I started NG tube feeding 'cause other people there had gone through it and it's not, like, something a 12-year old really knows... I guess, like, especially I had to get the tube put in and stuff and I was really worried about that...Just reading other people's things you could tell, like, what was happening to me.

Participants who joined these forums became Facebook friends with many of the other adolescents on these forums, and they keep in touch with one another through email, Facebook and via phone.

Some other participants do not spend a lot of time on these forums, especially as they have become accustomed to living with CD. However, when they do go on, they think "to see...everyone's stories is cool," and "knowing that there's other people out that have the same thing." This latter part brings them some measure of comfort and minimizes their sense of feeling different from their non-CD friends.

One of the main methods participants used to meet others like them was by taking advantage of the opportunity to attend Camp Brigadoon - a camp located in the Annapolis Valley, NS, for children and youth with chronic illnesses. These youth attended this camp during their summer vacations and it lasted for one week. The youth got to spend a week with other adolescents with chronic illnesses including CD and they got to swim, camp, build fires, and hang out with one another. Most participants spent very little time focused on discussing symptoms, treatments and procedures with other attendees at the camp. Once again the comfort came from “more knowing someone was going through the same thing as you... So, it wasn’t like you were the only person.” Another participant summed up his experience at Camp Brigadoon by saying,

It’s really wonderful being in a place where, like, you are just one of the other kids. You’re just completely regular, completely normal. There is nothing different about you....For me just being regular without a difference really can sometimes be one of the best feelings because there is nothing to segregate you from anybody else, there is, like, no discrimination, no segregation...

Everybody’s equal and it’s really nice to have that feeling.

These participants have remained in contact via phone, email and Facebook with people from this camp, and for some participants these individuals from Camp Brigadoon have become their closest friends. In fact, one participant was in the midst of “making plans for March break” with another girl from this camp and the plan was to have her “come down and hang out at my place for...most of the whole March break.”

Lastly, a couple of participants, now in late adolescence and who are very proficient living with their disease, elect to minimize their sense of feeling different by

focusing on anything but their CD. These two individuals have been living with CD for quite some time; one has been in remission for almost four years. Their goal is “to get back to normal life.” This means they have no interest in joining forums, camps, or Facebook groups for adolescents with CD. They spend their time hanging out with the healthy friends they already have. One of these participants also elected to forego all these groups because,

Well, I’m doing fine with it right, I don’t really feel I need the support of it, of other friends,” while the other felt “I don’t know, I just wouldn’t wish that upon them. I don’t know...It doesn’t matter to me, knowing someone with CD. I have all the support I need in my friends and family.

In summary, for the theme *Embracing and Accepting Differences*, the youth outlined measures they take to minimize the sense of difference they feel from their non-CD peers. These measures include acknowledging and accepting they are different; answering questions about and explaining their illness to non-CD peers; and seeking out others with CD via Facebook/web CD support groups, Remicade™ Clinic, and through attending Camp Brigadoon. For others, they minimize their sense of difference by not focusing on any aspect of their illness, not becoming part of any CD group, and investing their time in nurturing the few close non-CD friendships they have. As was stated previously, recruiting social support and active problem-solving are two qualities often found in resilient individuals living with chronic illness. The adolescents in this study certainly demonstrated these qualities.

### **3. Attitudes/Personal Beliefs**

The attitudes and personal beliefs of the participants are instrumental in helping the adolescents accept their illness and successfully integrate it into their everyday life.

Within this theme, two sub-patterns/themes emerged:

### **3a) Acceptance of Diagnosis**

Most of these adolescents were diagnosed pre-early adolescence. The adolescents used a combination of progressive and stable illness narratives to describe their reaction to being given the news they have CD. In most cases, the adolescents felt “relieved that” they “finally knew what it is” and “we could start doing something about it.” Other participants stoically accepted their diagnosis and adopted the attitude “someone’s got to do it” and “well, I really quickly realized it’s not going to go away and it’s something I have to live with and that’s that...just had to deal with it.”

Participants who have parents and/or siblings with CD who were willing to share their experiences and knowledge around living well with their illness saw their disease as “not that big of a deal” and “it wasn’t that scary...I knew I wasn’t going to die...” One participant also shared,

My dad had it so we were pretty OK with it. We already knew generally the stuff my dad went through and how it was going to be harder so we just got ready for it and when it came it was a breeze... The disease is simple and it’s, like, just a chronic illness.

Two participants, however, did not embrace nor accept their CD diagnosis as easily. One 13-year old participant and her family were “just really confused.” The confusion came from not knowing what CD is and what to expect. This confusion decreased as the participant acquired knowledge and began to understand her disease

more. The other participant, when given the news he has CD, was originally fine with the diagnosis since his mom had it, but weeks later when his 24-hour tube feedings began he “realized that it was pretty bad.” The “immobility” the tube feeding presented, making it harder to move around for the first four years of his diagnosis, was a terrible inconvenience to him. He continues to see all aspects of his disease as an inconvenience, but has accepted his diagnosis fully.

### **3b) Sense of Hope/Meaning**

Many participants find some sense of hope and meaning from their experiences living with CD. For example, many youth, despite having experienced many failed therapies and severe side effects from various medications resulting in very poor QOL, continue to maintain a sense of hope and optimism about future treatments and feel,

That if one drug didn’t work they literally had thousands of drugs that they are able to use...they just keep moving up to the stronger drugs that work on different areas of the bowel.

Another older participant, who is in remission but struggles daily with side effects from Remicade™ Therapy that have impeded her ability to do her school work, continues to remain optimistic that she will be able to go off to university next year. She keeps up with her studies and she is “sure it will go over fine.”

Many of the participants, when reflecting upon their time living with CD, found some sense of meaning and purpose from everything they had gone through. For example, one participant, who lived with undiagnosed CD for 5 years, stated, “This experience has made me stronger...you can get through difficult times and things can get better.” For another younger participant, his illness journey, thus far, has taught him “I

got a really great family” and it is his family who he turns to in times of hardship, to help him resolve daily CD challenges he isn’t yet developmentally capable of resolving. And, finally, a few older participants who have lived with CD for quite some time and developmentally have reached the point of showing greater concern for others compared to themselves, shared the following about their experiences,

A better understanding of things like that, like people being sick...anybody who’s got a different situation has to make exceptions and stuff...like, I think I’m more understanding of that than other people might be. So, like, I’m grateful for that because I feel like that’s a good way to be.

These same participants, all currently receiving Remicade™, a therapy initiated when all other treatments have failed to control their CD, speak of how lucky they feel.

They feel lucky for a number of reasons:

- (a) “Sometimes I find that for other kids they don’t have as supportive of a background as me. So they find it a lot more difficult to deal with Crohns and for me it is just another thing, really;”
- (b) “A lot of them is way worse than anything I ever had, so it’s like I’m actually lucky even though I feel, like, so bad about having it, but I’m actually, like, one of the lucky people who has it;”
- (c) “A lot of kids that I meet at the Brigadoon summer camp have these, uhmmm, bad food issues, like they can’t eat, like, for example KFC, they can’t eat whole wheat, but for me I am so happy that I can eat almost anything...;”
- (d) When other adolescents miss out on activities due to their CD it makes “me feel bad because they can’t” and now “I can;”

And, finally, they feel lucky because the Remicade™ allows them to experience something they have not experienced much of - a remission from CD symptoms.

In summary, for this first theme of *Attitudes and Personal Beliefs*, two sub-themes emerged. The first sub-theme is “acceptance of diagnosis,” where participants have come to terms with the fact that they have CD and have learned what it means in terms of their daily living. The second sub-theme is “sense of hope/meaning,” where the participants feel hopeful about their future living with CD. They find meaning in their lives due to their CD having the effect of making them emotionally stronger, more grateful, and more compassionate. Resilient individuals who are successful in integrating a chronic illness into their daily lives often possess an optimistic, hopeful attitude and find some sense of meaning in living with their illness. These individuals typically fully embrace and accept their diagnosis as well. This was the case for these seven youth.

#### **4) Daily Coping Strategies**

In order to successfully manage and cope with the day-to-day issues the CD causes in the participants’ everyday lives, the adolescents have to constantly challenge themselves to actively come up with strategies to solve these issues. Most of these daily coping strategies require the capacity to problem solve; thus, these strategies are seen in the older youth who have developed these skills.

Four sub-themes emerged within this theme and they are as follows:

- *Distraction Activities*
- *Handling Embarrassing Situations*
- *Staying Aware/Being Proactive [Problem Solvers]*
- *Waiting it Out/Toughing Through It*



#### ***4 a) Distraction Activities***

When coping with side effects from treatments and when unable to get any relief from symptoms during active disease when QOL is poorest, the youth in this study simply employ distraction strategies to help keep their mind off the discomfort they are experiencing. These distraction activities involve “just not focusing” on symptoms, “lie on the couch all day watching TV...played videos or on the computer,” taking the day off school, sleeping, and learning how to play a musical instrument.

Once accustomed to living with symptoms and treatment side effects, older participants began using distraction activities that require them being out of the confines of their comfort zones, “their home,” by joining things like a student counsel, choir, or band. One participant shared,

I love music, so I'm glad I actually got into band and play songs with people there. I've actually... I also play guitar... Yeah, I just started, actually, five weeks ago...I mean, I just like being away from home sometimes” because “I don't know... I just get my mind off stuff. I just get away from, like, everything, and just have fun.

When reflecting about their CD and the medications required for it and knowing there is the potential of developing cancer in the future, the younger participants, unable developmentally to perceive future consequences, described their feelings the following way,

I try not to think about that stuff to be honest... Like I heard, like, in rare cases, like I think there is only five cases in the entire world where, like, it can cause cancer or something crazy like that.

#### ***4b) Handling Embarrassing Situations***

When embarrassing symptoms present, such as cramping, foul-smelling diarrhea, and frequency of washroom use, all participants, from the three distinct adolescent sub-phases, choose to also employ various distraction techniques to cope with these situations. For example, one boy who experienced severe cramping and was forced to use his friend's washroom, resulting in a foul odour that all his peers noticed, addressed the situation by,

I just went, "I went to the bathroom." I just went and almost make a joke out of it I guess, like when I came out, "Ahh, man..." like almost make a joke out of it and they go, "Oh wow..." just let it go...cause there's really not much detail to go into. Yeah, it stunk.

Another participant who was in active disease and spent a lot of time in the washroom at school shared,

I remember... I think it was grade 7 and one time I left and I came back and someone was like "You were in there for a while." And I was like... I don't remember what I said; I just kind of, like, ignored them.

Others who try to evade embarrassing situations like this avoid using the bathroom altogether at friends' places or at school, and they will,

Hold it in, all day at school, all pain and stuff like that... I thought it was normal, so that's pretty much it, really, toughing through your pain, avoiding the bathroom and trying to hold in your farts and stuff...Before I puke I get this feeling...concentrate on swallowing and concentrate on fighting back because I knew that I would puke...I knew I was gonna. There was a couple times that

happened, at a friend's house, too, and I would just not say a word, swallow maybe, and like a couple minutes later it would pass.

Many adolescents, especially in the beginning of their illness, said they avoid the above situations simply by "staying close to home" and not going out to eat or socialize with friends. One participant shared, "I wouldn't wanna go out because I'd be too fixated on the bathroom," while another shared, "I didn't want to go out anywhere during that time." They also choose to stay close to home when undergoing visible treatments that they find very embarrassing. For example, one participant who has an NG tube states,

I haven't really been to many parties and stuff...It kind of prevents me from going out and staying over at friends' houses and stuff... Again, it kind of stops friends from coming over, too, 'cause it's kind of embarrassing...putting a tube into my nose every night... all the meds.... It is just letting people seeing you taking all those meds...I just don't really want them to, 'cause it's kind of private, right.

When faced with embarrassing questions from peers about their illness, most participants choose to share as little as possible about their disease and the symptoms they are experiencing because,

I don't really feel comfortable talking about it to my friends" and "probably the reason I don't tell people what I have is because I don't want them to go Google it or anything...don't want people to know that stuff I guess.

Despite the majority of participants not being open about their illness because of its embarrassing nature, a couple of participants are very comfortable discussing their illness with peers and find it very helpful to do so. As one participant shared, "Most

people I know, if they are like...if they ask me, I'll say "Yes - I have Crohn's," Like, there's no reasons to hide it... like, I have it... big deal. It's over."

#### ***4c) Staying Aware/Being Proactive [Problem Solvers]***

Staying aware of issues and trying to find solutions to these issues are strategies most participants use, especially the older adolescents who are more capable of problem solving and perceiving future consequences. For example, one older adolescent, whose mom died from colon cancer and is keenly aware of her risk of developing colon cancer, decided she will combat this issue by "going to get tested when I get older." Another participant, who had issues with his feeding pump that caused it to beep in class all the time, decided to resolve this issue simply by "I just took a can with me and put a syringe in it and pumped it in like that."

Considering most of these participants suffer from extreme fatigue and do not have a lot of energy to invest in any activity, they try to find ways to be most efficient with their time. For example, they feel they can be more efficient with their school work and keep on top of things when they make an effort to try to stay organized. As one participant shares,

Last year it was really difficult for me...I had a binder...my stuff went everywhere, the binder got broken, I just couldn't manage with it. This year I use a different method. I used a bunch of pockets in my backpack to keep all my stuff separate...I use different scribblers...I used different...subjects in each scribbler. It's a lot easier...just staying busy, just staying organized.

Once again, side effects from treatment and active disease symptoms require the participants to stay vigilant in monitoring their health status, and monitoring helps decide

what course of action they will take. Most times this means prioritizing their lives and choosing what things they will focus on and what things they will let go of. For example, one participant shared,

Knowing when I am going to have to let something go... not doing an assignment or something because I need the sleep because it is better for my health... to not worry about it. Talking to my teachers about it... not to push myself too much...see if I can get extensions.

#### ***4d) Waiting it Out/Toughing Through It***

For many of these participants, young or old, when distraction tools fail and when strategies used to alleviate some of the side effects or symptoms of their CD fail, they go with the “waiting it out” and “toughing through it” approach. As one participant pointed out, when experiencing unrelenting pain in his stomach “I just, like, have to sit there and stand through it....tough through it” and this is the only thing that helps. Admitting somehow that there is nothing to be done and you have to “wait for it to pass” seems to bring these participants some measure of comfort.

Another participant coped with the severe side effects from his Methotrexate treatment by “just take[ing] it one day at a time...counting down the days until I was over with this.” And, lastly, other participants, when coping with severe side effects from their Prednisone™ and Methotrexate treatments, adopted the approach “It’s something I had to do” and “I just kept going.”

In summary, for the theme of *Daily Coping Strategies*, four sub-themes emerged. The first sub-theme is "distraction activities," where youth shared the various distraction techniques they use to get their minds off their symptoms and avoid thinking about

potential long-term negative consequences of having CD. The second sub-theme is "handling embarrassing situations," where the youth pointed out methods they institute to deal with various embarrassing situations that arise as a result of the CD, especially when around peers. The third sub-theme is "staying aware and being proactive problem-solvers," where the youth describe monitoring their health status closely and making daily decisions based on this appraisal. The fourth sub-theme is "waiting it out and toughing through it," where the youth explain how they stoically deal with untreatable symptoms and treatment side effects by waiting for them to pass.

Resilient individuals often possess a strong ability to problem-solve and are able to institute coping techniques like distraction that result in a positive outcome in the face of a stressor. The seven adolescents in this study, especially the older adolescents, all demonstrated the above qualities.

Numerous quotes are included in Tables found in Appendix (G) to assist in the understanding of all of the above themes/sub-themes.

### *Conclusion*

These seven participants face numerous challenges and issues related to their CD. They employ a series of strategies and coping mechanisms to help them manage these challenges and issues. During times of active disease and treatment phases that result in significant discomfort in the form of severe side effects, the adolescents enlist the unconditional support of parents, friends, teachers, and health care professionals.

These adolescents with CD deal with the immense sense of difference they feel from their healthy peers through embracing this sense of difference and through finding

ways to minimize this difference by seeking out others going through the same thing as them.

Other strategies and coping mechanisms include: accepting their diagnosis fully; maintaining hope that they can live well with CD despite past treatment failures and flare-ups; finding meaning in what they have gone through; and realizing that relatively speaking, in comparison to some other adolescent CD cases, they are doing remarkably well despite some setbacks. And finally, as they grow older, more confident, and more developmentally capable, they also draw upon their own internal capacities and knowledge, actively problem-solving their ways through certain challenges and difficulties.

## **Chapter Five**

### **Discussion**

The seven adolescents who shared their stories in this study draw on the following strengths, competencies, capacities and resources to help manage CD issues: (1) positive attitudes and beliefs; (2) enlisting the support of friends, teachers, health care professionals and parents; (3) instituting a series of daily coping strategies aimed at managing day-to-day CD issues; and (4) embracing and accepting their sense of difference from healthy peers. The findings in this study will be compared against existing adolescent CD literature. Given there is minimal research on exploring the experiences of adolescents with CD from a resiliency perspective, study results will also be compared against literature focused on exploring the experiences of adolescents with various chronic illnesses from a resiliency perspective. Chronic illnesses that are of an obvious visible nature, such as cystic fibrosis (CF) and cancer, will be thoroughly compared against these findings, since visibility of illness is a huge concern for these youth.

### **Themes/Patterns**

#### **1) Unconditional Support**

One of the most important tools utilized by resilient, chronically ill individuals is their ability to recruit support (Mandleco & Peery, 2000; Meijer et al., 2002; Ryan-Wenger, 1996; Steinhauer, 1998; Stewart et al., 1997). This study clearly shows the pivotal role this factor plays in allowing these adolescents to successfully integrate their CD into daily life. The individuals in this study recruit support from their parents, especially their mothers, as well as peers, teachers, and health professionals. Support



from these groups was accessed predominantly during the initial diagnosis and treatment phases of their illness journey, during active disease periods when QOL of life was poorest and during times in which the youth were developmentally incapable of resolving daily CD issues.

### *Parental Support*

Parents are an essential link to the successful transition to proficiency around illness related issues and according to Taylor et al. (2008), parents are “the best allies in helping young people with their disease and were important in guiding them through treatment” (p. 3089). This certainly was the case in this study as well as in other studies on adolescents with chronic illnesses (Decker, 2007; Rhee, Beylea & Brasch 2010; Taylor et al., 2008). Some examples of the ways in which parents provide support include attending treatments and appointments, helping with therapies, and helping to problem-solve CD issues. They also offer support in the form of sharing CD information with their child and their child’s peers and teachers. Parents of participants who have CD themselves offer support by sharing their experiences around living with CD with their child. High levels of family support, such as the examples listed above, good parent-child attachment as was evident in this study, and a caring, cohesive family that promotes shared problem solving are factors associated with resiliency, greater QOL, and greater adherence to the treatment regimes in adolescents with chronic illnesses (Mandleco & Peery, 2000; Steinhauer, 1998; Rhee et al., 2010; Stewart, et al., 1997; Walsh, 2003). This certainly is the case for all the youth in this study.

Despite the close supportive relationship most of these teens have with their fathers, the mother is most often turned to for help when encountering daily issues

pertaining to their CD. This was the case when these youth were in early adolescence, in active disease, about to undergo a procedure, or trying to develop strategies to combat treatment side effects. In a study on adolescents with cancer the same theme was found; the mother is the individual most adolescents often turn to for assistance in times of hardship (Decker, 2007).

Embedded in this theme is the subtheme of *mother as knowledge sharer*. Central to the mother's supportive role is her ability to connect and serve as the go-between and information sharer with the adolescent's friends, doctors, nurses, and teachers. For example, many adolescents spoke of how their mothers, early on in their disease course, informed their teachers about their CD and shared with them any special needs their child may have in the school setting, such as having ready access to a bathroom. Another study on adolescents with cancer indicates that the mother became the greatest source of illness-related information and distribution (Decker, 2007).

Being readily available to listen to their son or daughter vent their feelings and frustration around CD is another form of support parents provide. The youth indicated this act to be mostly beneficial in the beginning of their illness and during times of active disease, when symptoms and side effects are at their worst. Venting of feelings and frustration, which falls under the domain of emotional expression, is seen as a positive therapeutic coping strategy in adolescents living with chronic illnesses and is associated with better QOL (Jaser & White, 2010). In this study, this is also seen as an effective coping strategy, but it does not have a positive impact on the adolescents' QOL. Venting serves as a comfort measure; it does not decrease the symptoms and side effects they

were experience. It was only when these two factors (symptoms and side effects) decrease that the adolescents reported a better QOL.

Adolescents from each of the three distinct adolescent sub-phases shared stories of venting to their parents about their illness, so this appears to be helpful in each stage. In addition, this act of venting and sharing feelings of frustration with parents is not a theme previously reported in research on adolescents with chronic illnesses. In one study on adolescent cancer survivors, it was found these individuals were reluctant to share their perceptions and feelings about their illness with their parents (Decker, 2007). One can postulate that coming to terms with one's own mortality can be a scary concept, one many adolescents may not want to give attention to. These adolescents may have observed the same fear in their parents, and in an attempt to protect them from experiencing any further emotional distress, kept their feelings about the matter to themselves. Adolescents with CD normally do not face mortality issues related to their illness unto well into adulthood. In addition, unlike adolescents with cancer, CD adolescents will always have to manage and seek treatment for their illness for the remainder of their lives. Strategies are needed to deal with this burdensome issue; in this study, the strategy of emotional expression proves effective.

Some studies indicate that when parents become over-involved in their child's illness management, the adolescents start to experience feelings of overprotection and feelings of ambivalence towards their parents (Fishman et al., 2010; Herzer et al., 2011). From a developmental perspective, during adolescence, particularly during middle adolescence, the parent-child relationship is at its lowest, most difficult point due to major battles over independence and control (Wong et al., 1999). In contrast, the youth

in this study reported having very close relationships with their parents and spoke of how grateful they were to have their parents as partners in care, especially during the initial treatment phases. In regards to the issue of independency, there has also been a lot of debate over whether dependency on parents due to illness and treatment related demands curtails the adolescent's ability to achieve the developmental milestone of independency (Brydolf & Segesten, 1996; Decker, 2000; Fishman et al., 2010; Herzer et al., 2011; Reichenberg et al., 2007). While the youth in this study do enlist the support of their parents on many occasions, especially in the beginning of their disease, this reliance is offset by the fact that the parents of these adolescents involve their son or daughter in all aspects of their care, especially medical decision making. As the youth in this study have become older, more able to problem-solve, and have acquired valuable experience in dealing with their illness, these same parents have increasingly encouraged their child to take on more roles pertaining to their care. They also convey to their child their belief in their capacity to manage their condition successfully. According to Meuleners et al. (2002), parents promote adolescent involvement in their care because they "understand the importance of adolescents taking control over this aspect of their life" (p. 347). The adolescents in this study did not share specific stories that suggest their parents share this philosophy, but one can deduce from the above actions that this is the case. Family attitude, family open-communications, clearly defined family/individual expectations, and encouragement of autonomy and independence are all protective factors linked to positive outcomes for adolescents coping with stressful situations such as living with a chronic illness (Brydolf & Segesten, 1996; Brydolf & Segesten, 1996; Haase, 2004; Mandleco & Peery, 2000; Meuleners et al., 2002; Steinhauer, 1998; Stewart, et al., 1997).

### *Friendship Support*

Peer acceptance and strong peer relations, which enhances the development of social skills, self-confidence, and a healthy self-concept, increase in importance in adolescence, especially in middle adolescence, and are two of the most important aspects of a young person's life (D'Auria et al., 2000; Brydolf & Segesten, 1996; Decker, 2000; Groothenuis et al., 2009; Koot & Bouman, 1999; Loonen et al., 2002; Lynch & Spence, 2007; Taylor et al., 2008). Many studies have shown that children with chronic illnesses such as CD have more problems socializing with their peers and achieving the above stated developmental milestones (D'Auria et al., 2000; Brydolf & Segesten, 1996; Calsbeek et al., 2006; Cotton et al., 2009; Decker, 2000; Groothenuis et al., 2009; Lynch & Spence, 2007; Taylor et al., 2008). The adolescents in this study, who are in middle or late adolescence, a time when peer acceptance is a major theme, shared many stories about how their CD interferes with their ability to socialize with friends, particularly during times of active disease and visible treatment phases. For example, medications such as steroids, which cause weight gain and a moon face, make them look visibly different from their peers. Additionally, the side effects affect their ability to attend school, participate in extracurricular activities, and spend time with peers. Nutritional therapies requiring nasogastric tubes, due to its visible nature, make them stay away from parties, eating out, and socializing.

A few adolescent CD studies indicate that an inability to socialize with peers has translates into accounts of feelings of loneliness and isolation (Brydolf & Segesten, 1996; Calsbeek et al., 2006; Cotton et al., 2009; Groothenuis et al., 2009; Lynch & Spence, 2007; Peterson, 2008; Salter, 1992; Taylor et al., 2008). This same sense of isolation was

expressed by many youth in this study, but this isolation does not produce feelings of loneliness. These youth, despite sticking close to home due to illness and treatment related issues, continue to maintain contact with peers through accessing adolescent CD web/Facebook support groups and by keeping in contact with friends through email and phone.

Many of the youth in this study had formed very strong friendships during elementary and pre-school, and these friendships carried over into adolescence. These friends provide support to these adolescents in a number of ways: through listening to them vent about their illness, staying with them while they carry out therapies such as NG therapy, and keeping them abreast of school work they miss due to treatment appointments. The bond between these youth and their friends appears to stay intact even during challenging times when these youth are unable to spend in-person time with their friends. These close friends also do not acknowledge or focus on physical differences between themselves and the youth in this study. This is significant, considering one of the main concerns of chronically ill youth is their fear of being ostracized from their peers for looking physically different (Brydolf & Segesten, 1996; Decker, 2000; Groothenuis et al., 2009; Lynch & Spence, 2007; Peterson, 2008). These strong peer relations ultimately end up helping these youth achieve all developmental peer-related milestones.

As these youth become older and more confident living with their illness and experience less active disease states, they are able to spend more in-person time with peers by joining new activities such as band and choir. Stories about social isolation disappear, and the theme of loneliness becomes non-existent. Reports of increased QOL

in the physical, social, and psychological domains were also emphasized. The literature notes that longer disease duration and symptom inactivity have been found to be predictors of greater QOL in adolescents with CD (Dorrian et al., 2009; Herzer et al., 2009). This is the case in this study as well.

According to Kyngas & Rissanen (2000), support from friends is a good predictor of adherence to treatment regimes by adolescents with chronic illnesses. None of the youth in this study shared any examples of non-adherence; they complied with all therapies, including the ones that caused dreadful side effects. However, while these youth appreciate the support they receive from a few close friends, they did not share stories that suggested their friends were a huge factor in why they complied with therapy. Nevertheless, having close friends that are not bothered by visible treatment modalities (NG tubes) and side effects may increase adherence to therapies as it does not appear to be interfering with these close friendships.

#### *Teacher Support*

Recruiting teacher support, especially upon diagnosis, during active disease, and during hospitalizations (when the youths' QOL is poorest) is also essential to these adolescents. Upon diagnosis, most of these youth were pre-early adolescent and they depended upon their teachers to explain and find ways to integrate their illness into their school life, as they were developmentally unable to do so.

Teacher support falls under the domain of community protective factors - individuals outside the friendship/family circle who form positive relationships with individuals like the ones in this study and find ways to support them given their unique circumstances (Mandleco & Peery, 2000; Stewart et al., 1997 Walsh, 2003). Some

examples of this support include helping the participants' classmates understand the illness, giving assignment extensions, and re-scheduling tests. Another form of teacher support includes finding ways of minimizing the sense of difference these youth feel from their classmates. This includes not paying attention to feeding pump alarms in class and letting them leave class, without permission, to fix their pump. In helping to minimize this sense of difference, a factor that can have a detrimental impact on adolescents' ability to come to terms with their illness and achieve all developmental milestones, the teachers have found an effective way to help these youth integrate their illness into everyday school life, increasing their school QOL.

One study suggests that teachers are not well-informed about chronic conditions experienced by their students and they do not have adequate knowledge to integrate a child's specific health condition into their classroom (Meuleners et al., 2002). The youth in this study shared positive stories that indicate their teachers do integrate their illness into the classroom quite well and they do possess adequate knowledge around their illness. This knowledge was acquired through conversations with the participants and their parents. Even when teachers do not possess any knowledge around CD, they are still supportive of these youth, accepting general explanations as to why they weren't able to complete a certain task. These youth all attend schools that foster and support students, a protective factor that promotes resiliency (Mandleco & Peery, 2000; Stewart et al., 1997; Walsh, 2003).

According to one study, teachers stress and promote the importance of a good education in chronically ill youth (Meuleners et al., 2000). The adolescents in this study did not share stories to that extent. Teacher support is most evident during initial



diagnosis and treatment phases, with the teachers focused on helping these youth overcome the present day-to-day challenges their disease presents them within the classroom and with their peers. At that time, these youth were only entering adolescence, were present-day focused developmentally, and wouldn't be graduating from school for quite some time, thus taking the emphasis off "future" talk. Despite the lack of emphasis on this from teachers, many of the older adolescents in this study do see the value of getting a good education, since it will lead to a good paying job. They know that living well with CD means abiding by a costly dietary regime and requires buying and paying for expensive medications. Woodgate (1998) presents the same theme in her book on chronically ill youth and offers up the same reasons as to why older chronically ill youth focus on seeking gainful employment.

In this current CD study the youth, especially the older youth, reveal they are on track developmentally; they are future-focused, able to perceive and act on long range operations, view problems comprehensively, and are in the process of exploring the concept of independence and separation from their parents.

#### *Health Professional Support – Customized care*

The youth in the current study enlist the support of health professionals, although this topic receives limited attention, despite receiving huge emphasis in other studies (D'Auria et al., 2000; Decker, 2007; Meuleners et al., 2000; Woodgate, 1998). The results of this study suggest that health professionals tailor their support depending on the adolescent's particular needs. For example, some youth identify needing advance notice of an upcoming procedure while others do not. During treatments, health professionals provide participants with as much or as little information as they prefer, since some cope

better with knowing more about their therapies while others cope better knowing less. In a similar study on adolescents with cancer, health care professionals also tailor their care to meet the unique knowledge needs of each chronically ill adolescent (Decker, 2007). In this study, health professionals tailor the knowledge given to each participant, taking into consideration their developmental capacity and ability to understand the information given to them.

Chronic illness resiliency literature suggests knowledge acquisition around a particular condition and the treatments required to manage it is essential and plays a pivotal role in determining how successful individuals will be at integrating their illness into daily life (Mandleco & Peery, 2000; Meijer et al., 2002; Ryan-Wenger, 1996; Steinhaurer, 1998; Stewart et al., 1997). In this current study, knowledge acquisition, in the form of information sharing by health professionals, serves as a risk factor for two of the participants. When given too much information about medications and therapies, these youth become very stressed and anxious around any issue that has to do with their CD. According to the resiliency literature, when the one risk factor, like the one stated above, is combined with other risk factors, such as developmental transitioning, which could hinder the adolescent's ability to understand the information given to him or her, it can result in a "pile up of stress" in the adolescent (Stewart et al., 1997). This can create overwhelming feelings of anxiety, tension and worry, and it is these kinds of feelings that can lead to mal-adaptation in the adolescent with a chronic illness (Kyngas & Rissanen, 2000). This mal-adaptation often manifests itself in the form of non-adherence to treatment regimes (Kyngas & Rissanen, 2000). No cases of non-adherence were reported by these youth who requested as little information as possible about their disease and its

treatment. This is not to negate the need for information around CD and its treatments and how essential this will become in helping these individuals live well with their disease, especially as they leave the confines of their parents' homes. It only means that one must look at the individual circumstances (age, temperament, attitude, developmental level, support system) to see if a certain resource will be of help or hindrance to the adolescent at each stage of their chronic illness experience.

For some of the adolescents in this study, who have undergone unsuccessful treatment trials, health professionals help them maintain a certain level of optimism by reassuring them that there are many more drugs they can use to bring their CD under control. A study on CF adolescents facing the same issue finds the same result, and as in this study, it finds that CF adolescents benefitted greatly from health professionals "who conveyed positive expectations and encouragement..." (D'Auria et al., 2000 p.180).

Desiring health professional support during "treatment" phases is a theme found both in this current CD study and in a study on adolescents with CF (D'Auria et al., 2000). This is not the case for all chronic illness studies. For example, a study on adolescents with cancer finds these individuals look to health professionals for support when treatments have ended and not during (Decker, 2007). It indicates that more support is needed after treatment because these adolescents have had more time to reflect on the serious implications of their disease and on their treatment experiences (Decker, 2007). CD adolescents can live well into adulthood with their disease and will have to undergo therapy for the rest of their lives, which may explain why they place more emphasis on the need for treatment support.

It has been indicated that chronically ill adolescents want health professionals to not treat them as “different” but rather just like “normal persons” (Woodgate, 1998). Adolescents with CD often look physically different from their peers, especially in the beginning of their disease and while undergoing treatments. This sense of difference can create great emotional distress (Brydolf & Segesten, 1996; Brydolf & Segesten, 1994; Calsbeek et al., 2006; Cotton et al., 2009; Decker, 2000; Hommel et al., 2011; Lynch & Spence, 2007; Peterson, 2008; Rayhorn, 2001). As much as the youths’ stories give the impression that health care professionals treat them as normally as possible, it also becomes apparent that these health professionals do see it as their duty to address the sense of difference these youth feel and to help find ways to minimize this sense of difference. This comes in the form of: (a) finding therapies with as few side effects as possible (fewer side effects means having to cope with fewer actual changes to the adolescents’ physical appearance, changes that make the adolescent look physically different from their peers); (b) stopping therapies when side effects become too much; and (c) by promoting opportunities that minimize the youth’s sense of difference. One such opportunity is Camp Brigadoon, a residential camp for children and youth living with chronic illnesses located in the Annapolis Valley, NS. The health professionals encourage all these youth to attend this camp, where they would have the opportunity to meet other youth with a chronic illness. This promoting of Camp Brigadoon may also be in response to the health professionals recognizing that CD’s symptoms and treatments can impede the formation of peer bonds and relations, and that this camp would be a viable way to help these youth achieve these developmental milestones. Three of the youth in this study who had attended Camp Brigadoon spoke of the positive impact it has

had on their lives. It reduced the sense of difference they were feeling from their healthy peers and it helped them form supportive long-lasting peer bonds with individuals like them - youth who understood fully what they were going through.

(<http://www.brigadoonvillage.org/index.php?option=content&task=view&id=17>).

## **2) Embracing and Accepting Differences**

Adolescents report fears of being ostracized from their healthy peers due to the physical differences caused by CD and its treatment (Brydolf & Segesten, 1996; Calsbeek et al., 2006; Cotton et al., 2009; Decker, 2000; Lynch & Spence, 2007; Peterson, 2008; Rayhorn, 2001). The youth in this study all share stories that stress a sense of feeling different from their healthy peers. The most prominent way these youth minimize this issue is through embracing and accepting their sense of difference. This practice was especially evident in the youth in early-mid adolescence in this study, since this issue was most prominent during that time. One study suggests adolescents struggle more with a sense of feeling different from peers when they undergo therapies that are more invasive and visible (Taylor et al., 2008). This is the case in this study as well, as they struggle more with this issue when they undergo visible and invasive therapies such as NG feeds. Taylor et al. (2008) also suggests that chronically ill adolescents, especially those in early adolescence, deal with their sense of difference through rejecting therapies. This is not the case in this current CD study, as all participants have been adhering to all treatments.

Another way these youth minimize their sense of feeling different is through seeking out other adolescents with CD. In this study, they do so by attending a summer camp for youth with chronic illnesses and by developing and maintaining friendships

with CD youth from the clinics they attend, from the choirs they joined, and from the adolescent CD web-support and social networking sites (Facebook) they joined. These youth take great comfort in meeting others who are going through the same thing as they are, as it provides them with feelings of acceptance that they do not often experience from their unaffected peers. This is a consistent theme in adolescent chronic illness literature (D'Auria et al. 2000; Ollson, Boyce, Toumbourou & Sawyer, 2005 & Thorne, 1993). According to Taylor et al. (2008), chronically ill youth, "found forming friendships with other young people with the same chronic illness to be beneficial because they were sharing the same experiences and did not have to keep secrets or hide visible differences" (p. 3087). Another study shows this strategy is beneficial because it helps chronically ill youth become more knowledgeable about their illness (D'Auria et al., 2008). These findings are in contrast to the stories shared in this study, as these youth do not look to other CD youth for knowledge about their illness and spend very little time discussing their illness experiences with other CD/chronically ill youth. This lack of focus on sharing illness-related information and experiences could be due to the embarrassing nature of CD.

Fielding and answering questions from as well as maintaining friendships with healthy peers helps to minimize the youths' sense of difference. Fielding and answering questions is a practice especially evident in the older adolescent, who is developmentally capable of resolving this issue on his/her own. Having relationships with both healthy peers and peers with the same illness is typical for chronically ill youth, and it has been proven beneficial, especially in regards to this "sense of difference" issue (Decker, 2007; Ollson et al., 2005). Maintaining friendships with healthy peers also helps these youth

achieve some sense of normalcy in their lives (Taylor et al., 2008). Achieving some sense of normalcy is a theme found in Taylor et al. (2008) critical review of the literature on adolescents with chronic illnesses. It is important because it helps the chronically ill youth move on with their lives (Taylor et al., 2008). This definitely is the case in this study as well.

For some participants, minimizing difference and normalizing their life has come about by not focusing on any aspect of their illness. This same theme is found in another study where the adolescents minimize differences by forgetting about their illness and seeing themselves as being like their healthy peers (Taylor et al., 2008). Two of the youth in this study are able to completely forget about their illness at times and do so by nurturing their friendships with healthy peers, by not becoming a part of any CD adolescent support group, and by filling their lives up with activities like military cadets. These same two youth, however, do not see themselves like their healthy peers, but always as individuals with an illness. This could be due to the fact their disease requires daily medical management, which serves as a reminder that they are different from the healthy peers.

Again, some of these youth have CD and non-CD friends, while others just have non-CD friends. As to which approach is best is a point of debate in the research literature (Taylor et al., 2008). If one prescribes to the notion that resiliency can be achieved through multiple, diverse pathways, it makes sense that both of these approaches are equally favourable (Ungar, 2004). These youth may be traversing different pathways, but it results in the same outcome - a minimization of the sense of difference they feel. This theme becomes a non-issue as the youth start to experience

more remissions and undergo therapies that do not result in vast changes to their appearance.

### **3) Attitudes/Personal Beliefs**

#### *Acceptance of Diagnosis/ Sense of Hope/Meaning*

Acceptance of diagnosis is something all these participants have in common. The journey into acceptance begins at diagnosis, with most participants experiencing a sense of relief when given the news they have CD. The relief comes from knowing that what they are experiencing is real and that it has a name. All participants recognize they have a disease that is not going away and that requires management. A study by Slimmer (2005), focusing on adolescents just diagnosed with depression, find the same themes. In this particular study, once the diagnosis was given, the adolescents felt validated, felt a sense of relief when the condition received a label, and saw their disease as something that requires treatment and management (Slimmer, 2005). And similar to this current CD study, the youth in Slimmer's study see their illness as part of their identity.

The adolescents in this study shared many stories documenting the adversity the CD brings into their daily lives. The adversity comes in the form of periods of active disease that bring embarrassing symptoms and treatments with severe side effects. These symptoms and side effects interfere with their ability to attend school, keep up with homework, socialize with friends, and engage in extracurricular activities. Other studies using various quantitative tools such as the Sickness Impact Profile note the same negative impact of CD and its treatments on adolescents' everyday lives (Britto et al., 2004; Brydolf & Segesten, 1996; Calsbeek et al., 2006; Cotton et al., 2009; Cunningham et al., 2007; Decker, 2000; Koot & Bouman, 1999; Loonen et al., 2002; Lynch &



Spencer, 2007; Maurice-Stam, Derkx & Last, 2009; Peterson, 2008; Sinclair, 2009). Despite the sense of adversity, the participants in this study also feel optimistic about living well with CD. In fact, they demonstrate a stronger sense of optimism during challenging times. Their sense of optimism also increases as they become more proficient in managing their disease and as their number of remissions increase. All seven youth in this study demonstrate a cyclical pattern between proficiency, optimism and resilience.

Studies show that “optimism can be the most influential factor to moderate life stressors in adolescents” with chronic illnesses (Mannix, Feldman & Moody, 2008, p. 484). A sense of optimism is associated with positive coping and positive re-interpretation of a stressor, especially if that stressor is a chronic illness (Weber et al., 2010). In a study on adolescents’ with cancer, optimism is associated with a higher QOL, and is correlated with less reported pain and higher reported psychological functioning (Mannix, Feldman & Moody, 2008). In this study, optimism is present particularly during times of active disease, when the adolescents’ QOL is poorest. Poor QOL is reported despite the presence of optimism because these youth continue to experience severe CD symptoms and severe treatment side effects. It also has no impact on the level of pain some of the adolescents feel during active disease. Optimism does, however, provide psychological comfort; that comfort comes in knowing that the CD symptoms will pass.

Many of the adolescents in this study also maintain a sense of hope and optimism around living with their disease by comparing their experiences against other CD adolescents and coming to the conclusion their CD experiences are far less severe. It is

interesting to note that these adolescents are all currently receiving Remicade™, a drug used for the most uncontrollable cases of CD. A study on adolescents with CF reveals these adolescents, too, feel more hopeful and positive when they see their circumstances as less severe than other CF adolescents (D'Auria, Christain, Henderson & Haynes, 2000). Reframing their disease is an effective coping mechanism; it helps them minimize the sense of difference they feel from their healthy peers and helps them feel a little more “normal” as compared to healthy peers (D'Auria et al., 2000).

The research literature indicates that hope is a pre-requisite for effective coping and decision making and is a protective function against the physiological and psychological stress of illness (Phillips-Salimi et al., 2007). Hope is also seen as an individual protective factor for enhancing resilience and QOL in adolescents with chronic illnesses (Phillips-Salimi et al., 2007). In this study, maintaining hope during active disease does relieve some of the psychological stress these adolescents experience, but it does not enhance their QOL nor decrease the physical stress their body experiences due to active disease.

In contrast, two of the participants in this study were resistant to accepting their diagnosis and do not feel or share the same sense of optimism as the other participants. In one of these cases, the participant was 13 years old, diagnosed at age 9 and only began to experience relief from her CD symptoms after starting Remicade™. Due to her young age, she possessed limited abstract reasoning ability, limited problem solving ability, and had trouble processing information given to her about her CD. These negative risk factors impacted her attitude towards her illness. However, despite all these negative risk factors, this participant appears to be living quite well with her disease as demonstrated

by her good attendance record at school, her continued academic success in school, and her leaving the safe confines of her own home to join a school band in the hopes of making new friends. According to the resiliency literature, resiliency is enhanced when there is a balance between risk and protective factors (Stewart et al., 1997; Ungar, 2004). The protective factors serve to minimize the negative influence of risk factors, increasing the likelihood of good adaptation to a stressor (Stewart et al., 1997; Ungar, 2004). This participant possessed numerous protective factors including support from family, teachers and friends; her parents helping her to process information around her CD; and her motivation to keep up with her responsibilities, especially her school responsibilities. Based on the resiliency literature, the above factors have allowed her to successfully integrate her CD into her life and accept her illness, albeit unwillingly.

In reflecting back upon their journey, most of the adolescents, especially the older ones who show greater concern for others than self, spoke of the sense of meaning and purpose from living with CD. They shared stories around being more compassionate towards others going through difficult times, how they feel their illness has made them stronger, and how they are helping younger adolescents newly diagnosed with CD by sharing information and their own experiences. As in this study, in a study on Korean adolescents living with disabilities, meaning in life was found when they realized they could use what they learned from living with their disability to help other individuals (Kim & Kang, 2003). This helping of others led to feelings of usefulness and “value” in one’s own existence (Kim & Kang, 2003). The youth in this study, despite finding a sense of meaning through helping others, did not disclose how the act of helping others makes them feel about themselves.

#### **4) Daily Coping Strategies**

The adolescents in this study use various known coping strategies that enable them to deal with the daily issues of their CD and which are indicative of resilient protective behaviours. Some of these daily coping strategies require the capacity to problem solve, and as such these strategies are often found in older youth who are developmentally capable of doing so.

##### *Distraction Activities*

One daily coping strategy embraced by all adolescents, especially in the beginning of their disease and during active disease states, is the use of distraction. Distraction is used as a means to help these youth “fit with or adapt to their environment,” and in this case it means finding a way to adapt to the symptoms and treatment side effects they are experiencing (Jaser & White, 2010, p. 336). These symptoms and treatment side effects are often unrelenting and there is little the adolescent can do medically to bring about relief. In order to keep their mind off these symptoms they play video games, sleep and watch TV. These distraction activities do provide the intended effect. Distraction is a coping technique that receives a lot of attention in the literature, and it is shown to be an effective, healthy coping mechanism for adolescents with chronic illnesses (Birks, 2008; Jaser & White 2010). To clarify, distraction is not to be confused with the techniques of withdrawal or denial, which are responses oriented away from the stressor and one’s response to it (Jaser & White, 2010). An example of this would be denying an illness needs management (Jaser & White, 2010). Withdrawal and avoidance are associated with poor psychosocial outcomes, poor treatment adherence, and reports of lower QOL in adolescents with chronic illness (Jaser

& White, 2010). None of the adolescents in this study shared stories that suggest any of the preceding three negative outcomes.

### *Handling Embarrassing Situations*

The adolescents in this study employ the strategy of “staying close to home” to help cut down on the number of potentially embarrassing CD situations they might find themselves in with their peers. This coping technique is employed when symptoms and side effects of treatments are at their worst, when QOL is poorest and when these things cause the adolescent to look physically different from their peers. Other studies show that this is a common strategy utilized by adolescents with CD when faced with embarrassing and uncontrollable symptoms and visible therapies like Prednisone™ and NG therapy (Brydolf & Segesten, 1996; Calsbeek et al., 2006; Cotton et al., 2009; Decker, 2000; Drossman et al., 1991; Hommel et al., 2011; Lynch & Spence, 2007; Peterson, 2008). The literature also extensively documents the emotional impact all of the above can have on CD adolescents, resulting in feelings of a sense of loss, powerlessness, low self-confidence and low self-esteem (Brydolf & Segesten, 1996; Calsbeek et al., 2006; Cotton et al., 2009; Decker, 2000; Lynch & Spence, 2007; Rayhorn, 2001; Szigethy, 2005). The adolescents in this study did report feelings of isolation and powerlessness during active disease and treatment phases that come with severe side effects. For many, these feelings go away as they become more adept at managing embarrassing symptoms and treatment side effects. They even start venturing outside the confines of their own home during these difficult times. None of the other emotions reported in the above studies are displayed by these teens. The strategies and themes are obviously overlapping as the youth enlist parental, teacher and health

professional support and employ daily coping strategies that allow them to gain control over their disease, resulting in feelings of high self-confidence and self-esteem. The above illustrates that resiliency and positive adaptation in chronically ill youth is enhanced when numerous protective factors are present.

The youth in this study handle embarrassing situations *outside* the home by employing such daily coping strategies as ignoring peers' comments and questions about their CD, avoiding using the bathroom at school, and making jokes about such things as embarrassing odours after having used the washroom at a friend's place. Ignoring and avoiding are words often associated with negative coping and poor adjustment to adverse circumstances (Jaser & White, 2010). However, these measures fall more under the domain of distraction activities, since the adolescents are once again trying to find ways to adapt to their environment. As was stated previously, distraction is deemed a healthy coping mechanism - one that helps individuals adapt to changes in their environment (Birks, 2008; Jaser & White 2010). Despite being defined as a positive coping technique, distraction is not listed in the resiliency literature as an individual protective factor that promotes resiliency; it is merely a tool one can use to adapt to a stressor.

#### *Staying Aware/Being Proactive [Problem Solvers]*

As these youth become older, more independent, more confident, more knowledgeable about their illness, more able to perceive future consequences, and more able to think through ideas and view problems comprehensively, they become more proactive in their care. Being proactive means such things as constantly staying aware of how they are feeling physically and using all their knowledge and problem-solving ability to decide if a certain CD issue warrants action. A similar theme is found in a study on CF

adolescents; these youth also stay vigilant in the monitoring of their health status and make decisions based on this status (D' Auria et al., 2000). All of the above characteristics and abilities are associated with adherence to treatment regimes and a better QOL in adolescents with chronic illnesses (Birks, 2008; Jaser & White, 2010; Mandleco & Peery, 2000; Meijer et al., 2002; Ryan-Wenger, 1996; Steinhaurer, 1998; Stewart et al., 1997). This is the case in this study as well. The ability to problem-solve and seek the necessary information to successfully manage an illness are two individual protective factors often found in resilient individuals (Mandleco & Peery, 2000; Meijer et al., 2002; Ryan-Wenger, 1996; Steinhaurer, 1998; Stewart et al., 1997). These two protective factors play a significant role in helping youth adapt to challenges their chronic illness may cause them (Mandleco & Peery, 2000; Meijer et al., 2002; Ryan-Wenger, 1996; Steinhaurer, 1998; Stewart et al., 1997). This is certainly the case in this study.

#### *Waiting It Out/Toughing Through It*

When any of the above coping strategies do not yield positive results and when the youth's problems do not warrant a hospital visit, they turn their focus on "just waiting out" or "toughing through" whatever issue they are experiencing while maintaining the hope that the episode will pass. All adolescents within all three distinct adolescent sub-phases use this approach.

In this study, as in other CD studies, there is a lot of emphasis on the unrelenting and often times untreatable abdominal pain these youth experience while in active disease (Lynch & Spencer, 2007; Merchant, 2007). The youth in this study are able to work through these pain episodes by adopting the above approach. The positive, hopeful self-efficacy statements which the youth employ during these pain episodes are associated

with more positive outcomes for adolescents experiencing pain (Hermann, Hohmeister, Zohsel, Ebinger, & Flor, 2007; Kobayashi, 2007; Libby & Glenwick, 2010). This approach has led to reports of reduced perception of pain intensity, reduced functional disability, and increased QOL in adolescents with chronic illnesses (Vervoort, Eccleston, Goubert, Buysse, Crombez, 2010). In this study, however, positive, hopeful self-efficacy talk did not result in stories of reduced pain intensity, reduced functional disability, nor reports of better QOL; it is simply a comfort measure, as this tool does not decrease nor minimize any of their painful symptoms. “Toughing through” a pain episode often implies acceptance of that episode. Acceptance of pain is associated with lower levels of distress but not with lower pain intensity (McCracken, Gauntlett-Gilbert, & Eccleston, 2010). The same theme is found in this study. A review of current literature pertaining to the themes of “waiting it out” and “toughing through” CD issues did not yield any results. This is noteworthy since this was a strategy employed by all youth in this study. More research into this area is needed to determine if this is an effective tool to promote in adolescents with CD.

### *Conclusion*

Resiliency in individuals is achieved when enough protective factors are present to help an individual adapt and deal effectively with a stressor or adverse circumstance like having to live with a chronic illness (Stewart et al., 1997). The adolescents in this study are able to harness many protective factors that allow them to overcome the challenges the CD brings into their daily life.

As in other studies, these youth enlist support from parents, friends, teachers, and health care professionals. Parents, especially mothers, are the best allies in helping these



youth manage their disease. Other studies reveal the same theme. Some studies suggest that parental involvement in their child's CD care promotes dependence, but that is not the case in this study. These youth all participate in medical decision-making, and as they become older they take on an increasingly bigger role managing their CD care.

The literature suggests teachers are not well equipped to provide for the needs of a chronically ill classmate. This is not the case in this study, as these teachers provide a tremendous amount of support to these youth and integrate their illness quite well into the classroom setting. This is an important finding to share with both clinicians and teachers.

Health professionals are an important source of support, but it did not receive as much attention in this study as it did in other studies. As in other studies, health care professionals customize the care they provide to the adolescent based on their needs and circumstances.

All study participants indicated their disease makes them feel different from healthy peers. Other studies indicate adolescents deal with this sense of difference through rejecting therapies, but that is not the case in this study. As in other CD studies, the youth in this study try to minimize their sense of difference by not focusing on any aspect of their illness and by nurturing existing non-CD friendships. Other youth minimize this difference through forming friendships with other CD youth. These adolescents do not share their experiences with other CD youth. They just draw comfort in the knowledge someone else is going through the same experiences they are. This is in contrast to other adolescent chronic illness studies, which indicate youth do share their experiences around living with their chronic illness with other ill youth.

Many literature studies indicate that adolescents with CD recount feelings of loneliness and isolation related to their inability to socialize with peers due to CD activity, treatment side effects, and visible therapies. The youth in this study do experience feelings of isolation but not feelings of loneliness, due to the fact they are able to stay connected with friends through the internet and phone.

Similar to other adolescent chronic illness studies, many of these youth accept their illness and remain optimistic in the face of adversity from living with their illness.

And finally, distraction, problem solving, and “staying close to home” to avoid embarrassing CD situations are daily coping strategies these adolescents employ. These same coping strategies are found in other adolescent chronic illness studies. The daily coping strategy of “waiting out” and “tough through” painful CD symptoms and severe treatments side effects, however, is not a theme present in other CD adolescent studies.

In terms of some discussion related to the method of narrative inquiry, it proves to be an appropriate and effective data collection tool to collect the adolescents’ perspectives. By doing the two-step analysis, it is clear the adolescents’ stories inform the themes but also provide a distinct dimension to helping us understand their experience of living with CD. This study shows the effectiveness of using narrative inquiry as a tool to explore sequentially with participants their experiences living with a particular illness (Bleakley, 2005). Narrative inquiry is also useful when the goal of research is to discover the meaning participants assign to various aspects of their illness experience and how that meaning changes over time and is influenced by a multitude of factors.

Most of the existing studies focused on adolescents with CD use quantitative methods and rely on IBD questionnaires as a means of identifying the needs and concerns

of this particular group. The validity and reliability of these questionnaires has been determined in adult populations but not in adolescent populations. Narrative inquiry can rectify some of the above issues since it gives direct voice to this group and allows for the direct exploration of the thoughts, feelings, beliefs, perceptions, worries, and concerns of the adolescent living with CD.

## **Chapter Six**

### **Conclusion**

Resiliency is defined as unusually good adaptation in the face of extreme stress, and is grounded in the belief that all individuals and families possess the necessary protective factors (tools, strengths, resources, abilities, and competencies) to manage a stressor or health care condition effectively (Feeley & Gottlieb, 2000; McAllister, 2003; Steinhauer, 1998). When these factors are utilized effectively, an individual is more likely to integrate a chronic illness successfully into their everyday life and manage stressors associated with that chronic illness quite well (Stewart, Reid & Mangham, 1997)

In resiliency literature, the resources, tools, competencies, and abilities individuals harness and utilize during times of extreme adversity are divided into three categories: individual protective factors, family protective factors, and community protective factors. Through the act of storytelling, the main feature of the narrative inquiry methodology, the youth, in this study, shared with the researcher all the protective factors they utilize daily to help them adjust to and incorporate the CD into their lives.

The protective factors they employ depends upon such things as their developmental level, disease activity status, severity of treatment side effects, and supports available to them during each stage of their illness journey. For example, in the beginning of their illness journey, the adolescents enlisted a major amount of help from their parents to resolve a lot of the CD/treatment issues they were experiencing. Most of these youth were only entering adolescence when first diagnosed and did not possess the problem solving ability to think through these issues and arrive at viable solutions.

Parental involvement decreases as they become older, more capable of understanding illness related information, and more capable of problem solving.

The adolescents in this study all possess an abundance of protective factors. From an individual perspective, most of these adolescents display the following personal protective factors: acceptance of diagnosis, positive attitude in the face of adversity, sense of hope and meaning, a desire to become more autonomous especially in the management of their disease, a desire to possess the knowledge necessary to manage their disease, and the will to overcome illness/treatment related issues. One of the most effective strategies these adolescents utilize is their ability to recruit social support. They enlist support from parents, friends, teachers and health care professionals. Enlisting the support of their parents is the most effective tool they employ to help them deal with issues surrounding their CD. Parents help with treatments, help to problem solve issues around their CD, share information with their children around CD and its management, and offer emotional support.

As the youth gain more experience in living with their CD and progress developmentally into viewing problems more comprehensively, they start to actively problem-solve any CD situation they run into. For example, when encountering an active disease state and decline in health status, these youth negotiate extensions with teachers because they know their bodies need the rest and that the active disease state will likely continue if they push themselves beyond their physical limits. They are also able to come up with active solutions to help minimize the sense of difference they feel from healthy peers, and they do so by becoming part of groups that contained other CD adolescents.

The second category of factors that foster resiliency in these adolescents is family protective factors. The youth in this study come from caring, cohesive, and supportive families with good parent-child attachment. The families all set high but achievable expectations for all family members including the child with CD. The parents and children in this study all share in the medical decision making process and all stay positive in the face of any CD issue. And finally, as the adolescents get older, the parents in this study encourage them to become more autonomous, especially in relation to their CD care. This is helping these youth achieve the adolescent developmental milestone of independence.

The final category of protective factors these youth accessed is community protective factors. The youth in this study have formed strong, helpful bonds with both health care professionals and teachers. These relationships have proven essential to helping them cope well with CD issues. Health care professionals provide them with the information necessary to live well with CD, and teachers help create classrooms that minimize the sense of difference these youth feel from non-CD classmates.

This study also shows that resiliency can be achieved through different pathways. For example, some of these adolescents deal with the sense of difference they feel from healthy peers through forming friendships with other CD youth. Others minimize this sense of difference by not focusing on any aspect of their illness and nurturing the few close non-CD friendships they have.

The seven youth in this study utilize the above individual, family, and community protective factors, and thus are able to not only integrate their illness into their daily life but do so successfully. They are also achieving all developmental milestones in spite of

their CD. These youth could benefit from having health professionals help them identify and maximize internal and external resources they possess or have access to. This will allow them to manage their CD as effectively as possible. This is more in keeping with the nursing philosophy of providing holistic, partnered care to its clients - care that focuses on empowering clients.

### *Strengths and Limitations of Study*

The following is a list of the strengths and limitations of this study:

(a) Narrative inquiry was viewed as a real strength and chosen for this study to give insight and meaning into each individual's experience while taking into consideration their own unique circumstances, values, opinions and perceptions. The student researcher accomplished the above through writing individual, interpretative accounts of each adolescent's illness journey. Seven participants were recruited, as the intent was to ensure in-depth narratives were captured and analyzed. It is imperative that small sample sizes are used in narrative inquiry to ensure a thorough understanding and analysis is implemented. The purpose of this research was to offer in-depth stories that can be read and easily understood by health care professionals, parents, and youth and then transferred into practice; it is 'transferable,' as the meaning is clearly articulated by the voices of the participants and analysis of the researcher. Historically, quantitative research has created assumptions that generalizations of findings are necessary for all research and if this is not accomplished, a 'limitation' is created. It is acknowledged that this research is unable to offer generalizations and may be considered to be a limitation by some, but the methodology of narrative inquiry advances previous research work and brings with it many strengths. The most important strength is it gives direct voice to

underrepresented groups and affords them the opportunity to share their own individual, unique journey through a particular experience.

(b) Due to time constraints, the researcher was unable to meet with participants to review their individual accounts and the study findings. Despite not being able to complete the above task, the researcher met with her thesis supervisor on a routine basis to review transcribed interviews, individual accounts written by the student researcher, and themes and concepts that evolved from the data. A nurse from the Gastroenterology clinic, who has worked with adolescents with CD for over 10 years, was consulted to review the themes and concepts that evolved from the data. All these measures were taken to ensure the student researcher was capturing the essence of what it was like for adolescents to live with this disease.

c) All participants were receiving Remicade™ Therapy, a therapy that is started when all other CD therapies have failed. Despite having lived with uncontrollable CD for quite some time, most of these youth are now in remission, and have been in remission anywhere from one to four years. Their stories, opinions, and feelings about their CD may have been influenced by this fact.

The researcher felt choosing this particular group (i.e., those receiving Remicade™ Therapy) would provide the most diverse sample of adolescents living with CD, but due to prolonged quiescent disease and remission states as described above, this was not the case. In addition, the only adolescents with CD receiving Remicade™ Therapy at the IWK Medical Day Assessment and Treatment Unit are those whose parents have a private drug plan or those who have applied for Family Pharmacare through the province of Nova Scotia. This serves as a limitation in this study, since the



researcher is only accessing a particular demographic of adolescents - those in a position to access the best possible health care. It would be interesting to interview participants in active disease and non-active disease and those receiving Remicade™ versus those who are not, and compare and contrast their perceptions around living with CD to see if the same kinds of themes emerge. To give a more accurate picture of what it is like to live with CD and the strategies adolescents employ to help resolve CD issues, it is important to initiate dialogue with the following CD adolescents: those with varying degrees of CD, with ostomies and fistulas, who have undergone surgery, from all three adolescent sub-phases and those receiving Remicade™ Therapy versus those who are not receiving this medication.

(d) Fortunately, the researcher was able to include adolescents from the three distinct adolescent sub-phases (early, middle, late adolescence), capturing an overall view of the adolescent experience of living with CD. This allowed for a comparison of the unique social, emotional, and management related strategies each of these groups utilize - strategies that are very much influenced by their developmental level. For example, for those individuals in early adolescence, who possess limited problem solving ability, they are often looking to external sources (parents, teachers, health professionals) to solve the daily challenges the CD brings into their life. Meanwhile older adolescents, who possess the developmental ability to think through ideas, view problems more comprehensively, and perceive consequences to their actions, participate in more internal problem solving behaviours. For instance, when realizing that they can no longer stay on top of school work due to a decline in health status, the older adolescents negotiate extensions with their teachers and make time to get more rest since it is better for their health.

(e) In this study the student researcher who has lived with chronic illness for ten years shared some of her experiences with the participants in this study. This is not necessarily a limitation since the student researcher's experience with chronic illness allowed her to focus on important concepts the youth spoke about like the social isolation chronic illness can sometimes impose.

(f) The interviews conducted in this study were semi-structured and this was considered a strength. These kinds of interviews are advised in narrative inquiry since this format is more likely to promote storytelling in individuals and allows for participants to give freer responses (McCance et al., 2001). In this study very few questions actually needed to be asked. Broad open-ended questions such as, "What it is like having a disease like CD?" led the adolescents into immediately recounting stories around their being diagnosed which then progressed to them sharing stories around various treatments they experienced.

(g) The clinic setting of the interviews was considered a strength as well as a limitation. It was a strength because these participants were interviewed in a familiar setting that they felt comfortable in. Individuals are more likely to talk openly and honestly when they are in a safe, secure setting. However, the interviews were often interrupted due to Remicade™ Therapy vital sign checks by the nurses present in the Gastroenterology Clinic. Each interview was stopped every time a nurse entered the room to protect the youth's privacy. This may have interrupted the flow and direction of the interview. The student researcher made every effort to get the interview back on track by reminding the participants of the topic they were sharing stories about. Two interviews were conducted within the Remicade™ Clinic-Medical Day Assessment and Treatment Unit because the

student researcher was not able to secure a private treatment room within which to conduct these interviews. Every possible measure was taken to ensure the youths' privacy, including pulling the curtains and talking in low and audible voices. These two adolescents were informed that their interviews could be postponed until the student researcher was able to secure a private room, but both adolescents expressed they felt comfortable doing the interviews in the setting they were currently in. They were also advised to let the researcher know if they became uncomfortable within that current setting. If they had voiced any concern, the student researcher was intent on stopping the interview and finding a more private location. This option was not pursued by either youth.

#### *Nursing Implications and Future Research*

The findings are helpful in enhancing our understanding as health professionals of the adolescent's experience of living with CD. In addition, it is evident the presence of some elements of their experience influence how they assign meaning to their experience, and is cyclical in nature. The meaning they assign to various aspects of their illness experience is influenced by such things as the amount of support they have access to during each illness phase, and their developmental level, which influences their ability to problem solve and to devise effective strategies to deal with CD issues. The meaning they assign to living with CD changes depending on whether they are in an active disease versus remission state. It changes depending on what treatment phase they are in and what degree of side effects they are experiencing in that particular treatment phase. And finally, it changes as they become more proficient at handling daily CD challenges.

Health care professionals can provide more comprehensive health care to the adolescent with CD when they have a clear and accurate picture of all of the above. In this study, one of the main areas of concern for these adolescents with CD is the sense of difference they felt from their healthy peers. The stories shared by the adolescents in this study indicate the health professionals understand this is an issue and work with these adolescents to identify ways to combat this issue. This “sense of difference” issue is a common theme found in both qualitative and quantitative adolescent chronic illness studies. Having the adolescent describe in their own words what this sense of difference means to them and how they minimize this sense of difference is something that is lacking in the research literature. This study was beneficial and effective because it gave some insight into how CD adolescents experienced and deal with this issue. More research focused on developing strategies to help CD youth minimize this sense of difference is needed.

Adolescents, including adolescents with CD, are one of the most underrepresented and under researched of all age groups. In addition, there are very few studies that focus on exploring the experiences of adolescents living with CD from a resiliency perspective. The studies in the research literature that do exist on this topic are deficit focused - all exploring and indicating the potential for poor physical, social, emotional and developmental outcomes in adolescents with CD. A resiliency approach to research promotes the notion that all families/individuals possess the abilities and strengths to manage effectively a health care issue (Feeley & Gottlieb, 2000; McAllister, 2003). In resiliency literature, strengths and resources families and individuals access and possess are labelled *protective factors* and these factors foster resilience in chronically ill

individuals. Resilient individuals are more likely to experience positive physical, social, emotional, and developmental outcomes even when face with having to live with a chronic illness. This is important because health care professionals and teachers are in a position to help families/individuals maximize their strengths and resources, thus helping to ensure that these individuals are living as well as possible with their illness (Feeley & Gottlieb, 2000; McAllister, 2003). Using a strengths-based approach to health care delivery is more in keeping with the nursing philosophy of providing holistic, partnered care to its clients - care that focuses on empowering clients (McAllister, 2003).

For health professionals interested in conducting CD adolescent research from a resiliency perspective, narrative inquiry is a methodology well suited to that framework. It is well suited because it allows an opportunity to explore directly with participants all the daily protective factors they utilize to help them integrate their illness into their lives (Bleakley, 2005). In this study, some of the daily positive actions they institute include staying positive and hopeful, and enlisting the support of friends, parents, teachers, and health professionals. It is also well suited because it allows for an exploration of how an illness can transform and changed the lives of those affected (Clandinin & Connelly, 2000). For example, many of the participants in this study spoke of how their illness experiences have made them into stronger and more compassionate individuals.

This study illustrates that resiliency can be achieved through multiple pathways, and suggests that health professionals should stay mindful of that fact. For example, some of the youth in this study were able to come to terms with feeling different from their healthy peers through forming relationships with other CD youth. Other youth

minimized this sense of difference through spending all their time with non-CD friends; these friendships originated in elementary school.

Another finding in this study, of interest to the health professional, is the pivotal role parents play in helping these adolescents successfully integrate their CD into daily life. Parents provide the following support: treatment assistance, help with medical decision making, help with problem solving CD issues, and being available to listen to their child vent their feelings and frustrations around living with CD. Health professionals can facilitate this process by finding ways to promote parental involvement in their child's care. Despite there being a lot of similarities in the way these parents provide support, it is still important for health professionals to understand each family's unique strengths and resources and ensure they are maximized in order to provide the most benefit to the chronically ill youth and their families.

The mothers of the participants are the most crucial form of support these youth access. It is unclear as to why this is. This area requires further research, especially considering the positive impact this form of support has on the adolescents. The mother also is the greatest source of illness related information and distribution. For example, they educate their children's teachers on CD, its symptoms, its treatments, and the issues their child may encounter in the classroom setting. Health professionals can assist this process by providing the mother with information packets on CD to give to the adolescent's teachers. It would be interesting to study the impact this role has on the mother, to see if this role causes great burden, and if so, what health professionals can do to relieve this burden.

This study's findings indicate how important it is for health professionals to customize the care they give to each adolescent with CD since each individual youth may respond positively or negatively to the same care provided to them. For example, some adolescents in this study cope better when the doctors and nurses give them advance notice about an upcoming procedure, while others, when given too much notice, develop great anxiety and stress. Having seen and understood the negative impact this has on a couple of adolescents, the doctors and nurses adapt their approach and make sure to give these youth as little notice as possible about upcoming procedures. Customizing care also means taking into consideration the adolescent's age, developmental level, temperament, problem solving ability, beliefs, attitudes, and resources available to them.

Understanding adolescent development and how CD can interfere with that development is paramount to the health professional that cares for the adolescent with CD. It is paramount because the health professional can then turn their attention to helping the adolescent find ways to achieve all developmental milestones in spite of their CD. For example, CD's symptoms and treatments can interfere with normal adolescent social development, especially the development of social skills and the formation of peer relations. The health care professionals in this study help the youth overcome this issue through promoting opportunities for socialization and peer bonding. One such opportunity is Camp Brigadoon. The youth who attended this camp formed and maintained strong peer bonds with many of those in attendance. It may be important for the camp organizers to know how integral this experience is to the wellbeing of the adolescents. More research is needed to discover ways to help youth with CD achieve all developmental milestones.

This study identified **new themes and strategies** not yet touched on in other CD adolescent studies. In this study, when other coping strategies fail, the youth institute the strategies of “toughing through” and “waiting out” painful symptoms and severe treatment side effects. More research is needed to see if these strategies are truly beneficial to the adolescent living with CD.

And finally, this study provides some insight into the adolescents’ QOL during periods of active and non-active disease. It also offers insight into how disease activity can impact the meaning adolescents assign to living with CD. This area requires further investigation since it has the potential to influence what strategies health professionals promote and adolescents utilize during periods of active versus non-active disease. In regards to QOL issues, a stark contrast was found in this study. This contrast is the fact that certain measures, such as possessing high levels of optimism, positive self-talk, and the institution of distraction strategies do not result in reports of better QOL in these youth. This is a finding found in many other adolescent chronic illness studies. It does not result in reports of better QOL because these measures do not decrease the severity of their symptoms or side effects from treatments. It does appear, however, to provide some level of self-comfort and control over their own emotional management or response to the challenges the disease carries. This area needs more investigation and replication of findings to see if this is truly the case for all adolescents with CD.

#### *Transferability of Study*

In order to achieve transferability in this study, the student researcher wrote seven easy-to-read and understand narrative, descriptive accounts of each adolescent’s experience living with CD. In addition, the themes representing the emotional, social,



and management related strategies the adolescents used to improve and maintain their QOL were also thoroughly described. These narratives and themes were substantiated by numerous participant quotes that clearly articulated the experiences of these adolescents. This was done so that individuals, including health professionals, parents, and adolescents living with CD could read the data and easily evaluate the applicability of these findings to the setting they find themselves. There were consistent themes within their stories and these may resonate with other adolescents, families and care providers. Transferability and uptake of findings will be dependent upon how likely these experiences are similar to those of others.

Knowledge transfer is essential to the research process, and in order for transferability to be achieved in the research process, the researcher must find ways to disseminate her findings to all respected parties affected by this research. The student researcher will give an oral presentation, presenting her findings to the health professionals at the IWK, especially the ones who work with CD youth. She will present her findings at various health care conferences, workshops, and “lunch and learns.” In addition, the researcher plans on publishing her research study in a gastroenterology nursing journal for other health professionals, working with this population, to read. The findings will also be published in a parenting journal/magazine and put online for youth with CD and teachers to access. Disseminating the findings will help with transferability, as all respected groups will have ready access to these findings and can easily determine if these findings are applicable to them.

## Appendix A

### Letter of Collaboration

#### **Pediatric Gastroenterology Research**

Anthony Otley, MD, MSc, FRCPC  
Mohsin Rashid, MD, MEd, FRCPC  
Christine Chambers, PhD  
Barbara Christensen, RN, Research Coordinator  
Tracey Williams, Research Assistant  
Coordinator: 902-470-7009  
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Doctor's Office: 902-470-8746  
FAX: 902-470-7249

December 11, 2007

Research Ethics Board  
IWK Health Centre  
Halifax, NS B3K 6R8

**RE: Adolescents Perceptions of Living with Crohn's Disease (CD)  
Evelyn Haas, Dalhousie University**

To Whom It May Concern;

This letter is to confirm my collaboration in Evelyn Haas' above-named research study. My involvement will be to inform patients that there is a research study ongoing when they are receiving Remicade® infusions in the Medical Day Assessment and Treatment Unit. If they are interested in finding out more about the research, Ms. Haas will explain the study and obtain informed consent.

Patients will know that their participation is completely voluntary and that if they decline participation, their care at the IWK will not be affected.

If you have any questions or concerns, please get in touch with me.

Yours truly,

Anthony Otley, MD, MSc, FRCPC

## Appendix B



### *Introduction to Study by Dr Anthony Otley*

We have a student researcher, Evelyn Haas, from the Dalhousie University School of Nursing, in the clinic today. She is doing a study to learn about teen's experiences living with Crohn's Disease (CD). She, especially, would like to talk with you about some of the things you do to help you cope with, and manage, your CD when it is in remission, but also when it is active.

You only have to participate in this study if you want to and you can withdraw from this study at anytime. If you and your parents are interested in hearing more about this study, Evelyn will be available to talk with you while you are receiving your infusion

Sincerely,

Anthony Otley MD FRCPC

Division Head, Gastroenterology & Nutrition.

## Appendix C



### *Introduction to Study to Potential Research Participants and Their parents By Student Researcher*

I am a student researcher, from the Dalhousie University School of Nursing. I am carrying out a study exploring your experiences living with Crohn's Disease (CD). I especially would like to talk with you about some of the things you do to help you cope with and manage both the active and non-active phases of your CD.

You may be eligible to take part in this study, if you are:

- (a) Between the ages of 13-17;
- (b) Living with CD for greater than one year;
- (c) Living in Nova Scotia, New Brunswick, or Prince Edward Island; and
- (d) Interested in talking about your experiences.

You only have to participate in this study if you want to and you can withdraw from this study at anytime without it affecting the care you have been receiving at the IWK. If you and your parents agree to your participation in this study, I will be available to meet with and interview you while you are receiving your Remicade® Therapy.



## Information and Parental Authorization Form

Study Title: Adolescent Perceptions of Living with Crohn's Disease

Principal Investigator: Evelyn Haas, RN Graduate Student  
Dalhousie University Master's of Nursing Program.

Co-Principal Investigator: Angela Arra-Robar, RN, BN, MSN, MA  
Clinical Nurse Specialist, Chronic Illnesses, Children's  
Medical Care, IWK Health Center

### **Introduction**

Your child is invited to take part in this research study. It is very important that you know the risks and the benefits of this study, time requirements and what this study will be asking of your child, before you decide if you want your child to take part in this study. This information and the parental authorization form will be given to you to read and will help you decide if this study is a good fit for you and your child. Parental Authorization starts with the first meeting between you and the researcher and it continues until the end of the study or until you and your child choose to withdraw from the study.

Your child does not have to take part in this study and your child also has the right to change his/her mind and withdraw from this study at anytime. Leaving this study will not in any way change the care that you and your child have been receiving at the IWK Health Center. If you have any questions that this form does not answer please feel free to ask, the study researcher will gladly give you the information that you need.

### **Why is the researcher doing this study?**

The purpose of this study is to explore your child's experiences of living with Crohn's Disease (CD). Of special interest to the student researcher are the things your child does to help him/her cope with and manage both the active and non-active phases of their CD. This may help health care professionals in the future be better able to help your child and others like him/her deal with their illness in the best way possible.

### **How will the researcher do the study?**

Five to ten adolescents will be asked to take part in this narrative descriptive study. In this type of study the researcher spends time with your child and asks them a few questions to learn more about their experiences living with Crohn's Disease. The information gathered from each interview will be studied and used to create stories that focus on describing these experiences. All the things that adolescents do to help them

cope with and managed both the active and non-active phases of their CD will be included in these stories.

**What will your child be asked to do?**

You will be asked to sign this parental authorization form. This parental authorization form tells you about this study and gives the researcher permission to meet with your child privately. As well, your child will be asked to sign a consent form indicating that they are willing to take part in this study.

The meeting between your child and the student researcher will take between one to two hours and this meeting will be taped. During the meeting, the student researcher will ask your child some questions. These questions will focus on exploring your child's experiences of living with Crohn's. They will also focus on exploring some of the things your child does to him/her cope with and manage both the active and non-active phases of their Crohn's.

**What are the burdens, harms and potential harms?**

Sharing memories and feelings around living with Crohn's may be upsetting for your child. Should your child become upset during the meeting, they or the researcher may stop the meeting. Dr. Otley will also be available to talk to your child afterwards if they wish.

**What are the possible benefits?**

At this point in time, taking part in this study may be of no help to your child but it may provide your child with the chance to share their feelings and experiences around living with Crohn's.

**What alternatives to participation does your child have?**

Your child does not have to take part in this study. Not taking part will not affect the care you or your child will receive from the IWK.

**Can your child withdraw from the study?**

Your child has the right to withdraw from this study at anytime. Leaving this study will not in anyway change the care your child will receive from the IWK Health Center. Should your child decide to withdraw the researcher will ask whether they will agree to allow use of the stories they shared up until the time of withdrawal. If your child does not wish to have this material used, it will be destroyed and the researcher will not contact your child again.

**Will the study cost your child anything and, if so, how will they be reimbursed?**

Your child will receive \$20 in Empire Theater Movie Money for taking part. There will be no cost to you and your child in this study. Remicade® therapy requires a four to five hour stay at the IWK Medical Day Assessment and Treatment Unit. The interview between your child and the student researcher will take between one to two hours.

**Are there any conflicts of interests?**

There are no conflicts of interest in this study.

**How will your child be informed of study results?**

Once the study is finished and the results have been written up, if he/she wishes, your child may be sent a short letter telling them about the findings. No one will be able to tell what information your child gave to the final research results. Your child can indicate on the signature page of their consent form if they would like a copy of the results.

**How will your child's privacy be protected?**

The meeting between your child and the researcher will be recorded using a tape recorder. If your child does not wish to have their stories audio-taped then your child will not be able to participate in this study. When the information on the tape is copied to a printed format any private information such as your child's name will be removed. Information from the tape recorded meeting between the researcher and your child will be put onto a computer disc and this disc and the tapes will be kept in locked filing cabinets at Dalhousie University School of Nursing for a minimum of five years, after which both the disc and the tapes will be destroyed. As part of any research study, the IWK Health Center Research Ethics Board may, at anytime, review all research records from this study.

To further protect your child's privacy, upon entering the study your child will be given a number and your child's name will not be placed in any of the researcher's notes. Only the researcher will be aware of this number and the consent forms and your child's number will be kept apart from one another at all times and they will also be kept apart from the tape recorded meeting between your child and the researcher. If the results in this study are printed in a journal, it will not contain any information that will identify your child.

Members of the Medical Day Assessment and Treatment Unit may become aware of your child's participation in this study. They will not have access to the information your child shares.

The researcher, as a nurse, has to talk to and tell social services and the IWK Health Center if your child shares they may do harm to themselves or they have experienced or are experiencing any type of physical, sexual or emotional abuse.

**What if I have any questions?**

If you have any questions before the interview with your child, please ask the researcher for this study, Evelyn Haas. She can be reached at (902) 423-3665 or [ehaas@al.ca](mailto:ehaas@al.ca). You may also contact Angela Arra-Robar, RN, BN, MSN, MA, Clinical Nurse Specialist, Chronic Illnesses, Children's Medical Care, IWK Health Center. She may be contacted at (902) 470-7836.

**What are my child's research rights?**

Your signature on this parental authorization form only indicates that you have understood to your satisfaction the information regarding your child's participation in the study and agree to allow your child to participate as a subject. In no way does this waive

your child's legal rights nor release the investigator or involved institutions from their legal and professional responsibilities.

If you have any questions at any time during or after the study about research in general please contact the Research Office of the IWK Health Center at (902) 470-8765, Monday to Friday between 9a.m and 5p.m.

**Study Title: Adolescent Perceptions of Living with Crohn's Disease**

Parental ID: \_\_\_\_\_

Parental INITIALS: \_\_\_\_\_

**Parental Authorization**

I have read or had read to me the information and authorization form and have had the chance to ask questions which have been answered to my satisfaction before signing my name. I understand the nature of this study and I understand the potential risks. I understand that my child has a right to withdraw from the study at any time without it affecting their care in anyway. I have received a copy of the Information and Parental Authorization Form for future reference. I freely agree to allow my child to participate in this research study.

Name of Parent(s): (Print) \_\_\_\_\_

Parental Signature: \_\_\_\_\_

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

**STATEMENT BY PERSON PROVIDING INFORMATION ON STUDY**

I have explained the nature and demands of the research study and judge that the parent(s) named above understands the nature and demands of the study.

Name (Print) \_\_\_\_\_ Position: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_ Time: \_\_\_\_\_

**STATEMENT BY PERSON OBTAINING PARENTAL AUTHORIZATION**

I have explained the nature of the authorization process to the parent(s) and judge that they understand that their child's participation is voluntary and that their child may withdraw at any time from participating.

Name: (Print) \_\_\_\_\_ Position: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_ Time: \_\_\_\_\_





## Information and Consent Form

Study Title: Adolescent Perceptions of Living with Crohn's Disease

Principal Investigator: Evelyn Haas, RN Graduate Student  
Dalhousie University Master's of Nursing Program.

Co-Principal Investigator: Angela Arra-Robar, RN, BN, MSN, MA  
Clinical Nurse Specialist, Chronic Illnesses, Children's  
Medical Care, IWK Health Center

### **Introduction**

You are invited to take part in this research study. It is very important that you know the risks and the benefits of this study, time requirements and what this study will be asking of you, before you decide if you want to take part in this study. This information and the consent form will be given to you to read and will help you decide if this study is a good fit for you. Informed consent starts with the first meeting between you and the researcher and it continues until the end of the study.

You do not have to take part in this study and you also have the right to change your mind and withdraw from this study at anytime. Leaving this study will not in any way change the care that you have been receiving at the IWK Health Center. If you have any questions that this form does not answer please feel free to ask, the study researcher will gladly give you the information that you need.

### **Why is the researcher doing this study?**

The purpose of this study is to explore your experiences living with Crohn's Disease (CD). Of special interest to the student researcher are the things you do to help you cope with and manage both the active and non-active phases of your CD. This may help health care professionals in the future be better able to help you and others like you deal with your illness in the best way possible.

### **How will the researcher do the study?**

Five to ten adolescents will be asked to take part in this narrative descriptive study. In this type of study the researcher spends time with you and asks you a few questions to learn more about your experiences of living with Crohn's. The information gathered from each interview will be studied and used to create stories that focus on describing these experiences. All the things you and other adolescents do to help you

cope with and manage both the active and non-active phases of this particular illness will be included in these stories.

**What will I be asked to do?**

Your parents will be asked to sign a parental authorization form. This parental authorization form tells your parents about this study and gives the researcher permission to meet with you privately. As well, you will be asked to sign this consent form indicating that you are willing to take part in this study.

The meeting between you and the student researcher will take between one to two hours and this meeting will be taped. During the meeting, the student researcher will ask you some questions. These questions will focus on exploring your experiences of living with Crohn's Disease. They will also focus on exploring some of the things you do to help you cope with and manage both the active and non-active phases of your Crohn's.

**What are the burdens, harms and potential harms?**

Sharing memories and feelings around living with Crohn's may be upsetting for you. Should you become upset during the meeting, you or the researcher may stop the meeting. Dr. Otley will also be available to talk to you afterwards if you wish.

**What are the possible benefits?**

At this point in time, taking part in this study may be of no help to you but it may provide you with the chance to share your feelings and experiences around living with Crohn's.

**What alternatives to participation do I have?**

You do not have to take part in this study. Not taking part will not affect the care you or your family members receive at the IWK.

**Can I withdraw from the study?**

You have the right to withdraw from this study at anytime. Leaving this study will not in anyway change the care you have been receiving at the IWK Health Center. Should you decide to withdraw the researcher will ask whether you agree to allow use of the stories you shared up until the time of withdrawal. If you do not wish to have this material used, it will be destroyed and the researcher will not contact you again.

**Will the study cost me anything and, if so, how will I be reimbursed?**

You will receive \$20 in Empire Theater Movie Money for taking part. There will be no cost to you in this study. Remicade® therapy requires a four to five hour stay at the IWK Medical Day Assessment and Treatment Unit. The interview between you and the student researcher will take between one to two hours.

**Are there any conflicts of interests?**

There are no conflicts of interest in this study.

### **How will I be informed of study results?**

Once the study is finished and the results have been written up, if you wish, you may be sent a short letter telling you about the findings. No one will be able to tell what information you gave to the final research results. You can indicate on the signature page if you would like a copy of the results.

### **How will my privacy be protected?**

The meeting between you and the researcher will be recorded using a tape recorder. If you do not wish to have the stories you share taped then you will not be able to participate in this study. When the information on the tape is copied to a printed format any private information such as your name will be removed. Information from the tape recorded meeting between the researcher and you will be put onto a computer disc and this disc and the tapes will be kept in locked filing cabinets at Dalhousie University School of Nursing for a minimum of five years, after which both the disc and the tapes will be destroyed. As part of any research study, the IWK Health Center Research Ethics Board may, at anytime, review all research records from this study.

To further protect your privacy, upon entering the study you will be given a number and your name will not be placed in any of the researcher's notes. Only the researcher will be aware of this number and the consent forms and your number will be kept apart from one another at all times and they will also be kept apart from the tape recorded meeting between you and the researcher. If the results in this study are printed in a journal, it will not contain any information that will identify you.

Members of the Medical Day Assessment and Treatment Unit may be aware of your participation in this study. They will not have access to the information you share.

The researcher, as a nurse, has to talk to and tell social services and the IWK Health Center if you share that you may do harm to yourself or that you have experienced or are experiencing any type of physical, sexual or emotional abuse.

### **What if I have any questions?**

If you have any questions before or during the interview, please ask the researcher for this study, Evelyn Haas. She can be reached at (902) 423-3665 or [ehaas@al.ca](mailto:ehaas@al.ca). You may also contact Angela Arra-Robar, RN, BN, MSN, MA, Clinical Nurse Specialist, Chronic Illnesses, Children's Medical Care, IWK Health Center. She may be contacted at (902) 470-7836.

### **What are my research rights?**

Your signature on this consent form only indicates that you have understood to your satisfaction the information regarding your participation in the study and agree to participate as a subject. In no way does this waive your legal rights nor release the investigator or involved institutions from their legal and professional responsibilities.

If you have any questions at any time during or after the study about research in general please contact the Research Office of the IWK Health Center at (902) 470-8765, Monday to Friday between 9a.m and 5p.m.

**Study Title: Adolescent Perceptions of Living with Crohn's Disease**

Participant ID: \_\_\_\_\_

Participant INITIALS: \_\_\_\_\_

**Participant Consent**

I have read or had read to me the information and consent form and have had the chance to ask questions which have been answered to my satisfaction before signing my name. I understand the nature of this study and I understand the potential risks. I understand that I have a right to withdraw from the study at any time without such withdrawal affecting my care in any way. I have received a copy of the Information and Consent Form for future reference. I freely agree to participate in this research study.

Name of Participant: (Print) \_\_\_\_\_

Participant Signature: \_\_\_\_\_

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

Would you like a copy of the results? Yes\_\_ No\_\_

Would you like to receive a copy of the study results? Yes\_\_ No\_\_

Please provide your address: \_\_\_\_\_

**STATEMENT BY PERSON PROVIDING INFORMATION ON STUDY**

I have explained the nature and demands of the research study and judge that the participant named above understands the nature and demands of the study.

Name (Print) \_\_\_\_\_ Position: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_ Time: \_\_\_\_\_

**STATEMENT BY PERSON OBTAINING CONSENT**

I have explained the nature of the consent process to the participant and judge that they understand that participation is voluntary and that they may withdraw at any time from participating.

Name: (Print) \_\_\_\_\_ Position: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_ Time: \_\_\_\_\_

*Thesis Questionnaire*  
*Demographics*

1. Tell me a little about yourself?

Probes:

- a. Age
- b. Family
- c. School
- d. Diagnosis/Treatments

*Narrative Inquiry*

2. What is it like having a disease like Crohn's?

3. Can you share with me some of your experiences around living with Crohn's?

Social Probes:

- a. What has it been like for you and your family since your diagnosis?
- b. What is it like to have Crohn's and keep up with your social life and your friends?
- c. How does your Crohn's influence your everyday activities? Probes: (a) daily routine (b) sports and (c) hobbies. Does it change the things you like or need to do everyday?
- d. Have you been travelling or been on holiday since your diagnosis? What have those times been like for you?
- e. Have there been people/groups/social media (facebook/twitter) who you feel you can too talk about your Crohn's?

Emotional Probes:

- f. Can you share with me any occasions where you have been upset because of your Crohn's? How were you able to work through those feelings?
- g. Have there been instances where you have felt well but have found yourself concerned about your Crohn's and potential new flare-ups?
- h. Have you experienced any uneasy/awkward moments at home, at school, and out with friends because of your bowel condition? What has helped relieve or lessen some of this awkwardness and uneasiness?
- i. Do you spent time thinking about your future and living with Crohn's?  
What are some of the thoughts that come to your mind during those times?

4. You have shared with me some of your experiences around living with CD. What are some of the things you feel you have done to help you successfully manage your way through some of these experiences?

Emotional Probes:

- a. Is there anything in your life you would change right now?
- b. What has living with Crohn's taught you about yourself and life?

5. Is there anything else you would like to share?

## Appendix G

### *Participant Quotes and Study Themes*

**Table 1**

#### **Unconditional Support**

<b>Parental</b>
<p>School Support: Informing teacher about diagnosis and CD symptoms. Negotiating bathroom privileges with teachers.</p>
<p><b><i>Logistical Support</i></b></p>
<p>Attending Appointments/Treatments; Pickups/Drop-offs to/from School:</p>
<p>“My mom’s really supportive. Like I said before she takes me up to a lot of the appointments...”</p>
<p>“They remember which drugs I had to take...uhmmm my mom has been here every single treatment, my dad has to work...uhmmm but my mom is a home base business so she gets to come with me whenever she wants. And it’s really awesome because they are always here, they know everything. We actually have this book that we have our families medical in, it’s pretty...I really enjoy being here...I get two days off school and that’s always a bonus.”</p>
<p>“Ah shortly after my step mom and mine’s last fight, I was diagnosed, I had to go on Remicade cause I had another fistula... Ah usually mom will take me up to my appointments, and dad was like “Oh, no, like take him up to this one” and being helpful.”</p>
<p>Hospital Stay: “Ahhh he just ahh...like he would stay with me in the hospital and stuff like that. He would just like ahhh like we would basically talk and stuff about everything, like what’s going on, we talk... and that’ that’s pretty much the bases of how he supports me.”</p>
<p>“Ah, when I was bored we’d go to, I can’t remember, the centre, the Teen Centre, I’m not sure, where all the games are and everything, and they’d help me with my ah IV or whatever line... Ah just move the machine out of the way and unplug it form the wall and stuff like that.”</p>
<p>“I don’t know, my, they just visit, like my aunt and cousin visited when I was in, oh yea and my other cousins visited too when I was in the hospital for 10 days that time.”</p>
<p>Pickups/Drop offs: “I wasn’t sure if I was going to be feeling well, like I might be feeling ok then but by the time I get to school I feel sick and I just like go back and forth...like through elementary school I’d be like back and forth between school multiple times in the</p>

day sometimes... Well he always...he works from home a lot and so if I ever need to be picked up and stuff ...he's like there if I do need to talk but I don't normally need to talk about it though..."

Treatment Support:

NG Support:

"It was really supported of my mom, my day had to work that day, but my mom came with me too...when I first got my feeding tube and they had this head...this... that was cut in half to show us exactly how to put it in...my mother learn how to put it in and I...it was really weird cause I was like 9 years old and it was pretty scary for me to have to deal with that. I had seen it on tv and usually people... it was really difficult for people...like it looked really painful to me...when I was looking at it. But then later after my mom put it in, we found out it was really simple."

Would provide moral support during NG insertion or "And so I do that until it get right, down my throat, when I swallow it, like when like I'm gonna gag or something than I get a glass like, like I always have a glass of water there with a straw, so then I just drink the water as like maybe my brother or my mom, somebody will keep just putting it in while I drink the water, till it gets to a certain point. Then you know it's in, and then they just tape it on my cheek or something and then we got to check placement."

Advocated against NG therapy because they didn't want him to be "be the only kid walking around with a thing in my nose"

My dad "Ah, when I had a, or first had the pump or NG tubes, he made stands for it."

"Ah when I first got it, I'd named the pump...she yea, she helped out with it (the naming)...Every now and then she'd let me take a night off, though I wasn't supposed to" and he appreciated that.

Methotrexate:

Phobia of needle. "My mom would give it to me... she always did it, I could never do it...I just thought I'd do it wrong... I thought I'd mess up the needle, cause you have to inject it into your leg."

### ***Being a Parent***

Available to Talk/Validate Feelings/Helping Problem Solve:

"Yea, she's always there to talk about Crohn's 'cause she was diagnosed with Crohn's when she was in her 30's."

Talk to "my mom...just my mom...Ah just when I am not feeling good and stuff like

that.”

“Like my mom had cancer than so like she was really sick too and so I kind of had her because we were both sick.”

“We would basically talk and stuff about everything, like what’s going...”

“The...the bonds I have with my family, like how I could talk to them about anything really.”

“Well she’s like, well like everything that has to do with Crohn’s she’s always been there with me and we get along really well.”

“Mom and I are kind of the authority on that.” Sister “wouldn’t be bale to understand anything about CD. I Probably ask mom...Just the way it is.”

Parents listen to him vent his frustration with Picc Line: “After a while I really wanted to eat something or drink but I couldn’t...”

“I guess like he can validate...like if I’m not feeling well especially if my sister doesn’t get it or something he can explain it to her...he can understand more what its like and I guess he paid more attention than my sister when I was younger about how I was feeling and stuff. So he gets it, like if I tell him I’m not feeling well, he knows that can get worst.”

“My dad has been there and he has seen me go through it...I guess like he can validate...like if I’m not feeling well...he can understand more what its like and I guess he paid more attention...about how I was feeling and stuff. So he gets it...”

“If I’m not feeling well especially if my sister doesn’t get it or something he can explain it to her.”

“People would actually thought I fake and my friends actually thought I fake being sick, like I just didn’t wanna do anything.” “But it was basically my parents backing me up” and sharing with his friend’s things like, “well “X” just puked and they be like, “oh really...Oh yeah he is really sick.”

“Like he like sometimes notices that I’m not looking good before I notice I’m not doing well. And he always there like telling me to talk to my teachers and stuff too. Like sometimes I might not and I might let it go on longer and get more stressed. So he tells me when I should probably talk to my teachers sometimes... I understand like why he does it and it is the right thing to do.”

“Well my mom and I usually talk and like what we’re going to do about it kind of thing. “Like if the feeling is too bad, are we going to go to the hospital.”



Mother suggested “just to rest or different stuff like that” when coping with overwhelming fatigue.

Mother suggested to “go in at lunch time to keep up with school work”

Mother and son figured out “are we going to go to the hospital...’Cause I know from like before I be kind of scared of hospital, like you know everyone gets the willies in hospital. But ever since Feb, it’s like I know the hospital is a good place to be (giggles) when you’re in pain because they can make you feel better. Cause they had me on morphine too for pain killer...ahhh I felt great. I really enjoyed the morphine...so I know its a good place to be when you’re in pain and they make you feel better.”

“Talk to my dad he’s like...I tell him like how I feel I guess and ask him what he thinks I should do if I should talk to my teachers about it...”

Sharing Information/Sharing Experiences:

Telling “me all the set backs, all the problems, if there’s anything to do with Crohn’s that might bother me they always bring it to my attention.”

How to manage symptoms, side effects and school problems.

“Ah, how to manage it, why I take so many pills, like that sort of stuff.”

Mother explained “just what it was, and what it would do and how it would affect me...more at first when I first got it.”

Colonoscopy: “It was really weird because it’s the first time I ever had to be put to sleep...my parents were there the whole time...like they had experiences because of their diseases...they both have chronic illnesses and so they just told me their experiences, what it’s going to be like and they explain to me how they felt when they had theirs...and/or when they were put to sleep, what its like when you wake up...it made it a lot better to be put to sleep and to be waking up later because they were right there.”

Sibling who had CD shared with his brother who was scheduled for a colonoscopy “your throat is, that’s the only thing that will hurt after...wouldn’t be that bad”

“How to deal with it...how to make it like not as big of a deal...just some relaxation stuff.” Explained why he had to take various meds. Any questions “about like the pain or if anything did happen in the WR then I could ask mom and she could tell me to the best of her abilities like with her experiences with it and stuff.”

Mom explained “just what it was, and what it would do and how it would affect me.”

“Like the pain or if anything did happen in the washroom then I could ask mom and she could tell me to the best of her abilities like with her experiences with it and stuff.”

Wanting to know about CD since it “was...some scary stuff when I was younger, not knowing what it was and what exactly was going on.”

***Encouraging Autonomy:***

“It is my disease, so they just realize that and they just help me make my decisions”

“Well, they always bring me into any decision that has to do with my Crohn’s.  
“they ask my opinion...do you think, do you want too”

“My parents always ask me what I want and if I think it is going to work...It is my disease, so they just realize that and they just help me make my decisions... It makes me feel pretty good, like my parents have always really trusted me and its pretty good.”

Support my decision to: “clean out my bowels,” have a Picc line inserted and to start Remicade therapy.

“I’m always included in the decision making.” “. But if it’s something that affected me they will check and see my opinion on it.”

“If I really wanted to do the tube feeding they probably would have thought it over and let me do that for a while.”

“Ah when I had the choices to either come for the ten days, or I think it was either continued with the needle, I decided to go for the ten days.”

“They ask my opinion and stuff like and what I..they ask my opinion, “do you think, do you want too.” Stuff like that.”

**Friendship**

“Ah, I’ve known most of my friends since I was five or six.” “One of my good friends moved away at the beginning of this year...that sucked...he was in cadets, he was in my school, he was in most of my classes, he went to preschool with me...” When I am having a hard time with the CD he “tells me it’ll get better at the end...that it will be gone, like all this stuff.” They now kept in contact via facebook and text messaging.

“Well it is the same people I’ve been friends with like all through elementary school. So it’s really good like because like they know what I am going through. They knew like when I started to get sick...I missed a bunch of school.”

NG Therapy: “My friends would have understood and all that but ah I don’t think my parents wanted that for me” due to its visibility.

“They ah, well at lunch time when I would push the stuff in with the syringe; they’d stay in the class room and hang out with me.”

Remicade Infusion: Missing school due to treatment, my friend is “the one informing me of what I’m missing today” in school...I have a lot people and friends who I just randomly hang out with, but she’s like my best friend cause we’ve been friends since grade 3...she’s my best friend and we do everything together...well this one time my hamster died and I was upset, cause I was like 4, or well not 4, grade 4, so I talked to her, and she also got upset.”

School: “I slept; actually there were a couple of classes I would actually fall asleep in. A few yes. Sometimes friends would just nudge me before, like if the teacher was going to pass something out to the class and they would just nudge me, you know. Get me up and stuff.”

Talk to “my cousin, is my, she’s just about a couple months older than me and we been like best friends forever. Yeah best. We been like...we always hangout, we always talk and stuff...she has a little brother, she’s exactly my sister’s age and uhmmm little twin siblings are a boy and a girl and the boy is the only boy in their family and I guess he must find it hard because he is exactly like my sister sometimes. Really rotten, really cranky, really spoiled sometimes but so I just talk to my cousin, just she always been really a lot more mature than I have and she always just like telling me to say, “whatever X.” It always ok.”

When upset I “talk to my friends.”

**Teacher**

NG Therapy: “When I had my first feeding tube and that is when the teacher explained to everybody why I had the feeding tube, what it was all about, what the disease was and it made it a lot easier on me. When people know it makes it better because you don’t have to explain it and it is a lot easier on you.”

NG pump beeping off in class and “they just kept talking.” Permission always given to go to the bathroom to fix the pump.

Hospital Stay: “Ah no, they gave me work to do while I was gone...My English teacher sent me a card with everyone’s signature.”

Upon returned to school after a hospital stay, the teacher encouraged the participant to do “a word search for my class” to help his classmates understand his disease.

Guidance Counsellor: “Like you tell them what’s going on and they can tell your teacher. If you go through them, usually your teacher is like more supportive, like really helping you to get caught up and stuff.”

Teacher/Classroom Support: “Giving me extra time to do stuff, and different things.”

“Give you an extension and stuff and they’re pretty good about that.”

“They’re really awesome, like I miss something, like I miss every six weeks, they just

come and find me or I go find them, and they catch me up.”

“They understand, they know I have this, well most of them do, so... Well if I miss a test they mm, give it do me during class or something... Or just at lunch.” Or I would “phone” them at anytime “and say I don’t understand this, can you explain this to me.”

“If I wasn’t feeling good and had to use the washroom and had to leave they were good about that” and “my teacher just let me sleep because I wasn’t feeling too great.”

“Well first of all I go to my teachers and figure out what I missed and then I just figure out what that is and then I study it... I look it up on the internet...”

“Well I just get really confused because if I’m behind I don’t know what’s going on in school and yeah... I just get really confused... Basically I just phone the teacher and say I don’t understand this can you explain this to me.”

“Definitely like talking to my teachers, cause like school work and they can give you an extension and stuff and they’re pretty good about that. I’ve been in situations like this over and over again and I usually get out of it fine and I just let it go its course...”

Gym Teacher: “My gym teacher, like last year, he kept telling me that if I can’t, like, he knew I was low on energy, so he just told me like if I wasn’t feeling like I could do it, to not do it.”

“I couldn’t do” gym class because of the arthritic type pain from the Imuran and Prednisone. Gym teacher accepted his explanation and allowed him to sit out.

### **Health Professional**

“They’re really good... Ah I don’t know, they just joke around and stuff like that... Ah, giving me medication.”

“Everybody here is extremely kind... they are always helping you... they are always just being like generally nice...”

“They usually been like supportive and they usually give me heads up in what I’m doin before I do it and stuff...”

“Like my scopes for instance, they tell me what was going to happen, how I’d be afterwards and I’d be like ok.”

Doctors reassured “me like if this doesn’t work we like have all these other things we can try...”

“The doctors made it quite clear to me when we started this that if one drug didn’t work they had literally thousands of drugs that they are ale to use.”

Colonoscopy:

“The nurse told me” about the colonoscopy and stated “it wouldn’t be that bad.”

Not sharing information about a procedure “unless I asked.”

Given as least information as possible due to attitude of “it comes and I will deal with it.”

“I asked her not to” share information since the less he knew the better.

Treatment:

“I’m just curious how like, this clear fluid like stuff helps my Crohn’s.”

Doctors share little very little information, “so long as it works” is the approach the participant goes with.

Less I know the better: “Not really, I just know it works...and it’s definitely worth it.”

“Well, they made it sound really good, like...this will make you better, this is what most of the kids take” and all that good stuff. Yea so, I didn’t really know, I’d never had it before, so I guess I was ok.”

Picc Line:

Administered “ativan” to help reduced pre-procedure anxiety.

NG Therapy:

Nurses state “yeah, its going to be scary at first...you don’t know what to expect” and “it turned out to be actually not that bad.”

Doctors and nurses explain the process using “this head...to show us exactly how to put it in”

**Table 2**

**Embracing Difference**

Dealing with Feeling Different:

“Like you’re different, you know even if they don’t know it, you know it and that kind of keeps you away from everybody else. Like outside of that you maybe really popular and you may have fun all the time but it like its really hard being different...I am ok with it. I’m perfectly fine with it but everybody...I just feel sometimes that being different is really hard for them to accept of me...so I don’t know...it’s like its call subconscious...I subconsciously stay a little aloof from everybody else, like uhmm displace the word is, a little out of it...I do have friends but...yeah...”

“Me it’s no big deal, I’m, I’m always different from other people, like everybody is different, I’m different from you and you’re different from me and I’m different from the kid over there.”

Dealing with Undiagnosed CD for 5 years:

“They think I might have had it for years and years undiagnosed. Cause I had fissures and fistulas...I actually thought I felt normal, I thought everyone felt like that. And I was thinking what, everyone feels like this, this is weird. This kind of stuff. Like for example everyone would eat and eat and eat. And I’ll be thinking, I’ll be thinking in my head how can these people eat and eat so much you know, in so much pain. These guys, I thought they be in pain too but I guess they weren’t.”

Minimizing Difference Through Information Sharing:

NG Therapy:

“Well first like people were like, what is that? Explained to them what it was for, that I couldn’t eat normal food. And like people got that and I don’t think like my friends ever treated me differently because of that.”

Remicade:

“I usually like if it’s a friend, I’ll like try to explain to them that because I’m on immunosuppressants. I can’t just like push pass some things and I’ve actually have to like just rest and get better... They’re pretty good, like they get it, “ohhhh I didn’t realized that.”

School/Negotiating Extensions:

“I don’t like getting extensions I guess. I just wanna be like everyone else and get stuff in on time.”

Minimizing Differences with Non-CD Peers By Acknowledging “They just don’t get it:”

“Ahhh whenever I kind of tell him he kind of does his own thing...like oh yeah, it kind of grosses him out that stuff. It’s understandable but still.”

“OK I have been pretty lucky ‘cause the remicade has been managing it really well but it can be really hard because of the side effect of the remciade that I get sick really easily, to keep up with school and stuff because sometimes I can be completely tired and exhausted and I might miss school just because I am tired and like some people don’t understand like ‘cause there like, “ohhh your just tired and you’re not sick” or if I had like a cold, they’re like, “ohhh you can just push past that and you’ll get better in a few days” but I won’t if I do that, I have to like get extra sleep and stuff...I get that they just probably don’t understand it...”

“Yeah I just don’t think they really understand, actually yeah. Cause you really don’t understand what someone’s goes through if you don’t...yeah.”

“Whatever, I guess, they don’t wanna hear about it, they don’t want to hear about it” and “talk it out with my parents.”

Friends: “Not as many as I would like. Like again like you’re different, you know even if they don’t know it, you know it and that kind of keeps you away from everybody else. Like outside of that you maybe really popular and you may have fun all the time but it like its really hard being different...I am ok with it. I’m perfectly fine with it but everybody...I just feel sometimes that being different is really hard for them to accept of me...”

“They had me go to a psychologist but that really didn’t help... Uhmm, I don’t find like talking things out to people helps me. I don’t know..it’s like, ohhh well how do they know, they don’t understand that...kind of thing...I don’t know... Uhmmm I just don’t like telling how I’m feeling, what I’m going through. And like watching them ohhhh maybe it’s this...ohhh it’s this...like ok (snickers). I guess...like unless you actually gone through it, it’s different, it’s just how I feel about it... Like it’s easier if I were to...like talk to someone who had Crohn’s. Like it would be easier than talking to a psychologist.”

“We like got a lot circle of friends and its kind of hard to talk to him about Crohn’s, like all the really nasty stuff I can’t really tell them about it and like they’re not cool with that. Since you know what everyone is saying and everything and ahh but I actually know people who tube fed, who had Crohn’s and stuff like that. And talking to them about it and it almost like bonding through a disease you know so yeah.”

Seeking Out Other’s Like You:

NG Therapy/School:

“Actually I know a couple of people, like back from where I live who has done it.”

“There’s one girl that goes to my school, like she was diagnosed like I think a couple months after me. So we were both on tube feeding at the same time. Well it’s was just like more knowing someone was going through the same thing as you especially we both like had to have our tubes at school and stuff. So it’s it wasn’t like you were the only person.”

“I actually know people who tube fed, who had Crohn’s and stuff like that. And talking to them about it and it almost like bonding through a disease you know so yeah.”  
it almost like bonding through a disease.”

Socializing:

“It was actually just the other night...ahhh at a concert, like we were outside and I was telling people like.” ohhh yeah I got Crohn’s.” and stuff like that. And she came right out and she wasn’t embarrassed at all, usually you would think girls would be embarrassed about this stuff and she came right out with it, like she...like I have Crohn’s, did you have to get a colonoscopy too?” Like she was right out with it and talking about her enema and everything. I was really surprised, like is she really asking me about this. Like I’m perfectly fine with talking about that stuff, like I’ve been talking about that stuff like my whole life, it doesn’t phase me, but that coming from a girl, like wow.”

Choir:

“Actually yeah the first time I got remicade there were two girls here and they were actually in the choir that I had than joined...my sister was in the choir before me and she knew them and like I got to talk to them and it was cool cause like yeah...hey they knew like what I was going through...”

Facebook/Online Group for Adolescents with CD:

“Some of my best friends really actually have Crohn’s Disease... Well I have one of them on facebook, and it’s a lot...its really cool just to speak with them.”

Online Adolescent Support Group:

“Yeah, I joined that but I don’t do anything on it though...Sometimes... Yeah, its like to see like everyone’s stories is cool...knowing that’s there other people out that have the same thing.”

“I think When I just got diagnosed I think I was part of like a web forum for people with Crohn’s and I’m actually like facebook friends when some of those people but I haven’t like talk to them in years... at that time it was helpful because I didn’t know how I was really going to know like anything especially like when I started NG tube feeding cause other people there had gone through it and its not like something a 12 yr old really knows... I guess like especially I had to get the tube put in and stuff and I was really worried about that...Just reading other people’s things you could tell like what was happening to me when I was like doing this test or stuff like that.”

Part of Facebook CD group but doesn’t go on “a whole lot.” (Discuss in findings and then remove).

“Didn’t even know there were any...I would consider it.” “I think just talking to my mom about Crohn’s and stuff is good enough” and I “work through it in my head most times...just thinking...”

NG Therapy:

“Reached out to a web forum for people with Crohn’s” and found it “helpful because I didn’t know how I was really going to know like anything especially like when I started



NG tube feeding cause other people there had gone through it and its not like something a 12 yr old really knows.”

#### Camp Brigadoon:

“It’s really wonderful being in a place where like you are just one of the other kids. You’re just completely regular, completely normal; there is nothing different about you. Some people might find that really weird and really bad actually...I might, I may be speaking for all Crohn’s kids but for me just being regular without a difference really can sometimes be one of the best feelings because there is nothing to segregate you from anybody else, there is like no discrimination, no segregation, everybody’s equal and its really nice to have that feeling.”

#### Symptoms/Sharing Experiences:

“We talk about that kind of stuff at camp. But not a whole lot, we all had and we knew what was going on... hospital stuff...we just ask each other what we had to go through.”

“Well it’s was just like more knowing someone was going through the same thing as you... So, it wasn’t like you were the only person.”

Attended “a camp a couple months ago” and “it was “amazing.” Talked about CD “somewhat, we just had fun...having fun and hanging out.” Remain in contact via Facebook and chat

#### Staying in Contact via Facebook/Email/Phone:

“Talk all the time and we’re like all share their troubles and like their emotional and relationship issues and we all just like talk. It’s really more of a conversation thing...I get to keep in contact with them really great...thank you facebook.”

Chat about “just how fun the camp was, and me and this friend are actually we’re making plans for march break where she comes down and hangs out at my place for like most the whole march break.”

#### Seeking Normalization Through Electing Not being Part of Any CD Groups:

“I think I have the support I need right now but you never know maybe in the future, why not maybe.”

“Just living a normal life”

“I don’t know...I’d just rather be with my friends or go to my cottage or do different stuff.”

Wishes to know no one with CD because “I don’t know, I just wouldn’t wish that upon

them, I don't know." "It doesn't matter to me, knowing someone with CD. I have all the support I need in my friends and family."

"Just no interest, I go to cadet camp every summer... "Well I'm doing fine with it right, I don't really feel I need the support of it, of other friends." Getting all the support he needs from his mom.

After having CD for a while I am "just trying to get back to normal and different stuff... Ah I just don't worry about different things and ah stay calm." Staying calm with "everyday life, like doing school work and stuff like that."

Remicade Impact:

"Remicade in general. Keep me in good shape."

"Really good, like I've got my energy back and I'm eating normally now." Remission "since I started Remciade, so about 2 years ago." Weight "it's very stabilized, it's staying around about 110 now and I'm happy about"

"Ah, I'm never had pain, and it's been a year, so that's good." "And my growth is normal, so everything's good."

"Uhhmmm I don't know like, I haven't' been in a flare for so long so I don't even remember what its like that much..."

"Eating, it's fine actually. See ahhh, its awesome having to go to places and not have to worry about the BR. I'm lovin that."

Focused on "just living a normal life."

**Table 3**

**Attitudes/Personal Beliefs**

<b>Acceptance Of Diagnosis/Hope/Meaning</b>
<p>"It was just like, it was a big relief to know that it had a name so that we could start doing something about it."</p> <p>"My dad had it so they were pretty ok with it. They "already knew generally the stuff my dad went through and how it was going to be harder so we just got ready for it and when it came it was a breeze...The disease is simple and it's like just a chronic illness...And the fact that for me on the remission...I have been in remission for about a year now I think. Yeah, it's easy for me..."</p> <p>"It wasn't that scary...I knew I wasn't going to die and so yeah it wasn't too much of a big deal for me."</p>

“To be honest I’d seen it coming. Once I started hearing about Crohn’s. It was in the IWK that Dr “a” came in and said it was like Crohn’s. I always knew in the back of my head that it was Crohn’s... Relieved that they finally know what it is.”

“It didn’t matter much to me...it’s not that big of a deal...the treatments are the worst...”

“I don’t know, it’s not that big of a deal.”

“I’m 95% sure you have Crohn’s and like I’m like ok, cause mom has it and mom’s sister had it.””

“I’m kind of happy how I am”

“It didn’t matter much to me.”

“Someone’s got to do it”

“Well, I really quickly realized it’s not going to go away and it’s something I have to live with and that’s that...just had to deal with it”

“Whatever, mom has it, so mom’s ok, it can’t be that bad. Then I realized that it was pretty bad...it’s an inconvenience...all of it...the fatigue and the immobility of it”

“I didn’t know what it was, so I was kind of confused...curious about what it was...how it would affect me...it’s not really bad in fatal ways...will this remicade actually work or will I get my symptoms back...I’m very positive about most things.”

Treatment:

“That if one drug didn’t work they literally had thousands of drugs that they are able to use...they just keep moving up to the stronger drugs that work on different areas of the bowel.”

“Coming to the hospital and the doctors telling me, reassuring me like of this doesn’t work we like have all these other things we can try, makes me hopeful.”

Living with CD:

Experience has “made me stronger...you can get through it...Things can get better...Optimistic...”

“I’m very positive about most things”

Made me stronger “in general...I can’t think of a way to describe it.”

Working through symptoms “makes me feel good about myself and being able to do the things I wanna do.”

“It taught me I got a really great family and that I got a really good background and that I am extremely lucky to be where I am today. I am perfectly healthy and I got back all the weight that I needed...uhmmm and I’m in remission right now.”

Gave me “a better understanding of things like that, like people being sick...anybody whose got a different situation, has to make exceptions and stuff...like I think I’m more understanding of that than other people might be. So like I’m grateful for that because I feel likes that’s a good way to be.”

Thinking about future flare-ups:

“If it happens, it happens.”

Helping Others: “I’ve actually gotten the chance to talk to other young kids who have learn or just become just diagnose with Crohns’ and it was a actually a really fun experience for me...I got to meet this young kid and uhmm I got to talk, explain to him about the feeding tube...how in my opinion it is better than steroids because it stunts your growth.”

“I was pretty lucky to not have to deal with it for long...”

“Pretty lucky especially since they caught it fast.”

“I am definitely one of the better cases.”

“I learned that it’s a lot better to be healthy than to be sick.”

“Sometimes I find it for other kids they don’t have as supportive of a background as me. So they find it a lot more difficult to deal with Crohn’s and for me it is just another thing really.”

When other adolescents miss out on activities due to their CD it makes me “feel bad because they can’t” and that “I” can.

“A lot of them is way worse than anything I ever had so its like I’m actually lucky even though I feel like so bad about having it but I’m actually like one of the lucky people who has it because I tend to do, fair pretty well with it...”

“A lot of kids that I meet at the Brigadoom summer camp have these uhmmm bad food issues, like they can’t eat like for example KFC, they can’t eat whole wheat, but for me I am so happy that I can eat almost anything, in the 4 yrs I had Crohn’s the only thing that has ever bother me was these turnips that I grew this summer, yeah they weren’t that great, they caused a lot of stomach pains.”

**Table 4**  
**Daily Coping Strategies**

***Distraction Activities:***

Watched tv, played video games, taught themselves how to play a musical instrument such as guitar, “just not focusing” on their symptoms, spend time on computer. (Remove after stating in findings.

“Just not focusing” on the symptoms.

“That’s how I lived my life, tv, video games and guitar.”

“I would just lie on the couch all day watching TV and not eating a lot...I played videos or on the computer.”

“Ah fresh air” and “gravol...I’d either be sleeping or playing video games.”

Pain:

“I’ll probably just take the day off school...relax on the couch, sleep, watch tv.”

“Ah sometimes it would get really bad, but just make me cringe and stuff.” “Ah, kind of like someone stabbing you, it’s like a really sharp pain...ah just taking Tylenol and stuff...sleep, try to sleep it away.”

Activities:

Choir: “Well I really like it cause its something I do every week and its just like, I don’t know, it’s a big group of us and its like belonging to something... it’s like something fun, something like I can do even if I’m not feeling well but its like something fun.”

“Well I like it cause it’s, I love music it so, I’m glad I actually got into band and play songs with people there. I’ve actually, I also play guitar... Yea, I just started actually, five weeks ago...I mean I just like being away from home sometimes” because “I especially like with my friends and stuff cause then, I don’t know I just get my mind off stuff, I just get away from like everything, and just have fun.” What is on her mind: CD and “and school sometimes because I’m just really behind and I get confused about this.”

Keeps minds off CD by ““school events, student counsel and working with the town counsel...they...have this new...project in Amherst...and I was thinking about applying for that. So getting busy with helping other people...school events.”

Developing Cancer:

“I don’t know if that would ever be a problem really...Like I don’t think about it too

much.”

“I try not to think about that stuff to be honest... Like I heard like in rare cases, like I think there is only 5 cases in the entire world where like it can cause cancer or something crazy like that. So at first I was a little...like oh god this is what its going to be like. But it’s awesome.”

Remicade therapy:

“I’m just thinking like will this Remicade actually work, or will I get my symptoms back?” Keeps her mind of this by “just being with my friends, keeping my mind off it. I like to go for walks with the dog... I like to play my trumpet, my guitar, I like to read, I love reading...”

Step-Mom: Deals with frustration with step-mom by “I’ll just go for a walk or something...went to moms once and just didn’t come back for a while, but...”

### ***Handling Embarrassing Situations:***

Bathroom:

“I just went, I went to the bathroom, I just went and almost make a joke out of it I guess, like when I came out, “ahh man” like almost make a joke out of it and they go, “oh wow.” I guess it must have been really bad cause I could even smell it myself. Like lets say right now, I would get up, I would be able to smell it myself, it was that bad. It was pretty embarrassing in school, like lets say for example at the end of the day where you put your chairs up I’d be able to smell it. I’m thinking, “man I hope nobody else can smell that.” But no I guess they could cause nobody actually confronted or said anything. I never seen anything cause “X” told me like recently after everything like, “man, no offence you could smell, you could smell something.”

Dealing with odour from washroom at friends place I would “just let it go...cause there’s really not much detail to go into. Yeah, it stunk.”

“I remember I think it was grade 7 and one time I left and I came back and someone was like “you were in there for a while.” And I was like, I don’t remember what I said I just kind of like ignored them.”

“For me I have to go to the bathroom with Crohn’s a lot more than regular kids so using school bathrooms is really disgusting and its really embarrassing and I’m always worried that someone would catch me...I try to not use the bathroom at school but sometimes if I am in a flare-up or something happens and I really have to go...I’ll use it and I’m always like just praying that no one will not walk in behind me and use the bathroom.”

“Like travelling is always an issue because like you have to go sometime. And one time this old man came in and I just sat there quietly waiting for him to leave and that is

generally what I do.”

Tried “not use the bathroom at school.”

If someone walked in the bathroom he hoped “nobody else can smell that.” If they did he would “just basically agree...just let it go.”

“I would never really try to use the bathroom because I was always embarrassed kind of thing. And so I would always just hold it in, all day at school, all pain and stuff like that... I thought it was normal, so that pretty much it really, toughing through your pain, avoiding the bathroom and trying hold in your farts and stuff...before I puke I get this feeling...concentrate on swallowing and concentrate on fighting back because I knew that I would puke...I knew I was gonna. There was a couple times that happen, at a friends house too and I would just not say a word, swallow maybe and like a couple minutes later it would pass.”

“And it just be so embarrassing, like I would avoid the bathroom, whole it in as much as I can.”

At Friends Place: “The stink, cause like inflammation, its like it had this weird smell to it. Yeah I guess it was mostly everything like it had this weird smell to it. And it just be so embarrassing, like I would avoid the bathroom, whole it in as much as I can.”

Fistula:

“I actually felt little stains, almost like stains you know. Like even in the mirror and stuff, like I’d be like, “x”, that’s my brother’s name too by the way. I’ll asked him like in private, lets’ say we’re in school, “so is there stuff showing on my butt and stuff...And it just, ohhh I couldn’t stand up for too long...leakage... So maybe go to the bathroom all the time, like at break, I go to the bathroom as much as I can and try to clean up as best as I could, all the time... just cleaned up which is probably why it stunk so bad...Just try to dry wipe it off really. I couldn’t really do anything about it. It wasn’t too noticeable I guess but you could see it...I tried setting down as much as possible. And walking around I would mostly just like, lets say people are in a group and lets say someone wanted to walk around, I would just stand there and concentrate on holding it in... like when I would get up there be little stains on the chair and that was pretty embarrassing but yeah...Ignore it and just hope to god nobody see’s it. Ohhh maybe try to hide it, like push the chair in a certain way or maybe you know what I mean, try to hide it kind of thing.

Staying Close to Home:

“I wouldn’t wanna go out because I’d be too fixated on the bathroom. Like well is there a bathroom there...how do I get access...ohhh no there is not, maybe I shouldn’t go cause pain. Really fatigue too, you probably know some side effects too, like fatigue, like I didn’t want to do anything, lied around watched tv and stuff, did nothing. So

yeah...”

Even when choosing to go out, “I was familiar with the area and knew where the bathroom was.”

Not travelling during active disease because “I don’t like having to deal with being sick if I’m not at home.”

“I would just rather not sit in the car for hours on end hunched over in my seat. And I use to get car sick a lot too and that contributed to it.”

“I didn’t want to go out any where during that time...Because I just didn’t feel very good and I just wanted to stay home on the couch.”

Didn’t leave home “when I was like younger” because “I can’t hangout cause I don’t feel well all the time.”

“Sometimes I would try to avoid going out to eat with friend’s cause of the bathroom, heavy foods like Macdonald’s and stuff. Heavy food you know you got to go to the bathroom with that stuff so maybe I usually, actually I would eat it anyway but if I had where’s the bathroom and how do I get access to it... I was familiar with the area and knew where the bathroom is... I don’t wanna do anything, just stay home.”

“Now I go out and everything but still like I’m almost...like I guess if I’m in a flare stay home but if not...”

NG Therapy:

“I haven’t really been to many parties and stuff...it kind of prevents me from going out and staying over at friends houses and stuff... Again, it kind of stops friends from coming over too, cause it’s kind of embarrassing...putting a tube into my nose every night... All the meds. Is it just letting people seeing you taking all those meds...I just don’t really want them to, cause it’s kind of private right.”

“I just go out and do whatever I want.” (Outlier, removed when discussed).

Asked Question By Peers About Their CD:

“She just knows that I’ve been really sick over the past couple years.” “I just don’t really feel comfortable talking about it to my friends”

“If they ask I’ll tell them about it but...I have Crohn’s Disease basically I don’t absorb all the nutrients from my food...other than that, I don’t talk about it really.”

“Don’t really feel comfortable talking about it to my friends” and “probably the reason I don’t tell people what I have because I don’t want them to go Google it or



anything...don't want people to know that stuff I guess."

"I just said it was something that doesn't really, it's not really bad in like fatal ways, but it does affect like the digestive system and yeah that's it..."

"Yeah...well I don't like to talk about symptoms or anything but like normally if someone asks you what it is I will tell them like it is an autoimmune disease. I won't really tell them what it is."

NG Therapy:

Questioned by peers about "beeping" feeding pump I would state it is my, "Crohn's stuff and then I just wouldn't talk any more."

Openness About Disease:

"Most people I know, if they like...if they ask me I'll say yes I have Crohn's, likes there's no reasons to hide it I find...like I have it, big deal, it's over. Uhhmm a lot of people take it the wrong way, like some people think some...I've actually had a couple people ask me if I'm going to die...I find that quite funny because like I know I'm not. I'm perfectly fine. The disease is simple and it's like "just a chronic illness." When asked about it she states, "it was something that doesn't really, it's not really bad in like fatal ways, but it does affect like the digestive system and yea that's it, I say that and..."

Open about illness but "they don't really ask about it too much...just about the pain..."

### ***Staying Aware/Being Proactive***

NG Therapy:

"And they're like, "do you want your mom to put in it for you? And I was like, "No, I'll do it" and just put it in."

"Ah, at school it was hard because I have a pump in my backpack with me and it'd be pumping and it would start beeping when something was wrong and that was just really embarrassed. After about a month of that in school, I just took a can with me and put a syringe in it and pumped it in like that."

Pump would beep of in class and I would, "go to the bathroom and fix it."

"I know like that cancer can be genetic...and hereditary, so I don't know but I'm going to get tested for it when I'm older...I don't know if that would ever be a problem really."

Fistula:

“But ah than after the diagnosis when I ended up getting back in school and I knew there was a fistula and stuff like that, I actually started wearing the pads. To catch the leakage. And that seemed to help, I think it helped, it still was uncomfortable, at least it helped and didn’t go on my pants any which is good. But yeah...Just wear a pad pretty much. Maybe a sitz bath if it gets pretty raw. ”

Keeping up with School:

“If school is difficult then I just start flaring up and yeah... I just...uhmmm try to stay busy or try to stay organized...like last year it was really difficult for me...I had a binder...my stuff went everywhere, the binder got broken, I just couldn’t manage with it...this year I use a different method. I used a bunch of pockets in my backpack keep all my stuff separate...I use different scribblars...I used different uhmmm really subjects in each scribblars, it’s a lot easier...just staying busy, just staying organized I find.”

“I stay very organized...I make sure I can find everything... Cause it’s terrible if I can’t find sheets that we were working on or something.”

“Knowing when I am going to have to let something go, not doing an assignment or something because I need the sleep because it is better for my health, to not worry about it..., talking to my teachers about it, not too push myself too much.”

“Definitely, like a lot last year because I had a really hard course load and when I would get so tired and I just couldn’t keep up with it. I would get so upset, it was just really stressful... Well I like cry, sad about it...I guess those are the times when I get worry about what is going to happen in university when I feel like I’m sick and I can’t keep up... I usually just let it out and than once I’m calmer and I can think about it and usually the best to do is to see if I can get extensions or just like even if I hand something in late, plan out what I’m going to do, what work...”

Made sleep a priority and “just managing how much I’m pushing myself and being aware of how I am feeling.”

“I was tire a lot...like I’d go home from school and sleep.”

Remicade/Immunosuppressant Properties:

Letting school work go since “it is better for my health.”

Remicade/Nausea:

“The first few times I felt kind of sick to my stomach though until I got use to it. The first 2 yrs, I take the day of school or the next day and relax. And that wore off...So just taking a little bit of time.”

A Look Back:

Prednisone: “My mood will swing downwards. I’ll get crankier you know and a lot more irritable...like I just stop and I just say, “ok you’re doing...you’re being pretty crappy right now...like you gotta stop.” (Put in rest of quote)

During times of active disease he “cannot run, cannot jog...it seems as if all my breath is gone, my energy is completely gone during a flare-up...“I just like stop and I like start breathing really slowly, like I take really deep breathes and I start slowly decreasing the amount of breathe I’m taking in and I’m that helps me a lot.”

***Waiting it Out/Toughing Through It:***

Prednisone:

“Really bad mood swings, you can get really angry... it makes you really hungry all the time and like I gained a lot of weight when I was on it, more than I want to.” Coped by “just waiting it out, like there wasn’t a lot I could do”

“Just kept going.”

“I just got through it.”

“It’s something I had to do but when another treatment came round I took it.”

Prednisone/Imuran (Arthritic Pain/Fatigue):

I just went through life, not much you can do.”

Methotrexate:

“That was the worst pill ever...I got the H1N1 at the end of my methothrexate treatment and that made me just throw up every pill that I took down. I was just like screaming, “ I can’t do this anymore...It just really made it easier to just take it one day at a time...counting down the days until I was over with this.”

Pain:

A hot water bottle on their stomach, taking medication such as Tylenol, trying to sleep away their pain, watching tv, playing videos games.

“I just like have to sit there and stand through it...tough through it”

“Tylenol or something, you know, just let it pass.”

“Maybe try not to think about it... everything that I would try like lay in bed, everything, it would be same as it is... I would just have to tough through it pretty much, maybe try

to watch tv, or like play video games, keep my mind of it but it still always be there. You couldn't avoid it no matter how hard you try."

"You couldn't avoid it no matter how hard you try and you would to just wait for it too pass.

"Its really good if you have, if you're really comfortable...like for me it was late at night and I was in my bed and I just lay there and waited and that is the way it has been for me."

"Ah, one day I had gym in the morning, I felt sick, and I just had to throw up, so I did and I just kept going... But I didn't go home that day, there was pain, but I just went through it."

"One time I didn't want to go to basketball because my stomach hurt, but I ended up going anyways."

Relying on Past Experiences:

Going of to university next year: "what happens if I get sick and I can't keep up with all the assignments and stuff...sure it will go over fine...I've been in situations like this over and over again and I usually get out of it fine."

Give me My Space:

"If I was mad at a friend, usually wouldn't say much, I'll be honest we would usually just go at it...I kind of have a tendency to be a bit of a hot head when I'm upset and they know...they usually stay out of my way."

Open Communication

"At mom's I've got five or six pills I will take and then there I've got fourteen that I take every morning" due to step-mom's belief in naturopathic medicine. Expressed to step-mom, "I feel that I don't really need all of it...and that is what some of the falling outs are over... she's not open to adjustments."

Observing Parent with CD: "Pretty much just what I have seen growing up. If I did ask her something she probably, she'd help but I just never really had to ask her."

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