

Adolescents' and Young Adults' Lived Experience
of Living with IBD and an Ostomy

by

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Abstract

According to the Crohn's and Colitis Foundation of Canada, there is approximately 1 in every 200 individuals who is living with inflammatory bowel disease (IBD). Many of those living with IBD also need to have an ostomy. The literature on the effects IBD and an ostomy has on adolescents and young adults lacks consensus. Therefore, the purpose of this phenomenological study was to try to understand the lived experiences of adolescents and young adults (N=6) living with IBD and an ostomy. Sociodemographic information was collected, and the participants were interviewed in person using a semi-structured interview guide. The work of van Manen (1990) was used as a guide for data collection, analysis and interpretation of this study.

Analysis revealed the essence of the adolescents' and young adults' lived experience as being "Concealing and Revealing the Self". Three themes communicate the essence of their lived experience: (a) Uneasy feelings, (b) "It's hard...", and (c) A renewed sense of self. The needs of the adolescents and young adults, along with their recommendations to health care providers, are addressed. The study findings inform nurses in the areas of practice, education and research. Practice recommendations include being cognizant that these individuals need holistic care that addresses their psychological, psychosocial and physical needs. This study forms the basis for future research to explore some of the themes in greater detail, as well as a recommendation for a longitudinal study.

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Chapter One: Introduction

Chapter One provides the reader with a brief overview of inflammatory bowel disease (IBD) and discusses the significance of the problem in adolescents and young adults living with IBD and an ostomy. It also describes the purpose of this phenomenological study and addresses the research questions. Finally, the researcher's assumptions are explored.

Ulcerative colitis (UC) and Crohn's disease (CD) are collectively referred to as inflammatory bowel disease. These two chronic and lifelong gastrointestinal disorders, characterized by periods of remission and exacerbations, are grouped together because of their similar symptoms (Pearson, 2004). Initial case reports of IBD were reported between the late 19th century and the 1930s, and, since then, the incidence and prevalence of ulcerative colitis and Crohn's disease have increased significantly until the 1970s (Kim & Ferry, 2004). Loftus (2004) however, says that the incidence and prevalence are only now beginning to stabilize in areas such as North America. Manitoba is reported to have one of the highest incidence rates of IBD in the world; in fact, this Canadian province reports the highest incidence of Crohn's disease to date (Bernstein, Blanchard, Rawsthorne, & Wajda, 1999).

According to the Crohn's and Colitis Foundation of Canada (n.d.), there are approximately 170,000 men, women, and children who live with IBD. The diagnosis tends to be bimodal with it most frequently occurring between the ages of 15-25 and 45-55. Ulcerative colitis and Crohn's disease primarily affect young adults, and are believed to be the most significant chronic disorders affecting children and adolescents (Leshem, 2003). However, little attention and research has been given to understanding the effects

of this chronic illness on children, adolescents and young adults (Daniel, 2001; Decker, 2000). Evidence suggests an increased vulnerability with emotional and behavioral development of children living with a chronic illness, this despite the fact that adolescence is already a time of great physical and psychological change (Brydolf & Segesten, 1996; Mackner, Crandall, & Szigethy, 2006).

Individuals who suffer from ulcerative colitis, and less often those with Crohn's disease, may, at some point during their illness, need surgery resulting in an ostomy (Reynaud & Meeker, 2002). Ostomy surgery has been performed since the 1700s (Shipes, 1987) and an estimated 30,000 to 45,000 ostomy surgeries are performed annually in Canada (United Ostomy Association of Canada, personal communication, October 4, 2001).

Significance of the Problem

Bernstein et al. (1999) studied the epidemiology of IBD in Manitoba, Canada, and found the overall incidence rates for both CD and UC were highest between the ages of 20-29 years of age. Green, Elliot, Beaudoin, and Bernstein (2006) looked at geographic variations in the incidence of IBD in Manitoba, Canada between the years of 1990-2001 and came to the same conclusions. Green et al. (2006) further indicated that the prevalence of both CD and UC are continuing to increase in Manitoba, particularly among the young adult population. Dr. Moroz, a gastroenterologist at a large tertiary care hospital in Manitoba, who studied the epidemiology of pediatric IBD in Manitoba from 1978 – 2002, also found the incidence and prevalence of both CD and UC to continue to rise among the pediatric population as well (> 17 years) (personal communication,

September 10th, 2007). These studies are among a paucity that have looked at the incidence and prevalence of IBD in North America.

Approximately 25% of all new cases of Crohn's disease and between 15 and 40% of all new ulcerative colitis cases are diagnosed in persons younger than 20 years of age, making inflammatory bowel disease a significant illness among the population (Rayhorn, 2001). Chronic illness generally upsets an individual's steady state, disrupts one's interpersonal relationships, and is often associated with a change of role functioning (Leshem, 2003). Not only is there empirical evidence, but common knowledge also demonstrates that adolescence is marked by a critical and significant transition during one's life span. This transition includes physical, psychological, social, cognitive, physiological and developmental changes (Petersen & Hamburg, 1986). When children, adolescents or young adults are faced with having a chronic illness, there have been suggestions that the illness can prevent or disrupt the accomplishment of developmental tasks viewed as essential for entry into healthy adulthood (Kellerman, Zeltzer, Ellenberg, Dash, & Rigler, 1980).

There has been speculation in the literature about what life with inflammatory disease and living with an ostomy is like, but young adults have rarely been asked about their perceptions (Daniel, 2001). Additionally, little research is available on the effects IBD has on adolescents and young adults (Decker, 2000). There continues to be a need for more research on the impact this illness and an ostomy can have on an individual (Brown & Randle, 2005; Karadag et al., 2003; O'Brien, 1999). Of the research done on adolescents and young adults, a lack of consensus as to how IBD affects this population socially and psychologically remains. Some studies revealed that IBD has negative

social, psychological, and psychosocial effects such as alienation, reduced living space, feelings of helplessness, and anxiety (Brydolf & Segesten, 1996; Dudley-Brown, 1996; Mackner & Crandall, 2006; Wood et al., 1987), whereas others revealed that people with IBD cope well and are psychologically healthy (Joachim & Milne, 1987; Lask, Jenkins, Nabarro, & Booth, 1987; Mackner & Crandall, 2005). Studies done on individuals living with ostomies revealed that they face many lifestyle challenges that include physical and psychological adjustments (Manderson, 2005; Reynaud & Meeker, 2002; Rheaume & Gooding, 1991; Salter, 1992). Others have found that patients with a stoma had perceived negative body image feelings and expressed difficulties in coming to terms with having the stoma (Black, 2004; Casati, Toner, De Rooy, Drossman, & Maunder, 2000; Junkin & Beitz, 2005; Karadag et al., 2003; Nugent et al., 1999; O'Brien, 1999; Salter, 1992).

Many published studies have used quantitative methodology, which make it difficult to extrapolate perceptions and feelings of these individuals. Quantitative measures frequently use standardized tools that are designed for use with healthy individuals. These measures are often not equipped to capture the thoughts, feelings and meanings that individuals ascribe to their experiences (Woodgate, 1998). It is therefore imperative that more qualitative research be directed towards gaining knowledge about the lived experiences of adolescents and young adults living with IBD and an ostomy (Daniel, 2001). By gaining valuable insight and understanding into these experiences, nurses will be able to utilize that knowledge and provide better holistic care to those individuals and their families.

Purpose of the Study

The purpose of this phenomenology study was to arrive at an understanding of the lived experiences of adolescents and young adults living with inflammatory bowel disease and an ostomy. Special attention was paid to what characterizes the experience of living with inflammatory bowel disease, what characterizes the experience of living with an ostomy, the meaning these individuals assign to these experiences, and their recommendations for health care professionals.

Research Questions

The research questions addressed in this study include:

1. What meanings do adolescents and young adults assign to the experience of having inflammatory bowel disease with an ostomy?
2. What effect does having inflammatory bowel disease and an ostomy have on the lives of adolescents and young adults?
3. What are the needs of adolescents and young adults who have IBD and an ostomy?
4. What recommendations do adolescents and young adults have about how health professionals can best support them in living life with inflammatory bowel disease and an ostomy?

Assumptions

Van Manen (1990) suggests that the researcher's assumptions and biases are always present and that he or she should acknowledge and accept them. Assumptions for this study included: a belief that every individual has their own perspective of their lived experience; adolescents and young adults with IBD and an ostomy face many challenges

related to psychological and social functions; and, a belief that their adjustment is positively associated with a strong social network.

Chapter Summary

This chapter provided an overview of inflammatory bowel disease and the rationale for research directed at understanding the lived experiences of adolescents and young adults living with inflammatory bowel disease and an ostomy. There has been little published exploring what it is like for these individuals to experience life with an ostomy. If more studies such as this one continue to be published, it is reasonable to expect that all those who choose to have an interest will have a greater understanding. Nurses who have a comprehensive understanding of these lived experiences may be better able to provide physical, psychological and psychosocial care to these individuals and their families.

Chapter Two: Literature Review

This chapter reviews the literature in an effort to establish a comprehensive understanding of what we know about adolescents and young adults living with IBD and an ostomy. A review of research related to childhood chronic illness, inflammatory bowel disease, and adolescents and young adults living with an ostomy is presented.

Overview of Inflammatory Bowel Disease

Inflammatory bowel disease is an umbrella term used for Crohn's disease and ulcerative colitis. These two similar yet distinct disorders are grouped together because of the similarity of their symptoms and medical treatments (Pearson, 2004; Rayhorn, 2001). Ulcerative colitis is a superficial inflammation of the mucosal and submucosal layers of the colon whereby the tissue becomes friable and bleeds easily (Listrom & Holt, 2004; Mason, 2001; Pearson, 2004; Veronesi, 2003). It always affects the rectum, can extend to varying levels of colonic involvement, and usually spares the rest of the gastrointestinal tract (Listrom & Holt, 2004; Mason, 2001; Pearson, 2004). Sole involvement of the rectum occurs in 40 to 50% of patients. The disease extends to the descending colon in 30 to 40% of patients and the entire colon (pancolitis) is affected in 20% of patients (Listrom & Holt, 2004). The majority of patients with UC will initially present with rectal bleeding, urgency and tenesmus (Listrom & Holt, 2004; Pearson, 2004). Abdominal pain and cramping are also common, which is usually most intense during bowel movements (Hendrickson, Gokhale, & Cho, 2002).

Crohn's disease is a transmural disease affecting all layers of the bowel wall. It can occur in any part of the gastrointestinal tract from the mouth to the anus (Mason, 2001; Rayhorn, 2001; Veronesi, 2003). A hallmark characteristic of CD is its "skip

lesions”—characterized by inflamed and affected areas interspersed with areas of normal bowel tissue (Listrom & Holt, 2004; Veronesi, 2003). In certain patients, because the inflammation can affect the whole layer of the bowel mucosa, common manifestations are fistulae, abscesses, strictures and obstruction (Listrom & Holt, 2004; Pearson, 2004). Symptoms exhibited among patients with CD vary slightly when compared to those who have UC. Typically, they present with low-grade fever, malaise, weight loss, growth failure (in children), non-bloody diarrhea and abdominal pain and cramping (Rayhorn, 2001; Veronesi, 2003). The fact that between 25 and 36% of patients with IBD will develop extra-gastrointestinal manifestations strongly suggests that IBD is a systemic disease (Listrom & Holt, 2004; Pearson, 2004). The organs affected may include the skin, eyes, joints and hepatobiliary system (Pearson, 2004).

To date, the cause of IBD is unknown (Daniel, 2001; Joachim, 2002; Rayhorn, 2001). Research has, however, speculated on the role of several etiological factors such as genetics, environment, and the immune system (Daniel, 2001; Listrom & Holt, 2004; Pearson, 2004; Rayhorn, 2001; Veronesi, 2003).

Worldwide, the incidence of IBD is approximately four to seven cases per 100,000 (Kim & Ferry, 2004; Listrom & Holt, 2004). Although its onset can occur at any time throughout one’s lifetime, a bimodal distribution has been observed (Listrom & Holt, 2004). The typical age of onset has been noted to be between the ages of 15 and 25 years with a second peak between the ages of 45 and 55 years (Crohn’s and Colitis Foundation of Canada, n.d.). Approximately 25% of all new Crohn’s disease cases and between 15 and 40% of all new ulcerative colitis cases are diagnosed in individuals younger than 20 years of age, making these illnesses an area of concern for practitioners

(Kim & Ferry, 2004; Rayhorn, 2001). It is said that IBD is among one of the most significant chronic illnesses affecting children and adolescents today (Leshem, 2003). This underscores the importance of understanding what it is like for these individuals to live with Crohn's disease and ulcerative colitis.

Childhood Chronic Illness

It is estimated that approximately 10 to 15% of children and adolescents have some type of chronic illness (Pless, Cripps, Davies, & Wadsworth, 1989; Suris, Michaud, & Viner, 2004). Leshem (2003) states that chronic illness generally disrupts the person's state and requires a shift in behavior, attitude and role expectation. Brydolf and Segesten (1996) describe the period of adolescence as a time of great fluctuation in the biologic, psychological and social realms along with role changes within the family and group of friends. All of these changes and disruptions, compounded by the onset of a chronic illness, can sometimes lead to an overwhelming experience and transition throughout adolescence (Decker, 2000).

In attempting to address the impact of chronic illness on adolescents and young adults, some research has been conducted evaluating their psychological and psychosocial functioning.

Psychological and Psychosocial Effects of Chronic Illness

When researching psychological well-being among adolescents with chronic illnesses, findings have been conflicting. Wood et al. (1987) studied psychological functioning in children with Crohn's disease and ulcerative colitis and found that children with IBD have greater psychological dysfunction than the normal population. Findings revealed that level of psychological functioning was not associated with disease severity,

duration or activity. The style of psychological functioning or the way in which psychological problems were expressed, however, was associated with disease activity. Others (Mackner & Crandall, 2006; Mackner, Crandall, & Szigethy, 2006; Mackner, Sisson, & Crandall, 2004) support this finding by saying that disease severity has not been consistently associated with behavioural and emotional symptoms. Research in other pediatric chronic illnesses has shown factors such as family functioning, stress and coping strategies are more predictive of behavioural and emotional functioning than illness factors (Mackner et al., 2006). This underscores the importance of examining other risk factors that could contribute to poor adjustment (Mackner et al. 2004).

An analysis of 87 studies of the psychosocial adjustment to pediatric physical disorders in children concluded that those with physical disabilities were at increased risk for the development of psychological adjustment problems such as anxiety, depression and social withdrawal (Lavigne & Faier-Routman, 1992). Seigel, Golden, Gough, Lashley, and Sacker (1990) studied a low socioeconomic status adolescent population with sickle cell disease, asthma and diabetes and found that these adolescents had a higher rate of depression and lower self-esteem score than their healthy counterparts. They speculate that their findings reflect the notion that perhaps individuals from low socioeconomic status do not have adequate resources available or do not have access to these resources, and therefore experience increased psychological maladjustment. Wolman, Resnick, Harris, and Blum (1994) studied whether adolescents with and without chronic conditions differed in emotional well-being, worries, concerns and body image. Findings revealed that those with chronic conditions had lower feelings of emotional well-being, worried more about dying, school, future work, and had a poorer body image.

In contrast, other studies revealed that chronically ill adolescents did not experience increased psychological difficulties. Pless et al. (1989) conducted a longitudinal study, which consisted of 5362 children with chronic physical disorders. Findings revealed that the prognosis for these children was remarkably good. They were shown to have similar chances of marriage and of becoming parents as their healthy counterparts. Jacobson et al. (1997) studied psychological adjustment in children and adolescents with insulin dependent diabetes and found that overall, they appeared to be as psychologically well adjusted as those without a chronic illness. A study by Suris, Parera, and Puig (1996) on chronic illness and emotional distress in adolescence revealed that females with chronic conditions were more likely to experience emotional problems than their ill counterparts, although this did not appear to be true for the males. Finally, Mackner and Crandall (2005) concluded that children with IBD report normal psychosocial functioning similar to that of healthy children. It must be mentioned however that the children had mild IBD and all had been diagnosed for at least a year.

The literature search for this section revealed conflicting findings for the effects of chronic illness on adolescence. All of these studies were of quantitative methodology and most were cross sectional studies using varying sample sizes. Longitudinal research that would allow follow up with adolescents over time is needed to understand the long term impact chronic illness has on psychological and psychosocial functioning.

Relationships and Social Issues

Developmental issues associated with adolescence are often magnified when the adolescent has a chronic illness, in particular social acceptance. This may be exacerbated for adolescents with a chronic illness who unwillingly spend greater amounts of time

away from their peers (Boice, 1998). It is during the adolescent years that peer relationships become increasingly important. More time is usually spent with peers than with the parents as the adolescent struggles to find autonomy and independence (Petersen & Hamburg, 1986). One of the best ways for the adolescent to find his/her independence is to engage with and depend on his/her peers. Peers provide the adolescent with the support needed to find their independence (Suris et al., 2004). However, the adolescent with a chronic illness may at times find it difficult to establish and maintain successful relationships with friends. Rechner (1990) found all but one of the adolescents interviewed in her study perceived changes in their friendships. Most attributed these changes to their illness and the demands it asked of them. Zeltzer, Kellerman, Ellenberg, Dash, and Rigler (1980) found similar results in that some of the adolescents expressed the illness disrupted not only their lives in general, but their relationships with friends and family.

Although evidence suggests that some adolescents with a chronic illness have greater difficulty developing normal peer relationships, many studies have found the contrary. Noll et al. (2000) found that many young individuals with chronic illnesses report having excellent peer relationships. Cappelli et al. (1989) studied adolescents with cystic fibrosis and diabetes and found that overall they perceived themselves as having social competency and being in control of their lives. Noll et al. (1999) studied children with cancer and found they had no difficulties with social functioning. In fact, they scored higher than their healthy counterparts and fared similarly with regards to emotional well-being. Adolescence can be a difficult time at best, and those with chronic

illnesses may face even greater challenges. It is therefore important to provide them with the support needed to develop relationships that are meaningful to them.

The extent to which an adolescent will experience social adjustment issues varies with the stability and predictability of the illness, and can also be influenced by family factors such as stress and support (Daniels, Moos, Billings, & Miller, 1987; Eiser, 1990; McAnarney, 1985). Wolman et al. (1994) looked at family connectedness as a measure of emotional well-being and investigated whether adolescents with chronic conditions and those without differed on several psychological measures. They reported that higher emotional well-being scores were significantly related to higher levels of family connectedness. Hamlett, Pellegrini, and Katz (1992) studied the impact of family functioning on chronic illness and found that the psychological adjustment of the child with chronic illness improved with higher family functioning and was adversely affected by maternal perception of decreased social support. The adolescent may place importance on becoming his/her own person and finding his/her individuality, however, having a family support system in place and feeling a sense of belonging is indispensable to his/her emotional well-being. Evaluating the family structure, looking at the nature of their relationships and their ability to adapt is important in order to facilitate healthy adjustment (Geist, Grdisa, & Otley, 2003).

The focus of much of the research on childhood and adolescent chronic illness has been on the investigation of psychological and psychosocial adjustment. Although important and of value, much of this research has been conducted through quantitative methodology (Woodgate, 1998). These measures are often not equipped to capture feelings, thoughts, perspectives and the meanings these individuals ascribe to their

experiences. Qualitative research such as phenomenology is designed specifically to capture these thoughts and feelings. Researchers are becoming increasingly aware the importance qualitative research has in extrapolating and understanding these lived experiences (Woodgate, 1998).

Adolescents and Young Adults Living with IBD

A review of the literature has revealed limited available research on the lived experiences of adolescents and young adults living with IBD (Daniel, 2001; Decker, 2000). Daniel (2001) discusses how most of the research available focuses on specific issues such as coping behaviors, emotional responses, and psychosocial distress rather than on the lived experiences. Most of these studies use quantitative methodology and have been derived using various methods such as surveys, questionnaires and structured interviews, thus making it difficult to understand their perspectives and interpretation of their experiences. Mackner et al. (2004) echo these critiques by also adding that many of the studies on children with IBD employ small sample sizes, utilize unpublished measures, and are characterized by poor methodology. The following is a review of the literature on adolescents and young adults living with IBD. Studies of quantitative and qualitative methodology have both been reviewed.

Emotional Effects of Living with IBD

A number of studies have documented the emotional effects living with IBD can have on an individual (Brydolf & Segesten, 1996; Daniel, 2001; Dudley-Brown, 1996; Engstrom, 1999; Kurina, Goldacre, Yeates, & Gill, 2001; Rayhorn, 2001). Daniel (2001) describes how the participants expressed feelings of shock and dread to relief and acceptance when told of their diagnosis. These responses were a result of each of their

beliefs and views of IBD. All the participants also expressed feelings of anger, depression, guilt, and self-blame when thinking about their chronic illness. These feelings surfaced when they realized that they would have this for the rest of their lives.

A common theme among some studies has been the expression of fear, embarrassment and humiliation when faced with the potential for or the actual experience of fecal incontinence (Brydolf & Segesten, 1996; Daniel, 2001; Dudley-Brown, 1996). Because IBD is an illness characterized by remissions and exacerbations, many studies have reported individuals having feelings of uncertainty (Dudley-Brown, 1996; Rayhorn, 2001). These feelings of uncertainty will often subsequently lead to a feeling of lack of control (Casati et al., 2000). All the individuals in Daniel (2001) mentioned how this loss of control over the illness and their bodily functions was a major source of concern.

A study by Kurina et al. (2001) found that individuals with IBD are at an increased risk, particularly within the first year of diagnosis, of depression or anxiety. These two co-morbid diagnoses were more common in individuals with CD, whereas anxiety was seen most often in those living with UC. Engstrom (1999) found similar results in children and adolescents with IBD where they observed this group to have a higher risk of psychiatric disorder such as depression and anxiety than the comparison groups of children with diabetes, chronic tension headaches and healthy children. Mackner and Crandall (2006) looked at anxiety and depression when studying adolescent psychosocial adjustment in IBD. Results indicated they were reported to have worse anxiety and depressive symptoms than their healthy counterparts. They do, however, mention that these symptoms did not reach clinical significance.

In contrast to these findings, Mackner and Crandall (2005) studied long-term psychosocial outcomes on children and adolescents with IBD and found normal psychosocial functioning similar to that of healthy cohorts. All of their participants were diagnosed with mild IBD and had been diagnosed for at least one year. It should be noted that many of the other studies that report increased risk of anxiety and/or depression either do not mention the severity of the illness or the time since diagnosis, both of which can have an impact on adjustment.

Physical Changes Associated with IBD

Adolescence and young adulthood is a time where body image is an important aspect of one's life. It is during this time that many physical changes take place, which can be a source of distress for some individuals. Those living with IBD often undergo additional physical changes related to treatment, surgery and medications. Several studies note how these changes have an impact on one's self-esteem and body image (Brown & Randle, 2005; Brydolf & Segesten, 1996; Casati et al., 2000; Daniel, 2001; Decker, 2000; Giese & Terrell, 1996; Junkin & Beitz, 2005; Rayhorn, 2001). Body image and personal appearance can often become a concern for these individuals at a time where this is considered to be of great importance. Failure of growth and sexual development are noted to be serious and common problems in adolescents with IBD (Ghosh, Drummond, & Ferguson, 1998; Rayhorn, 2001). Growth failure, retarded bone development and slowed sexual maturation may sometimes precede weight loss, leading to a delay in diagnosis (Rayhorn, 2001).

Individuals with IBD are often required to take medications for their illness in an effort to control symptoms (Rayhorn, 2001). Some of these medications' side effects can

often alter one's physical appearance, thereby causing concern for some individuals (Casati et al., 2000; Daniel, 2001; Giese & Terrell, 1996). These changes include rapid weight gain or loss, fluid retention, stunted growth, acne, and loss of energy (Brydolf & Segesten, 1996; Daniel, 2001; Decker, 2000). Studies have additionally noted that often these changes leave the individuals feeling "damaged" and different than their peers (Brydolf & Segesten, 1996; Daniel, 2001; Dudley-Brown, 1996). Casati et al. (2000) explain how, although the side effects are only temporary, the impact this can have on an individual, especially in a society that puts tremendous emphasis on attractiveness, can greatly affect one's body image.

Reduced Living Space

Living space has been described as "the sphere one acts within in one's daily life" (Brydolf & Segesten, 1996, p. 42). It includes routines, physical, social and cultural activities and can change during the different phases of one's life. Living space is also considered to be meaningful to the person. A common theme among some studies (Brydolf & Segesten, 1996; Daniel, 2001; Dudley-Brown, 1996) was the issue that most individuals felt their living space was reduced. They needed to know where the locations of the washrooms were at all times when out in public, which led to feelings of dependency. Several studies indicate how this dependency on being near washrooms is restricting to many individuals (Brydolf & Segesten, 1996; Carlsson, Berglund, & Nordgren, 2001; Daniel, 2001). This restriction will often limit one's social activities where some individuals no longer partake in sports, travel or even an activity as simple as going to the movies. Moody, Eaden, and Mayberry (1999) reported how the majority of

the children with CD were unable to participate in sports, leave their homes or play outside with their friends.

Relationships with Individuals and IBD

Having inflammatory bowel disease can have a profound effect on one's social and family life (Dudley-Brown, 1996). Because of disease symptoms and reduced living space, most individuals in Daniel's (2001) study felt they had fewer close interpersonal relationships, and that their social interactions were severely restricted compared to those who did not have IBD. They also described their personal relationships as stressful because they felt they could not discuss their illness socially. As a result, full disclosure to friends was often seen as a major obstacle to overcome. Moody et al. (1999) found that half of the children with Crohn's disease were unable to play with their friends because of their illness. Dudley-Brown's (1996) research further support these findings. All participants in this study spoke of a decreased social life and difficulty with work or school as a result of their illness.

A natural response by the family and particularly the parents of an adolescent diagnosed with IBD is to try and help and protect the individual (Decker, 2000). Being too protective may create barriers and prevent the normal movement towards independence, ultimately resulting sometimes in isolation (Decker, 2000; Rayhorn, 2001). This feeling of isolation can be further exacerbated by the physical implications of this disease. The unpredictable and embarrassing nature of the illness can often restrict one's social activities, thereby contributing to the feeling of isolation (Casati et al., 2000).

Chronic illness is also often associated with a changing pattern of role functioning, which requires adaptations by family members. The individual who is ill

often requires help in making lifestyle adjustments (Leshem, 2003). Northen (as cited in Leshem, 2003), found that planned groups are effective in helping patients and their families deal with the emotional and social stressors that usually accompany an illness. To maintain the functioning roles in the family, it has been recommended that the entire family be included in support groups and activities (Brydolf & Segesten, 1996). The major goals of these family support groups are to improve communication, to clarify role expectations, and to resolve problems in interpersonal relationships (Northen, as cited in Leshem, 2003). While some studies report that support groups for adolescents with IBD have been beneficial in helping to develop a personal sense of maturity and self-esteem (Brydolf & Segesten, 1996), others report that people with IBD cope well, are psychologically healthy and may not have a need for support groups at all (Joachim, 2002; Joachim & Milne, 1987; Kinash, Fisher, Lukie, & Carr, 1993). It therefore remains difficult to understand how to best provide support to individuals with IBD (Joachim, 2002). A systematic study of their social support needs is an essential first step to ensure they receive the proper care.

Stress and IBD

Several studies have focused on the relationship between stress and IBD. While there remains some speculation as to whether or not stress acts as an etiological factor, the focus of this section will be on how stress affects an individual with IBD. Daniel (2001) found that all of his participants mentioned stress as a major factor in their lives. Most felt the stress affected flare-ups and increased the severity of their symptoms. Dudley-Brown (2002) writes on how it is possible to influence the impact of the disease by preventing the psychological distress so commonly encountered. In order to try to

prevent the stress associated with IBD, it is important to identify risk factors. Dudley-Brown lists such risk factors such as symptom exacerbation, co-morbid psychiatric diagnosis (i.e., depression), uncertainty, lack of social support, and significant degree of social impairment. Symptom exacerbation is often accompanied by uncertainty due to the unpredictable nature of the disease. This has been noted to be of great stress for some individuals (Daniel, 2001; Dudley-Brown, 2002; Rayhorn, 2001). Having a co-morbid psychiatric diagnosis such as depression contributes to the complexity and management of the illness. As noted by Kurina et al. (2001), individuals with IBD are at increased risk of anxiety, which can ultimately lead to stress, and the cycle continues. Lack of information about the disease such as its etiological factors, course of the disease, and treatment are also noted to be risk factors for the development of psychological distress (Brydolf & Segesten, 1996; Daniel, 2001; Dudley-Brown, 2002; Mason, 2001). Because the etiology of IBD is still unknown, health care providers may not be able to provide all the answers to questions such as origin and course of disease, thereby further contributing to the uncertainty and stress for the individual.

In Daniel's (2001) study of young adults, it was expressed that they felt a need to manage their stress. Anxiety and stress play an important role in the ability to cope with symptoms, uncertainty and lack of information associated with IBD (Rayhorn, 2001). Results of Milne, Joachim, and Niedhart's (1986) study revealed stress management techniques might have a significant therapeutic benefit for individuals living with IBD. A stress management program resulted in reduced disease activity and improved psychological functioning in a significant number of patients. An understanding of the

risk factors associated with increased stress and ways to manage stress may help individuals adapt and cope with the uncertainty of the illness.

Adolescents and Young Adults with Ostomies

There can be several reasons why a person may require an ostomy, such as birth defects, injury, malignancy or illnesses like Crohn's and ulcerative colitis (Erwin-Toth, 1999; Kelman & Minkler, 1989; Martinsson, Josefsson, & Ek, 1991). Whether it be temporary or permanent, life saving or to improve quality of life, ostomy surgery is usually accompanied by psychological and psychosocial concerns and can have an impact on an individual's quality of life, body image and self-esteem (Black, 2004; Casati et al., 2000; Junkin & Beitz, 2005; Karadag et al., 2003; Kelman & Minkler, 1989; Nugent et al., 1999; O'Brien, 1999; Shipes, 1987).

Temporary Versus Permanent Ostomy

This literature review uncovered studies done on both temporary and permanent ostomies (Brown & Randle, 2005; Deeny & McCrea, 1991; Gooszen, Geelkerken, Herman, Lagaay, & Gooszen, 2000; Karadag et al., 2003; Manworren, 1996; Nessar et al., 2006; Nugent et al., 1999; Silva, Ratnayake, & Deen, 2003). Brown and Randle (2005) did a review of the literature on living with a stoma and found no conclusive findings. They did however indicate that, in the short term, most individuals experience negative feelings towards their ostomy. Nugent et al. (1999) looked at quality of life in individuals with permanent ostomies and found that many individuals cope extremely well with a stoma, whereas some have more difficulties. They attributed this to age and reason for the ostomy operation. They also suggested that perhaps, with proper preoperative counseling, some individuals might cope better in the long term. Karadag et

al. (2003) also studied individuals with permanent ostomies, and concluded that having an ileostomy or colostomy profoundly negatively impacts on quality of life. This impact resulted from the stoma related problems encountered on a daily basis.

Similar results were found in those who looked at individuals with temporary ostomies. Silva et al. (2003) concluded that individuals had a significantly impaired quality of life as a result of their temporary ileostomy or colostomy. Quality of life factors included the effect on ability to travel and exercise, and on hygiene and sexual relationships. Gooszen et al. (2000) indicated how stoma surgery has a great impact on an individual's daily life and routines. They found there was a clear relation between the number of stoma care problems and the degree of social restriction.

Body Image

As discussed earlier, adolescence is a time of discovery, achieving independence and becoming self-expressive. Having an ostomy may delay the attainment of independence, and bring the individual back to a more dependent state. The adolescent may, as a result, interact less with peers and subsequently develop low self-esteem, ultimately affecting body image (Shipes, 1987). It is well documented in the literature that a stoma will have an impact on body image (Black, 2004; Casati et al., 2000; Junkin & Beitz, 2005; Karadag et al., 2003; Nugent et al., 1999; O'Brien, 1999). Gradual physical changes in the body, as happens during adolescence, provide the individual time to adjust to their image. Abrupt changes such as those resulting from ostomy surgery do not allow the same leisurely adjustment. This can result in a distorted body image and may hinder proper adaptation (Shipes, 1987), whereas Beitz (1999) discusses how these changes can be threatening to the self. Some individuals report a sense of missing their

body part or feel some sort of alienation from their body. Feelings of being different, loss of wholeness, decreased self-respect and confidence are all common reactions (Beitz, 1999; Erwin-Toth, 1999; Persson & Hellstrom, 2002; Pieper & Mikols, 1996; Salter, 1992). Some participants in Beitz' (1999) study often used the third person when referring to their bodies and would described their ostomy as "it". Feelings of shame, fear, anger, disbelief, denial and grief are also all common emotions felt by adolescents who undergo an altered body image due to ostomy surgery (O'Brien, 1999; Shipes, 1987). These emotions will vary with the reason for the ostomy. If the ostomy is made to cure a disease such as UC, then, because of improved lifestyle and health, the ostomy may be viewed in a positive light.

In contrast, Lask et al. (1987) found no evidence that stoma surgery in childhood is psychologically harmful and found no evidence that depression or social isolation commonly occurred. O'Brien (1999) and Junkin and Beitz (2005) indicate how, for some, the ostomy is viewed positively. Many look forward to their surgery so they can once again feel better, healthier and have a chance at a normal lifestyle.

Seeking Control and Not Looking Back

Because of the uncontrollable symptoms that can accompany Crohn's disease and ulcerative colitis, research had shown that a number of individuals express a strong desire for a sense of control in their lives. Some of these individuals will find that sense of control with ostomy surgery. Beitz (1999) found that all participants commented on their desire for control while they suffered with UC. "In fact the desire for control of their bodily functions and the associated freedom from pain and urgency was the overriding impetus for surgery" (p. 191). Once adaptation from the surgery occurred, some of the

participants developed a new outlook and were not bothered by having the ostomy once they compared their life to what it used to be. Other researchers have found similar results when it came to how some individuals reacted to having the surgery. Because many afflicted with CD and UC are so ill, they actually look forward to their surgery so they can feel better and healthier (Motta, 1987; O'Brien, 1999). Many have expressed they wished they could have had the surgery sooner and that they would never want to return to their pre-stoma lifestyle (Carlsson et al., 2001; Lask et al., 1987).

Maintaining a Sense of Normalcy

As described earlier, several reactions occur when one undergoes ostomy surgery. These reactions range anywhere from shock to relief and embarrassment to acceptance. Salter (1992) described how some individuals had feelings of not being normal while they had the stoma. It made them feel repulsive and different from the others. This feeling is echoed in other studies as well (Erwin-Toth, 1999; Persson & Hellstrom, 2002). Maintaining a sense of normalcy in life is a key issue and expressed as being very important throughout childhood and adolescence (Erwin-Toth, 1999; Motta, 1987). Being perceived by themselves and by others as normal was important and was derived primarily from the behaviors of friends and siblings. As long as they fit in with their peers and could maintain day-to-day activities, they felt normal (Erwin-Toth, 1999; Motta, 1987). Some of the fears expressed by some teens were that their clothing choices would have to change or be limited (Gooszen et al., 2000; Motta, 1987; Salter, 1992). The perception was that they would feel different because their clothing was not like the rest of their friends. O'Brien (1999) describes how some adolescents may feel compelled to buy larger clothing to hide the stoma, but this may only exacerbate feelings of

alienation and inadequacy. Finding clothes that reflect the style and personality of the individual yet still conceal the stoma is very important in maintaining one's self-esteem and feelings of normalcy.

Leisure Activities/Travel/Work/School

Research has shown that most individuals report a reduction in leisure activities after having ostomy surgery. Studies by Salter (1992), Carlsson et al. (2001), and Thomas, Madden and Jehu (1987) found that most of the individuals had restricted their social and leisure activities significantly as a result of the stoma. Participants expressed that they missed the ability to participate in sports. They spent most of their leisure time doing relatively inactive activities such as reading, writing, walking and listening to music. In contrast, Martinsson et al. (1991) found that most of their participants reported no change at all in their leisure activities and that the surgery had had no effect whatsoever on their choice of activities and social or family life. For teens especially, the ability to participate in sports is important. Erwin-Toth (1999) describes how the inability to participate fully in school was a source of painful memory for most of the individuals. When it came to gym class, most were excused from participation even though only two had sufficient medical reasons to be banned from intense physical contact. All participants who had been banned from gym echoed feelings of anger, shame and depression. For those who were able to participate in gym class, they described this as a positive experience and the teachers were great at accommodating their needs. O'Brien (1999) suggests encouraging non-contact sports and involving the gym teachers and coaches as necessary in order to help maintain a sense of normalcy.

As children and adolescents enter school, care of the ostomy is very important and of great significance. Leakage, odors and frequent emptying of the pouch can be a source of embarrassment especially if classmates are merciless. Motta (1987) suggests alerting teachers to the presence of the ostomy but being careful not to single out the student for special attention.

When it comes to work related issues for young adults, Carlsson et al. (2001) found that most of their subjects felt incapable of working full-time because handling the stoma and other parts of their medical management amounted to at least a half-time job in itself. In contrast, Thomas et al. (1987) and Martinsson et al. (1991) found that the majority of their subjects were able to return to work without any difficulties. It was not mentioned, however, whether or not they were returning to full time work. In Carlsson et al.'s (2001) study, traveling, going to the movies and theatre was viewed as a great problem for all of the subjects. They missed being able to be spontaneous.

Sexuality

Talking about sex and sexuality is a very common subject among adolescents and young adults. Sexual relationships can be a source of stress for some individuals at the best of times. For the person with an ostomy, this stress can be quite exacerbated. Research has shown conflicting results as to whether or not sex has a negative impact on the individual and his or her self-esteem. A study by Kelly (1991) regarding individuals with ostomies revealed sexual relationships were a source of anxiety for some of the respondents and particularly for those who were not married or had no current partner. Erwin-Toth (1999) found however that all his adolescent participants reported lengthy relationships before beginning any sexual activity. This was based on the desire to know

and trust their partners before a sexual experience. All the participants felt their first sexual experiences were positive and gave them confidence for the future. None of the participants felt their ostomy was an issue in their sexual relationships as young adults. This was in part due to the fact that their partners were understanding, as is reflected in some of the literature (Black, 2004; Salter, 1992). Martinsson et al. (1991) found similar results in their study of individuals with ileostomies. Out of the 53 participants, 36 said the ileostomy had no effect at all on their sex life, 7 said there had been a positive change and 10 felt it had a negative effect on their sex life. It is important to note however that 38 out of the 53 participants were married.

Other studies revealed a negative impact on individuals (Black, 2004; Carlsson et al., 2001; Manderson, 2005; Nugent et al., 1999; Persson & Hellstrom, 2002; Salter, 1992). For women, embarrassment and feelings of insecurity related to the stoma is a common concern, whereas for men, impotence is most often revealed as a source of concern (Beitz, 1999; Carlsson et al., 2001; Deeny & McCrea, 1991). Some of the literature indicates that some partners have difficulty accepting the ostomy, and are therefore not supportive (Manderson, 2005). Support and understanding from the significant other has been most often revealed as very important in helping to alleviate the fear of intimacy (Carlsson et al., 2001; Deeny & McCrea, 1991; Junkin & Beitz, 2005; Nugent et al., 1999).

Support from Family and Friends

Responses to ostomy surgery are often dependent on a number of factors such as personality, previous experiences with illness, beliefs and views about their chronic illness, coping mechanisms, and their support networks (Daniel, 2001; Rheaume &

Gooding, 1991). Social support for an individual can vary from family and friends to professionals and support groups. It is believed each social support system can satisfy different needs for that individual, and therefore having several in place can help increase one's quality of life (Rheume & Gooding, 1991). For instance, Beitz (1999) reported that although the participants found their family and friends to be supportive, they thought they did not fully understand what it was they were going through. In this respect, support groups served as a way for them to obtain true understanding from other patients who knew and understood what they were going through. Carlsson et al. (2001) agree with the above notion that having that support in place is highly associated with quality of life. All of the participants in their study revealed that support is very important and were much appreciative of it.

Rheume and Gooding (1991) believe that people will generally appear to withstand stress better when they have a strong social system surrounding them. By having this social network, the individual may feel confident in trying to use a larger number of coping mechanisms because he or she has a support system ready to step in and help at any time if needed. Several studies document how individuals stress the importance of having support from family, friends or support groups (Bray & Sanders, 2006; Brown & Randle, 2005; Brydolf & Segesten, 1996; Carlsson et al., 2001; Erwin-Toth, 1999; Nugent et al., 1999; Rheume & Gooding, 1991; Salter, 1992). Erwin-Toth (1999), Salter (1992), O'Brien (1999) and Shipes (1987) found that participants expressed how their families and significant others' reaction and emotional support were influential in their adjustment to having ostomy surgery. Follick, Smith and Turk (1984) did a quantitative study on psychosocial adjustment following ostomy surgery and 18%

of the participants indicated that social support made no difference in their adjustment, 35% described it as helpful while 47% believed it was very helpful.

Support from health care professionals is also regarded as crucial for proper adaptation (Carlsson et al., 2001; Daniel, 2001; Notter & Burnard, 2005; Persson, Gustavsson, Hellstrom, Lappas, & Hulten, 2005; Persson & Larsson, 2005). Delivering holistic care such as fulfilling their psychological, psychosocial and physical needs is important. A trusting relationship, which meets each individual's needs and concerns, may help alleviate some fears (Junkin & Beitz, 2005). The literature also indicates how the relationship with the enterostomal nurse is very important (Marquis, Marrel, & Jambon, 2003; Persson & Larsson, 2005). Marquis et al. (2003) express how the quality of the relationship with the ET nurse can influence the quality of life of that individual.

Implications for Nursing Practice

A review of the literature suggests there are several areas that have implications for nursing practice. Keeping the individual informed throughout the illness trajectory is very important. From pre-diagnosis onwards, it is imperative that there be effective communication between the individual, the family and the health care professionals. Whether it be explaining tests and procedures or medication side effects, the literature demonstrates that individuals have a need to be properly informed. Education is also an important element in any surgical procedure and ostomy surgery is no exception. Patients need to be properly and thoroughly informed of what it is they can expect before, during and after the surgery. Technical issues, such as how to care for the ostomy, need to be explained along with the expected bodily changes and sensations. The impact the ostomy may have on body image must be realistically portrayed. They must be helped to

anticipate the need for prolonged adaptation and be provided with strategies for coping with this new adjustment (Beitz, 1999).

Identification of usual coping methods that are being used is important, and nurses need to be aware of how the patient is coping. An individual who is using ineffective coping mechanisms should be encouraged to use alternate coping strategies. These strategies may include introducing the patient to a style he or she does not ordinarily use (Rheaume & Gooding, 1991). Although coping mechanisms are very important to the rehabilitation of the individual, identifying what support systems are in place is crucial to his or her adjustment. Encouraging the individual to rely on his or her social network will help that individual become more confident in his or her abilities to handle stressful situations. Introducing the patient to organized social support groups is also encouraged because, as noted above, these groups tend to be formed by individuals who have gone through similar experiences, and can therefore relate to one another. Lask et al. (1987) and O'Brien (1999) suggest that individuals should have the opportunity to meet someone who has already gone through with the ostomy operation. Perhaps even someone their own age (Erwin-Toth, 1999; Manworren, 1996), as this opportunity will allow individuals to ask all of the questions that perhaps they may not want or feel comfortable asking the health care professionals.

Adolescents need to be involved in making their own decisions regarding their care and treatment (Brydolf & Segesten, 1996). Due to the lack of control some individuals may feel with IBD, allowing them the opportunity to be involved in some of the decision-making is important. Also, encouraging the individual to express his or her concerns and fears requires good communication skills. As we have seen in the literature,

many individuals may feel anger, embarrassment or grief over their illness or the fact that they may have an ostomy. Allowing them to express their feelings and assisting them to identify personal strengths will enable them to feel more confident and sure of themselves.

Due to the overwhelming emphasis society places on body image, adolescents and young adults undergoing ostomy surgery may feel insecure. Nurses must help to identify ways in which individuals can feel comfortable in their own skin. Focusing on the qualities that make that individual unique and special is important. Developing therapeutic relationships that foster open communication can help pave the way.

An issue that is of concern to many individuals and yet is often overlooked and not discussed is sexuality and what to expect after surgery. It is well documented in the literature that an area in which individuals have difficulty obtaining information from their health care professionals is sex (Black, 2004; Irvine, 2004; Persson et al., 2005). Few physicians and nurses bring the subject up spontaneously and, more often than not, individuals are embarrassed to ask any questions. Sexual counseling should be a part of the teaching sessions and should include spouses and significant others.

Although one might expect that individuals with temporary ostomies would cope better, this review indicates otherwise. It therefore underscores the importance of paying attention to the concerns of the individual undergoing surgery, whether it be temporary or permanent. Depending on the circumstances surrounding the ostomy surgery, hope for a better quality of life for patients and their families is an important message that should be relayed. This in turn may assist them in dealing and coping with the challenges that may lie ahead (Beitz, 1999).

Chapter Summary

This literature review demonstrates that there is a limited body of literature regarding adolescents and young adults living with IBD and ostomies. A little more than half the studies reviewed were of a quantitative nature with the remaining being of qualitative design. Although some of the qualitative studies reviewed used phenomenology as the method of choice, their focus was not on the lived experiences of adolescents and young adults. It therefore appears there is a lack of studies focusing on the subjective and lived experiences of this population, the meanings they subscribe to their experiences, and how to best understand their world. It is therefore important to understand what it is these individuals experience in order to help them cope and develop positive self-images of themselves. It is also important to understand their lived experiences so that nurses are able to provide the proper care needed. This literature review provided support for a study examining the lived experiences of adolescents and young adults living with IBD and an ostomy.

Chapter Three: Methodology and Method

Chapter Three describes the methodology and method of the research study. The methodology section introduces the reader to two philosophical traditions, and the method section will discuss research design, data collection methods, and analysis. Methodological rigor and ethical considerations are also addressed.

Methodology

This section introduces the reader to the Husserlian and the hermeneutic-phenomenologic traditions. It also describes hermeneutic phenomenology and the reasons why it was chosen as the methodology to explore the lived experiences of adolescents and young adults living with IBD and an ostomy.

The Husserlian Tradition

Phenomenology became the methodology elaborated by Edmund Husserl (1859-1938) (Koch, 1995), also referred to as the father of phenomenology (Morse, 1994). Phenomenology is considered to be first and foremost a philosophy, however, Husserl considered it to be not only a philosophy, but an approach and a method as well (Morse, 1994). Husserl's approach to phenomenology is epistemologic and its goal is to describe and clarify experiences as they are lived (Morse, 1994). His philosophy emphasizes descriptions of the meaning of human experience (Polit, Tatano Beck, & Hungler, 2001). It attempts to gain insightful descriptions of the way we experience the world. It asks "What is that experience like?" (van Manen, 1990). Husserl envisioned phenomenology to be a process whereby describing the lived experience would take into account three essential notions: intentionality, essences, and phenomenological reduction, otherwise known as bracketing (Koch, 1995).

Intentionality. According to Husserl's theory of intentionality, awareness is being aware of an object or directedness towards an object (Morse, 1994; Paley, 1997). Object is used as a generic term referring to things in the external world such as facts, dreams, concepts or anything that presents itself to the consciousness (Paley, 1997). "In phenomenology all experience involves an object of thought, and all thought involves experience. Thus intentionality is the direction of the mind towards an object which, even if it does not exist, is accorded the status of existence." (Rose, Beeby, & Parker, 1995, p. 1125). The researcher must then look at the phenomenon with all knowledge held at bay (Oiler, 1981).

Essences. Essences represent the basic units of common understanding of any phenomenon under investigation and identify what an experience means to the person in question (Streubert & Carpenter, 1999). One of Husserl's goals for phenomenology was that it be a descriptive psychology describing the essences that constitute the consciousness of the life world (Paley, 1997).

Bracketing. Husserl believed that in order to achieve description in its purest form, one must practice phenomenological reduction through bracketing (Speziale & Carpenter, 2007). Bracketing begins with suspension of beliefs, preconceived ideas, assumptions and biases about the phenomenon under study (Speziale & Carpenter, 2007). Husserl believed the only way to really see the world is to remain as free as possible from preconceived ideas. Essentially, the researcher must set aside all previous knowledge or beliefs about the phenomenon in order to prevent it from interfering with the recovery of the true meaning of the phenomenon (Speziale & Carpenter, 2007). This notion of

objectivity has come under criticism in other phenomenological works such as those of Heidegger.

Hermeneutical Phenomenology

Phenomenology was reinterpreted as hermeneutical or interpretive phenomenology by Heidegger (1889-1976), a student of Husserl. Whereas Husserlian phenomenology tries to describe essences, hermeneutic phenomenology is designed to uncover and understand otherwise concealed meanings in the phenomena (Spiegelberg as cited in Streubert & Carpenter, 1999). “A phenomenological-hermeneutic approach is essentially a philosophy of the nature of understanding a particular phenomenon and the scientific interpretation of phenomena appearing in text or written word” (Speziale & Carpenter, 2007, p. 88). Heidegger claims we cannot have a world except through acts of interpretation. Phenomenology offers the possibility of thoughts and insights that bring us closer and in more direct contact with the world (van Manen, 1990).

Heidegger tries to search for the meaning of ‘Being’ (Morse, 1994). ‘Being’ refers to the self-manifesting of entities and collective beings (or humanity); it is ‘Dasein’, the world in which entities can manifest themselves (Morse, 1994). Phenomenology is the study of the lifeworld, the world as individuals immediately experience it. It is a human science, since the subject matter is the structures of meaning of the human lived world (van Manen, 1990). Heidegger emphasized that humans are inseparable from the world, they are a unity, and that humans understand the world through their existence within it (Morse, 1994). He believes that beings were constructed by the world in which they lived and, at the same time, constructed the world by their own background and experiences

(Koch, 1995). Understanding occurs because humans are born into the world. It is no longer a way of knowing but a mode of being (Koch, 1995).

One of the central distinctions between Husserlian and Heideggerian approaches is that Heidegger does not believe in suspending or bracketing preconceived notions. These biases are what constitute the possibility of meaning, of truly understanding the lived experience (Morse, 1994). Human beings always come to a situation with a pre-understanding; these are within our common background (Koch, 1995). “Pre-understanding is a structure of our ‘being-in-the-world’. It is not something we can eliminate, or bracket, it is already with us in the world.” (p. 831) The hermeneutic circle, which includes the notions of background, pre-understanding and co-constitution, has the premise that all understanding is circular because all interpretation must itself be based on a prior understanding, which, in turn is meant to help interpret the phenomena under study (Koch, 1995). Heidegger believes the circle cannot be avoided; the researcher must bring forth presuppositions in order to truly understand the phenomenon (Koch, 1995).

Method

This section details the research design that was utilized to obtain information-rich data, study samples, settings, data collection methods and data analysis. Ethical issues considered throughout the research study as well as methodological rigor will be addressed.

Research Design

A qualitative research design was ensued to elicit detailed descriptions of the lived experiences of adolescents and young adults living with IBD and an ostomy. Qualitative research, particularly phenomenology, is warranted when little is known

about a phenomenon. This method is useful in gaining an understanding of life experiences and what it is like being in that world (van Manen, 1990). The emphasis of this study was the exploration of their experience as they see it in their world.

The work of van Manen (1990) was used as a guide for data collection, analysis and interpretation of this study. The six methodological themes within van Manen's approach were used to structure the research process:

1. Turning to a phenomenon which seriously interests us and commits us to the world

This was accomplished by doing a literature review and by recruiting participants.

2. Investigating experiences as we live it rather than as we conceptualize it

Van Manen (1990) suggests utilizing in-depth interviews as a way to explore the deeper understanding of the phenomenon. The process of conducting one to two interviews was anticipated for this study. Close observation, being attentive to the participant's body language and writing these descriptions down was done as a way to generate different forms of data and material (van Manen, 1990).

3. Reflecting on the essential themes which characterize the phenomenon

"The purpose of phenomenological reflection is to try to grasp the essential meaning of something" (van Manen, 1990, p. 77). This was accomplished by conducting thematic analysis.

4. Describing the phenomenon through the art of writing and rewriting

Writing and rewriting is the very activity of doing phenomenology (van Manen, 1990). Achieving an understanding of the phenomenon was accomplished by interpreting emerging themes and by writing and rewriting these themes.

5. Maintaining a strong and oriented pedagogical relation to the phenomenon

The researcher was required to remain strong in his or her orientation to the fundamental question, which initially guided the study (van Manen, 1990). The researcher regularly referred to the research questions and purpose throughout the research process.

6. Balancing the research context by considering parts and the whole

It is important to step back and take a look at the overall text, the contextual givens and see how each of the parts plays a role in describing the phenomenon (van Manen, 1990). Analysis of the themes to determine what each narrative revealed was accomplished.

Sample Recruitment and Access

The criteria for sample selection, size and recruitment along with the process for participant access are described in the following sections.

Criteria for Sample Selection

In phenomenological research, studies are designed to describe the essence of a given experience, and therefore participants who live or have lived the phenomenon in question are considered the only legitimate source of data (Baker, Wuest, & Stern, 1992). They are selected for the purpose of describing an experience in which they have been a part of. It is because of this that phenomenologists most commonly use purposive sampling (Speziale & Carpenter, 2007), and the sample size is deliberately kept small (Baker et al., 1992). Selection sample for this study focused on adolescents and young adults who lived with IBD and had an ostomy as a result. The participants in this study met the following criteria: (a) were between the ages of 18 and 24, (b) were able to speak,

read and write English, (c) each had been diagnosed with IBD, (d) each had an operation for an ostomy, and (f) all had a willingness to reflect on and communicate their lived experience.

Sample Size

In keeping with phenomenological inquiry, sample size was kept small with the aim of elucidating the richness of the individual experience (Baker et al., 1992). There were a total of six participants for this study. Data were collected until the researcher found repetition and confirmation of previously collected data.

Participant Access

Participant access was sought through the St-Boniface General Hospital Research Review Committee (RRC). An application requesting permission to access young adults living with IBD and an ostomy was sent to the committee. The Research Review Committee granted permission to access these participants for the study. Please refer to Appendices A and B for a copy of the RRC provisional approval (dated June 9, 2006) and official approval (dated October 17, 2006).

Sample recruitment. Participants were recruited with the assistance of two enterostomal therapy nurses who both work out of St-Boniface General Hospital. The researcher met and provided general information about the study to the nurses via personal letters (Appendix C). The study purpose and design was described and questions were then answered (Appendix D). After ensuring that the nurses had a clear understanding of the eligibility criteria, they were asked to act as intermediary and mail potential participants a recruitment letter (Appendix E). A reply form was included with the recruitment letter, and potential participants were asked to notify the researcher of

their interest in learning more about the study by returning this form (Appendix F).

After five participants indicated their interest in partaking in this study, an attempt to recruit more potential participants was made by mailing the recruitment letter one more time. There were no replies from other potential participants the second time around. The researcher then asked each of the five participants if they knew of anyone who met the eligibility criteria. They were asked to have those potential participants contact the researcher. One more participant contacted the researcher, for a total of six participants.

Once the researcher received the reply forms, the potential participants were contacted by telephone. The initial telephone call was to describe the study in greater detail and explore their willingness to participate (Appendix G). All participants who were contacted agreed to participate in the study. All were informed of their right to withdraw from the study at any point, refuse to answer any questions, or end the interview at any point. An in person meeting was then arranged for the interview.

Data Collection Methods

Data collection methods included having each participant fill out a demographic form, utilizing the semi-structured interview technique and taking field notes throughout the interview process.

Demographic Form

Each participant filled out a demographic form prior to the interview (Appendix H). The researcher and her supervisor developed this form for this particular study. The demographic form provided useful information, which allowed the researcher to have some description of each participant.

Semi-Structured Interviews

In phenomenology, the main source of data is in-depth conversations. It is through these conversations that the researcher strives to gain full access into the participants' world and their lived experiences (Polit et al., 2001). The researcher helps the participant describe these lived experiences without leading the discussion (Polit et al., 2001; Streubert & Carpenter, 1999). This was achieved by using semi-structured and open-ended interviews (Appendix I) thereby allowing them to explore and describe their emotions, reflections, memories and descriptions of what it is like living with IBD and an ostomy.

These interviews took place in a setting of choice by the participant. They were asked to participate in two interviews all the while knowing that they could decline at any time. All participants agreed to a second interview. This interview allowed them to expand on their thoughts and ideas and to add anything they felt the researcher should know. This follow-up interview also provided the opportunity for the researcher to clarify any information previously given. The length of the first interviews lasted from 30 minutes to 150 minutes with a total of 455 minutes for six participants. The second interviews lasted from 30 minutes to 75 minutes with a total of 290 minutes for all six. The total length of time for both interviews combined was 745 minutes.

All interviews were audio taped in order to preserve its authenticity and facilitate data analysis. After signing a pledge of confidentiality form, a transcriptionist transcribed all interviews. Throughout the interviews, care was taken to ensure the equipment was functioning properly by regularly checking it. Spare batteries and tapes were always kept readily available. Despite these best efforts, one 15 minute segment was not audio taped.

Field notes were taken immediately following the interview in order to capture the main elements of what the participant had said. The participant agreed to redo that segment during the second interview.

Field Notes

Field notes were used as a third data collection method and were taken throughout the research study. Notes were used to record the setting, nonverbal cues from participants, any interruption that occurred, and any thoughts the researcher had. In phenomenological research, the researcher must identify any preconceived notions about the phenomenon under investigation. He or she must set aside all personal beliefs or previous knowledge about the phenomenon to prevent this information from interfering with the collection of a pure description; this is called bracketing (Streubert & Carpenter, 1999). However, in using van Manen (1990) as a guide, and in keeping the philosophical underpinnings of Heidegger, the researcher wrote down all personal biases and beliefs. The researcher came to terms with these assumptions, and held them at bay in order to facilitate the understanding of the participants' lived experiences (van Manen, 1990). Field notes were made subsequent to each interview. Regular meetings were held with the researcher's thesis supervisor to discuss issues pertinent to the study.

Research Setting

Interviews were conducted at a time and place convenient for each participant. This was done in order to help them feel more comfortable throughout the interview process. For the first and second interviews, four participants were interviewed in their own home, one chose to be interviewed at the researcher's home, and one was interviewed over the telephone.

Data Analysis

According to Speziale & Carpenter (2007), data analysis begins simultaneously with data collection. The moment participants began describing their experiences, analysis occurred. The meaning of the phenomenon is uncovered by analyzing these lived experiences (Woodgate, 2000). Analysis also requires the researcher to become immersed in the data (Speziale & Carpenter, 2007). Each interview was listened to immediately after the interview and after transcription in order to support the immersion process.

Analysis for this study was guided by the procedures outlined in van Manen (1990). This process included uncovering thematic aspects, isolating thematic statements, and composing linguistic transformations. Thematic aspects were discovered by repeatedly reviewing the transcripts in an attempt to find significant statements and understand the meanings of the experiences. Van Manen's selective highlight approach was used to isolate thematic statements. Here, phrases and sentence clusters that stood out as essential or revealing about the lived experiences were highlighted. These highlighted phrases and sentence clusters were studied until essential themes that represented these experiences began to emerge. Linguistic transformation was used to capture the essence of the themes. This occurred by writing and re-writing paragraphs until an interpretation of the essential themes developed. The end result was to describe and interpret the possible experience of adolescents and young adults living with IBD and an ostomy (van Manen, 1990). This description and interpretation, co-created by the researcher and thesis supervisor, resulted in the development of the essence and themes of this study.

Methodological Rigor

Rigor in qualitative research is demonstrated by the ability of the researcher to confirm information discovery. The goal is to accurately represent the lived experiences of each participant (Streubert & Carpenter, 1999). Just as there is a need to look at the accuracy and trustworthiness of quantitative data, there is also a need to look at qualitative data to ensure the quality of the finding (Krefting, 1991). Guba (1981) proposed a model for qualitative research to ensure rigor and to assess the trustworthiness of qualitative data. This model is based on four aspects of trustworthiness: credibility, transferability, dependability and confirmability (Lincoln & Guba 1985).

Credibility

Credibility is the process whereby the researcher assures the study findings are meaningful and reflect accurately the experience described by the participants (Lincoln & Guba, 1985). One way to establish credibility is through prolonged engagement with the phenomenon (Guba, 1981). Data collection took place over two interviews, with the first interview lasting between 30 and 150 minutes, and the second between 30 and 75 minutes.

Demonstrating that the findings and interpretations of the lived experiences reflect accurately their descriptions is also a way to confirm credibility (Lincoln & Guba, 1985). Participants were asked during and immediately following the interview if the researcher's interpretation was accurate and reflective of what they perceived their experience to be. The follow-up interviews also served as a way to clarify and validate the findings.

One other way to establish credibility is through peer review and debriefing (Guba, 1981). The researcher met on a regular basis with her thesis advisor to discuss findings and interpretations. Together, they developed an interpretation of the essence of the adolescents' and young adults' lived experience.

Transferability

Transferability refers to whether the findings of a particular study can be transferred to another similar situation and still preserve its meanings and particular interpretations (Morse, 1994). The expectation for determining whether the findings are transferable rests with the users and readers of the study, not with the researcher (Guba, 1981). The researcher needs to present sufficient descriptive data in order to accomplish this (Krefting, 1991). This was addressed by providing detailed descriptions of the interviews, processes and methods used by the researcher.

Dependability

Dependability is demonstrated when there is evidence of stability of data (Guba, 1981). However, variability is expected in qualitative data; it emphasizes the uniqueness of the human experience. Therefore, to ensure dependability of qualitative data, the variability needs to be tracked to identified sources (Krefting, 1991). The establishment of an audit trail was done to support the dependability of this study. This audit trail included documentation in the form of field notes, analytical decisions and personal reflections.

Confirmability

Confirmability is concerned with demonstrating that the findings are derived from the data and not from the researcher's personal thoughts and reflections (Guba, 1981). It

means obtaining affirmation that what the researcher has heard or seen is directly from the phenomena under study (Morse, 1994). This was achieved by validating findings with participants during and following the interviews, transcribing the interviews using exact quotes, and using a journal to express the researcher's own biases and personal thoughts.

Ethical Considerations

Permission to conduct this study was obtained from the researcher's thesis committee, the University of Manitoba, Education/Nursing Research Ethics Board (ENREB) and the St-Boniface General Hospital RRC. A certificate of ethical approval was received from the ENREB. Please refer to Appendix J for a copy of the certificate (dated June 19, 2006). The RRC provided access to participants. Please refer to Appendices A and B for a copy of RRC provisional approval (dated June 9, 2006) and official approval (dated October 17, 2006).

The researcher did not know the names of potential participants until they made the initial contact. Having an intermediary mail the recruitment letters on the researcher's behalf ensured this confidentiality. Once the desire to participate in the study was determined, written consent was obtained from each participant (Appendix K). Process informed consent, an appropriate method for the conduct of qualitative research, was ensued (Speziale & Carpenter, 2007). This required the researcher to periodically re-evaluate the participants' consent to participate. It was also discussed prior to every interview that this was voluntary and that withdrawal from the study was allowed at any time throughout the process. Participants were also given the opportunity to refuse a second interview. Interviews occurred at a time and place convenient for each participant.

The risk inherent in participating in a study of this nature is that one may recall

painful or disturbing memories. Caution and sensitivity were exercised when interacting with participants in order to prevent the possibility of undue stress. All known risks and benefits were discussed prior to every interview. If participants experienced signs of increased stress, the interview was stopped in order to allow the participant to compose him/herself. As much time as needed was given and the interview only resumed when the participant felt comfortable to do so. Although referrals to Social Work at the St-Boniface General Hospital were offered, none were needed.

Although the interviews are designed to reveal and describe detailed descriptions of their lived experience, every effort was made to ensure anonymity and confidentiality. While the names of participants were known in order to secure their written informed consent, no names were attached to any of the data collection methods (e.g., Demographic Form, transcripts of the interviews, field notes). Only the researcher had access to the participants' names. The transcriptionist and researcher were the only ones who listened to the audiotapes. The thesis supervisor, the researcher and the transcriptionist were the only ones who read the transcribed data. Code numbers were used on all sources of data. Two separate lists, one with the participants' names and the other with participants' code numbers were kept in separate files, locked in a cabinet in the researcher's home. No reference to either the specific geographic study location or to hospital names will be provided in any future publication of the study. As well, all participants will be assigned a pseudonym and any identifying information will be altered. The data will be confidentially destroyed 7 years after the completion of the study.

Chapter Summary

This hermeneutic phenomenological study was designed to gain an understanding of what it is like for adolescents and young adults to live with IBD and an ostomy. Data were gathered through semi-structured interviews, demographic questionnaires and field notes. Analysis was guided by van Manen's (1990) approach. The establishment of methodological rigor and ethical considerations was considered and described.

Chapter Four: Findings

Introduction

In Chapter Four, the findings of this phenomenological study are presented. The chapter begins with a portrayal of the participants, and is then followed by a description of the essence of the adolescents' and young adults' lived experience of living with IBD and an ostomy. Three themes supporting this essence are then also described. Data analysis revealed the essence to be "Concealing and Revealing the Self." The three themes that emerged from the interviews were: (a) Uneasy feelings, (b) "It's hard...", and (c) A renewed sense of self. The chapter concludes with a discussion of the adolescents' and young adults' needs, and finally, with their recommendations for health care professionals.

Description of the Participants

There were a total of 6 participants in this study with 5 being female and 1 male. All of the participants had been diagnosed with ulcerative colitis. At the time of the interviews, the age range of the participants was from 19 to 24 with a mean average age of 21. The mean time since diagnosis was 8 years with a range of 3 to 13 years, and the mean time since having the ostomy was 3 years with a range from 1 to 8 years. All of the participants had had an operation for a temporary ostomy. At the time of the interviews, 5 had a reversal (pelvic pouch procedure) and 1 of the participants still had an ostomy. All of the participants were Caucasian and 5 of them were living in the city with 1 living outside of the province. One participant attended university. All participants either worked full time or part-time. None of the participants was married, one was engaged to be married and another had been in a relationship for 6 months. The other participants

were not in a relationship at the time of the interviews. Four of the participants were living at home with their parent(s) and sibling(s), one was living with her fiancé, and the other was living with three other roommates. None of them had any children. Table 1 presents a summary of the participant demographics.

Table 1

Participant Demographics

Characteristic	Number (%)
Sex	
Female	5 (83%)
Male	1 (17%)
Diagnosis	
Ulcerative colitis	6 (100%)
Crohn's Disease	0 (0%)
Average age (years)	21 (19-24)
Mean time since diagnosis (years)	8 (3-13)
Mean time since ostomy (years)	3 (1-8)
Ostomy	
Temporary	6 (100%)
Permanent	0 (0%)
Ethnic background	
Caucasian	6 (100%)
Living areas	
Urban	5 (83%)
Out of province	1 (17%)
University/Working life	
University	1 (17%)
Work full time	3 (50%)
Work part time	3 (50%)
Relationships	
Married	0 (100%)
Engaged	1 (16.5%)
Committed	1 (16.5%)
None	4 (67%)
Living arrangements	
Family	4 (67%)
Significant other	1 (16.5%)
Roommates	1 (16.5%)

Main Findings

The essence of the adolescents' and young adults' lived experience and the themes that communicate the meaning of this essence are presented in the next section.

The following research questions will address the essence and themes of this study:

1. What meanings do adolescents and young adults assign to the experience of having inflammatory bowel disease with an ostomy?
2. What effect does having inflammatory bowel disease and an ostomy have on the lives of adolescents and young adults?

The Essence of Adolescents' and Young Adults' Lived Experience: Concealing and Revealing the Self

The essence of the lived experience of the adolescents and young adults in this study is described as "Concealing and Revealing the Self." This was evident throughout the illness trajectory from the time when participants first experienced their symptoms, to when they had to adjust to life with an ostomy. Their sense of self was affected by the symptoms of the illness and by their changing bodies. That is, when they were experiencing their symptoms, which to them were perceived as embarrassing, the participants initially chose to not disclose this to family or friends. This concealment was a way for them to hide from what was really happening, thus concealing their true self. The medication side effects and the temporary ostomy changed their bodily appearance, which in turn affected their sense of self. All were embarrassed of their new body image and all had wished they did not have to take medication. It was when they were no longer having the side effects did they feel better and more like themselves. Concealing the ostomy was also important to them. This concealment prevented them from revealing

who they really were as individuals and from developing a true sense of confidence.

They were not yet comfortable in their own skin and therefore not ready to reveal whom it was they really were.

Eventually, the participants came to terms with their illness and subsequently their temporary ostomy. Part of this was because they felt better and healthier, and part of it was because they knew the ostomy was temporary. Their bodies would eventually return to “normal” once they would have the pelvic pouch procedure. They began to feel more comfortable with themselves which, in turn, allowed their true sense of self to shine through. They were able to accept it and move on with living their life.

Concealing the symptoms. Initially, some of the participants hid the symptoms from their parents because they never thought the symptoms were anything to be worried about, others were scared of what the symptoms might mean, and some hid the symptoms because they were embarrassed due to the nature of the symptoms.

They started like early into, they started before that but I never, I never thought of it as anything and I never told my parents. (P3, age 19, female)

Like just like, um, at first probably minor symptoms like looser bowel movements and things like that. And, um, gradually I started noticing, uh, like blood in my stool. Um. And I was at first really like scared. It didn't, it was like very, very frightening for me. So, um, I didn't know like what was going on. And so I didn't even tell my parents at first. I kind of kept it a secret for probably about like a month before, yea. Um. Before I, I told them anything. (P5, age 22, female)

I, I think I just, mm, I don't know. I think because I was hoping that it would just go away on its own because it is an embarrassing topic. So I don't, I didn't really want to be like, “hey, dad, I'm sick but what's up?”, I don't know. So, yea, I think I just, I wanted it to go away on its own or, you know, it'll get better by itself kind of thing. (P2, age 21, female)

One participant described how she did not want to deal with the symptoms. It was her way to avoid dealing with her present life situation. She had the feeling that

something was not right, yet, at the time, she chose to ignore it and not deal with it.

This in turn meant concealing who she really was, because these symptoms were now a part of her and her life.

I think that with the symptoms before I was diagnosed and hiding those, I think that that was maybe a way of me trying to just not deal with the situation and not wanting to accept it. Um. Because I was so scared of what it might mean. But I think that, and so that was just me not wanting to deal with it. (P5, age 22, female)

Once the participants were diagnosed and knew they had ulcerative colitis, some of them wanted to initially hide their illness from their friends. Some felt there was a stigma attached to the illness and therefore felt more comfortable not talking about it to others. The symptoms within the context of a diagnosis of an illness and the pressure society places on individuals to be “perfect” affected their sense of self. They did not feel comfortable enough to disclose what it was they were going through at that time.

Um. I don't, yea, not a lot of people knew. It was more like they knew that I wasn't feeling well and I always said, “oh yea, I'm sick, I don't feel good”. But I didn't tell them what was wrong. Cuz kind of hard to explain to somebody like yea, “I'm bleeding in places I'm not supposed to be and it hurts and suffering”. I don't know. So. And it seems easier to say, “oh I'm not feeling well”...(P2, age 21, female)

I wouldn't have called acquaintances and told them about it. But I, I did call my very close friends and talk about it but I didn't want other people to know. I think it's because it's...a lot of people don't talk about colons or going to the bathroom and it's a, it's very hush hush, you don't hear a lot about it. And, uh, yea, it's kind of embarrassing I would say. I didn't want too many people to know. (P6, age 24, female)

Just because of the nature of the symptoms, they're, uh, so because of the nature of the symptoms, they're, you're, I think, much less likely to talk about them. I think that there really is like a social stigma associated with, you know, even simple diarrhea... So I think that definitely, if it had been something else, that it didn't have that negative stigma attached to it, I would have been more open about it. (P5, age 22, female)

Concealing the ostomy. Having the ostomy created a body image issue for most of the participants. Consequently they focused on hiding their ostomy by wearing baggy clothing. Concealing their ostomy was important to them, as they did not want others to judge them or look at them differently. This was another way for them to hide behind their illness. Their changing body image did not allow them to feel comfortable in their own skin and were therefore concealing their true sense of self.

And it was winter so I liked that better because you could wear more clothes. That was my biggest concern that it was visible for, you know, that's why I wore T-shirts that were bigger and I wore sweaters. (P2, age 21, female)

Because I wouldn't want to wear jeans because, I don't know, just nothing that really revealed it [the ostomy] I guess. Big sweaters. (P3, age 19, female)

[I try to hide it]...I wear baggy clothes...in case the bag gets full, you can kind of see (P1, age 20, male)

I, I wanted it to be concealed. And I think that that was, um, like I didn't, I didn't really want people to think that there was something strange about me because, you know, there's, what's that thing on her, her stomach. (P5, age 22, female)

Revealing the self. For some participants, being diagnosed was a relief because they finally knew what was happening to them. Others saw the illness as something they could not control and so they made the conscious effort to deal with it and move on. Finally, others saw the illness trajectory as an experience that helped them mature as human beings and felt that they had become better people because of it. This acceptance and sense of being comfortable with their life situation permitted them to move on with life. They became more comfortable in their own skin and with who they were as individuals. Some became proud of who they were and who they had become. They were finally able to accept themselves and thus be more open with others. This in turn enabled them to reveal their true self. They no longer felt the need to hide anything from anyone.

I was more accepting of it later on. Like once I, once I was diagnosed I was really happy. It was like, OK, good I know what it is. I know what it's not. So that was reassuring because it wasn't cancer or anything like that. And I got used to it or more comfortable with it. (P2, age 21, female)

I found out, OK, let's deal with it; let's try to get better. (P1, age 20, male)

[Before my diagnosis]...I saw myself as a normal person doing normal stuff like everybody else... I felt like I was able to be myself... and then when I had the illness, I felt like a complete new person is in my body...[now I see myself] as a lot better. I felt like I feel like myself... I'm able to go out and just enjoy my life as it is right now. (P4, age 20, female)

I think that the whole, uh, process of the disease and everything that I've gone through since I was, since I first experienced symptoms... I think that it's really helped me sort of mature, um, a lot. I think that it has allowed me to, to learn to accept, accept myself a little bit better and also, um, I think that it's also given me the tools to sort of deal with life's unexpected things a little bit better than I maybe would have before. Um. I think that, like I don't think I'd be the same person that I am today not having had ulcerative colitis. And, and I'm very happy with the person that I am today so I think that it's definitely had an effect on me and I think overall a positive effect. (P5, age 22, female)

All of the participants explained how they were relieved that the ostomy was only temporary. Thoughts that the ostomy was only temporary made it easier for some to deal with it, accept it, and move on. Knowing that the ostomy was temporary was especially important during the difficult times because they knew there was an ending in sight. Their body would eventually return to “normal”.

I think that, um, knowing that there was a light at the end of the tunnel kind of made it easier to get through it, knowing that it wasn't permanent. I think that I had an easier time accepting it. Because I knew that I would, you know, go through the second stage and have the pelvic pouch procedure and I wouldn't have to deal with the ostomy anymore. And so I think that that made it a lot easier to accept it and deal with it for, for the period of time that I had it. (P5, age 22, female)

Themes

Three themes emerged from the data in support of the essence of the adolescents' and young adults' lived experience of living with IBD and an ostomy. These themes were: (a) Uneasy feelings, (b) "It's hard...", and (c) Renewed sense of self.

Uneasy Feelings

There were many uneasy feelings felt by the participants throughout the illness trajectory. The most common feelings expressed by all of the participants were embarrassment and frustration. Additionally, some often worried about various components of their illness and others asked "why me?" These feelings, and more specifically the feelings of embarrassment, transpired because of how the participants felt about their sense of self. They were not yet comfortable in disclosing to others what it was they were going through at that time, and hence experienced the uneasy feelings.

Embarrassment. All of the participants expressed embarrassment at some point during their illness. Some initially felt embarrassed even before being diagnosed with ulcerative colitis. They felt embarrassed because of the nature of the symptoms they were experiencing and did not want anyone to know. Others felt embarrassment in front of their friends and acquaintances for fear of being judged.

I just felt like something was wrong with me and I was embarrassed about it. And didn't know what it was. I had like no idea why this was happening so I just, I didn't want to tell anyone because I was really embarrassed about it. Like it was just like, I didn't want kids to think that I was weird or that like they could get it or that it was contagious or something like that. And, I mean, you know how kids are when like they're that age, they're very like judgmental and they jump to conclusions really quickly. (P5, age 22, female)

Some of my friends knew that I wasn't feeling good. And I didn't really tell them why. Because it's hard to explain to someone that you're bleeding when you go to the bathroom. I don't know. A little embarrassing. (P2, age 21, female)

Most of the participants were embarrassed of the prednisone side-effects such as puffy cheeks and weight gain, which affected their body image, and self esteem. They knew they needed to take the medication in order to stop the symptoms but dreaded their new temporary appearance.

...it [prednisone] made me gain a lot of weight and my face was like really round.... you look, you're totally like a different person. And I don't know. It just doesn't, it's not good for your self-esteem. (P3, age 19, female)

And I just, I just felt so devastated and like just so embarrassed. So it was those, yea, the side effects of the pills I, I found to be really hard on me because, probably because of the age I was at. (P6, age 24, female)

[The prednisone side effects bothered me]...gaining weight. (P1, age 20, male)

And so I was upset when I was going to go on it [prednisone] but I wanted to get better so I did. And I also had the moon face and my skin felt different. Like it's hard to explain. It was, it felt gross kind of... And makes you feel fat I guess...(P2, age 21, female)

Having the ostomy was also embarrassing. Most wanted to hide the fact that they had an ostomy bag. The participants explained how their appliance would fill with air or make noises, which was a source of embarrassment.

I don't know, and if it like gets really big, you can see a big lump there and people probably think stuff and... and I just wanted to be like I was before. (P3, age 19, female)

...there's the, the, um, sort of embarrassment if you have an accident or a leakage or if, um, the ostomy bag would be, if it smells or if it makes noises or if your intestine does. (P6, age 24, female)

There were a couple participants who enjoyed wearing tighter clothing before the ostomy operation. However, due to the possibility that the ostomy appliance would show, they changed their wardrobe in order to conceal the ostomy.

I was still very self-conscious in public with it [ostomy] because I liked to wear tighter clothes and with that I didn't feel like I could because you could see it and, or I could, I could see. Most of the people probably would be like oh, I didn't see anything there at all but I would think they would see it. (P6, age 24, female)

For those participants who were in intimate relationships, the idea of being intimate with their partner was difficult and a little frightening to think about. All of them stated it was mainly because they had not yet come to terms with their ostomy; they still felt a little embarrassed and self-conscious about it. All the participants stated that their partners had indicated that it was not an issue for them to be intimate and had expressed the desire to be intimate.

And it got to the point where it's like, OK, I kind of have to tell him about this because it's kind of obvious, um, you know, when, if things are going to progress in our relationship, you know, it's kind of there. So that was really scary. Like I was really nervous telling him about that. Um. But he was, like he was really good about it. Like he was really like, like OK with it. And, um, it didn't seem to bother him at all. And he was just like really like supportive about it. And so like it was a lot easier than I thought it would be. (P5, age 22, female)

So I explained to him what was going to happen [the ostomy operation]. And was hoping it was OK. And it was. He's like, OK, yea. And that went OK. And, yea, we dated through the ostomy period. And were intimate but not often because I wasn't comfortable with the appliance and so we didn't do that kind of thing very often... It was in my head. Because he wanted to be intimate. And he didn't care but I did. So. But I'm just too uptight I guess. (P2, age 21, female)

Frustration. All of the participants expressed frustration with several aspects of their illness at one point or another. For some, the time it took to get a diagnosis and all the tests they had to go through was a frustrating process. Two participants described their experience:

Like I, I had started feeling sick so long before that. And I had gone in and they did one scope I think on me. But they didn't find anything. They're like a, we don't know. So nothing really happened after that. And so it was frustrating because I was sick obviously because things would happen that shouldn't. And nobody was telling me what it was. (P2, age 21, female)

Yea. Cuz I never knew what I had and it's been, it was going on for like a month or two [and so that was frustrating]. (P1, age 20, male)

The ostomy itself was a great source of frustration and stress for some participants. Part of their frustration was related to being hospitalized in general. They did not want to be there as they felt they were missing out on so many things. Another frustrating time was when the health care professionals were teaching them how to care for the stoma and appliance. Their frustration stemmed from the fact that they were upset at having to get the ostomy in the first place.

I just wasn't emotionally ready I don't think. Psychologically ready for having it [ostomy] there and using it. So there was a lot of nurse teaching and I was just frustrated because I was on drugs and I couldn't figure it out and I didn't want to figure out as I didn't like it...I was definitely upset and crying a lot because the nurse there I remember...he was like, OK now, like this is, it's your turn to try and empty it and stuff. So he would get me and all my IV poles and stuff and we'd all go to the washroom and like, OK, you do it instead of him doing it at the bedside or something. So that, to begin with, that was very frustrating because it's not what I wanted to do. I just wanted to let them do it and I didn't want to have to deal with it yet. (P2, age 21, female)

Others were frustrated with the medications they had to be on and how they depended on these medications to get better.

So it was kind of like this accordion effect for a couple of months where I would lower my prednisone dose and get sick again. So I'd take a little bit more. But like, every time I tried to lower the amount of prednisone I was taking, I'd get sick again. And I just got really frustrated that I couldn't live my life without it. And knowing that both of the medications that I was on were sort of, there was a time limit on them. And at one point that time limit was going to run out. (P5, age 22, female)

Worry. All of the participants had worries and concerns about their illness but interestingly, each of them expressed different concerns at the time of the interviews. For

example, one participant had to miss quite a bit of school because of the severity of her illness and she worried about getting behind in her classes:

...if I didn't complete the last part of Grade 11, then what, it was just so unknown for me. Um. So I was worried at that point. I thought I would be able to catch up. I didn't think that my disease would take me into the hospital for so long....I worried a lot about getting behind in school too much...(P6, age 24, female)

Another participant had worries during her active disease related to managing her illness. This included worries about having to take so many pills and felt her life revolved around her illness. When asked what the worst part of having ulcerative colitis was she responded:

I would say that the worst thing for me about having ulcerative colitis, um, was the stress and the anxiety that I had associated with the symptoms. And, uh, just needing to know, you know, where the bathrooms were all the time. That was extremely like stressful and, uh, it made, it made my daily life very difficult... (P5, age 22, female)

She explained how at times, she was relieved to have the ostomy so that she would not have to worry about these things:

Because it was, like it was so dramatic, uh, just the way that I felt having the ostomy compared to the way that I felt before I had it. And I was sick for so long that I didn't even know what being healthy felt like any more. And not having to take pills every day, and not having to worry about where the bathrooms were...(P5, age 22, female)

A couple of participants felt that having ulcerative colitis meant worrying about things that impacted on their daily life activities such as what food they could or could not eat, what clothes they could and could not wear and, of course, knowing where all the bathrooms were at all times.

I'm not stressed out all the time like I was, like I was then. I don't, I feel like I don't have to worry about where the nearest bathroom is or I don't have to worry about even like having a change of clothes or I can, I can eat what I want now. (P5, age 22, female)

If I eat fruit, I have to go to the washroom two seconds later and like it just, it affects me going to work because then I have to stop working and worry about other things like that. (P3, age 19, female)

And I didn't eat too much before I went out because I wanted my pouch to be OK and fine... But the worst thing was shopping for the right stuff because I had, I wanted something that my pouch wouldn't show and that. Because when, like when you try clothes on, like tops or something going near it, it could stretch it against the pouch and you would worry about it, uh, not sticking properly... (P4, age 20, female)

One of the five participants who had an operation for the reversal explained how having the reversal lessened the work of all the worrying.

Because, um, having the pouch was a good thing. But in a way not fun because it was just never working out for me. And I was excited about the reversal because I wouldn't be needing to look at that, need to worry about that because I would know it would be inside of me, like a J pouch... And it was just going to be a relief for me that I didn't need to worry about it at all any more. (P4, age 20, female)

The one individual who was still waiting for the reversal surgery, looked forward to the day when the surgery would take place, as he would no longer have to worry about having an appliance and ordering all of the supplies.

Why me? Initially, when the participants received their diagnosis, most of them wondered “Why me?” They questioned why they were the ones chosen to have to go through all of this pain and suffering. Some initially even wondered if maybe it was their fault and they had done something to bring it on. While others knew that it was not their fault but yet still wondered why this was happening to them.

Yes. I would always say, why did, why was it me that I had to through all this pain, going through this whole process. (P4, age 20, female)

Um. I've definitely said why me. And why not someone else. Not that I'd want someone else to have it. But, yea, I've. And sometimes jokingly kind of say to dad, like oh, thanks a lot for giving me this. That was a lovely gift... (P2, age 21, female)

No. I don't think, I didn't think, oh I deserved this or something like I did something to bring this on. I don't think I ever did that because, I don't know, I'm, I'm more science based so I don't, I just, yea. It happened because of genetics and life. (P2, age 21, female)

Another participant who initially questioned why she became ill thought that maybe she had done something to bring it on even though she had just started to make a lifestyle change by trying to eat right and going to the gym:

I was, I was, I felt like why me? Why me? What did I do? I was trying to, like before that, I mentioned how me and my friends were going to the gym and, um, my, I was trying to eat healthier. Like why? Why at this time in my life? Everything was going so good... But, yea, in a way I felt like it was, it was partially my fault and if I could have done something to prevent it. (P6, age 24, female)

Eventually all of the participants realized at some time or other that it was not their fault, and that it was something that was out of their control.

I, uh, it took me quite a while to, probably years, to realize that everything happens to people for a reason. (P6, age 24, female)

I think, um, I was more mature and I understood at that point, uh, like I would have been 20, 21 at that point. I understood more that it wasn't something that was my fault and it wasn't something that I could control. (P5, age 22, female)

"It's Hard..."

All of the participants described in one way or another how difficult this illness could be. Many components played a part in this and, to further illustrate, four sub-themes will be discussed: the restrictions the illness posed on them and their lifestyle, the unpredictability of the illness and subsequent feeling of loss control, the pain they had to endure and, finally, the fact that at times they felt different from their peers.

Restrictions. In general, most participants felt that having ulcerative colitis restricted them more so than having the ostomy. Participants discussed many ways in

which the illness, and at times the ostomy, restricted their activities, the clothes they would wear and the foods they could eat. For example, most agreed that their activities were restricted because they would never know if they would need to find a bathroom, or if their ostomy bag would leak.

And I couldn't go out to the mall, go to movies without knowing everything's going to react for me... [so that prevented me from doing] A lot of stuff. I had to rent movies or my friends had to come over here because I couldn't go there without problems. Couldn't really do much. I took dance class but it was really hard for me to do that. (P4, age 21, female)

...stayed inside most of the time played video games...barely could go out anywhere because I always had to be by a bathroom. (P1, age 20, male)

When I had the ostomy, I felt restricted, uh, activity wise I guess because swimming wasn't going to happen... I have no idea how you cover that up. (P2, age 21, female)

Being at the age that most participants were at the time of their illness, going out with friends was important and often times they were unable to attend gatherings or parties because of the constraints of the illness.

And then when I was really, really sick I think I was invited to parties but I was so sick I couldn't go. And that just, I was so disappointed. I was crying like a lot. I just couldn't handle. I was just like this is just not cool. We can't go to [name]'s birthday party because you're so sick. It made me so sad that day. Yea. That's why it was so hard. (P4, age 21, female)

I had to have a colonoscopy or barium enema or something that I had to prepare for the night before by taking a Fleet laxative to clean me out. That night was a party with a lot of kids in my grade...I wasn't able to go because of this laxative obviously... [I wanted to go to that party] I did. It was a big popular one. Everybody was going to be there. It was frustrating because it just, like if it could have been any other day, it would have been better. But it was then and that's when the party happened to be and I was like shoot, it sucks. So real aggravating. (P2, age 21, female)

When it came to having the ostomy, most wanted to conceal the stoma and appliance while others wanted to feel comfortable and not have anything tight or

restrictive around the bag. The type of clothes they wore were not always ones that they would normally choose to wear.

But, but the only thing is I could wear different tops but I couldn't wear a certain pant. And that kind of sucked because there's so many different fashions out there and I couldn't wear too much except sweat pants. (P4, age 20, female)

I used to wear shorter shirts or just not being able to show off my stomach because, again, I was just a very conservative person and I, uh, I only wanted the people very close to me to know what happened to me rather than, than everyone. So, um, and not being able to wear bikinis like the rest of the, like the rest of the girls or just not being able to be like the rest of people. (P6, age 24, female)

When asked what was the worst part about having ulcerative colitis, one participant said:

Um. Always being tired. Being weak. Not able to eat a lot of stuff while I was on it when I had the illness and not being able to go out and enjoy life and going to school. (P4, age 20, female)

Finally, the participants looked forward to having the operation for their reversal because they felt they would have fewer restrictions and would be able do more of the things they wanted to do.

It was just, I don't know, I was just scared because I, it [the ostomy] kinda stopped me from doing a lot of things because I was worried I was going to hit it or, you know, like damage it in some kind of way. Now [after the reversal] I can do basically whatever I want and then I could do, like I don't know, some things were kind of risky I guess. (P3, age 19, female)

I'm not stressed out all the time like I was, like I was then. I don't, I feel like I don't have to worry about where the nearest bathroom is or I don't have to worry about even like having a change of clothes or I can, I can eat what I want now. (P5, age 22, female)

Unpredictability/loss of control. The participants felt that their illness was unpredictable because they never knew when they would need to find a bathroom. Most of the time, if they needed to go to the bathroom, they needed to go immediately.

Because of this, they would sometimes stay at home and have friends come over instead. This simplified things for them because if they did decide to go out, they would often feel anxious for fear of a possible accident.

I, like I just going to the bathroom like 12 times a day, like sometimes even more than that. And it was always painful and there was, it was always bloody. And, uh, I was having problems with incontinence and like I would be taking the bus to work. And at this point like I was living here and working in [name of area]. And so I was on the bus for an hour and a half on the way to work. And it was like terrifying, like I was like if I have to go to the bathroom, where can I get off. (P5, age 22, female)

...because you never knew when it was going to come, when you need to go, when you, or if you're in public you never know if you could wait that minute. That's why it was so hard for me to go out so and that. And my mom asked me, do you want to go with me? I'm like, no I better stay home just in case, you know. It was hard. (P4, age 20, female)

Along with this unpredictability came a sense of loss of control over the illness that some participants had a hard time with.

Like at the beginning it wasn't so bad because the symptoms weren't so bad. Like I felt like, like I still had a lot of control... But towards the, like getting towards the end of like, my symptoms were getting a lot worse. Um. I just felt like every time I went out I had to know where all the bathrooms were and I was really like conscious of that. And if I was like out with, um, with my friends, like if we were in a car, I'm like, there were times where there was guys, we have to stop. Like I have to find a bathroom now. And I felt like it was really starting to affect my social life to the point where I didn't want to go out because it was easier just to be at home. Because I knew that if I was at home, I'd be able to get into the bathroom like lickety split. So that was really hard. (P5, age 22, female)

I felt, um, because my life was like, because I had all that anxiety about, you know, having to know, you know, where all the bathrooms were and having to, you know, be prepared for accidents and things like that, I really felt like like my ulcerative colitis controlled what I could do and where I could go and when I could go. And, you know, it was like if I'm ready to leave the house and all of a sudden have to go to the bathroom, you know, it's like that's a whole, you know, it really, there's no holding it. There's no, you know. If you're in the car and you're on a car trip, there's no waiting until the next rest stop. It's like what do you do. And so I think that it definitely, um, definitely had a big control over my life. (P5, age 22, female)

In dealing with the loss of control, one participant felt that the best thing she could do was to just deal with her illness.

Not really [I wasn't upset] because it just happens. Like I couldn't control it, I couldn't stop it. So just have to deal with it. (P3, age 19, female)

The pain. All participants explained how physically and emotionally painful this illness can be and how much of a big part it played in their life during that time. When asked what the worst thing about having ulcerative colitis was most said it was the pain they had to endure.

The worse thing about ulcerative colitis to me was the pain and forgetting what it feels like to be healthy. (P6, age 24, female)

[This ostomy operation meant] That I was kinda getting cured. I wasn't going to get any pain any more or anything. (P3, age 19, female)

[The worst part of having] ulcerative colitis [is] pain and bloating. And the frequent washroom trips not very good. But mostly, I think mostly the pain in the abdomen. (P2, age 21, female)

When it came to dating and relationships, one participant mentioned how intimacy was physically painful. Some expressed how they would sometimes not want to eat to avoid going to the bathroom because they knew going to the bathroom meant having pain.

...And the pain...you know, it was fairly constant. And especially when you're going to the bathroom 10, 15 times a day and it's painful every time. That's, it was a big part of my life that I felt like I didn't, that shouldn't have been there. (P6, age 24, female)

I stopped eating as much so. Um. Just because I found it, when I ate, I went to the bathroom more and it hurt so there was like a pain associated with that too so it was sort of like an automatic reaction. If I don't eat as much, then there's going to be less pain. (P5, age 22, female)

As much as most of the participants were not looking forward to having an ostomy, they were looking forward to having the surgery because, for them, it meant a life without physical pain.

I would rather that [have the operation] than always be in pain and just in the hospital... (P3, age 19, female)

Like I was, I had just mixed feelings. I wanted it [the surgery] but I didn't want it. And I knew that the medications just weren't helping so that I knew that's the last. I went to the end of my rope and that's what the surgeon doctor recommended that I get the surgery so. Yea, I, um, I don't think I was ever mentally prepared enough to get it because, just I didn't, I didn't want it but I didn't want to be in pain kind of thing. (P6, age 24, female)

There was also emotional pain involved with this illness. Some individuals found that the illness was at times very hard to deal with, and for some, it caused great stress and anxiety almost on a daily basis. For one participant, the hospitalizations were very difficult. She had had many complications and at one point felt hopeless. She thought she would never get better.

...having ulcerative colitis...the stress and the anxiety that I had...it made my daily life very difficult. (P5, age 22, female)

And I started to have complications...there was a lot of things going wrong...so then I felt hopeless then. I, I uh, just looked around me and life was going on without me. But I was still in the same situation. I wasn't. I didn't see myself getting better because of all these setbacks. (P6, age 24, female)

Having the ostomy meant big adjustments; it meant a change in lifestyle. For some the adjustment was so painful that it was to the point where at times they wished they had never gone through with the operation. For one individual who enjoyed sports, having the ostomy presented a challenge. She was afraid to get it hit during contact sports, and other times, the appliance would not stay on properly. She found that hard to deal with.

And so then I had, was having problems again with it [the ostomy] like leaking at inopportune moments. And so, um, it started becoming stressful again, like having the ostomy...there were a couple of times where I was just so stressed out that I wished I'd never gone through with the whole thing. And it was difficult... (P5, age 22, female)

Yea. It was a big adjustment... I would be there kind of crying... (P2, age 21, female)

[sports with the ostomy]...it would get hard because it'd get like, one thing I had a problem with it would get really red around where like it tapes on. And nothing would ever work...I had to duct tape it to like my stomach. Yea. It was really bad. (P3, age 19, female)

Feeling different. All of the participants felt different than their peers or other people at one point in their illness trajectory. Some felt different when they were diagnosed with ulcerative colitis because they felt like the only ones with a chronic illness amongst their friends. The illness resulted in them doing things that their friends did not do including needing to stay at home more often, going to the hospital, and being on several medications. All of these factors made them feel as though they did not have a normal childhood.

[I wasn't motivated to get up and go out so I was] Bummed out because I was just sitting at home doing nothing so it was kind of like, yea, boring and it's not like a normal childhood. So it sucked. [I felt different than others] Because I wasn't going out and having fun. (P3, age 19, female)

[I didn't want to tell my friends] And, I mean, you know how kids are when like they're that age, they're very like judgmental and they jump to conclusions really quickly. And, um, I just didn't want anyone to think that I was different... And I didn't want to be the girl with the disease. (P5, age 22, female)

...to have an ileostomy at 16 I felt like, felt very, very different and I just picturing myself as being the only one in my, in my whole school with one...I spent probably a couple of years coming to terms with my illness and the scar and how I was different. How I felt different as a person compared to the rest of people I knew... (P6, age 24, female)

[I feel different than others because] I have an ostomy. (P1, age 20, male)

When it came to relationships and body image, the participants felt awkward in front of their partners for fear of being judged.

Yea, I worried about that too. Just what, uh, what he would think and, and, uh, how it would affect our relationship basically. It's like, so yea I was concerned what he would think... And I found I was always often wondering what people would think or concerned about others, what people think. (P2, age 21, female)

...when you are dating someone, it feels like, what would they think. Would they think this is the ugliest thing they'll ever look at or would they think, oh, it's no big deal. And that's why I was kind of worried about what would his feelings be when he sees this. (P4, age 20, female)

Those who were not in relationships also had concerns when it came to having the ostomy. Most did not want others to see the ostomy for fear of being judged and many avoided going swimming so that they did not have to wear swimwear. This exacerbated their feelings of being different because they could not wear the clothes they wanted or do an activity that others were doing. This was because they had an ostomy, their lived body was now different than their peers, and thereby making them feel different.

[I was trying to conceal the ostomy] Just so no one notices it... Because then they think differently... I don't know. They would think it's weird. Like what is that big like bump in her stomach. (P3, age 19, female)

So for me to like go to the beach and wear a bathing suit and have it be obvious, um, I just felt like I would be uncomfortable and people would be looking at me and like wondering what that was. Not knowing what it was would like make judgments. And I felt self-conscious about it. (P5, age 22, female)

Although most of the participants had mixed emotions about having the operation for the ostomy, they were looking forward to having a more “normal” life. For them, this meant a life without pain, with less unpredictability, and less anxiety. They were eager to do most things their peers were able to do, they were eager to go out and have a social life, and to be able to eat most of what it is they wanted.

I felt really healthy again which it was, it was a really good feeling. And I felt like I could do most of the things that I, I would do, like before I had the ostomy when I was healthy and, um. Like there were certain things that I didn't think that I would be able to do that I actually was able to do... I felt like having the disease had affected my social life. And so now that I had the ostomy, I wanted to be able to be normal again and do, and have a normal social life. And not have that affect my social life. (P5, age 22, female)

Renewed Sense of Self

Most of the participants felt a renewed sense of self once they had the ostomy because of how healthy they felt. They were no longer in pain, no longer had to worry about where all of the bathrooms were, and felt less restricted. Because the ostomy was temporary, those participants who had the reversal felt these feelings even more so. Their bodies would now be similar to others and this would allow them to finally reveal their true sense of self. The two sub-themes explaining these feelings are freedom and new lease on life.

Freedom. All of the participants expressed how, in the end, they really had no regrets with going through with the ostomy surgery and the reversal surgery. The ostomy gave them a sense of feeling healthy; a feeling they had not felt in a very long time. It also provided them with a little more freedom to do the things they were unable to do when they were sick with ulcerative colitis. For some, it meant finally being able to be more like themselves and the freedom to reveal their true sense of self.

This [the ostomy] meant a brand new life for me being healthy and be able to do more stuff that I couldn't do before. I did so many different things that I couldn't do before. My mom was so happy to see the girl that she always saw in her life but the new person, you know. I was still my same self but I was a little bit of a new person because I was healthy and everything like that. (P4, age 20, female)

I think that overall the whole experience of the ostomy has been like a positive one. And I think that it was definitely something I needed to do. And I don't regret doing it because I definitely would not be as healthy as I am now without having

done that. But there were definitely times where it was stressful. (P5, age 22, female)

...after I had the ostomy like no pain. And no blood. It was like, after 3 years of having diarrhea constant in my life, it was just amazing. Like I really felt healthy again. That was really, really like, just like incredible. Because it was, like it was so dramatic, uh, just the way that I felt having the ostomy compared to the way that I felt before I had it... like I felt more free I guess. (P6, age 24, female)

Now I'm actually able to go out and not look for bathrooms and have a normal life. (P1, age 20, male)

Once they had the reversal surgery, their feelings of freedom, feeling normal and having a little more confidence intensified.

And after the reversal, I, I started feeling. I feel I have more confidence. Like I did a lot of public speaking and, and I may, I probably wouldn't have felt as comfortable in, in public speaking in certain situations with an ostomy... So, yea, after my reversal, I, I feel I have a lot more confidence to, to do activities and to be in certain social situations. (P6, age 24, female)

I remember really excited. On the day before [the surgery], um, I remember feeling like my life was going to change... I don't like using the term normal but having more normal bowel movements. Being able to, to, uh, go to the bathroom. It almost felt like I'd forgot, I forgot to, uh, I forgot to, I forgot what it was like to go to the bathroom. Like a person with a colon. But, uh, overall it was, I felt like my life was going to change because getting the confidence back, being able to, to feel more like my friends...the word freedom comes to mind. (P6, age 24, female)

New lease on life. Most of those who had the reversal stated how it changed their lives for the better. One participant explained how she chose her career path because of her experience with ulcerative colitis. In general, life was now much better. Some participants thought they became better people because of their experience. This enabled them to feel comfortable and happy with whom they now were.

I was excited about that. [the reversal] Because it'd be a different experience without it. Um. I would have a different life with the second surgery... It did [change my life] actually. I didn't need to worry about the pouch being in the way. And be able just to go out with my friends without. And I would be able to go shopping, eat food, go to the movies and just go out and have a good time. And

swimming and dancing. Just everything. Made a big difference for me. (P4, age 20, female)

...for some reason I was sort of proud of [my scar]. Like I like that it's there and I don't mind people seeing it... Maybe it, because, I don't know, not a lot of people have big surgery. And I'm like yea, I just had this big surgery and now I'm better because of it so. (P2, age 21, female)

But it's [the surgery] definitely like health-wise, it's the best decision that someone could make if they were in my position because it's, it's just made me feel so much better. And I feel, I feel like I'm just, um, like I feel better about myself now and health-wise like I feel better because I'm not sick any more. And...then it's like I'm happier and it's just, it's made a huge difference in my life so. (P5, age 22, female)

But I think it [ulcerative colitis] was one of the best things that could have happened to me because, uh, I found my career path with it and I also became a better person I think. (P6, age 24, female)

The Needs of Adolescents and Young Adults

This section will address the third research question: What are the needs of adolescents and young adults who have IBD and an ostomy? The answers to this question would often be expressed when they would discuss what advice they would give to family and friends. Overall, participants summed up what they needed most was support from all individuals important to them in their lives. All of the participants stressed how support from family and friends was very much needed and so important to them and their recovery. Whether it involved coming to visit them in the hospital, sending them cards and flowers or just sitting and listening to them, all of these things were important to the participants. One participant mentioned how it was important that her friends accept her, as she was, illness and all. She needed their acceptance and support in order to feel normal. Two other participants mentioned how they needed hugs almost on a daily

basis, and especially on bad days when things were not going so well. Following are a

few quotes from some of the participants:

They were there... they would, when I didn't go anywhere yet because I was still recovering, they would come over. And watch TV with me. Hang out. And after that, then, I don't know, we were just, they were still my friends... (P2, age 21, female)

They came to see me in the hospital. They were there. (P1, age 20, male)

They [friends] were there for me when I needed just someone to come and hang out or just needed to talk or they were just there for me when I was like in the hospital they were always there for me. They didn't turn their back on me at any time. (P4, age 20, female)

[My advice] For family, is to be always there for them. If they're in need, um, help on something or just need someone, family members or friends just to be there to listen to them talk about what's going on with them. It's good just to be there and support them. And just be there when they need just the little things from you, it's just the best support they can give...[I got that support]... Yes. Just for the little things. Just for anything, they were there for me. (P4, age 20, female)

I think the most important thing is just that like they be supportive of the person and, uh, just really let them know that, that they're there like they're there for you no matter, no matter what happens. And that like lots of hugs. Hugs are good. Um. And that, you know, like for a person that's going through what I went through, that like they're going to have bad days obviously. And just to know that, that if, if they're upset, then, you know, maybe they just need you to sit there and like listen and let them talk. And, uh, yea, just to be very supportive, that's the most important thing. It's, you know, letting the person, the people that you care about know that you're there for them. (P5, age 22, female)

The health care professionals also provided support to these individuals. Most participants felt as though they were given plenty of information about their illness and surgery. They felt as though they were well supported and prepared for any upcoming procedures.

I got tons of pamphlets and all that... [they were helpful... it prepared me for afterwards]. (P1, age 20, male)

They [the nurses] did a good job... I got all the answers I needed answered from them. (P4, age 20, female)

Participants thought the enterostomal nurses (ET) and the staff nurses were great sources of support. Most participants felt at ease with the nurses and valued their supportive activities, which included the nurses providing information, being accessible, and generally just making them feel comfortable.

...the ET nurse came and showed me and told me what I had to do. And it was a good experience for me. (P4, age 20, female)

I had met with, um, the ET nurses...and, uh, and they went through like, showed me, you know, the appliance and, you know, the whole process of that...like that was pretty helpful. (P5, age 22, female)

...I had visits from the enterostomal nurses as well. And they explained things a lot better, you know, in using visuals and the, uh, the bags itself. And the nurses were very supportive...like I really, I really enjoyed their company... they made me feel very comfortable. (P6, age 24, female)

Finally, some described the little things the hospital staff would do that would help them get through the difficult times. They stressed it was the little things that made such a big difference such as someone being extra cheerful and telling jokes, or simply providing them with a warm blanket.

I liked the nurse who could joke with me and tell me stories. Like I just loved that. Just, um, keep me company. (P6, age 24, female)

I just remember this one guy was like really upbeat and like whistling and stuff like that so that kind of made me feel better...and like I just, like I was laying in like the bed and they had me in, covered in a nice warm blanket...(P5, age 22, female)

Adolescents' and Young Adults' Recommendations for Health Care Professionals

This section will address the fourth research question: What recommendations do adolescents and young adults have about how health professionals can best support them

in living life with inflammatory bowel disease and an ostomy? Over all, all of the participants were quite satisfied with the care they received from the health care professionals. They were pleased with most of the information they were given and with how accessible the enterostomal nurses were throughout the process. There were however some recommendations given and, interestingly enough, most of the suggestions were different for each participant. One participant felt that she was not quite prepared on how the ostomy appliance worked and would have wanted some time before the surgery to handle and play with it so that she would know what to expect afterwards.

I think I would have liked to have seen her [the ET nurse] come and explain the product, like the bag and everything to me and let me figure it out before I had the surgery so that I was a little more prepared after when I actually had it and was scared to death of it. Like I remember I could not figure out the little clip and it was partly because of the morphine I think. And I was very afraid. So I could not figure out what I was doing and it was very frustrating. (P2, age 21, female)

The same participant indicated that she would have wanted the nurses to be more empathetic. She indicated how she knew that they were very busy during the day but wanted them to sometimes take the time to focus on the person, anticipate her needs and try to truly understand what it is the individual is going through.

I think they just, they need to be less busy and more into you as a person I think. And talk to you more about your feelings and what you're going through instead of focusing on the appliance so much. (P2, age 21, female)

Similar to the above recommendation, a couple of other participants expressed how lonely it could be while in hospital, and sometimes a little company would be nice. They fully understand how health care professionals are busy, and therefore even just a small visit to check in on them and see how they are doing would have been appreciated.

To also for health professionals to be, to be very friendly and, depending on the personality, like I liked the nurse who could joke with me and tell me stories. Like

I just loved that. Just, um, keep me company. And I know there's not, not a lot of time in a day for a nurse to do that but as much as they can. Oh and to also, um, it was really nice of the nurses to allow my mom to stay overnight. That really helped me deal with, uh, with feeling alone or needing someone close to me while I was, while I was sick. (P6, age 24, female)

Another suggestion given by one participant was for the health care professionals to treat every case individually. She described how the nurses had explained to her that she would feel so much better once she had the ostomy surgery. She did *not* have that experience and therefore felt as though she was given a false sense of hope. It took months of living through complications before she felt better, and therefore would have rather the nurses reinforce that she *may* feel much better as opposed to telling her that she *would* feel much better immediately after the surgery.

Most participants also suggested that the ostomy visitor be of similar age to the patient going through with the operation. One participant explained how she had an older person come and visit and discuss her experience. As much as this was helpful, she would have perhaps been more comfortable and open in talking about issues with someone closer in age. Providing the individual and the family members with as much detail as possible about the illness, the complications, the medications and their side effects were also mentioned. However, it was also suggested that the information be tailored to meet the needs of the individual and his or her family. Another participant felt more opportunity should be provided for individuals to seek out help from professionals about their illness or care of their ostomy.

One participant who had many problems with the appliance not fitting properly and skin reactions to the adhesive did not know that there were other types of appliances available. Nor did she know that what she was actually having was a skin reaction to the

adhesive. She felt it was something she was doing wrong and therefore did not seek help earlier. She would have appreciated the help sooner had she known what to expect.

Um. I think that, one thing that would have helped me would be knowing, like having them tell me, you know, this is what could happen. Like because when I had, when I first left the hospital and had the first type of appliance, I didn't know that there was any other. Like I didn't know that, you know, there were other shapes that would fit your body better. You know I was really like, it's like, this is the thing that I'm sort of stuck with... Or, you know, like not knowing the signs of, that my skin was reacting to the adhesive. I think that it would have been helpful to know things to look for that were negative so that I could, um, so that I would know immediately. (P5, age 22, female)

Finally, some participants similarly mentioned how health care professionals do not often broach the subject of intimacy. Although they realize that this can be a sensitive and perhaps embarrassing topic to discuss, there were nonetheless those who had questions and would have liked to talk about sex and intimacy.

That's one thing that there isn't a lot of information on. Um. And, you know, that is sort of one subject [intimacy] that I think isn't really broached by doctors... I think that, um, it, it probably would have been a good idea for them to ask that question so that, like if I had had anything I wanted to talk about, that the door sort of already would have been open. (P5, age 22, female)

...they never went into specific details. Um. I kind of wanted them to. I think more or less they touched on it. They, they, oh they did mention that people, people lead normal, healthy lives with their partners and... intimacy. I guess maybe I think it would have been nice to hear other stories from other people... somebody else that's been in that situation and they can share their stories. But some people don't want to ask about stuff and intimacy so it's another one of those things that a lot of people just wonder about or deal with it when it comes. (P6, age 24, female)

Chapter Summary

Chapter Four presented the reader with a detailed description of the research findings. A demographic profile of the research participants was presented, followed by a discussion of the essence of the adolescents' and young adults' lived experience. Three

themes that communicated the substance of this essence were described: (a) Uneasy feelings, (b), “It’s hard...”, and (c) Renewed sense of self. The first theme described how all of the participants at one time or other during their illness felt feelings of embarrassment, frustration, worry and feelings of “why me?” The second theme referred to how this illness was really hard on all of the participants. They often endured tremendous physical pain, restrictions, unpredictability and feelings of being different than their peers. The third theme described how the participants experienced a sense of freedom with a new lease on life once they had their ostomy operation and subsequently their reversal operation. They had no more worries, restrictions or pain; they felt great. Finally, the needs of the participants and their recommendations for health care professionals were also presented. The following chapter will be a discussion of the findings.

Chapter Five: Discussion of Findings

Introduction

Chapter Five presents a discussion of the findings. The purpose of this phenomenological study was to arrive at an understanding of the lived experience of adolescents and young adults living with inflammatory bowel disease and an ostomy. The essence of their lived experience, themes supporting the essence, the needs of the adolescents and young adults, and their recommendations to health care professionals were identified through the analysis of their descriptions. In this chapter, these research findings are compared to the past and current literature and possible explanations for discrepancies are presented. Methodological strengths and limitations of the study are also identified. The chapter concludes with recommendations for nursing practice, education and research based on the knowledge gleaned from the participants of this study.

Concept definition

Sense of self

For the purpose of this document, sense of self will be defined according to Woodgate & McClement (1997). Sense of self refers to the individual's understanding of the self, which includes the thoughts and attitudes one has about their psychological, physical, social, and spiritual being. It also refers to the negative or positive value attributed to their self (Woodgate & McClement, 1997).

Research Findings

The essence of the lived experience of the adolescents and young adults, themes supporting the essence, the needs of the adolescents and young adults, and their

recommendations to health care professionals are discussed in this section. The following discussion includes a comparison of the current study to previous research findings related to adolescents and young adults living with inflammatory bowel disease and an ostomy.

The Essence of Adolescents' and Young Adults' Lived Experience: Concealing and Revealing the Self

The essence of the lived experience of the adolescents and young adults in this study was described as “Concealing and Revealing the Self.” From the onset of symptoms to the creation of the temporary ostomy, participants in this study at first tried to conceal their illness from family and friends. They were trying to hide behind their symptoms, which prevented them from revealing who it is they really were, their true sense of self. Their sense of self often depended on what was happening with their bodies. When experiencing symptoms such as blood and diarrhea, participants wanted to conceal this from family and friends. When their body image changed because of the medication side effects and the ostomy, participants were embarrassed and often wanted to hide and conceal their appearance. These findings are congruent with Woodgate’s (2005) study on adolescents’ experiences with cancer. Woodgate explains how “the changing sense of self in adolescents was tied closely to their changing body” (p. 13). The adolescents in this study experienced changes in their lived bodies because of their cancer symptoms, which in turn, affected their sense of self and how they saw themselves in this world. It was only when they were experiencing minimal symptoms that they felt more like themselves and were able to do the things they wanted to do (Woodgate, 2005). Manderson (2005) also discusses how an individuals’ sense of self is often affected by

their physical body. In this study, the men and women's sense of self as a valued individual was threatened by their illness as well as their ostomy. Manderson reinforces how personal worth cannot be determined by one's physical appearance.

In this study, the most cited reason for the concealment of their symptoms was because of the embarrassing nature of this illness, which is congruent with previous research (Carlsson et al, 2001; Daniel, 2001; Engstrom, 1999; Mackner et al., 2004; van der Zaag-Loonen, Grootenhuis, Last, & Derkx, 2004). In a study involving comparison groups of matched children with diabetes, tension headaches, and IBD, findings revealed that children with IBD seldom spoke of their illness because they perceived their symptoms as socially embarrassing (Engstrom, 1999). Engstrom also suggests that children with IBD tend to deny their problems when it comes to the symptoms of the disease. Likewise, the participants in this study also had initially denied the seriousness of their symptoms. They did so because they did not think it was anything to be worried about. However, although there was much hesitation at first, the participants in this study eventually told family and close friends about their symptoms. This finding is reflective of the study by Daniel (2001) who looked at the perceptions of adolescents with IBD. Four out of the five participants spoke of IBD as the kind of illness that is not talked about socially and full disclosure to friends was seen as a major hurdle to overcome.

All of the participants in this study wanted to conceal the ostomy. Their changed body image affected their sense of self. They were hiding behind their new temporary appearance because they were not comfortable in revealing who it was they really were. Most were uncomfortable with how it looked, and therefore changed their dressing attire to baggy clothes in order to conceal the appliance. Previous research reinforces that most

people are embarrassed having an ostomy and will try to hide it (Deeny & McCrea, 1991; Junkin & Beitz, 2005; Manderson, 2005; Manworren, 1996; Salter, 1992). Junkin and Beitz (2005) mention how adolescents experience fears and concerns possibly even more intensely than adults. Peer acceptance is crucial for this population and they may be more concerned that their appliance will be noticeable.

All of the participants in this study eventually accepted and came to terms with their illness. Most of them were able to adapt their lifestyle accordingly and some of them felt as though they became better people because of their illness. This in turn enabled them to reveal their true self to family and friends. They finally felt more comfortable in their own skin and were able to move on with their life. This finding is similar to one of the themes in a study by Erwin-Toth (1999). All of the participants in this study thought of themselves as survivors. One of the participants felt her experience with her illness helped her “grow as an individual”, and others thought of themselves as strong individuals who are able to overcome obstacles.

Research findings are conflicting in the study of psychosocial issues in children, adolescents and young adults with IBD. In their review on the psychosocial issues in childhood IBD, Mackner and colleagues revealed that this population might be at greater risk for difficulties in behavioural and emotional functioning than healthy children (Mackner et al., 2004; Mackner et al., 2006). Whereas Mackner and Crandall (2005) found that children with IBD, who have been diagnosed for at least a year, report psychosocial functioning that is normal to that of healthy children. The reason for this discrepancy in findings may be due to the fact that most of the research does not indicate the severity of the illness nor the length of time since diagnosis, both of which can play a

significant role in how an individual adapts to their illness.

All of the participants in this study eventually also came to terms with their ostomy as it made them feel better and healthier. One important factor contributing to this acceptance was that they knew it was only temporary. All mentioned that had the ostomy been permanent, this acceptance might have been delayed or non-existent. They also knew that their bodies would eventually become “normal” again once they had the surgery for the reversal. This change in body image enabled them to become more confident and more comfortable with their self. Most of the research found in this literature search looks at people with permanent ostomies. Junkin and Beitz (2005) and O’Brien (1999) indicate how many look forward to having the surgery so they can feel better and have a chance at better health. The stoma is often viewed positively as it can represent a more normal lifestyle. Although Erwin-Toth (1999) concluded that ostomy surgery performed between the ages of 6 and 12 years can have a long-term effect on psychosocial development, the majority of participants in her study adjusted well in the first years after surgery. They did however mention that their ostomy had a negative impact on their lives during adolescence. Not only was body image a concern, but they also reported feeling isolated and frightened.

Individual responses to one’s stoma are often dependent on factors such as personality, previous experiences with illness and coping techniques. Whether or not they adapt is often dependent on whether or not they are comfortable with their new body image (Rheaume & Gooding, 1991), and, more often than not, on their support network (Bray & Sanders, 2006; Brown & Randle, 2005; Erwin-Toth, 1999). All of the participants in this study indicated that they had a supportive network of family and

friends.

Themes

The three themes supporting the essence of the adolescents' and young adults' lived experience of living with inflammatory bowel disease and an ostomy will be discussed in this section. These themes were: (a) Uneasy feelings, (b) "It's hard...", and (c) Renewed sense of self.

Uneasy Feelings

All participants felt many feelings throughout the illness trajectory. Four of the most common uneasy feelings expressed by the participants will be discussed in this section. These feelings are: (a) embarrassment, (b) frustration, (c) worry, and, (d) "Why me?"

Embarrassment. All of the participants expressed the feeling of embarrassment at one point or other during their illness. Some were embarrassed of the frequency of which they needed to use the bathroom while others were embarrassed that their illness involved bodily fluids such as stool and blood. This is consistent with previous research findings. In particular, Daniel (2001) studied young adults' perceptions of living with IBD and found that all five participants described the difficulty of living with the symptoms of the disease. Bowel incontinence and urgency were a major source of embarrassment and humiliation to all participants.

Other participants in this study were embarrassed of the prednisone side effects, more specifically the weight gain associated with this medication. These side effects affected most of the participants in the sense that their body image was altered. Some had had no problems with body image prior to going on the medications. Other studies have

also identified medication side effects as a concern for individuals (Casati et al., 2000; Daniel, 2001; Giese & Terrell, 1996). Casati et al. (2000) explain how, although the medication side effects are only temporary, the impact this altered appearance can have on an individual, especially in a society that puts tremendous emphasis on attractiveness, can greatly affect one's body image.

Having the ostomy was also a source of embarrassment for all participants. Not only the way it looked, but the associated noises and how the bag filled up with air was also a concern. The literature reinforces how an ostomy can be seen as a nuisance or source of embarrassment in one's life (Carlsson, Bosaeus, & Nordgren, 2003; Gooszen et al., 2000; Karadag et al., 2003; Nugent et al., 1999), and that individuals have a hard time with the smell the ostomy can produce (Carlsson et al., 2003; Nugent et al., 1999; Persson & Hellstrom, 2002). Interestingly, none of the participants in this study mentioned that odor was a concern or a source of embarrassment for them.

Sex and intimacy was also a source of embarrassment for those who were in a relationship. One of the participants had stated that she felt "dirty" because she always worried about having to go to the bathroom during sex. Casati et al. (2000) support this finding by indicating that one of the concerns of people with IBD is the fact that they do feel dirty. This concern stems from the possibility of a lack of control over their bowel movements. As with previous studies (Black, 2004; Carlsson et al., 2001; Manderson, 2005; Nugent et al., 1999; Persson & Hellstrom, 2002; Salter, 1992), having an ostomy can be a source of embarrassment during sex and intimacy. The participants in this study who were in relationships were self-conscious of the ostomy. They were all reluctant to have sex for fear of what their partners would think. Some of them chose to, at times, not

be intimate despite the fact that their partners wanted to be, and had indicated that the ostomy did not bother them. Some of the literature supports that notion (Black, 2004; Manderson, 2005; Salter, 1992), whereas other research has demonstrated that the partner may also have issues with the stoma (Manderson, 2005). Thus the potential impact on both partners warrants future research.

Frustration. Some of the participants in this study felt frustration during several occasions throughout their illness trajectory. Some were frustrated with the health care system and how long it took to get a diagnosis, while others were frustrated that they needed to have the ostomy in the first place. Medication side effects and the number of medications they had to take was also a source of frustration for most of the participants. Although there is some evidence supporting this feeling of frustration (Casati et al., 2000), the emotion of frustration expressed by individuals has not been discussed in the literature. For example, Daniel (2001) discusses how all five participants spoke of a “difficult period” of undergoing misdiagnosis before learning they had IBD; the participants in this study described this “difficult period” as frustrating.

Worry. Some of the participants worried about several different things during their illness. Many of them missed school and were worried about getting behind in their classes. Some were in the hospital for months at a time and one individual missed an entire semester, while another had to drop out of school. Worry in relation to having to miss school is consistent with previous research (Akobeng et al., 1999; Erwin-Toth, 1999; Moody et al., 1999). Due to the potential severity of the characteristics of the illness, individuals will often unwillingly miss school. Future research could explore the impact this has on school aged adolescents from a qualitative perspective.

Participants in this study also worried about knowing where the bathrooms were at all times. Although only a couple had had accidents in public, some brought a change of clothes with them whenever they went out. Most worried about what they could and could not eat, what they could and could not wear, and all of them looked forward to the day where they did not have to worry about any of this at all. For some, this illness brought a great deal of stress and anxiety in their lives. Previous research reinforces these feelings of worry and concerns (Brydolf & Segesten, 1996; Daniel, 2001; Deeny & McCrea, 1991; Irvine, 2004); the characteristics of the illness often make it difficult not to experience these feelings.

Why me? Initially, most of the participants expressed some anger and questioned why they were chosen to go through all of this pain and suffering. Two of the participants also had thought that perhaps it was something they had done to bring it on. Previous research does not often mention whether or not individuals feel self-blame or ask themselves “why them?” Daniel (2001) mentions that the emotional effects of having a chronic illness resulted in feelings of anger and self-blame for the participants in his study, whereas Willis (1998) explains that some children may go through a phase of wondering “Why me? Why am I different?” Future research is warranted to explore these feelings in detail.

“It’s Hard...”

All of the participants described the difficulties of having this illness. All of them commonly expressed four difficult aspects of this illness: (a) restrictions, (b) unpredictability/loss of control, (c) the pain, and (d) feeling different. These findings correlate with a study done on adolescents’ perspectives of chronic illness (Woodgate,

1998). In this exploratory, qualitative study, adolescents with diabetes, asthma, arthritis, Crohn's Disease and ulcerative colitis were asked to describe their experiences with chronic illness. Although Woodgate (1998) studied adolescents with chronic illnesses other than only CD and UC, similarities were found in how they felt about their illness. The overall theme was described as "It's Hard" with four categories further emphasizing the difficulties encountered by each of the participants: (a) It takes extra effort, (b) It's restraining, (c) It's painful, and (d) It's a whole bunch of worries. The restrictions varied from what they could eat, to participating in physical activities, to going out with friends (Woodgate, 1998). The participants also described their illness as not only physically painful but also painful in the sense that they were not able to do some of the things they would want to do. One other painful aspect, which is similar to findings in this study, involves the pain caused by feeling different from others. Finally, the participants in Woodgate's (1998) study described how they worried about different aspects of their illness such as developing complications, future employment, isolation from others and even death. Although there were similarities in how the participants felt in Woodgate's study with this current study, one must keep in mind that there were also differences. These differences must be acknowledged when caring for adolescents with chronic illnesses so that the care they receive is individualized (Woodgate, 1998).

Restrictions. As reflected in much of the literature (Akobeng et al., 1999; Brydolf & Segesten, 1996; Carlsson et al., 2001; Casati et al., 2000; Daniel, 2001; Giese & Terrell, 1996; Gooszen et al., 2000; Mackner & Crandall, 2006; Moody et al., 1999; Persson & Hellstrom, 2002; Salter, 1992), many participants in this study felt their ulcerative colitis restricted many facets of their lives. The biggest restriction was always

needing to be near a bathroom, and therefore often times canceling or not attending social events or gatherings. This contributed to feelings of frustration, stress, and anxiety to some of the participants. Supporting this finding, Moody et al. (1999) studied children with CD and found that most of the participants in this study restricted their social activities because of the characteristics of the illness.

When the participants in this study had the ostomy, some of the restrictions included not being able to wear the clothes they wanted because they wanted to conceal the ostomy. Other restrictions included limiting their social activities because of fear of leakage and thus the potential for an embarrassing situation. Others limited their physical activities such as contact sports for fear of injuring the stoma. This fear has been noted in previous research (Persson & Hellstrom, 2002). Most of the participants in Persson and Hellstroms' study approached physical activities with caution for fear of damaging the stoma.

Unpredictability/loss of control. As previous research indicates (Casati et al., 2000; Daniel, 2001; Dudley-Brown, 2002; Persson & Hellstrom, 2002; Rayhorn, 2001; van der Zaag-Loonen et al., 2004), unpredictability is a major characteristic of inflammatory bowel disease. There is much ambiguity regarding the occurrence and pattern of symptoms, which often leaves the individual feeling as though they have no control over their illness. All of the participants in this study expressed frustration over the uncertainty and subsequent feeling of lack of control. Due to its unpredictable nature, participants felt it was easier to stay at home than go out with friends; this led to feelings of anger and frustration. Some felt as though they no longer had any control, the illness controlled what they could do, eat and wear.

Pain. All of the participants in this study spoke about how physically painful this illness was for them. There were mixed emotions when it came to how they felt about having the ostomy surgery. When they spoke about looking forward to the surgery, this meant they would have a chance at a life without physical pain. When asked, “what was the worst thing about having ulcerative colitis?”, most participants mentioned the pain. Although the literature mentions pain as one of the symptoms associated with IBD (Akobeng et al., 1999; Brydolf & Segesten, 1996; Casati et al., 2000; Daniel, 2001; Irvine, 2004; Mackner & Crandall, 2006; Mackner et al., 2004; Rayhorn, 2001), pain is not often discussed as a theme in qualitative research. For example, Casati et al. (2000) did a review of the literature on concerns of patients with IBD. There were eight concerns discussed, however, pain was not one of them. In contrast, quantitative studies that utilize IBD quality of life questionnaires will often include symptoms of this illness as a category with pain often being the most frequently reported symptom (Akobeng et al., 1999; Mackner et al., 2004). Perhaps future research could utilize a qualitative approach to fully understand the impact the physical pain can have on an individual with IBD.

Participants also had difficult periods throughout the illness trajectory, which could be referred to as emotional pain. Some felt stress and anxiety almost on a daily basis, while others had a difficult time adjusting to having the ostomy. They all mentioned how, at times, the illness was hard to deal with. Although the literature does not speak specifically of emotional pain, it does mention how many individuals have difficulties dealing with their illness and ostomy (Carlsson et al., 2001; Daniel, 2001; Gooszen et al., 2000; Persson & Hellstrom, 2002).

Feeling different. Having ulcerative colitis made the participants feel different in many ways throughout the illness trajectory. Before the ostomy surgery, many did not feel as though they had a normal childhood. Missing out on social events and activities, having to take medications, and having to go to the hospital made them feel different than their peers. They felt as though they were the only ones with a chronic illness, and the only ones going through this alone. This is consistent with previous literature (Brydolf & Segesten, 1996; Daniel, 2001; Irvine, 2004; Mackner et al., 2006). Daniel (2001) mentions how all five of the participants expressed the desire to live a normal life; they felt their disease made them feel different than others. Brydolf and Segesten (1996) describe how the physical changes of the illness led to feelings of embarrassment and diminished self-respect. These bodily changes influenced how the participants felt about themselves; many no longer recognized whom they were, they felt different from their peers.

When it came to having the ostomy, many felt even more different. Not only did they have a chronic illness, but now they had a visible stoma, which could potentially be seen by others. Many developed body image issues because of the ostomy, and felt as though others would judge them. It is well documented in the literature that a stoma can have an impact on body image (Black, 2004; Casati et al., 2000; Junkin & Beitz, 2005; Karadag et al., 2003; Nugent et al., 1999; O'Brien, 1999). This impact often leads to feelings of being different (Erwin-Toth, 1999; Persson & Hellstrom, 2002; Salter, 1992).

Renewed Sense of Self

Having had the ostomy, and, for 5 out of the 6 participants, the reversal gave the participants a sense of freedom and a new lease on life. Two sub-themes will be

discussed in this section.

Freedom. For most of the participants, having had the ostomy surgery gave them a feeling of being healthy, and free to do most of the things they wanted to do. With this sense of freedom came a newfound confidence, which enabled them to reveal their true sense of self to others. This is consistent with research done on adolescents' experiences with cancer (Woodgate, 2005). These adolescents experienced a renewed body when they were experiencing minimal symptoms. This renewed body enabled them to do the things they wanted to do and they now felt they could experience "life as a kid again" (Woodgate, 2005).

There are, however, conflicting findings in the literature when it comes to how patients feel with an ostomy. Some reports indicate that patients adapt well to the ostomy and welcome their newfound freedom and chance at better health (Bray & Sanders, 2006; Junkin & Beitz, 2005; Rheume & Gooding, 1991). Although all of the participants in Persson & Hellstrom's (2002) study felt the ostomy negatively affected their quality of life, two participants spoke of how the ostomy provided them with a life that was much more relaxing; they felt free to do the things they wanted. Erwin-Toth (1999) indicates how the majority of participants in her study adjusted well in the first years after surgery, however, all of them reported that their ostomy had a negative impact on their lives during adolescence.

Some studies indicate that having an ostomy brings about a negative impact on quality of life (Karadag et al., 2003; Persson & Hellstrom, 2002; Silva et al., 2003). Silva et al. (2003) concluded that individuals had a significantly impaired quality of life as a result of their temporary ileostomy or colostomy. Quality of life factors included the

effect on ability to travel and exercise, and on hygiene and sexual relationships.

Karadag et al., (2003) studied individuals with permanent ostomies, and concluded that having an ileostomy or colostomy profoundly negatively impacts on quality of life. This impact resulted from the stoma related problems encountered on a daily basis. The effects and impact ostomy surgery has on an individual's life warrants further research (Brown & Randle, 2005; Karadag et al., 2003; O'Brien, 1999).

New lease on life. Most of the participants in this study felt that the pelvic pouch procedure (reversal) had given them a new lease on life. They no longer felt self-conscious because of the ostomy, their self-esteem was high, and they finally felt normal. They were now able to reveal their true self to others. Most stated that their quality of life was better now that they had the reversal. Some of the literature reviewed correlates with this study's findings (Brown & Randle, 2005; Salter, 1992), however, other research indicates that quality of life after the reversal remained the same as when they had the ileostomy (Berndtsson & Oresland, 2003; Weinryb, Liljeqvist, Poppen, & Gustavsson, 2003). Longitudinal prospective studies investigating quality of life in individuals with temporary ileostomies who undergo the pelvic pouch procedure are needed.

The Needs of Adolescents and Young Adults

The one overwhelming need expressed by all of the participants is support. All of them discussed how support from family and friends was very important to them. Giving a foot massage while in hospital, bringing flowers, giving hugs or just being there in time of need were some examples of what support meant to them. Several participants also described support from friends as "they were there...they were still my friends", for them, this meant acceptance for who they were, illness and all. The literature also stresses

how support from family and friends is very important to the individual with IBD (Bray & Sanders, 2006; Brown & Randle, 2005; Brydolf & Segesten, 1996; Carlsson et al., 2001; Erwin-Toth, 1999; Nugent et al., 1999; Rheume & Gooding, 1991; Salter, 1992). Brydolf and Segesten (1996) indicate how the most important factor for successful growth and development for an adolescent is a supportive environment. Research also shows that support or even perceived support is often responsible for a person's adaptation to either the illness or the ostomy (Carlsson et al., 2001; Erwin-Toth, 1999; Rheume & Gooding, 1991).

Support from the health care professionals was also regarded as important to all participants. Many enjoyed the little things like being given a warm blanket or simply having a nurse come in and talk to them. This is consistent with previous research in the sense that support from health care professionals is very important (Carlsson et al., 2001; Daniel, 2001; Notter & Burnard, 2005; Persson et al., 2005; Persson & Larsson, 2005). This support is often crucial for that individual's adaptation and adjustment in the months following surgery. The relationship with the ET nurse was also regarded as important to the participants in this study. The information given to them, an environment conducive to being able to ask questions and the accessibility of the ET nurse was what helped them adjust and adapt. Marquis et al. (2003) express how the quality of the relationship with the ET nurse can influence the quality of life of that individual.

Adolescents' and Young Adults' Recommendations for Health Care Professionals

Overall, the participants in this study indicated that they were satisfied with the care they received from health care professionals, which is consistent with some of the literature (Carlsson, et al., 2001; Marquis et al., 2003; Persson & Larsson, 2005), whereas

Persson et al. (2005) found that the participants in their study were not entirely satisfied with the quality of care they received as their care did not meet their expectations. Despite the fact that the participants in this study were satisfied with the care they received, they did have some recommendations including: more practical and psychological support, an ostomy visitor similar in age, more detailed information including information about complications, and more empathetic and individualized care. Although each participant had different recommendations, all of the suggestions were consistent with current research (Black, 2004; Bray & Sanders, 2006; Carlsson et al., 2001; Carlsson et al., 2003; Casati et al., 2000; Daniel, 2001; Deeny & McCrea, 1991; Engstrom, 1999; Erwin-Toth, 1999; Irvine, 2004; Manworren, 1996; Marquis et al., 2003; Nugent et al., 1999; O'Brien, 1999; Persson & Larsson, 2005; Persson et al., 2005).

One recommendation that has been mentioned often in this literature review, which was not specified by the participants in this study, is for health care professionals to promote self-care (Bekkers, van Knippenberg, van den Borne, & van Berge-Henegouwen, 1996; Erwin-Toth, 1999; Marquis et al. 2003; Persson & Larsson, 2005). Bekkers et al. (1996) found that patient self-care promoted feelings of personal competency, confidence and strong feelings of self-efficacy. Also, the ability of the patient to be self-caring after stoma surgery proved to be an important element in their psychological recovery. It must be noted however, that only in Persson and Larsson's (2005) study did the participants mention this recommendation themselves. Due to a small sample size and the fact that the researcher did not explore this avenue, could explain the reason for this discrepancy.

Methodological Strengths and Limitations

This section includes a discussion of the study's strengths and limitations with respect to research design and method. These strengths and limitations were considered in interpreting the findings of this study.

Research Design

Hermeneutic phenomenology, as interpreted by van Manen (1990), was an appropriate methodology for this study. Hermeneutic phenomenology offers a mode of inquiry that helps the researcher develop a deeper understanding of the human experience (Speziale & Carpenter, 2007). It is by understanding the philosophic underpinnings of hermeneutic phenomenology and using van Manen (1990) as a guide that the researcher was able to arrive at a deepened understanding of the lived experience of the adolescents and young adults in this study.

Typically, a qualitative approach to research does not yield findings that can be generalized to a broader population (Woodgate, 2000). The findings of this study were not expected to be generalizable to all adolescents and young adults who have IBD and an ostomy. Rather, the researcher was hopeful that the findings would further contribute to the existing literature, and even perhaps provide a new and deeper insight into their lived experience that may assist health care professionals in the care of adolescents and young adults living with IBD and an ostomy. In addition, it was anticipated that these findings could provide a basis for future research.

This study design was retrospective in that data was collected from the participants' memories of their IBD and ostomy experience. Data was not collected prospectively while they were going through the experience due to time constraints. It

could be that some individuals may not recall their experiences accurately, which could affect the findings of the study. However, in phenomenological research, lived experiences gain significance as individuals reflect on their memories. It is described as phenomenological reflection, which is not introspective, but rather retrospective (van Manen, 1990).

This study was cross-sectional in that data was collected at one point in time only. Longitudinal research permits the examination of changes in behaviours over time (Holmbeck, Bruno, & Jandasek, 2006). Longitudinal research would then be needed to capture the adolescents' and young adults' changing realities and its effects on their behaviours, thoughts, attitudes, and subsequently their lived experience.

Research Method

Van Manen's (1990) six methodological themes were used to guide the research process, which proved to be useful when conducting the specific research activities. It also helped to remind the researcher that the purpose of this study was to gain a deeper understanding of a phenomenon, more specifically, the lived experience of adolescents and young adults living with IBD and an ostomy.

In keeping with phenomenological inquiry, sample size of this study was small. There were a total of 6 participants with a total of 12 interviews. The aim of having a small sample size is to elucidate the richness of the individual experience (Baker et al., 1992). Data was collected until redundancy occurred and the researcher found no new emerging themes.

All participants in this study were Caucasian. It is possible that, had there been a more diverse ethnic group of participants, additional information may have been revealed

about their lived experience. All participants except one were female. Most of the literature reviewed has a mixture of male and female participants (Brydolf & Segesten, 1996; Daniel, 2001; Deeny & McCrea, 1999; Erwin-Toth, 1999; Salter, 1992), however, the study by Manworren (1996) studied only males. Perhaps the inclusion of additional males would have provided different themes.

Of the literature reviewed, some studies are similar to the current one with respect to research design, study sample, and illness. For instance, Erwin-Toth (1999) looked at the effect of ostomy surgery between the ages of 6 and 12 years on psychosocial development during childhood, adolescence, and young adulthood. The reason for the ostomy differed for many participants with only two of them having an ileostomy due to ulcerative colitis. This study was an ethnographic design. Deeny & McCrea (1991) studied individuals who had undergone stoma surgery and Daniel (2001) looked at the lived experience of young adults living with IBD, none had had surgery for an ileostomy. Salter (1992) studied individuals who had undergone surgery for an ostomy and compared this group to those who had had a pouch. She looked at the differences in body image between these two groups. Finally, Manworren (1996) researched developmental effects on the adolescent of a temporary ileostomy; all participants were male. Of the literature reviewed, the only study most similar to this current one is by Brydolf and Segesten (1996). This inductive qualitative approach interviewed 28 participants who were living with ulcerative colitis; 10 of the 28 participants had an ileostomy. They found similar results to the current one with respect to feelings of embarrassment, fear, blame, and feeling different from others. Other similarities included a dependency on washrooms, limited social life, and eventually an increased sense of maturity and self-

esteem because of what they had to go through with having the illness. Differences included the lack of support some of the participants in Brydolf and Segesten's (1996) study experienced as well as being teased and rejected by peers. They also explored in greater detail factors that caused low self-esteem. The reason for these discrepancies could be due in part to the larger sample size of their study.

Recommendations

The findings of this study, although based on a small population, nevertheless suggest recommendations for future research with adolescents and young adults living with IBD and an ostomy. These recommendations are presented in the areas of nursing practice, education and research.

Nursing Practice

The findings in this study revealed that adolescents and young adults with IBD and an ostomy might experience several uneasy feelings throughout the illness trajectory. Not only do they need to have their physical needs taken care of, but their psychosocial concerns addressed as well. Casati et al. (2000) explain how psychosocial concerns are influential in how an individual will cope with IBD. Therefore, carefully integrating these concerns into an effective intervention plan is important. Nurses are in a position where they are able to provide opportunities for these individuals to express their concerns in a supportive environment. Developing an empathetic relationship is crucial in order to allow the individual to express these feelings and concerns. Once these concerns are known, the implementation strategies can commence.

Findings also revealed that these individuals struggled with telling someone about their symptoms. Some kept these symptoms hidden for months thereby potentially

delaying a diagnosis. Nurses must encourage these individuals to report these symptoms as soon as they encounter them so that early intervention strategies can begin.

Individuals in this study also expressed frustration, worries and feelings of self-blame. These were often related to the medical process, medications and, at times, the unknown etiology of this illness. Careful and thorough explanations of every aspect of the illness, the tests and procedures involved, and the medications and their side effects may help alleviate some of these feelings.

The findings in this study also suggest that pain is an important part of this illness. Nurses need to be cognizant that not only can the illness cause painful symptoms, but some medical procedures such as colonoscopies as well. Finding strategies that may help reduce the pain would be an important step in alleviating this suffering. This illness can also cause great stress and anxiety to some individuals. Taking the time to listen to these individuals and allowing an avenue where they feel comfortable in venting these feelings is important. Suggesting different coping strategies would also be useful in helping them deal with the stress associated with this disease.

As seen in the literature, ostomy surgery can alter one's body image and ultimately affect one's self-esteem. Findings in this study suggest that, because of the ostomy, these individuals felt different than their peers. Nurses need to recognize this and give the patient time to come to terms with changes in their body image. Nurses need to find a balance between encouraging a return to normality and allowing a grieving period where the individual can mourn the loss of their changed body image.

Findings also suggest that support is an integral part of the illness trajectory. Assessment of the type and extent of social support is important when planning the care

of the individual. The nurse should actively encourage the use of this social support network. Nurses can also suggest other types of support systems such as local support groups. Although an ostomy visitor is often part of the hospital experience, nurses should try to arrange for a visitor that is similar in age.

Nursing Education

This study contributes to the existing body of knowledge on adolescents and young adults by helping nurses who care for this population understand their lived experience of living with IBD and an ostomy. While recognizing that these findings cannot be generalized to this entire population, and that each individual's experience is unique, these findings can serve as a starting point for conversations about their experiences. Nurses need to begin asking adolescents and young adults what their experience is like. Much can be learned by doing so, and together they may find interventions that may assist them through this experience. Nurses can also educate themselves by reading research articles and attending conferences and seminars that focus on this population.

Nursing Research

The themes identified in this study could be explored in greater depth. For example, the long-term effects of living with an unpredictable illness or the decreased opportunities for social activities could be a focus for future research.

This study was cross-sectional in the sense that data was collected at one time point only. Longitudinal research could look at different time frames throughout the illness trajectory to determine if experiences and perceptions of this population change through the passing of time.

All participants in this study had temporary ostomies, all had ulcerative colitis, and five of the six participants were female. Future research could compare those who have temporary and permanent ostomies, as this may produce themes that could be compared for similarities and differences. Having two comparison groups of ulcerative colitis and Crohn's disease could also reveal interesting differences, as would the experiences of male and female subjects.

All of the participants in this study were Caucasian. This study did not explore if there was any cultural influence on their lived experience. Further research could explore how culture influences one's experience with illness as well as explore other cultural groups' experience of living with IBD and an ostomy.

All of the participants who were in relationships had difficulty with intimacy because of the ostomy, yet none of their partners had indicated that they were bothered by the ostomy. This literature review revealed conflicting findings when it looked at partners' reactions to the ostomy. The potential impact this may have on both partner warrants future research.

Worry associated with missing school was a big part of the participants' experiences. Future research exploring the changing nature of the school and work environment as experienced by adolescents and young adults with IBD and an ostomy is warranted.

As well, further detailing of the changing emotions and feelings experienced by adolescents and young adults with IBD and an ostomy is needed.

In this study, physical pain was noted as being a very big part of their lives. Pain is often mentioned in quantitative research but this literature review revealed no studies

mentioning pain from a qualitative perspective. Future research could utilize a qualitative methodology to fully understand the impact that physical pain can have on an individual with IBD.

Chapter Summary

This chapter presented a discussion of the findings. The essence of adolescents' and young adults' lived experience and three themes supporting the essence were discussed. The discussion of the research findings indicated the participants from this study had both similar and different experiences compared to other research studies. Methodological strengths and limitations of the study were presented. Recommendations for nursing practice, education and research were suggested.

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Appendix A



 Local: 235-3623 Fax: 237-9860

TO: Ms. Julie Savard
University of Manitoba
Faculty of Nursing
Winnipeg, MB

FROM: Dr. B. Light
Chairperson, Research Review Committee

DATE: June 9, 2006

SUBJECT: Experimental Protocol Submission

This is to inform you that the Research Review Committee, at its meeting held on June 7, 2006, reviewed the protocol entitled "Adolescents' and Young Adults' Lived Experience of Living with an Ostomy", Ref # RRC/2006/0752.

The Committee made the following provisos:

- i) That final University of Manitoba Research Ethics Board approval be provided to the Committee. This approval should list the documents with their version dates;
- ii) That an Agreement to Comply with Standard Operating Procedures be signed by Dr. Roberta Woodgate if she will be seeing patients, patient charts or any patient information at St. Boniface General Hospital;
- iii) That the signature of the Clinical Director, Surgery Program be provided to the Committee;
- iv) That the signature of the Program Director, Surgery Program be provided to the Committee;
- v) That the Demographic Form should have a version date and a place to input the patient identifier (patient initials, study code number, etc.);
- vi) That the Information Letter to Nurses, Recruitment Letter, Reply Form and Researcher's Telephone Script be dated;
- vii) That the first page of the Consent Form be placed on the appropriate letterhead;
- viii) That the Consent Form footer contain the version date of the document in the left hand corner and a spot for participant initials in the right hand corner of all pages;
- ix) That the Consent Form have the name of the study placed in the header on page 2 and all pages thereafter;
- x) That the following statement be inserted into the 2nd paragraph on page 2 of the consent form:
"Medical records that contain your identity will be treated as confidential in accordance with The Personal Health Information Act of Manitoba";
- xi) That you provide an SBGH employee letter of introduction to accompany the recruitment letter. Please contact Ms. Terry Sawicz-Hanesiak, Office of Clinical Research, SBGH at 237-2226 for assistance with this document

Final approval to proceed with the study will be granted in writing once an acceptable response to all provisos has been received and reviewed.

Appendix B



Hôpital général **St-Boniface** General Hospital

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Research Review Committee
Approval Form

Principal Investigator: Ms. Julie Savard
RRC Reference Number: RRC/2006/0752
Date: October 17, 2006
Protocol Title: Adolescents' and Young Adults' Lived Experience of Living with an Ostomy

The following is/are approved for use:

- Protocol submitted to June 7, 2006 Meeting
- Consent Form dated July 20, 2006
- Demographic Form, Initial Information Letter to Nurses, Information Letter to Nurses, Recruitment Letter, Reply Form and Researcher's Telephone Script dated July 20, 2006
- Letter of Introduction (undated)

The above was approved by Dr. B. Light, Chairperson, Research Review Committee, St. Boniface General Hospital, on behalf of the Committee. As the recommendations by the Research Review Committee have been met, final approval is now granted.

Sincerely yours,

Dr. B. Light
Chairperson, Research Review Committee
St. Boniface General Hospital

Please quote the above reference number on all correspondence.
Inquiries should be directed to the RRC Secretary
Telephone: (204) 235-3623 Fax: (204) 237-9860

409 Taché, Winnipeg, Manitoba, Canada R2H 2A6
Tel (204) 233-8563 Website: www.sbgh.mb.ca

A Grey Nun Corporation/Une corporation des Soeurs Grises
Affiliated with the University of Manitoba/Affilié à l'Université du Manitoba

Appendix C

Initial Information Letter to Nurses

Dear _____:

My name is Julie Savard and I am a nurse and a Master of Nursing student at the University of Manitoba. I am writing to inform you of a study I am conducting on adolescents and young adults living with ostomies due to Inflammatory Bowel Disease. Dr. Roberta Woodgate, Assistant Professor in the Faculty of Nursing at the University of Manitoba, will supervise this study. The title of the study is: **Adolescents' and Young Adults' Lived Experience of Living with an Ostomy**

I have received ethical approval to proceed with this study from the University of Manitoba Ethics Review Committee, and permission for access has been received from the St-Boniface General Hospital Research Review Committee.

I would very much appreciate meeting with you, at your earliest convenience, in order to provide you with more information about the study. I anticipate that our meeting will require fifteen to thirty minutes of your time. Please call xxx-xxxx.

I look forward to hearing from you.

Sincerely,

Julie Savard
Master of Nursing Student
University of Manitoba

July 20th, 2006

Appendix D

Information Letter to Nurses: Purpose of the Study, Eligibility Criteria and Design

Adolescents' and Young Adults' Lived Experience of Living with an Ostomy

The purpose of this phenomenology study is to arrive at an understanding of the lived experiences of adolescents and young adults living with inflammatory bowel disease (IBD) and particularly living with an ostomy. The research questions addressed in this study include:

1. What meanings do adolescents and young adults assign to the experience of having inflammatory bowel disease with an ostomy?
2. What effect does having inflammatory bowel disease and an ostomy have on the lives of adolescents and young adults?
3. What are the needs of adolescents and young adults who have IBD and an ostomy?
4. What recommendations do adolescents and young adults have about how health professionals can best support them in living life with inflammatory bowel disease and an ostomy?

Participant sample

Six to eight participants with IBD and an ostomy will be required for this study.

Eligibility criteria

- Male and female participants who have been diagnosed with either Crohn's Disease or ulcerative colitis and have an ostomy as a result
- Potential participants must be between the ages of 18 and 24 years of age
- Potential participants must be able to read and speak English

Recruitment procedures

The researcher will not approach potential participants for this study until they indicate that they are interested in hearing more about the study. Therefore, an invitation to participate must be provided by persons who have no involvement with the study.

July 20th, 2006

Once you have a clear understanding of the eligibility criteria, you will be asked to address the letters provided and mail them to the potential participants (stamped envelope will be provided). If the potential participants decide they would or would not be interested in hearing more about the study, a letter with a check box indicating their decision will be provided. They will need to return the decision letter (stamped envelope will be provided) to the researcher who will then contact them.

Thank you for your time and cooperation. Should you have any questions or concerns, please feel free to call me at xxx-xxxx.

Sincerely,

Julie Savard

Master of Nursing Student

July 20th, 2006

Appendix E
Recruitment Letter

Dear _____:

My name is Julie Savard, and I am a nurse and student in the Master of Nursing program at the University of Manitoba. This letter is being sent to you on my behalf by the enterostomal nurses at the St-Boniface General Hospital (I do not know your name or have any information about you or your family). Your name was selected from a list of patients who have received an ostomy as a result of either Crohn's Disease or ulcerative colitis.

To complete my nursing program, I am doing a study about what it is like to live with inflammatory bowel disease and an ostomy. Dr. Roberta Woodgate of the Faculty of Nursing, University of Manitoba is supervising this research study. Dr. Ruth Dean from the University of Manitoba and Dr. Steven Latosinsky from Cancer Care Manitoba are the other two members of my thesis committee. This study has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba and from the Research Review Committee at the St-Boniface General Hospital.

It is my intention to interview a small group of patients to learn more about their experiences with inflammatory bowel disease and life with an ostomy. Each participant will be interviewed one to two times and the first interview will last approximately from 30 minutes to two hours. If you agreed to be interviewed a second time, a second interview would be planned and would last less than one hour. The interviews will be audio tape-recorded. You would also be asked to complete a Demographic Form for background information about yourself, which would take about 10 minutes to complete.

The information I get from the interviews will be written up for my thesis, I plan to publish the study findings in a professional journal and present them at a health conference. In all instances, your identity would be kept confidential and would not be shared with anyone. A summary of the study would be mailed to you if you wanted one.

If you agree to be interviewed, you can drop out of the study at any time, ask to stop the interview at any point, or refuse to answer any question. If you decide not to take part in this study, you can say no without any problem.

If, after reviewing this information, you decide you would or would not like to hear more about the study, **check the box on page two and return it in the enclosed, stamped and self-addressed envelope. If you are interested, please provide your phone number and I will call and tell you more about the study.** If you decide to participate after talking to me, we will set up an interview time and place convenient for you. **Participation is entirely voluntary.**

July 20th, 2006

Thank you for your time and consideration,

Julie Savard
Master of Nursing Student
University of Manitoba

July 20th, 2006

Appendix F

Reply Form

**An invitation to participate in the following study:
Adolescents' and Young Adults' Lived Experience of Living with an Ostomy**

Please complete and return this form whether you are or are not interested in participating in this study.

Are you interested in participating in this study?

YES, I have read this letter and would like further information about the study. You may contact me at the telephone number given below:

Name _____

Phone number(s) _____

The best time to contact me is _____

NO, I am not interested in hearing more about the study.
(If you choose "NO", do not indicate your name or phone number)

Please return this sheet in the enclosed stamped and self-addressed envelope

July 20th, 2006

Appendix G

Researcher's Telephone Script

Hello <Name>:

My name is Julie Savard, and I am a nurse and student in the Master of Nursing program at the University of Manitoba. I have received your reply form and understand that you are interested in hearing more about the study.

To complete my nursing program, I am doing a study about what it is like to live with inflammatory bowel disease and an ostomy. Dr. Roberta Woodgate of the Faculty of Nursing, University of Manitoba is supervising this research study. Dr. Ruth Dean from the University of Manitoba and Dr. Steven Latosinsky from Cancer Care Manitoba are the other two members of my thesis committee. This study has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba and from the Research Review Committee at the St- Boniface General Hospital.

There is not a lot of research written about the experiences of adolescents and young adults living with inflammatory bowel disease and an ostomy. I believe it is important for nurses and health care professionals who care for these patients to fully understand the impact it can have on their lives.

It is my intention to interview a small group of patients to learn more about their experiences with inflammatory bowel disease and life with an ostomy. Each participant will be interviewed one to two times and the first interview will last approximately from 30 minutes to two hours. If you agree to be interviewed a second time, a second interview will be planned and will last less than one hour. The interviews will be audio tape-recorded so that I do not miss any important information. You will also be asked to complete a Demographic Form for background information about yourself, which will take about 10 minutes to complete. All interviews will be done at a time and place convenient for you.

A transcriber will type the interviews, and then I will read them and look for common issues and themes. All names will be removed from the transcribed interviews and will be replaced with a code. Dr. Roberta Woodgate, my supervisor, will also read the transcribed interviews. The tapes and transcripts will be stored securely and destroyed when no longer required.

July 20th, 2006

The information I get from the interviews will be written up for my thesis and you will be given an opportunity to review the information beforehand. I also plan to publish the study in a professional journal and present them at a health conference. In all instances, your identity would be kept confidential and would not be shared with anyone. A summary of the study would be mailed to you if you wanted one.

If you agree to be interviewed, you can drop out of the study at any time, ask to stop the interview at any point, or refuse to answer any question. If you decide not to take part in this study, you can say no without any problem.

Are there any questions you would like to ask about the study?

Do you think you would like to be part of the study?

(If “no”) Thank you very much for your time. I appreciate having the opportunity to speak with you.

(If “I would like to think about it”) I would certainly appreciate you doing that. When should I call you back for your decision? <Date> and <Time> for return phone call.

(If “yes”) Thank you for your interest. When would be a good time and place to do the first interview? <Date>, <Time> and <Location> for first interview.

When we meet, I will ask you to sign a consent form saying you will participate in this study based on the information I have given you, and I will also ask you to fill out a short form for background information about yourself.

For the interview, it may be helpful to think about your experiences with IBD and having an ostomy. I am interested in your thoughts, ideas and views surrounding your particular experiences.

Thank you for your time. I will look forward to meeting you on <Date> at <Time> at <Location>.

(Any questions that arise out of this conversation will be answered and noted on this sheet)

July 20th, 2006

Appendix H

Demographic Form

Information gathered in this form will help us get to know you better. All information will be kept confidential.

1. Have you been diagnosed with:
 - Crohn's Disease
 - Ulcerative colitis

2. On a scale of 0 – 10 (with 10 being the worst), how severe is your disease?
_____ Can you describe what you mean by this number? (i.e. any medical treatments) _____

3. What age were you first diagnosed? _____

4. How old were you when you first got your ostomy? _____

5. How old are you right now? _____(years)

6. Are you:
 - Male
 - Female

7. Do you attend school or university/college?
 - Yes
 - NoIf yes, what grade or year of university are you in? _____

8. Are you currently working full-time or part-time?
 - Not working
 - Full-time
 - Part-timeIf part-time, how many hours per week do you work? _____

9. Which of the following best describes your racial/ethnic background?
- White (Caucasian)
 - Aboriginal (First Nations, Métis, Inuit)
 - Asian
 - Other (please specify): _____
10. Do you live in the city or outside the city?
- In the city
 - Outside the city
11. Are you married?
- Yes
 - No
12. Are you dating or in a serious/committed relationship?
- Yes
 - No
- If yes, how many months/years? _____
13. Do you have children?
- Yes
 - No
- If yes, how many? _____
14. Do you live with anyone?
- Yes
 - No
- If yes, with whom? _____

Appendix I

Interview Guide

Introduction to the interview: I would like to learn more about what it is like for adolescents and young adults to go through the experience of living with inflammatory bowel disease and having an ostomy. I would like you to share your experiences from the time prior to your diagnosis to today. To help you tell your story, I am going to ask you to talk about each period of your illness including the time before, during and after the diagnosis, as well as the time before, during and after you got your ostomy. For each period, I would like you to talk about the changes that occurred in your lives, the type of needs that you had, the type of support and help that you received, the ways that you coped, and any other thoughts or feelings that come to mind.

1. Tell me a little about yourself and how your life was like before your diagnosis.
2. Tell me what it was like when you learned about your diagnosis
3. Tell me what it was like the days and weeks following your diagnosis
4. Tell me what it was like when you first found out you needed an ostomy
5. Tell me what your day was like the day you had your ostomy surgery
6. Tell me what it was like the days and weeks following your ostomy surgery
7. Did anyone come and talk to you pre-operatively or post-operatively about what to expect afterwards?
8. Tell me what your life is like now
9. Tell me what it is you remember the most about your experience
10. Based on your experience, what advice would you give others about life with IBD and an ostomy
11. What suggestions would you give to health care professionals about how they can best help adolescents and young adults go through an experience similar to yours?
12. What suggestions would you give to families and friends about how they can best help adolescents and young adults who have to go through an experience similar to yours?
13. If you had 3 wishes, what would they be?

14. Is there anything else you like to talk about that you feel is important for me to know?

Probes:

- Tell me what day-to-day life used to be like for you
- Can you give me some examples?
- Tell me about some good times or experiences that you had.
- Tell me about some bad or difficult times you had
- What type of things do you do to cope when things are not going well?
- Who do you turn to in times of need?
- What kinds of things did/do you need help with?
- Is there anything that you feel would help you?
- Do you have any other support systems?
- How were you feeling?
- What kind of activities do you do?
- What kind of information was given to you surrounding your hospital experience for the ostomy surgery

Appendix J



UNIVERSITY
OF MANITOBA

OFFICE OF RESEARCH
SERVICES
Office of the Vice-President (Research)

CTC Building
208 - 194 Dafoe Road
Winnipeg, MB R3T 2N2
Fax (204) 269-7173
www.umanitoba.ca/research

APPROVAL CERTIFICATE

19 June 2006

TO: **Julie Savard** (Advisor R. Woodgate)
Principal Investigator

FROM: **Stan Straw, Chair**
Education/Nursing Research Ethics Board (ENREB)

Re: **Protocol #E2006:056**
"Adolescents' and Young Adults' Lived Experience of Living with an Ostomy"

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- if you have funds pending human ethics approval, the auditor requires that you submit a copy of this Approval Certificate to Kathryn Bartmanovich, Research Grants & Contract Services (fax 261-0325), including the Sponsor name, before your account can be opened.
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

Appendix K



UNIVERSITY
OF MANITOBA

Faculty of Nursing

Consent Form

Faculty of Nursing
Helen Glass Centre for Nursing
Winnipeg, Manitoba
Canada R3T 2N2
Telephone: (204) 474-7456
Fax: (204) 474-7682

Research project's title:
Adolescents' and Young Adults' Lived Experience of Living with an Ostomy

Study's researcher:

Julie Savard
Phone number: xxx-xxxx

Supervisor/Committee Chair:

Dr. Roberta Woodgate
Assistant Professor, Faculty of Nursing, University of Manitoba
Phone number: 474-xxxx

Committee members:

Dr. Ruth Dean
Faculty of Nursing, University of Manitoba
Dr. Steven Latosinsky
Cancer Care Manitoba, Winnipeg, Manitoba

I, _____, state that I am ____ years of age and wish to take part in the above study. I understand that the purpose of this study is to better understand what it is like for adolescents and young adults living with inflammatory bowel disease and an ostomy. I understand the study is being done by Julie Savard, a registered nurse and student in the Master of Nursing program at the University of Manitoba, for her thesis. Dr. Roberta Woodgate of the Faculty of Nursing, University of Manitoba is supervising this research study. Dr. R. Dean from the University of Manitoba and Dr. S. Latosinsky from Cancer Care Manitoba, are the other two members of Julie's thesis committee.

Taking part in this study means that I will be asked to take part in one to two interviews. The first interview will take about 30 minutes to two hours to complete and the second up to one hour to complete. I understand that I will be asked questions about what it is like living with inflammatory bowel disease and having an ostomy. The interviews will be audio tape-recorded. I understand that although two interviews are planned, I may decline to do a second interview.

July 20th, 2006

Initial _____

I also understand that field notes will be taken throughout the interviews and afterwards in order to capture any additional information such as nonverbal cues. I will also be asked to fill out a Demographic Form for background information about myself, which will take about 10 minutes to do.

I understand that my participation in this study is entirely voluntary. I can drop out of the study at any time, ask to stop the interview at any point, or refuse to answer any question. I understand that a summary of the study will be provided to me, if I want one.

I understand that there are no known risks to my taking part in the study. However, I am aware that having the opportunity to talk about my experiences may make me more aware of some of my feelings. I understand that this study will result in knowledge that will help health care professionals better support adolescents and young adults living with IBD and an ostomy.

I understand that what is learned from this study will be written up for Julie's thesis, and it may be published in a health journal and presented at a health conference. I understand that my name will not be shared with anyone. I am aware that medical records containing my identity will be treated as confidential in accordance with the Personal Health Information Act of Manitoba. I am aware that my name will be replaced with a code number. Only Julie, the transcriptionist and Dr. Roberta Woodgate will read the interviews. I understand that all data including the audiotapes, interview transcripts, and demographic information will be stored in a locked filing cabinet and computer protected by a password known only to Julie. I understand that all data will be destroyed seven years following completion of the study.

My signature on this form indicates that I have understood to my satisfaction the information regarding participation in the research project and agree to participate. In no way does this waive my legal rights nor release the researchers, or involved institutions from their legal or professional responsibilities. I understand that my continued participation should be as informed as my initial consent, so I should feel free to ask for clarification or new information throughout my participation. I understand that I may contact Julie Savard (xxx-xxxx) if I have any concerns, questions, or need additional information. I may also contact Julie's supervisor, Dr. Roberta Woodgate, at 474-xxxx.

I understand this research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba and the Research Review Committee at St-Boniface General Hospital. If I have any concerns or complaints about this project, I may contact any of the above-named persons or the Human Ethics Secretariat at 204-474-xxxx. A copy of this consent form has been given to me to keep for my records and reference.

Signature of Researcher

Participant's Signature

Date _____

July 20th, 2006

Initial _____

I would like a summary report of the findings:

Yes _____ No _____

Please mail a summary report to:

Name _____

Mailing Address _____

Postal Code _____

July 20th, 2006

Initial _____