SURGERY AND ME: THE EXPERIENCE OF SURGERY AS A TRANSITION IN YOUNG ADULTS WITH INFLAMMATORY BOWEL DISEASE

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A thesis submitted to Cardiff University for the degree of PhD (Nursing)

May 2015

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This work has not been submitted in substance for any other degree or award at this or any other university or place of learning, nor is being submitted concurrently in candidature for any degree or other award.

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ABSTRACT

The peak incidence of Inflammatory Bowel Disease is between 15 – 25 years. A significant number of young people whose disease is not controlled by medication undergo surgery. However, the experiences of young adults with Inflammatory Bowel Disease have not been well researched.

The aim of this two phase exploratory mixed methods sequential study was to investigate the process of transition in young adults aged 18 – 25 years with Inflammatory Bowel Disease who faced the prospect of, or had undergone, surgery. Schlossberg's Transition Theory (Goodman et al, 2006) was used to identify the important factors that influenced their experience. Phase1 was qualitative and exploratory and obtained narratives from semi structured interviews with 24 young adults. Phase 2 was a survey. In order to establish whether findings from Phase 1 could be generalised a questionnaire developed from the Phase 1 findings was developed and sent to 158 young adults randomly sampled from seven NHS centres in England,. One hundred and twenty people responded (76%).

Key findings from Phase 1 were that preoperatively most young people knew that their disease was out of control. Afterwards they perceived that surgery had improved their physical health and positively changed their lives. The key findings from Phase 2 were that 72 (60%) young people had a positive perception of their surgery. Participants also experienced an improvement in physical health and made a good psychological recovery. The majority of participants (n=106, 84%) received appropriate support and used positive coping strategies such as acceptance and positive reframing. Fear, worry, uncertainty, negative experiences of surgery and body image concerns hindered the process of transition. The specialist Inflammatory Bowel Disease or stoma nurse had a key role in facilitating a positive transition.

The study findings will enable health care practitioners to provide appropriate information, care and support for young adult patients with Inflammatory Bowel Disease facing surgery.

ACKNOWLEDGEMENTS

I should like to thank the following for their support with this project:

Crohns and Colitis UK for the research grant that enabled the study to be conducted.

My Research Management Team: Professor Dinah Gould, Professor Daniel Kelly and Dr James Lindsay, to who I am indebted for sharing their knowledge, giving sound advice and guidance and supporting me at every stage of the study from inception to completion.

Mr Christopher Chan, who generously shared his understanding and experience of surgery for Inflammatory Bowel Disease with me on so many occasions, answered questions, listened to and encouraged me throughout the study.

Dr Una Molyneux, for teaching me what I needed to know to complete the statistical analysis and systematic review.

Medical and nursing colleagues at all the participating centres who assisted with Phase 2, most particularly Dr Natalie Direkze and the Inflammatory Bowel Disease specialist and research nurses who made time in their busy schedules to collect data.

The many young people with Inflammatory Bowel Disease who agreed to participate in the study for their openness in sharing their experiences and willingness to take time to complete questionnaires.

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CHAPTER 1: INTRODUCTION

This study investigated the experience of surgery as a transition in the lives of young adults with Inflammatory Bowel Disease (IBD). It was originally conceived as an investigation into the experiences and concerns about sexuality and close personal relationships of adolescents and young adults with IBD who faced the prospect of, or had undergone, surgery for the condition, to find out their needs for information. However, early qualitative data obtained in this study indicated that such issues were not being expressed as a primary concern for these young people. The stories that they told revealed that multiple factors influenced their attitudes towards an operation and following surgery, within the context of their individual lives. Whilst comfortable to discuss sexuality and their personal relationships, their narratives disclosed a variety of other issues and concerns related to this experience which appeared to affect them more in their decision making prior to surgery and in their lives afterwards. In the light of this information, and consistent with the flexibility associated with a qualitative approach, initial thinking was broadened and deepened. The impact of surgery, the factors and experiences which affected how young adults coped with and perceived their operations, and their journey from decision making to recovery became the primary focus of the study. The study was reconceptualised commensurate with this more productive line of investigation and new research questions developed.

1.1 BACKGROUND TO THE STUDY

1.1.1. Introduction

Inflammatory Bowel Disease comprises two major chronic intestinal disorders, Crohn's disease (CD) and ulcerative colitis (UC). About 240,000 people are affected by IBD in the UK (British Society of Gastroenterology, 2003, Rubin et al, 2000). Crohn's disease develops during childhood or adolescence in approximately 20 – 25% of patients and between 15 – 40% of all new cases of ulcerative colitis develop before the age of 20 (Rayhorn, 2001). The peak incidence of IBD is between 15 – 25 years. Therefore, IBD has been described as the most significant chronic disease of childhood and adolescence (Moses et al, 1998) and many young people will learn of their diagnosis and require medical or surgical treatment for IBD as they reach older adolescence and young adulthood. There is a predominance of CD in women, whereas the incidence of UC is higher in men (Lennard-Jones and Shivananda, 1997, Björnsson and Jóhannsson, 2000, Bernstein et al, 2006). Whilst the incidence of UC has remained stable, there has been a steady rise in the number of cases of CD in children over the last three decades (Armitage et al, 2001), so in the future more young people will experience the challenges of living with this illness for which there is no known medical cure.

1.1.2. Physical Effects of Inflammatory Bowel Disease

Both diseases are characterised by periods of active disease and periods of remission (Nicholas et al, 2007), but they differ in anatomical location and the nature of inflammation. UC is confined to the colon and inflammation restricted to the mucosal layer (Russell et al, 2004). The pattern of inflammation tends to start at the rectum with proximal and continuous disease extension. In contrast, CD may be present anywhere in the gastrointestinal tract from the mouth to the anus. Sections of unaffected bowel separate areas of inflammation which can be transmural- leading to fistulation (entero-enteric, enterocutaneous, and perianal), perforation and abscess formation (Ghosh et al, 2000, Carty and Rampton, 2003).

Physical symptoms of IBD result from its effects on the gastrointestinal tract and include abdominal pain, weight loss, restriction in linear growth, diarrhoea and bleeding (Ballinger et al, 2003). Extraintestinal manifestations of IBD include arthritis and arthralgias, skin lesions (erythema nodosum or pyoderma gangrenosum), eye inflammation (uveitis, conjunctivitis, episcleritis), liver disease (sclerosing cholangitis), renal calculi and cholelithiasis (gallstones) (Rayhorn, 2001). These physical symptoms have the potential to severely affect the lives of adolescents and young adults with the disease; frequent, copious diarrhoea and urgency threaten bowel control; malnutrition leads to weight loss, growth retardation (which sometimes cannot be reversed) and fatigue; abdominal pain and joint involvement restrict activity; skin lesions cause pain and are unsightly (Wolfe and Sirois, 2008).

1.1.3. Surgical Treatment

Medical treatment in adolescents is directed towards controlling the disease and its symptoms and correcting nutritional impairment to maximise growth and allow pubertal development (Beattie, 2010), enabling young people to feel well again. Advances in medical treatment may improve the control of IBD for longer, but failure of medical management remains the most common indication for surgical intervention (Hwang and Varma, 2008). As childhood onset IBD appears to be extensive and progressive, with higher rates of panenteric (upper gastrointestinal tract as well as lower) inflammation and more extensive inflammation and complications (structuring and fistulation) over time than adult onset disease (Van Limbergen et al, 2008, Vernier-Massouille et al, 2008), the need for an operation may arise at any age and in patients with disease of long or short duration. The possibility of surgery is a well recognised concern for young people and adults (Daniel, 2002, Levenstein et al, 2001, Blondel- Kucharski et al, 2001, Lynch and Spence, 2007) and this is not unreasonable; estimates of the incidence of surgery in those diagnosed with CD before adulthood vary between 28 – 80% (Gupta et al, 2006, Freeman, 2004) and of those who have UC with moderate to severe disease at diagnosis, 25% require colectomy within 5 years (Hyams et al, 1996).

1.1.4. Previous Research And Patients' Experiences Of Inflammatory Bowel Disease Surgery

To date, studies have only examined patient experiences of surgery for IBD with particular focus on stoma formation and ileoanal pouch procedures, both of which result in a change in the normal manner of bowel elimination (Beitz, 1999, Notter and Bernard, 2006, Savard and Woodgate, 2009, Sinclair, 2009). Little attention has been directed towards the effects of other commonly performed abdominal procedures in which bowel is resected and intestinal continuity restored, although these are also major operations which too can alter the pattern of faecal elimination. There appears to be no published work on patients' experiences of perianal surgery, even though this is commonly undertaken when Crohn's disease involves this area.

1.1.5. Stoma Formation

Adolescents and adults alike greatly fear the prospect of surgery for IBD because of its association with stoma formation, where faecal flow is diverted into an external bag fitted to the abdomen (Moser et al, 1995, Daniel, 2002, Savard and Woodgate, 2009). As a consequence they may resist surgery, sometimes struggling on in the presence of severe disease in an effort to defer or avoid an operation, with detriment to their body (Lynch and Spence, 2007). This widespread patient concern has generated a considerable amount of literature that not only quantitatively delineates the impact of stoma formation in terms of its effect on lifestyle and quality of life, but also describes the patient experience and explores the significance and meaning of the changes in body appearance and function imposed by stoma forming surgery (Thomas et al, 1987, White and Unwin, 1998, Persson and Hellström, 2002, Brown and Randle, 2005, Richbourg et al, 2007, Thorpe et al, 2009, Savard and Woodgate, 2009).

1.1.6. Ileoanal Pouch (IAP) Procedures

With advances in surgery, many young people whose UC cannot be controlled with medication undergo restorative proctocolectomy and ileal pouch formation (IAP) (Dolgin et al, 1999). This operation is curative as the diseased bowel is completely removed and children and adults have experienced significant improvements in quality of life and minimal life style restrictions afterwards (Camilleri-Brennan et al, 2003, Wewer et al, 2005, Wheeler et al, 2005). The surgery is now often done laparoscopically and in selected cases, a temporary diverting stoma and its associated problems can be avoided (Gorfine et al, 1995). Since intestinal continuity is restored, bowel movements occur in a normal manner (Rayhorn, 2001) although more frequently than those of healthy people (Dolgin et al, 1999). Most people will be completely continent (Wheeler et al, 2005, Lillehei et al, 2009) but faecal urgency, leakage and nocturnal soiling may occur and if these symptoms are intolerable may lead to conversion to a permanent stoma (Lichtenstein et al, 2006).

1.1.7. Surgery For Crohn's Disease

Inflammation in CD can occur throughout the gastrointestinal tract so there is no curative surgical procedure (Rayhorn, 2001). Young people will often need more than one operation to treat the problems that arise in CD (Galandiuk et al, 2005). Stricture formation and obstruction resulting from ileal inflammation can require resection of the affected bowel (Van Limbergen et al, 2008). Scarring, fibrosis, stricturing and sepsis associated with perianal involvement and fistulising disease, if not resolved medically, also call for surgical intervention which may include a temporary or permanent stoma if they persist or recur (van Dongen and Lubbers, 1996, Schwartz et al, 2001, Pikarsky et al, 2002). Following procedures such as stoma formation and the insertion of draining setons into anal fistulae, some patients may have to cope with changes in body appearance and function for a significant amount of time (Scott and Northover, 1996, Regueiro and Mardini, 2003).

1.1.8. Surgery In Young Adults With Inflammatory Bowel Disease

In previous quantitative research, in contrast to older adults and adolescents and children, young people with IBD aged 18 – 25 are rarely considered as a specific group. They are viewed as adults and incorporated into samples that extend from early adulthood into old age. Demographic data often reveals that they represent only a small proportion of the total sample and results are usually not stratified according to age. Therefore it is difficult to determine whether the findings are truly representative of their situation or their views. In terms of psychosocial development, ways of thinking and experience, emerging adulthood is now recognised as a distinct stage in life (Arnett, 2000) and it is reasonable to conclude that the perceptions and concerns of young adults may differ from those who are older. Several qualitative studies have focussed on young adults'perceptions of living with IBD, but the experience of surgery has not previously been explored in depth (Lynch and Spence, 2007, Daniel, 2002, Savard and Woodgate, 2009).

It is hard for health professionals who care for these young people to see them struggling with uncontrolled disease while they continue to resist an operation, especially as, in clinical practice, many of those who do have surgery say how much better they feel and describe how their lives have improved afterwards. They may also have difficulty articulating and communicating their fears and concerns, particularly during clinic appointments where the focus is on trying to assuage the physical effects of their illness. This inevitably results in an incomplete understanding of what the issues are for young people who face the prospect of surgery and so limits the help and support that they can be given to enable them to move forward and consent to an operation.

In summary, there is little information pertaining to the experience of surgery in young adults with IBD. More specifically we do not know how it is perceived, what factors affect their decision making, how they cope and adjust afterwards and what factors and experiences affect them. Therefore this study aimed to explore the experience of surgery from the perspective of young adults with IBD who are faced with and undergo an operation for their condition. The study findings added to the body of knowledge in this field and led to a deeper understanding of how they perceive, live through and adjust to this transition in their lives. Health care professionals can use this information to provide helpful and appropriate care for their own patients in a similar situation.

1.2. AIMS AND OBJECTIVES OF THE RESEARCH

The overall aim of this two phase exploratory mixed methods qualitative and quantitative study was to investigate the process of transition through surgery as it was experienced by young adults with IBD who faced the prospect of, or had undergone, surgery for their condition, in relation to Schlossberg's Transition Theory (Goodman et al, 2006).

The specific objectives for this study were:

- In Phase 1 to use semi structured interviews to investigate the experiences of 24 young adults (18-25 years) with IBD (CD or UC) who faced the prospect of (n=2), or had undergone (n=22) surgery for their condition.

The research questions formulated for phase 1 were:

What were the thoughts, feelings and experiences of young adults with IBD:

i. when they first learned they might need an operation for their condition?
ii. in the time before the operation took place?
iii. after their operation?

- To use Schlossberg's Transition Theory to identify factors that helped or hindered the transition through surgery and adjustment to an operation using the 4S system- Situation, Self, Support and Strategies (Goodman et al, 2006).
- As there were insufficient tools already available, to develop and validate six new instruments, designed by the author, to measure patients' initial reactions to surgery; pre-

operative concerns about the surgery; what patients did to prepare for surgery; what patients did that helped; social support of parent, partner and friends, and post-operative perceptions of surgery.

- In the Phase 2 survey (n=120), to investigate the process of transition through surgery in a large sample of young adults (18-25 years) with IBD (CD or UC) who had undergone surgery for their condition.
  - To identify factors which helped and hindered the transition through surgery, including characteristics of the situation (emergency vs. non-emergency, disease group, with or without stoma), of the self (patient gender, initial reactions, pre-operative concerns and post-operative perceptions), support, and pre and post-operative coping strategies
  - To use Schlossberg's Transition Theory (Goodman et al, 2006) to analyze reasons why certain patients may have positive or negative experiences and successfully or unsuccessfully negotiate their way through the surgical transition

- To make recommendations for practice to help young adult IBD patients to successfully transition through the surgical experience.

It was anticipated that these objectives would lead to a better understanding of the surgery process, and the specific concerns, perceptions, reactions and needs of these patients to enable health care practitioners to develop guidelines to inform the provision of appropriate information, education and support for young adult IBD patients who have surgery in the future.

1.3. RESEARCH APPROACH

This was a two phase exploratory mixed methods study to investigate the process of transition as it was experienced by young adults with IBD who faced the prospect of, or had previously undergone, surgery for their condition. Phase 1 was a qualitative exploration of perceptions, views, concerns and experiences of surgery using a semi structured interview. Narratives from 24 young adults with IBD who attended a specialist clinic at a single tertiary referral centre were collected. The rationale for initial qualitative data collection was that there was a paucity of published data and no existing instrument to assess the process of transition in young adults with IBD as they face the need for surgery and live through this experience. Schlossberg's Theory (Schlossberg, 1981a, Goodman et al, 2006) was used to analyse these stories of transition. Each narrative was examined to determine the key factors which had been influential in deciding whether and when to have surgery, and those which affected patients' preoperative preparation, postoperative adjustment and experiences. The theory was subsequently used as an organising framework for instrument development, with the specific content of a questionnaire derived from the findings in Phase 1. This instrument was used in Phase 2, a quantitative survey to measure the views of a random national sample of 120 young adults with IBD in England about their experiences of surgery.

1.4. THEORETICAL FRAMEWORK

The researcher examined and analysed initial data and the literature to develop an informed understanding of the process of transition as it was experienced by participants. In comparison with other frameworks, Schlossberg's model (Goodman et al, 2006) appeared to provide the best structure for understanding individual stories, comparing elements between them and for explicating the nature of the surgical event, its context, significance and impact on the lives of the young people in this study (see Chapter 5: Findings) and was subsequently used as the organising framework for the study.

1.5. THE RESEARCHER

At the time of conducting this study the researcher was employed as a Consultant Nurse in a Department of Colorectal Surgery at an NHS Trust hospital which served a multiethnic inner city population. Fifty two percent of the population are white British, thirty four percent Bangladeshi and smaller cultural and ethnic groups constitute the remaining population; Bangladeshis have resided in the local community for over 50 years, with the majority of young adults having been born and educated there (Dobbs et al, 2006). With long experience as a working professional in this local community, the researcher brought to the enquiry knowledge and experience of similar patients with IBD who have undergone surgery. Whilst this was an asset in that she already had an insight into the area of study, it could also have made her susceptible to bias in her observations and interpretation of findings. A Steering Committee was convened for this project from its inception which advised and scrutinised decision making and provided an objective view to strengthen the credibility of the research. The Steering Committee was made up of a Consultant Gastroenterologist, a Professor of Nursing, a Professor of Nursing Research and the Director of Policy, Public Affairs and Research at Crohn's and Colitis UK. Steps were also taken by the researcher to enhance the trustworthiness of the qualitative phase, which have been described in Chapter 4 (Methods).

1.6. THE RESEARCHER'S ASSUMPTIONS

It is already known from the literature that following stoma formation, adults in established relationships experience changes in intimacy and sexual relationships, together with inability to feel a sexual human being or to embark on new intimate relationships because of the need for disclosure (Manderson, 2005). Young adults are engaged in socialising into adulthood, which includes establishing relationships with other adults as an equal adult (Arnett, 2001), developing a satisfying personal life which may include an intimate partner, and children (Strough et al, 1996, Young et al, 2001, Arnett, 2001). They are also less likely than older adults to be in stable relationships and may still be developing self confidence and acceptance of a disease which is associated with body image changes, feelings of embarrassment, decreased self respect and a sense of alienation (Brydolf and Segestren, 1996). Against this background, it seemed reasonable to assume that a reason for young people to delay surgery would be because of concerns about these issues, and this formed the basis for the development of the initial qualitative study. This assumption was only partially supported in the data provided by participants in the early phase of data collection, in that it was a concern but was not the primary consideration that affected decision making.

The researcher, who was white, middle aged and female, also assumed that participants would be willing to talk about their relationships and sexuality with her. Difficulties in eliciting information about any sexual matters have been described in Chapter 4 (Methods) and this led to reconceptualisation of the study. In fact, the two participants (both female and with perianal CD) who did have sexual problems described these openly and freely. Male and female participants also spoke often of relationship concerns but these were related more to body image issues, finding a partner and disclosing the presence of a stoma.

1.7. POTENTIAL CONTRIBUTION OF THIS STUDY

This study was intended to extend knowledge about the experience of surgery in young adults with IBD. It was anticipated that through investigating the process of transition, new perspectives concerning their perceptions of surgery, individual characteristics that affected or are affected by transition, the support available and the strategies they use to cope, would be revealed. This knowledge will be of interest to health professionals as it makes available new information that has the potential to be applied in practice to improve the quality of care provided for similar young people and assist them to adapt to and cope with this experience The study also gave these young people the opportunity to express themselves about an event that they may find difficult. Previous qualitative studies and the recent NACC (now Crohn's and Colitis UK) report on the experiences of young people with IBD, and what they say they need to help them to cope with their illness, have indicated that they may have different issues and concerns from older adults (Lynch and Spence, 2007, Daniel, 2001, Savard and Woodgate, 2009, Gray and Clarke, 2006). This research was intended to complement the existing literature by presenting the patient's perspective on the experience of surgery.

This research was also intended to make a methodological contribution to the field of IBD research as it is one of the first to use a mixed methods approach. The value of mixed methods studies in health care research is becoming increasingly recognised (O'Cathain et al, 2007) and this study provides an example of how one model of a sequential mixed methods design can be used.

1.8. DEFINITIONS

Young adult: In this study a young adult was a male or female aged between 18 and 25 years. The term was used interchangeably with **young person.**

Transition: In this study, transition was defined as: 'the inner reorientation and self-redefinition that people go through in order to incorporate change into their lives' (Bridges, 2004, pxii) occurring if an event or non-event results in a change in assumptions about oneself and the world and thus requires a corresponding change in one's behaviour and relationships' (Schlossberg, 1981a, p5). Transition involves the key elements of process, movement, variability, perception, and time span (Meleis, 2010), and also transformative learning whereby people acquire knowledge to make meaning of their lives and find new ways to locate themselves in an altered world (Cranton, 1996, Bridges, 2004).

1.9. STRUCTURE OF THE THESIS

Chapter 2 contains a systematic literature review which places the current study in the context of what is already known about the topic and provides justification for the investigation. Chapter 3 describes the concept of transition, outlines and evaluates Schlossberg's Transition Theory (Goodman et al, 2006) and justifies its selection as the theoretical framework for the study. Chapter 4 outlines the methods used in Phase 1 and Phase 2 of the study. Chapter 5 presents the findings from Phase 1. Chapter 6 presents the results of scale validation for the questionnaire used in Phase 2. Chapter 7 presents the results of the cross-sectional survey. Chapter 8 presents the results of the multivariate analysis. Chapter 9 completes the thesis with the discussion.

CHAPTER 2: SYSTEMATIC LITERATURE REVIEW

This chapter first outlines the background of the systematic review, its aims and objectives and the formulation of the research question. The method of the review is then described. This is followed by an assessment of the quality of the quantitative studies. A critical appraisal of the methodology of the quantitative studies follows. The chapter then describes the characteristics of the included studies. The outcome measure results for the quantitative studies are then presented. An assessment of the quality of the qualitative studies is then described, followed by presentation of the qualitative findings which are integrated into Schlossberg's 4S framework (Goodman et al, 2006). The chapter concludes by justifying the need for the current study.

2.1. BACKGROUND

This review aimed to synthesise the published literature from both qualitative and quantitative studies on this topic, identify what was already known and to ascertain that there was a need for the present study. This was the first systematic review on IBD surgery that focussed on the patient experience. The review followed the PRISMA statement for reporting systematic reviews (Liberati, et al, 2009).

2.2. AIM AND OBJECTIVES

The aim of this review was to investigate the experience of young adults aged 18–25 years who faced the prospect of, or had undergone, surgery for IBD. Prior to conducting primary research, a systematic review was carried out to find previous research on this topic, to determine and critically review the current evidence from previous studies on adults' experiences of IBD surgery. The literature review was deliberately focussed. It addressed adults' experiences of IBD surgery in preference to reviewing the literature on young adults with other chronic conditions because they are not directly comparable: many young people with chronic conditions such as diabetes, cardiac conditions, asthma, obesity, end stage renal disease, psychiatric disorders, rheumatologic conditions, and cerebral palsy, manage their condition medically so do not have comparable experiences. Also IBD is associated with disease specific issues such as body image, the stigma of altered bowel function and compromised continence which affect the experiences of adults at any age.

2.3. RESEARCH QUESTION FORMULATION

Framing the research question for this systematic review was essential to focus the review, so that relevant studies could be identified (Magarey, 2001, Khan et al, 2003). Khan et al (2003) recommend that the research question for a systematic review should be clear, well-structured, and include four PICO components: the ‘Patient group being investigated, Intervention, Comparative interventions and the Outcomes used to measure the effect.’ However, there was no comparator group for this review so a modified format was used which excluded this component.

2.3.1. Research Questions

The review addressed the following questions:

1. What psychosocial factors are associated with the experience of IBD surgery, from the patients’ perspective, in the young adult IBD population?
2. What have been the experiences of young adults with IBD who face the prospect of, or have had, surgery for this condition?

2.4. METHOD

The work for the original review commenced in April 2010 with an initial literature search for relevant peer reviewed primary research papers and was completed in September 2010. A final systematic literature search was undertaken in March 2014 to identify the most recent research in the field.The work of updating the review commenced May 2014 and followed PRISMA guidelines for reporting systematic reviews in healthcare. The final document synthesises all secondary research available on adult experiences of IBD surgery.

2.4.1. Inclusion and Exclusion Criteria

A modified PICO framework was used to establish the inclusion and exclusion criteria for this review (Centre for Reviews and Dissemination, 2008), to identify relevant studies. The PICO components included were (P) population; (I) intervention (study design/publication) and (O) outcomes. Table 2.1 (Appendix 1) summarises the PIO inclusion and exclusion criteria used in this review. The search was restricted to qualitative and descriptive quantitative studies published between 1999 and 2014 in the English language (due to time constraints and translation costs). All studies that addressed the experiences of adult patients undergoing surgery for IBD were eligible for inclusion.

2.4.2. Information Sources

A comprehensive search for relevant literature was carried out in three electronic databases, including PubMed, CINAHL, and ProQuest initially using the key words “young adult”, “surgery” and “Inflammatory Bowel Disease” or “IBD” or “Crohn’s Disease” or “ulcerative colitis”. The dates searched ranged from 1999 to 2014 and the date last searched was March 2014. The year 1999 was selected to capture the earliest studies describing outcomes from laparoscopic as well as conventional surgery and to reflect current practice in that IBD specialist nurses only began to be appointed in the mid 1990's. The initial free text electronic search yielded only three studies whose titles and abstract focussed specifically on this topic area. Therefore it was decided to extend the search to include studies which investigated adults with IBD over the age of 25 years together with young adults. Papers investigating patients of mixed aetiology were included if more than 50% of participants had an IBD diagnosis.

2.4.3. Search Strategy

The search strategy focused on primary studies using the information sources and eligibility criteria detailed above. The term 'Inflammatory Bowel Disease' rather than 'IBD' was used. Search terms used included MeSH terms: "Inflammatory Bowel Disease/surgery" OR "ulcerative colitis/surgery" OR "Crohn's disease/surgery" AND "surgery" with searches in all fields for: "experience" OR "perception" OR "adjustment" OR "adaptation" OR "outcome" OR "follow up" OR "concerns" OR "anxiety" OR "satisfaction" OR "recovery" OR "function" OR "quality of life" OR "body image" OR "coping" OR "support" in all fields. In addition, specific surgery types: "ileoanal pouch", "stoma" OR "perianal fistula" OR "bowel resection" were used as search terms. The full updated list of search terms used for searching each database are detailed in the search strategy in Appendix 2.

2.4.4. Other Sources

In addition to the database search results, the reference lists of retrieved papers were screened for additional potentially relevant studies. Efforts were also made to identify relevant previous systematic reviews or key review articles to determine if the present review is the first systematic review on the topic or if it is work is updating an existing evidence base.

2.4.5. Search Results

Using these search criteria, the literature search identified 154 potentially relevant articles which matched the specified search terms and appeared to be most relevant to the systematic review questions.

2.4.6. Study Selection

The study selection was performed in stages. Primary screening of titles and abstracts and decisions to include papers were conducted by the author and based on a global search in databases and screened based on relevance. The abstracts of selected papers were then reviewed to determine if they met the inclusion criteria. Relevant full text articles for the topic under review were obtained for data extraction and critical appraisal (Centre for Reviews and

Dissemination, 2008). Any duplicates were removed. Simultaneously, the full texts of any papers that did not meet the inclusion criteria but were deemed informative supplementary background material, were sought.

After titles and abstracts of all identified publications were screened, full texts of potentially relevant studies were retrieved and screened against the PIO inclusion criteria. A total of 32 published studies met the inclusion criteria, and were included in this review.

Figure 2.1 (Appendix 3) shows a flow chart of the study selection process, eligible studies, and excluded studies at each stage. The 32 eligible studies included 28 quantitative studies and four qualitative studies.

2.4.7. Data Collection Process

Table 2.2 (Appendix 4) summarises the characteristics of the 28 eligible quantitative studies reviewed. After deciding the studies for inclusion in this systematic review, a data extraction form was created by the reviewer in Microsoft Excel to summarise each study's characteristics (White and Schmidt, 2005, Victor, 2008). The following data were extracted:

- Authors
- Aim of Study
- Study Design
- Study Sample
- Surgical Intervention/Experience
- Outcome Measures
- Findings
- Study Quality and Limitations

2.5. CRITICAL APPRAISAL OF STUDY QUALITY

2.5.1. Critical Appraisal Tool Used To Assess The Quality Of The Quantitative Studies

To find the appropriate critical appraisal tool for this review, the author initially searched the CASP Critical Appraisal Skills Programme for quality and validity critical appraisal checklists. However, CASP tools are tailored to assess specific study designs (e.g., qualitative, cohort, randomised control trials, and systematic reviews), whereas the study designs included in this review vary and many are ambiguous (i.e., not specifically disclosed or defined in the abstract and method sections of selected publications). After carefully reviewing each CASP tool against the quantitative study designs in this review, the author found no appropriate CASP checklist, and searched for a more generic critical appraisal tool. The author finally chose Glynn's (2006) Evidence Based Librarianship (EBL) generic critical appraisal tool. The EBL is a generic critical appraisal checklist which contains 22 questions and it provides sufficient flexibility to appraise quality of intervention and observational studies (e.g., cohort, questionnaire-based studies). The EBL assesses methodological quality in four sections, as follows: (1) population, (2) data collection, (3) study design, and (4) results; and calculates a section validity (Y+N+U=T), and overall validity (Y+N+U=T); where Y=yes, N=no, U=unclear, and T=total. If Y/T ≥ 75%, then we can safely conclude that the study is valid (Glynn, 2006).

2.5.2. Study Quality Appraisal Results

Table 2.3 (Appendix 5) shows the results of the EBL quality appraisal of 28 quantitative studies included in this review. Only 10 (36%) of studies were deemed valid overall (i.e., they met 75% of more specific quality criteria), whereas 18 (64%) of studies had low validity and had poor methodological quality.   Only five studied (18%) met validity criteria for their population; 22 studies (79%) met validity criteria for their data collection; 13 studies (46%) used a valid study design; and only 1 study (4%) met the criteria for reporting valid results.

In terms of Section A: Study Population, the most common issue across the studies was that the sample size was not large enough for sufficiently precise estimates, and in 23 of the 28 studies, the response rate was below 80%, whereas a valid response rate is ≥80% (Polit and Beck, 2008). On a positive note, in 22 of the 28 studies (79%), the study population appeared to be representative of all eligible users, who might be included in the study and the choice of population was bias-free. Fourteen of the 28 studies (50%) did not state if informed consent was obtained from their participants, which could be a violation of ethics or a reporting oversight in the publication. In terms of Section B: Data Collection, most studies had a high quality of data collection, with only four studies using non-validated instruments (Bullen et al, 2012, Larson et al, 2008, Mahadev et al, 2011 and Persson and Hellström, 2002). Three studies did not describe data collection methods clearly enough to allow replication (Andersson et al, 2011; da Silva et al, 2008; and Thaler, 2005). There were no other issues with data collection. In terms of Section C: Study Design, the main limitation was that authors did not report if ethics approval was obtained in 14 of 28 studies (43%). There were no other issues with study design, which was appropriate to meet the aims of each study. Most studies collected their data from a single centre, possibly due to ethics constraints of accessing multi-centre sites, or preference to investigate outcomes in their own patient cohorts. In terms of results, the statistical results were clearly reported in all 28 studies, and the conclusions accurately reflect the analysis. However, confounding variables were not accounted for in 21 of the 28 studies (75%) studies, which means that the researchers have not controlled for additional variables that may have influenced the results. Finally, the majority of quantitative studies did not provide any suggestions for further areas to research in their discussion or conclusion sections; this is a limitation, as the reader cannot determine what issues still need to be addressed through further research. Instead, most authors focused on providing practical clinical implications, which they possibly consider more appropriate and for their clinical readership.

2.6. CHARACTERISTICS OF INCLUDED STUDIES

The 32 eligible studies were published in English between 1999 and 2014. In terms of country of study, 14 studies were carried out in Europe (3 UK, 4 Sweden, 2 Austria, 1 Denmark, 1 Germany, 1 Netherlands, 1 Norway, and 1 Switzerland), 8 were based in USA, 6 in Canada, and 4 in Australia.

2.6.1. Description of Methods

Table 2.4 (below) summarises the study design of 32 studies included in this review. Twenty-eight of the studies employed quantitative methods and 4 studies used qualitative methods. Eighteen of the quantitative studies used a single centre cross sectional retrospective questionnaire survey; two were multicentre cross sectional retrospective surveys, one was a case-control study, 7 were pre-post-surgery prospective studies with follow-up ranging from 3 months to 7 years. Three qualitative studies collected interview data using a qualitative phenomenological approach; and one qualitative study used narrative inquiry, also with in-depth interviews. Thus the majority of studies on biopsychosocial outcomes following IBD surgery were quantitative, which highlights a need for more mixed methods and qualitative research to understand the patient experience of surgery and transition in more depth. There is also a lack of pre-post prospective cohort longitudinal quality of life (QOL) studies that track patients after IBD surgery.

Table 2.4. Study Design Employed In The 32 Studies Included In This Review

Method	Frequency	Research Design	Study Authors
Quantitative	18	Single centre cross sectional retrospective questionnaire survey	Andersson et al (2011); Berndtsson et al (2011); Byrne et al (2007), Carlsson et al (2003); Delaney et al (2003); Dunker et al (2001); Garcia-Aguilar et al (2000); Kasparek et al (2007); Kuruvilla et al (2012); Larson et al (2008); Mahadev et al (2011); Moskovitz et al (2000a); Moskovitz et al (2000b); Persson et al (2005); Rini et al (2011); Riss et al (2013); Thaler et al (2005); Wuthrich et al (2009)
	6	Single centre prospective cohort study, baseline and follow-up	Bullen et al (2012); Davies et al (2008); Thirlby et al (2001); Tillinger et al (1999); Wang et al 2011; Weinryb et al (2003)
	2	Multi centre retrospective cross sectional, questionnaire survey	Brandsborg et al (2013); Knowles et al (2013b)
	1	Multi centre prospective case control, questionnaire survey	Cornish et al (2012)
	1	Multi-centre prospective cohort study, baseline and follow-up	da Silva et al (2008)
Qualitative	3	Phenomenology (in-depth interviews)	Beitz (1999); Notter and Burnard (2006); Savard and Woodgate (2009)
	1	Narrative inquiry (in-depth interviews)	Sinclair (2009)

2.6.2. Description Of Participants

The 32 studies incorporated a total of 3240 patients. In the 28 quantitative studies, the sample sizes ranged from 16 – 1047. The study participants included 2053 patients with UC and 736 patients with abdominal or perianal CD, although 4 studies did not separate patients into disease types. Most patients (n= 1936, 60%) had undergone IAP surgery. Five hundred and twenty (16%) patients had perianal surgery and 413 (13%) had had a bowel resection. There were 304 patients (9%) with a stoma and 67 (2%) patients had undergone other abdominal surgery that did not involve a stoma. The quantitative studies included patients of each gender in almost equal numbers (1568 male, 1623 female). All included studies met the age criteria (18 years and over), however one study divided patients only into those above the age of 65 years and those below. The average age of participants in the remaining quantitative studies was 43 years (range 18 – 92). Data on participant ethnicity and socioeconomic status were not extracted, as this information was infrequently reported.

Qualitative studies investigated mainly female experiences (8 male, 116 female). Only one qualitative study recruited patients in the same age range as those in the present study, although the largest (n=50) qualitative study did not report the age range of participants. Therefore, this review found only one qualitative study focussing on emerging adults as a specific study group, which highlights the need for the current research to address this gap.

2.6.3. Description Of Measures And Outcomes

Outcome measures varied. Table 2.5 (below) summarises the outcomes assessed in the 28 quantitative studies.

Twenty different measures assessed quality of life (QoL). Six different measures assessed body image; five measures assessed bowel function and incontinence, four assessed surgical decision-making; three assessed urinary function; three assessed sexual functioning. Less frequent outcomes assessed include symptom severity, preference for surgery; what patients did to prepare for surgery; quality of care, patient satisfaction; surgery experience, illness perceptions, social support, self-esteem, coping, anxiety symptoms, depression symptoms, and psychological adjustment to illness. This array of outcome measures suggests that medical professionals focus mainly on quality of life as an indicator of positive adjustment to surgery and less on the psychosocial and transition aspects of the surgery experience such as surgical decision-making, body image, adjustment, quality of care and patient satisfaction. Surprisingly, several important aspects of the patient experience were not assessed in the 28 quantitative studies, including patient needs, pain, pre-operative anxiety, health status (apart from bowel function and symptom severity) and differential pre-post concerns/outcomes between men and women.

Table 2.5: Outcomes Assessed in the 28 Quantitative Studies

Continence	Andersson et al (2011); Cornish et al (2012)
Bowel function	Garcia-Aguilar et al (2000); Dunker et al (2001); Wuthrich et al (2009); Brandsborg et al (2013)
Symptom severity	Moskovitz et al (2000a); Moskovitz et al (2000b)
Illness perceptions	Knowles et al (2013b)
Psychological adjustment to illness	Weinryb et al (2003)
Quality of life	Tillinger et al (1999); Moskovitz et al (2000a); Moskovitz et al (2000b); Dunker et al (2001); Thirlby et al (2001); Carlsson et al (2003); Delaney et al (2003); Weinryb et al (2003); Thaler et al (2005); Kasparek et al (2007); Larson et al (2008); Davies et al (2008); Wuthrich et al (2009); Andersson et al (2011); Berndtsson et al (2011); Mahadev et al (2011); Wang et al (2011); Bullen et al (2012); Kuruvilla et al (2012); Riss et al (2013); Brandsborg et al (2013); Knowles et al (2013b)
Patient satisfaction	Garcia-Aguilar et al (2000)
Social support	Moskovitz et al (2000a)
Sexual function	da Silva et al (2008); Davies et al (2008) Larson et al (2008); Wang et al (2011); Riss et al (2013); Cornish et al (2012)
Body image	Dunker et al (2001); da Silva et al (2008); Larson et al (2008); Bullen et al (2012)
Coping	Moskovitz et al (2000a); Carlsson et al (2003)
Self esteem	da Silva et al (2008)
Depression/Anxiety	Tillinger et al (1999) Bullen et al (2012); Knowles et al (2013b)
Urinary function	Wang et al (2011); Cornish et al (2012)
Quality of care	Persson et al (2005)
Community resource use	Moskovitz et al (2000b)
Preference for surgery	Byrne et al (2007)
Influence on surgical decision making	Rini et al (2011)

2.7. OUTCOME MEASURE RESULTS FOR THE QUANTITATIVE STUDIES

2.7.1. Quality Of Life

This section summarises the results from quantitative quality of life assessments found in this review that investigated QoL in five IBD surgery patient groups (i.e., ileoanal pouch, stoma, bowel resection, abdominal surgery, and anal fistula surgery). The majority of studies investigated both physical functioning and psychosocial aspects of quality of life, ranging from anal pain, faecal incontinence, sleep disturbance, to body image and emotional distress. Table 2.6 summarises the quality of life measures included in this review. As can be seen, 20 different quality of life measures were used to assess level of functioning and wellbeing, although SF-36, which measures generic quality of life was by far the most common assessment, enabling cross-study comparison.

Table 2.6. Summary of 20 Quality of Life Scales Reported by Author and Type of IBD Surgery

Scale	**Operation type**	**Author**
Cleveland Global QoL	IAP	Kuruvilla et al (2012)
	Stoma	Kuruvilla et al (2012)
	Anal fistula	Kasparek et al (2007)
DQO	Bowel resection for IBD	Tillinger et al (1999)
EQ-5D-3L	IAP	Kuruvilla et al (2012)
	Stoma	Kuruvilla et al (2012)
FIQL	IAP	Kuruvilla et al (2012)
	Stoma	Kuruvilla et al (2012)
General wellbeing – Likert scale	Bowel resection for IBD	Tillinger et al (1999)
GIQLI	IAP	Dunker et al (2001)
	Bowel resection for IBD	Thaler et al (2005)
	Anal fistula	Kasparek et al (2007)
HSQ (modified SF36)	IAP	Thirlby et al (2001)
	Bowel resection for IBD	Thirlby et al (2001)
IBDQ	IAP	Moskovitz et al (2000a); Moskovitz et al (2000b); Wang et al (2011); Brandsborg et al (2013)
	Stoma	Wang et al (2011)
	Bowel resection for IBD	Moskovitz et al (2000a); Moskovitz et al (2000b)
	Anal fistula	Riss et al (2013)
Oresland score	IAP	Berndtsson et al (2011)
Ostomy adjustment scale	IAP	Berndtsson et al (2011)
Overall impact perianal disease on QoL	Anal fistula	Mahadev et al (2011)
RFIPC	Stoma	Carlsson et al (2003)
	Bowel resection for IBD	Tillinger et al (1999)
Self-devised	IAP	Berndtsson et al (2011)
	Stoma	Carlsson et al (2003)
	Anal fistula	Mahadev et al (2011)
SF12	Anal fistula	Riss et al (2013)
SF36	IAP	Dunker et al (2001); Wuthrich et al (2009); Andersson et al (2011); Wang et al (2011);
	Stoma	Carlsson et al (2003); Wang et al (2011); Bullen et al (2012)
	Bowel resection for IBD	Thaler et al (2005)
	Abdominal surgery (other)	da Silva et al (2008)
	Anal fistula	Kasparek et al (2007)
SF8	IAP	Larson et al (2008)
SIBDQ	IAP	Davies et al (2008); Kuruvilla et al (2012)
	Stoma	Kuruvilla et al (2012)
	Anal fistula	Kasparek et al (2007)
Stoma QoL scale	Stoma	Kuruvilla et al (2012); Knowles et al (2013b)
TTO	Bowel resection for IBD	Tillinger et al (1999)
Well-being profile	IAP	Weinryb et al (2003)

This section summarises the quality of life outcomes for the five IBD surgery patient groups.

2.7.1.1 Quality Of Life - Ileoanal Pouch Patients

Thirteen studies assessed QoL in ileoanal pouch patients, including Moskovitz et al (2000a, 2000b), Dunker et al (2001), Thirlby et al (2001), Weinryb et al (2003), Davies et al (2008), Larson et al, (2008), Wuthrich et al (2009), Andersson et al (2011), Berndtsson et al (2011), Wang et al (2011), Kuruvilla et al (2012) and Brandsborg et al (2013)

Moskovitz et al (2000a, 2000b) administered the Inflammatory Bowel Disease Questionnaire (IBDQ) (Guyatt et al, 1989) to patients with UC or CD, 34% of whom had an IAP, an average of 9 months after surgery. The mean IBDQ was 161.9 +/- 37. Mean IBDQ did not differ between groups defined by gender, diagnosis, type of surgery (IAP/other bowel resection), age or time since surgery. Use of professional/individual resources preoperatively had an effect on post surgical QoL in comparison with social/educational resources ($p=0.015$) (Moskovitz et al, 2000b). Patients with a lower quality of life used more maladaptive coping behaviour ($p=0.002$), had less perceived social support ($p<0.0001$), and more disease related symptoms ($p<0.0001$) (Moskovitz et al, 2000a).

Dunker et al (2001) used the SF-36 (Ware and Sherbourne, 1992) and Gastrointestinal Quality of Life Index (GIQLI) (Eypasch et al, 1995) in patients undergoing laparoscopic assisted and conventional IAP. Quality of life was the same in both groups, with scores of at least 50/100 for physical functioning, general health, vitality, social functioning and mental health. However, global physical functioning was higher in the laparoscopic assisted IAP group ($p=0.05$). GIQLI QoL scores were the same for both groups with scores greater than 100 out of 144.

Thirlby et al (2001) used the Health Status Questionnaire (HSQ) (Radosevich et al, 1994) to determine QoL at 3, 6 and 12 months after surgery and at each subsequent follow up visit. Average and Gain HSQ scores for all assessments showed poor preoperative scores for general health (health perception), role limitations due to physical health, social functioning and energy level. Postoperatively scores were comparable to the general population. There was improvement in postoperative scores for UC patients (78 of 85 had an IAP) in health perception ($p<0.05$), physical functioning ($p<0.05$), role physical ($p<0.05$), role emotional ($p<0.05$), social functioning ($p<0.05$), mental health ($p<0.05$), bodily pain ($p<0.05$), energy/vitality ($p<0.05$). Preoperatively, UC patients had the lowest scores in physical health, social function and energy level. At an average follow up of 5 months (range 3 – 70), scores equalled or excelled those in the general population in all but role limitations due to physical health. For those (n=12) who had had surgery over a year ago (mean 32 months, range 12 – 70), results were similar to the early results but were lower than for the general population. Improvements in ability to function at home and work, social functioning, bodily pain and energy, were significant (*p*<0.001). Short and long term Gain scores were compared with preoperative scores. They were highest in long term patients (mean 29 months, range 12 – 76) and these changes were significant in all scales for UC but only 1(not stated) for CD (p<0.05). Patients were further analysed by age (divided by the mean age of 49 years) and sex. Older patients benefitted as much as younger and more in role limitations due to physical health and bodily pain. No differences in QoL were found between men and women except that females had more bodily pain.

Weinryb et al (2003) used the Psychological Adjustment to Illness Scale (PAIS) (Derogatis, 1986) with UC patients having an IAP while they had the stoma and at 18 months and 7 years after ileostomy closure. They found that PAIS was good at all stages of IAP, with no significant differences in most PAIS mean scores over all three assessments, over time. However, health care orientation (patients preoccupation with health care concerns and trust in the health care system) improved at short term but deteriorated at long term follow up, although it remained better than pre-operatively (p=0.001). For domestic environment (relationships at home) and PAIS total there was a deterioration between short term follow up (p=0.038) and long term follow up (p=0.029). Men had more problems than women at long term follow up with extended family relationships outside the nuclear family (p<0.006). Wellbeing profile scores were good at all stages of surgery with a mean of 15.63 preoperatively, 15.9 at 3 months and 17 at 7 years (best possible score 11, worst 44).

Davies et al (2008) assessed QoL using the disease specific Short Inflammatory Bowel Disease Questionnaire (SIBDQ) (Irvine et al, 1996) preoperatively and at six and 12 months after surgery. Mean SIBDQ scores increased for men and women at both 6 months (men, p=0.012, women, p=0.004) and 12 months after the operation (men, p=0.002, women, p<0.001).

Larson et al (2008) used the SF-8 (Ware et al, 2001) to compare QoL in patients undergoing either laparoscopic or conventional IAP. Quality of life was the same for men and women and did not differ between operations.

Wuthrich et al (2009) assessed QoL using the SF-36: IAP patients scored slightly higher than the general population in the physical component summary and slightly lower in the mental component summary than the general population but neither patient condition (UC or other) nor surgical variables e.g pouch size, surgical technique were associated with a better quality of life (p>0.05).

Andersson et al (2011) used the SF-36 to evaluate long term quality of life an average of 12 years after IAP surgery. Patients scored significantly lower than the general population in 4 of the 6 health domains: social functioning (p<0.01), mental health (p<0.001), vitality (p<0.001) and general health perception (p=0.001). Overall QoL could not be measured, due to different versions of the SF-36 being administered to each group. Frequency of defaecation at night, faecal incontinence and urgency were found to be independent negative prognostic factors of quality of life. Women scored significantly lower than men in all six domains. Females had lower scores than the general female population in all domains. Male patients had lower scores than the general population in general health, vitality and mental health (data not shown).

Berndtsson et al (2011) devised an open ended questionnaire to determine factors that contributed to good quality of life. Most frequent was health (58%), followed by family (33%), restroom access (22%), friends (22%), employment (21%) and economy (12%).

Wang et al (2011) administered the IBDQ and SF-36 to patients having an ileoanal pouch or permanent stoma before and 6 months after surgery and found men with IAP had significantly improved IBDQ total scores (p=0.001) and improved scores in individual IBDQ domains (emotional health, p<0.001, systemic symptoms, p=0.02, social function p<0.001) except for bowel symptoms. Scores for SF-36 physical component scale (p=0.001) and mental component scale (p=0.004) also improved. Women with IAP had significant improvement in the IBDQ total score (p=0.04) and the emotional health subscale (p=0.01). SF36 scores improved significantly on the mental component summary (p=0.02) and physical component summary (p=0.03).

Kuruvilla et al (2012) used multiple measures, the EuroQol questionnaire (EQ-5D-3L) (The EuroQol Group, 1990), SIBDQ, Cleveland Global Quality of Life Questionnaire (CGQL) (Kiran et al, 2003), Faecal Incontinence Quality of Life Scale (FIQL) (Rockwood et al, 2000) and Stoma Quality of Life Scale (SQL) (Baxter et al, 2006) to compare long term QoL in patients with an IAP or a stoma. There were no differences between groups as measured by the EQ-5D-3L, SIBDQ or FIQL. IAP patients scored higher on the CGQL for Fazio score (p=0.03), current quality of health (p=0.01) and energy level (p=0.05). Using the SQL, sexuality/ body image (p<0.001), work/social (p=0.01) were better in IAP patients but skin irritation (p=0.02) was worse.

Finally, Brandsborg et al (2013) administered the generic SF-36 and disease specific IBDQ to a national population of 1047 ileoanal pouch patients who had had surgery 0 – 10 years, 11 – 20 years and 21 – 30 years previously. Male patients had significantly better scores in the SF-36 dimensions for physical problems, bodily pain, general health perception, vitality and mental health than female patients ($p<0.001$). There was no difference between the three ‘time’ groups in any domain. Male patients also had higher IBDQ scores than female patients and patients who had been operated on 21 – 30 years previously achieved higher scores than those whose surgery was 0 – 10 years ago ($p<0.001$).

2.7.1.2. Quality Of Life - Stoma Patients

Five studies assessed quality of life in stoma patients, including Carlsson et al, 2003, Bullen et al, 2012, Wang et al, 2011, Kuruvilla et al, 2012 and Knowles et al, 2013b.

Carlsson et al (2003) used the SF-36 and a visual analogue scale. They found that most HRQoL scores were similar to the general population, although the ileostomy group had significantly lower vitality ($p<0.05$). Patients’ definition of the positive attributes associated with good quality of life mainly concerned social dimensions of life and health (e.g family, work). Obstacles to a good quality of life mainly concerned psychological aspects (e.g psychological bad health, not daring to have a sexual relationship). Low perceived quality of life correlated with greater worries and concerns ($p=0.002$).

Wang et al. (2011) administered the IBDQ and SF-36 and found both men ($p<0.001$) and women ($p=0.04$) with IAP or a permanent stoma reported improved IBD-specific QoL after surgery. Men and women also had improved general QoL scores for physical component (men, $p=0.001$, women, $p=0.02$) and mental component (men, $p=0.003$, women, $p=0.02$).

Bullen et al (2012) administered the SF-36, and found stoma patients had significantly lower physical component scores at follow-up than non-stoma patients ($p=0.006$). There was no difference between patients with and without a stoma in mental health component scores ($p=0.167$).

Kuruvilla et al (2012) compared QoL between IPAA and ileostomy (stoma) patients using the EQ-5D-3L, SIBDQ, CGQL, FIQL and SQL. The EQ-5D-3L, SIBDQ and FIQL found no group differences in QoL. The CGQL found IAP patients had significantly higher current quality of health ($p=0.01$), and higher energy level ($p=0.05$) than stoma patients, but no group difference in QoL was found ($p=0.34$). The SQL revealed that stoma patients had lower scores for sexuality/ body image ($p<0.001$), and work/social function ($p= 0.01$), but less skin irritation ($p=0.02$) than IAP patients.

Finally, Knowles et al (2013b) used the SQL and found no stoma related QoL differences based on gender, planned vs emergency surgery, type of stoma, number of operations, or current use of psychological services. Lower stoma QoL was associated with having more negative illness beliefs ($p<0.05$), higher anxiety ($p<0.05$) and depression ($p<0.05$).

2.7.1.3. Quality Of Life - Bowel Resection For Inflammatory Bowel Disease

Six studies assessed the quality of life in IBD patients who had a bowel resection (Tillinger et al, 1999, Moskovitz et al, 2000a, 2000b, Thirlby et al, 2001, Delaney et al, 2003 and Thaler et al, 2005.

Tillinger et al (1999) assessed QoL using the Rating Form of Inflammatory Bowel Disease Patient Concerns (RFIPC) (Drossman et al, 1991), Time Trade off Technique (TTO) (Torrance, 1986) and Direct Questioning of Objectives (DQO) (McLeod et al, 1991). Three months after surgery patients had significant improvement in QoL compared with preoperatively ($p<0.005$) and at 6 months follow-up ($p=0.04$). Twenty four months after the operation, patients in remission still showed improvement compared with pre-operatively ($p=0.006$). At month 3 after surgery all patients had a improvement in TTO ($p<0.005$) and DQO ($p<0.05$). At 6 months follow up, this improvement was only sustained for DQO ($p<0.005$). At 24 months there was significant improvement in TTO ($p<0.005$) and TTO ($p<0.005$) only for patients in remission from chronic active CD.

Moskovitz et al (2000a, 2000b) administered the IBDQ to IBD patients, 57% of whom had a bowel resection. There were no differences in QoL by gender, diagnosis, type of surgery or time since surgery. Perceive social support ($p=0.001$), current IBD symptoms ($p<0.001$) and maladaptive coping ($p=0.006$) differed between high and low QoL groups (Moskovitz et al, 2000a). Professional/individual resource use before surgery in preparation for surgery had a positive effect on post-surgical quality of life ($p=0.015$) (Moskovitz et al, 2000b).

Thirlby et al (2001) used the HSQ with CD patients who had bowel resection. HSQ scores increased across all quality of life domains at 5 months but did not reach significance. Neither did they reach the level of the general population except in mental health ($p<0.05$) and bodily pain ($p<0.05$) (average follow up 16 months (range 3 – 76). For those patients who had surgery for CD over a year ago (mean 26 months) n=22, mean scores were higher than those in whole group (CD and UC) ($p<0.05$).

Delaney et al (2003) assessed quality of life using the CGQL and found significant improvement in QoL 30 days postoperatively (p<0.001). Fifty four bowel resection patients improved, 8 had no change, and 20 were worse. Current QoL(CQL) (p=0.036), current quality of health (CQH) (p<0.001), current energy level (CEL) (p<0.001), overall quality of health (OQH) (p=0.003) and global quality of life score (GQL) (p<0.001) all significantly improved. Significantly greater improvement in OQH was found in female patients (p=0.008) and those without any complications (p=0.013). Those with abdominal procedures had greater improvement in CQH than patients with perineal procedures (p=0.012). Those on steroids at time of surgery showed greater improvement in CQL (p=0.016). In contrast, those with unimproved CGQL had more complications (p=0.03) and readmissions (p=0.04). Improvement in CGQL was greater in patients having abdominal procedures (p=0.03), and those on medication at time of surgery (p=0.03)

Finally, Thaler et al (2005) assessed quality of life in two groups of CD patients (open surgery versus laparoscopic resection), at a minimum of 8 months after surgery, using SF-36 and GIQLI scales, to compare patient scores with healthy age-matched individuals. Compared to the general US population, mean GIQLI scores (p=0.001) were significantly lower in CD patients than in healthy individuals. CD patients had significantly lower QoL on the physical component summary than the healthy population (p=0.001), with lower SF-36 scores in 6 out of 8 domains (physical functioning, physical role limitations, bodily pain, general health perception, vitality and social functioning) (p<0.05). Disease recurrence was the only factor predicting lower QoL scores (SF-36 physical component summary, p=0.026, GICLI (p=0.018).

2.7.1.4. Quality Of Life - Abdominal Surgery (Inflammatory Bowel Disease And Others)

One study, by da Silva et al (2008) used the SF-36 to compare quality of life in 93 female patients (mean age 43 years) who had undergone abdominal surgery (39%) or pelvic surgery (61%); and found no difference in general quality of life between groups. Both groups showed improved physical and mental health-related quality of life, with slight improvement in MCS at 6 months and significant improvement at 12 months (p=0.007). PCS was significantly improved 6 months after surgery (p value not stated) with no significant improvement in the next 6 months. At 6 months follow-up, abdominal surgery patients had recovered faster than pelvic surgery patients (p=0.003).

2.7.1.5. Quality Of Life - Anal Fistula Surgery

Three studies assessed QoL for anal fistula patients (Kasparek et al, 2007; Mahadev et al, 2011 and Riss et al, 2013).

Kasparek et al (2007) administered four standardised QoL scales and developed a new scale to measure limitations of the stoma. The SF-36 and CGQL scales found no overall difference in QoL between diverted (with a stoma) and non-diverted patients. In contrast, the SIBDQ found that diverted patients scored better on bowel function ($p<0.0001$); and the GIQLI found that diverted patients had better QoL, including fewer GI symptoms ($p<0.001$), than non-diverted patients. Additional questions in a newly developed QoL questionnaire designed for diverted patients found that 85% of faecally diverted patients reported better QoL in general, as compared with pre-operatively; 29% reported no restrictions in everyday life, 56% had minor restrictions, and 15% reported post-operative restrictions that led them to avoid activities e.g. sports, swimming, and sex. Despite these restrictions, 97% of diverted patients indicated they would opt for diversion again and 44% of the diverted patients were less likely to complain of CD symptoms, as compared with 79% of undiverted patients ($p<0.05$). Results were not dependent on length of time since diversion.

Mahadav et al (2011) developed a new measure to assess 16 aspects of QoL domains, including physical, functional, emotional, and cosmetic. Patients ranked the importance of symptoms which most frequently affected their quality of life as follows: anal pain (40%), anal discharge (39%), physical activity restriction (39%), sleep interference (39%), feeling unclean (39%), anal incontinence (38%), and emotional distress (38%). Patients also ranked their aversion to particular symptoms, and reported greater aversion to the physical and functioning aspects, including anal incontinence (85%), anal pain (81%), anal discharge (78%), physical activity restriction (77%) and loss of independence (77%); whereas they were less slightly bothered by sleep interference (75%), social activity and sexual activity restriction (75%). Overall, the findings suggest that patients are more affected by physical issues than social issues, except that women gave equally high importance to physical and emotional aspects of QoL. Compared with 19% of men, 53% women reported anal pain as highly important ($p<0.005$). The presence of a drain (seton stitch) related to 13 or 16 domains and was most predictive of ratings for incontinence ($p=0.002$), social activity restriction ($p=0.004$), feeling unclean ($p=0.001$), sleep interference ($p=0.001$) and confidence to go out ($p=0.001$). Having a past or current stoma predicted psychosocial aspects including sleep interference ($p=0.004$) and confidence to go out ($p=0.003$).

Riss et al (2013) evaluated QoL using the SF-12 (Ware et al, 1996) and IBDQ. The SF-12 found the physical health of anal fistula patients after surgery was lower than healthy matched controls ($p=0.03$), but there were no group differences in mental health. IBD patients had significantly lower IBDQ scores than healthy controls ($p<0.0001$). Loose seton drainage ($p=0.03$), complex fistula ($p=0.004$), current active CD ($p<0.0001$) and current perianal complaints ($p<0.0001$) were found to significantly impact QoL. Quality of life was also adversely affected in both male and female patients with faecal incontinence ($p=0.0006$).

2.7.1.6. Quality Of Life In Four Qualitative Studies

Interestingly, quality of life, as a concept, did not emerge spontaneously in patient narratives in the three phenomenological studies or the narrative inquiry study, which suggests that when participants discuss their experience of IBD surgery in their own words, quality of life is not a primary concern; however it is the primary outcome measure used in medicine, indicating there is some dissonance between what is important to IBD patients versus medical professionals, in terms of outcomes that should be assessed.

2.7.2. Physical Function Outcomes

2.7.2.1. Bowel Function

Three studies all used a self devised questionnaire to investigate bowel function, including faecal continence, in IAP patients (Dunker et al, 2001, Wuthrich et al, 2009 and Brandsborg et al, 2013). Two further studies (Andersson et al, 2011, Cornish et al, 2012). also assessed bowel function using the Wexner score (Jorge and Wexner, 1993) to assess faecal incontinence in IAP patients. One study investigated faecal incontinence in patients after perianal fistula surgery with a self devised questionnaire (Garcia-Aguilar, 2000).

Dunker et al (2001) devised a questionnaire to assess functional outcome in patients who had had either laparoscopic or conventional IAP surgery an average of 15 months previously. Functional outcome was the same in both groups who on average passed stools 6 times during the day and once or twice at night. Most patients passed semi solid stools, had soiling less than once a week and were never passively incontinent. They were able to hold stool for more than 15 minutes, had flatus incontinence and took no anti-diarrhoeal medicine. The only significant difference was that the patients who had conventional surgery were more likely to make minor dietary restrictions ($p<0.05$).

Wuthrich et al (2009) used a specifically devised questionnaire to investigate long term bowel function in paients after IAP surgery (median 83 months, range 4 – 230). Two thirds (n=46, 66%) opened their bowels 5 – 10 times during the day, 20 (28%) less than five times a day, and only four (6%) more than 10 times a day. Most patients (n=48, 69%) opened their bowels 1 – 4 times a night. A further 27% (n=19) never had nocturnal bowel movements. Daytime continence was good to excellent for 77%, 23% had some soiling and none were incontinent. Similar results pertained to night time continence. Two thirds of patients never used a pad, 7% sometimes and 28% often used one. The majority of patients either never experienced pouchitis (53%) or had had only one or two episodes (19%), 11% had less than five and 17% had more than five episodes. Thirty percent of patients stated they were preoccupied with their intestinal function which had a significant impact on their daily activities but 42% were never bothered by their intestinal function.

Brandsborg et al (2013) used a specifically devised questionnaire to assess bowel function in IAP patients in the preceding two weeks. More women experienced urgency than male patients (56% vs 44%, p=0.0021).There was a gender difference in the median number of bowel movements in 24 hours, 7 (range 1 – 23) in women and 6 (range 1 – 20) in men (p<0.001). Pad usage was more frequent in women (62% vs 38%, p<0.001). Patients operated on 21 – 30 years previously had more major incontinence (p=0.009) and used more pads (p=0.01) than those who had their surgery 0 – 10 and 11 – 20 years previously. The proportion of patients with urgency was significantly higher for patients operated on 0 – 10 years previously than for those whose surgery was 11 – 20 years ago (p=0.009).

Andersson et al (2011) used the Wexner continence grading scale to assess long term defaecatory function in IAP patients whose median time following surgery was 12 years (range 2 – 22 years). The median frequency of bowel movements was 7 (range 3 – 12) during the day and 2 (range 0 – 6) at night. Although 46 (42%) used anti diarrhoeal medicine, 31 (30%) never needed to. The majority of patients had some degree of incontinence (mean Wexner score 7.8, range 0 – 17). Only 38 (36%) never had leakage during the day and 18 (17%) never had leakage during the night. Sixty percent (n=65, 75% men and 25% women) reported they were always or usually able to defer defaecation for a minimum of 15 minutes. Fifty six patients (51%) who were unable to discriminate between stool and gas had more frequent episodes of faecal incontinence (p=0.002). Slightly less than half the patients (47%) were more content with their bowel function than prior to IAP and 13% less content. Frequency of defaecation at night correlated strongly with HRQoL (SF36) in 6 domains: physical function (p<0.01), social function (p<0.01), mental health (p=0.03), vitality (p<0.01), bodily pain (p<0.01) and general health (p<0.01). Faecal incontinence was related to HRQol in general health (p<0.01), vitality (p<0.03) and social functioning (p<0.04). Multiple linear regression analysis showed that physical function was associated with night defaecation frequency, Wexner score and defaecatory urgency ($p<0.05$). Social function was associated with night frequency and urgency ($p<0.05$). Mental health was associated with night time frequency, Wexner score and age ($p<0.05$). Vitality was associated with night time frequency and Wexner score ($p<0.05$). Bodily pain was associated with night time function ($p<0.05$). General health was associated with night time frequency and Wexner score ($p<0.05$). Female patients scored lower than male patients across all health dimensions.

Cornish et al (2012) compared female IAP patients with a control group of female UC patients using the Wexner score. Those with IAP had less urgency than UC patients (47.9% vs 75%, $p=0.006$) but increased frequency (IAP median 5.5 +/- 3 vs UC median 3 +/- 3, $p<0.001$). They also had more night time bowel movements (IAP 82% vs UC 49%, $p<0.001$) and night time seepage (IAP 61.8% vs UC 30.9%, $p=0.001$). They were also more likely to use loperamide to control bowel function (IAP 72% vs UC 50%, $p=0.02$). Women who had IAP following vaginal delivery were more likely to have day time seepage (62.5% vs no delivery 33%, $p=0.046$) and require pads (46.2% vs no delivery 11.4%, $p=0.026$)

Garcia-Aguilar et al (2000) devised a questionnaire to assess type, grade and duration of faecal incontinence in patients following anal fistula surgery. Anal incontinence, including soiling, accidental bowel movements or difficulty controlling flatus was reported by 139 (46%). Soiling of underwear ($p<.001$) and accidental bowel movements ($p=0.008$) were significantly associated with patient satisfaction and dissatisfaction increased linearly with the number of incontinence problems. Only 1.9% of patients without incontinence were dissatisfied whereas 50% of patients with soiling, difficulty holding flatus and accidental bowel movements were dissatisfied. Eighty four percent of patient dissatisfaction was attributable to anal incontinence. Of the patients with anal incontinence, 47% (65) indicated that one or more physical (30%, $p=0.041$), social (40%, $p<0.001$) or sexual (28%, $p=0.03$) activities were affected to some extent or greatly by it.

2.7.2.2. Urinary Function

Two studies investigate urinary function, Wang et al (2011) and Cornish et al (2012).
Wang et al (2011) used the American Urological Association Symptom Index (AUASI) (Barry et al, 1992) and Urinary Incontinence Questionnaire (UIQ) (Diokno et al, 1988) to assess urinary function in men and women following proctectomy with either a stoma or IAP. There were no significant changes on the AUASI or UIQ for either men or women following surgery.

Cornish et al (2012) administered the King’s Health Questionnaire (Kelleher et al, 1997) to female patients undergoing IAP. Compared to a control group of women with UC who had not had surgery, they experienced bladder dysfunction (urgency, frequency or incontinence) at a mean age of 37.6 years, 10 years before the controls (p=0.044). The severity of bladder symptoms was also worse for IAP patients (p=0.004).

2.7.2.3. Sexual Function

Six studies investigated sexual function (da Silva et al, 2008, Davies et al, 2008, Larson et al, 2008, Wang et al, 2011, Cornish et al, 2012, Riss et al, 2013).

da Silva et al (2008) used the Female Sexual Function Index (FSFI) (Rosen et al, 2000) with women who had pelvic surgery (n=48, 84.2%), including 34 with an IAP, and abdominal surgery predominantly for benign colorectal disease (n= 29, 80.6%). Fifty seven had a stoma. There was a significant deterioration in sexual function at 6 months post operatively with an 8% increase in dyspareunia, 9.8% decline in lubrication, 8.1% decline in arousal, 7.9% decline in orgasm, 4.9% decline in libido and 4.8% decline in sexual satisfaction. There was a partial improvement in sexual desire, satisfaction and dyspareunia at 12 months (p=0.02). However, at 12 months sexual function had not returned to preoperative levels. Patients with a stoma had less sexual desire (p=0.05) and lower scores for orgasmic function (p=0.04). Patients with better self esteem (p=0.043) and body image scores (<18) had significantly better sexual function, as did premenopausal women and those on HRT. Better sexual functioning was also seen in those who had higher PCS and MCS scores in the FS-36 at 6 months. 81.4% of women thought discussion of sexual issues to be extremely or somewhat important. Most also stated that discussion should take place before the operation and be initiated by health professionals.

Davies et al (2008) investigated sexual function following IAP surgery using the International Index of Erectile Function (IIEF) (Rosen et al, 1997) and FSFI. Men had high mean and erectile function scores preoperatively and scores had not decreased at 6 and 12 months after surgery. Measured with the FSFI, there was a high proportion of abnormal sexual function in women preoperatively (73%) which decreased post op to 25% (*p*=0.001). Mean FSFI scores increased post operatively to 12 months (*p*=0.031).

Larson et al (2008) also used IIEF and FSFI to investigate sexual function one year after IAP surgery, comparing laparoscopic and conventional surgery patients. There were no significant differences between the groups. Orgasmic function in men was poorer in the laparoscopic group (p=0.05). However in all sexual function domains except overall satisfaction, men with IAP scored better than the general population (95% confidence interval). In women sexual function was lower than for general population in all but one domain (satisfaction) (95% confidence interval).

Wang et al (2011) explored sexual function after proctectomy in patients with either a stoma or IAP using the IIEF, FSFI and Sexual Function Questionnaire (SFQ) (Quirk et al, 2002). Scores in the IIEF had improved for men in erectile dysfunction (p=0.05), sexual desire (p=0.02) and satisfaction with intercourse (p=0.01) 6 months postoperatively. Modified SFQ scores also improved overall (p=0.001) and in all subscales- desire (p=0.001), arousal/sensation (p=0.009), arousal/lubrication (p=0.01), orgasm (p=0.03), pain (p=0.006) and enjoyment (p=0.003). When the IIEF scores of men with a permanent ileostomy were compared to men with IAP, those with an ileostomy only showed improvement in orgasmic function (p=0.03) and IIEF total score (p=0.02) whereas in those with IAP the IIEF total score increased after surgery (p=0.05) with significant improvements in sexual desire (p=0.007). In the SFQ all domains except orgasm significantly improved (p=0.003). Although FSFI scores improved for women postoperatively, this was significant only in the desire subscale (p=0.03). SFQ scores for women did not improve after surgery.

Cornish et al (2012) compared long term sexual function in women following IAP surgery with UC patients who had not had surgery using the FSFI. There was no difference in overall FSFI score. Women with an IAP who were not sexually active had a higher desire score that UC patients who were not sexually active (p=0.003).

Finally, Riss et al (2013) investigated sexual function in patients who had surgery for CD using the IIEF and FSFI. Although the sexual function scores in FSFI were lower for women following fistula surgery, there was no significant difference in overall sexual function scores between men or women and a control group of healthy people in the general population. However, in women, additional pelvic floor operations and infliximab therapy postoperatively were associated with decreased FSFI score (p=0.002). In men, loose seton (p=0.013) and an abscess at the time of surgery (p=0.003) were associated with erectile dysfunction. Additional pelvic floor operations (p=0.013) and current pelvic complaints (p=0.003) impacted negatively on orgasmic function. Sexual desire in men was negatively influenced by an abscess at operation (p=0.046), a loose seton (p=0.046), current pelvic complaints (p=0.026) and complex fistula (p=0.024). Male patients with faecal incontinence had reduced orgasmic function (p=0.021).

2.7.3. Preparation For Surgery: Decision Making, Preferences For Surgery And Community Resource Use

Preparation for surgery was investigated in three studies (Moskovitz et al, 2000b, Byrne et al, 2007, Rini et al, 2011).

2.7.3.1. Community Resource Use

Moskovitz et al (2000b) surveyed the awareness of community agency resources among patients who had surgery for IBD to analyse the association between using these resources and qualitative surgical outcomes. Participants completed a self report list of local community resources they were aware of and had used preoperatively that was divided into social/educational (support groups/meetings, educational resources, magazines, speakers, charity days) and professional/individual (individual attention from trained personnel – nurses, physicians, trained lay visitors). Almost all (98%) were aware of at least 1 community resource: 22 (24%) of at least 1 social/educational, 20 (22%) of at least 1 professional, 26 (28%) aware of nothing and 24 (26%) aware of both resources. Half had participated in educational/social resources use at least once. Just under half (47%) had participated in professional resource use at least once. The use of professional/individual resources preoperatively had an effect on total post-surgical IBDQ QoL (p=0.015), systemic problems (p=0.007) and emotional problems (p=0.012).

2.7.3.2. Preferences For Surgery

Byrne et al (2007) used the prospective measure of preference method (Solomon et al, 2003) to present patients with CD, surgeons and gastroenterologists with six treatment scenarios to assess their willingness to gamble (WTG) and willingness to trade life expectancy (WTT) to avoid a treatment option. For avoiding ileocaecal resection the preferences of patients aligned with colorectal surgeons, but differed between patients and gastroenterologists (WTG p<0.001, WTT p<0.001) and between surgeons and gastroenterologists (WTG p<0.001), WTT p<0.001). For avoiding laparoscopic ileocolic resection the preferences of patients aligned with colorectal surgeons but differed between patients and gastroenterologists (WTG p<0.001, WTT p=0.03) and between surgeons and gastroenterologists (WTG p<0.001), WTT p<0.001). For avoiding subtotal colectomy, the preferences of patients aligned with colorectal surgeons and with gastroenterologists in WTT but differed with gastroenterologists in WTG (p=0.04) and between colorectal surgeons and gastroenterologists (WTG p<0.001, WTT p<0.01). For avoiding proctocolectomy with a stoma, patients with CD agreed with colorectal surgeons in WTG but disagreed in WTT (p=0.001) and patients' preferences aligned with those of the gastroenterologists. Gastroenterologists and surgeons disagreed in WTG ($p<0.001$) and WTT ($p=0.001$).

There were no differences between any groups for the scenario avoiding proctocolectomy with pouch. When medically and surgically treated patients were compared, those who had had surgery (59%) showed differences in WTG and WTT for avoiding laparoscopic ileocolic resection (WTG 0.47/0.29) or open resection (WTT 0.47/0.33). However, there was no significant difference between groups in preferences for the surgical treatment of colonic CD.

2.7.3.3. Decision Making

Rini et al (2011) investigated the influence of close others (partner, family and friends) on patients with IBD who underwent surgery to remove their colon using the Decisional Conflict Scale (O'Connor, 1999) and a close other decision influence tool developed for the study. Those who perceived they were at greater risk of colorectal cancer were more likely to have decided to have surgery ($p=0.01$). The perceived influence of the referring doctor on the surgical decision was greater than that of close others ($p<0.001$). The most common forms of influence by close others were: helping with understanding (76%), persuasion (83%), indirect influence (80%) and negative influence (23%). Greater decisional conflict was associated with a close female other ($p=0.04$), more hospital related admissions prior to surgical referral ($p= 0.02$) and lower physician trust ($p<0.001$). Less decisional conflict occurred if the close other helped with understanding the decision ($p=0.03$) and more conflict if the close other used negative influence ($p=0.02$). Negative influence (nagging, trying to take control, acting angry or disapproving) was associated with higher decisional conflict and lower likelihood of choosing surgery ($p<0.05$).

2.7.4. Body Image And Self-Esteem

Four studies explored body image (Dunker et al, 2001, Larson et al, 2008, da Silva et al, 2008 and Bullen et al, 2012) and one explored self-esteem (da Silva et al, 2008).

Dunker et al (2001) administered a self devised body image questionnaire to patients an average of 15 months after laparoscopic and open IAP surgery. Satisfaction with cosmetic appearance of the scar was higher in the laparoscopic group ($p=0.03$). Body image was also higher but this difference was not significant. There were no age or gender differences in body image and cosmesis.

Larson et al (2008) used the instrument devised by Dunker et al (2001) to investigate patients undergoing either laparoscopic or open IAP one year after surgery. Body image and cosmetic scores were high in both groups with no significant differences between them.

da Silva et al (2008) used the short Body Image Scale (BIS) (Hopwood et al, 2001) and a global self esteem scale to investigate 93 women following surgery for colorectal disease, with or without a stoma (34 IAP, 36 small/large bowel resection, 48 temporary stoma, 9 permanent stoma). Body image improved over time, with slight changes at 6 months after surgery and significant changes at 12 months (p=0.05). This change was more pronounced in the pelvic surgery group (60% IAP) (p=0.037) who had significantly worse body image scores preoperatively (p=0.0004). Patients with a stoma did not have a poorer body image. Better self esteem after surgery was related to older age (over 40), better mental health, body image and sexual function before and after surgery (p=0.04). Self esteem did not differ between the pelvic and abdominal groups and did not change significantly after surgery.

Bullen et al (2012) used the Body Image Ideals Questionnaire (BIQ) (Cash and Szymanski, 1995), the Appearance Schemas Inventory-Revised (ASIR) (Cash et al, 2004) and BIS with patients with and without a stoma after surgery for benign colorectal disease. Three months after surgery, those with a stoma had significantly higher body image disturbance (M=11.33) than non-stoma patients (M=4.24) (p=0.006). This body image disturbance also worsened over time (p=0.022). Negative body image before surgery was related to depression (p=0.000) and emotional quality of life (p=0.000).

2.7.5. Psychosocial Outcomes

This section summarises psychosocial outcomes including depression, anxiety, illness perceptions and social support.

2.7.5.1. Depression

Three studies explored depression following surgery, two in patients with a stoma (Bullen et al, 2012, Knowles et al, 2013b) and one in patients who had a bowel resection for IBD (Tillinger et al, 1999).

Bullen et al (2012) compared depression in patients who had had colorectal surgery with or without stoma formation using the Hospital Anxiety and Depression Scale (HADS) (Snaith and Zigmond, 1983). At baseline, planned stoma patients had significantly higher depression than non-stoma patients (p<0.05). At 3 months follow-up, stoma patients had significantly higher depression than non-stoma patients (p=0.006).

Knowles et al (2013b) administered the HADS to patients with CD with a stoma. Twenty six percent had probable depression and 16% reported severe depression. Depression was associated with poorer quality of life in subscales of sexuality/body image (p<0.05), work/social (p<0.01), stoma functioning (p<0.05) and financial concerns (p<0.01).

Tillinger et al (1999) used the Beck Depression Inventory (Beck et al, 1996) in patients with CD before and after bowel resection. There was a significant improvement in depression scores at 3 months (p=0.038) and 6 months (p=0.001) postoperatively and for those in remission at 24 months after surgery (p=0.01).

2.7.5.2. Anxiety

Anxiety, like depression, was not frequently assessed in IBD surgery patients, and when it was assessed, there was no recommended intervention. Two studies investigated anxiety in patients with a stoma (Bullen et al, 2012, Knowles et al, 2013b).

Using the HADS, Bullen et al (2012) found that although at baseline patients who were going to have a stoma did not differ in anxiety from those who were not, three months after surgery they had significantly higher anxiety (p=0.014).

Knowles et al (2013b) also administered the HADS and found that 39% of patients had probable anxiety and a further 10% had scores indicating severe anxiety. Higher levels of anxiety were associated with poorer QoL in work/social function (p<0.01), stoma function (p<0.05) and financial concerns (p<0.01).

2.7.5.3. Illness Perceptions

Only one study examined illness perceptions in patients with CD with a stoma using the Brief Illness Perceptions Questionnaire (Broadbent et al, 2006).

Knowles et al, 2013b found that patients with a temporary stoma had significantly higher illness beliefs than those with a permanent stoma (p<0.05) suggesting that they perceived having less control over their illness and believed that their disease would continue to adversely impact their lives and well being. For patients with both a temporary and permanent stoma, more negative illness beliefs were associated with higher anxiety ($p<0.05$), depression ($p<0.05$) and poorer SQL ($p<0.05$).

2.7.5.4. Coping

Carlsson et al (2003) used the Jalowiec Coping Scale (Jalowiec et al, 1984) with IBD patients who had a stoma. The most frequently used coping style was confronting the problem directly. The most frequent strategy was maintaining control over the situation, used often or almost always by 17 participants (sample n=22).

Moskovitz (2000a) administered the Ways of Coping questionnaire (Folkman and Lazarus, 1988) to patients who had undergone IAP and bowel resection. Both groups used adaptive coping most frequently. Adaptive coping did not differ between high QoL and low QoL patients. Maladaptive coping behaviour distinguished the low IBDQ group ($p=0.006$). Maladaptive coping (escape, self blame and self control) made a highly significant contribution to post surgical quality of life ($p=0.002$).

2.7.5.5. Social Support

Only one study (Moskovitz et al, 2000a) addressed social support using the Medical Outcomes Social Support Scale (Sherbourne and Stewart, 1991) in IBD patients following IAP or bowel resection. Perceived social support differed between the high quality of life group (mean score 81.58 =/- 13.92) and the low quality of life group (mean score 68.82 +/- 19.07) as measured by the IBDQ ($p<0.001$). Regression analysis revealed that current perceived social support ($p<0.0001$) was one factor that made a highly significant contribution to post-surgical QoL.

2.7.6. Quality Of Care And Patient Satisfaction

Surprisingly, only one study investigated quality of care which, combined with the lack of social support assessments, suggests a lack of insight into the importance of interpersonal aspects of the experience of surgery.

2.7.6.1. Quality Of Care

Persson et al (2005) administered the Quality of Care from the Patient’s Perspective questionnaire (QPP) (Wilde et al, 1994) to UC patients with an ileostomy and patients with a colostomy for cancer. Most patients rated many aspects of QoC as unsatisfactory. Fifty two percent of ileostomy patients were dissatisfied with information received about results of medical exams and laboratory tests ($p<0.03$). Significantly more ileostomy than colostomy patients thought talking to the ET (stoma) nurse about sexual issues was important ($p=0.01$), but ileostomy patients were most dissatisfied with their opportunities to discuss sexual issues ($p<0.05$). Patient ratings of the importance of information provision were very high in all areas: the surgical procedure (97%), the medical exam/results (98%), surgery results (97%), the responsible doctors (97%), the responsible ET nurse (95%), the special diet (95%), perceptions of participation in the decision-making process about medical care (92%), perceptions of participation in the decision-making process about personal care (93%), perceptions of communication with the ET nurse about health/life situation (89%) and sexual matters (83%). However, patient satisfaction with care was much lower in all areas: the surgical procedure (29% satisfied), the medical examination/results (52%), surgery results (32%), the responsible doctors (41%), the responsible ET nurse (10%), special diet (36%), perceptions of participation in the decision-making process about medical care (53%), perceptions of participation in the decision-making process about personal care (58%), perceptions of communication with the ET nurse about health/life situation (39%) and sexual matters (53%). Significantly more ileostomy patients without complications (58%) were dissatisfied with the opportunity to communicate with the ET nurse about their health and life situation than those with complications (48%) ($p=0.01$). Also, significantly more ileostomy patients with complications (73%) were dissatisfied with the ET nurses' understanding of their situation than those (31%) without complications ($p=0.03$).

2.7.6.2. Patient Satisfaction

Satisfaction with surgery has only been investigated in anal fistula patients, but not the four other patient groups (stoma, IAP, bowel resection and other surgery); the one study that investigated patient satisfaction is old and used a self developed questionnaire (Garcia-Aguilar et al, 2000). In total, 88% were satisfied with their surgery. Patient satisfaction was strongly associated with fistula recurrence ($p<0.001$), soiling of undergarments ($p<0.001$) and accidental bowel movements ($p=0.008$). Patient dissatisfaction increased linearly with the number of incontinence problems; 50% of patients with all three incontinence problems (difficulty holding gas, undergarment soiling and accidental bowel movements) were dissatisfied. Anal incontinence impacted on satisfaction with social activities ($p<0.001$), physical activities ($p=0.041$) and sexual activities ($p=0.03$). Only 1.9% of patients without incontinence were dissatisfied whereas 50% of patients with soiling, difficulty holding flatus and accidental bowel movements were dissatisfied. Patients with fistula recurrence reported a higher rate of dissatisfaction with surgery (61%) than those without (8%) ($p<0.001$).

2.8. ASSESSMENT OF THE QUALITY OF THE QUALITATIVE STUDIES

Four qualitative studies were identified during the search for this review. Three studies used a phenomenological approach (Beitz, 1999, Notter and Bernard, 2006, Savard and Woodgate, 2009) and one used narrative enquiry (Sinclair, 2009) The CASP guidelines for qualitative research were used to assess their quality (Critical Appraisal Skills Programme, 2015). This tool was selected because it is generic, clearly defines what is meant by each individual criterion and focusses more on determining whether a study is credible than its paradigmatic aspects (Hannes, 2011). Table 2.7 (Appendix 6) summarises the characteristics of the 4 qualitative studies reviewed.

2.8.1. Study Aims

The aims of the four studies were clearly stated. Beitz (1999) investigated the lived experience of patients who had IAP surgery. Notter and Bernard (2006) aimed to understand women's perceptions and experiences of IAP surgery. However, the focus of their study was on the time that participants had a temporary stoma. Savard and Woodgate (2009) explored how young people experience both IBD and a temporary stoma. Sinclair (2009) investigated how young people experience living with a permanent ileostomy. The qualitative studies focussed mainly on the experience of having a stoma but there are many other types of surgery which we do not understand the experience of yet, highlighting a need for further qualitative research.

2.8.2. Methodology And Study Design

Since very little previous research had addressed the experiences of IBD patients undergoing any type of surgery, all these studies were relevant to the purpose of the current study. A qualitative approach was also appropriate to meet the stated aims. Within that approach, three studies used phenomenology, which intends to investigate the perceptions of those who have lived the experience (Beitz, 1999, Notter and Bernard, 2006, Savard and Woodgate, 2009). The fourth study used narrative knowing (Sinclair, 2009), which seeks to give meaning to lived experiences by linking everyday actions and events into units and providing a framework for understanding past events and planning future actions. These are appropriate and justifiable research designs.

2.8.3. Study Participants

2.8.3.1. Recruitment

Two studies recruited participants through health professional or voluntary association intermediaries (Savard and Woodgate, 2009, Sinclair, 2009). One researcher (Beitz ,1999) attended an IAP support group meeting to recruit volunteers. One study (Notter and Bernard, 2006) did not state the recruitment process.

2.8.3.2. Sampling

Consistent with much qualitative research, all studies employed purposive sampling. Although qualitative research uses small samples, none of the studies justified the actual sample size chosen. In addition insufficient demographic and socioeconomic detail was provided to understand the context, which limits transferability of the findings. Three studies used white Caucasian/white American samples but failed to justify why they excluded other ethnic groups (Beitz, 1999, Savard and Woodgate, 2009 and Sinclair, 2009). However, English language was a requirement for inclusion. These oversights are compromising potentially high quality studies, as they limit transferability of the findings to other settings.

Beitz (1999) included 10 volunteer American adults with UC who had had IAP surgery. Notter and Bernard (2006) used purposive maximum variety sampling to select a heterogenous group of 50 women from a wide variety of backgrounds in England who had undergone the experience of loop ileostomy as part of an IAP procedure. They did not justify why only women were included and provided no age, socio-economic, cultural or relationship data, or any specific inclusion criteria. Although they stated they concentrated on the immediate postoperative period, time since ileostomy ranged from 6 weeks to several years later and an unspecified number of women were included who had not had a stoma at all. Notter and Bernard (2006) justified the much larger sample size as important for including as wide a cross section of participants as possible. However, this heterogeneity is actually a weakness because it is not the immediate postoperative sample and also because some experiences will be subject to recall bias. Savard and Woodgate (2009) interviewed six young American adults (1 male, 5 female) with UC, aged between 18 – 24, who had had a temporary ileostomy and were able to speak, read and write English. Sinclair (2009) recruited seven American adults (3 men, 4 women) who had been living with a permanent ileostomy for less than 4 years, were fluent in English and had medical, surgical and emotional stability.

2.8.3.3. Participant Characteristics

Beitz (1999) included 10 (4 male, 6 female) participants with UC following IAP surgery, whose average age at time of surgery was 37.7 years (range 26 – 51). Mean time elapsed since surgery was 2.6 years (range 6 months – 5 years). All participants were white, 8 had been university educated and all were employed. Notter and Bernard (2006) investigated 50 women who had undergone IAP surgery, most of whom had UC. Savard and Woodgate (2009) included six young American adults (1 male, 5 female) who had UC and had experienced a stoma. Five had had a reversal and IAP and one still had a temporary stoma. All were Caucasian and two were in a relationship. Sinclair's (2009) seven participants were American adults (3 men, 4 women) living with a permanent stoma for less than four years. The actual length of time they had had a permanent stoma ranged between 10 weeks and 3.5 years. Four had had a temporary stoma from 1- 10 years before having the permanent ileostomy. Age parameters were 20 – 40 years (young adults as described by Whitman, 1986). Six were aged from 31 – 40 and 1 between 24 and 30 years. All were Caucasian. Three were married and four were single. Most had undergone higher education or vocational training. Two studies (Beitz, 1999, Sinclair, 2009) provided sufficient demographic information to establish that all participants were well educated, which introduces bias into the sample.

2.8.4. Data Collection

Appropriately for phenomenological and narrative studies, data were collected, recorded and transcribed through in depth interviews. Savard and Woodgate (2009) conducted two interviews. Interviews were conducted by one researcher in three studies (Beitz, 1999, Savard and Woodgate, 2009 and Sinclair, 2009). The same three researchers also made and transcribed field notes. One study (Notter and Bernard, 2006) provided no information about the conduct or process of the interviews. Beitz (1999) conducted interviews in a private setting in a health care facility, school or the participant's home. Participants were asked to describe their experiences before, during and after the two stage IAP surgery. Savard and Woodgate (2009) conducted interviews at a time and place convenient for each participant using an interview guide based on literature specific to young people living with IBD and a stoma. Broad data generating questions were asked, with questions subsequently asked only to help the narration of the experience. Sinclair (2009) conducted an unstructured interview, allowing participants to begin where they wished and control the interview. One study (Savard and Woodgate, 2009) described collecting data until redundancy occurred. However, there is the potential for bias since data saturation could not be achieved with only one male participant.

2.8.5. Data Analysis

All the studies described in detail a systematic process of data analysis guided by a theoretical framework specific to the type of research undertaken (phenomenological, narrative inquiry) for guidance. The processes of organizing and retrieving data were explained, as well as the steps in coding and thematic analysis. In two studies (Beitz, 1999, Savard and Woodgate, 2009) two researchers analysed the data.

Beitz (1999) and Savard and Woodgate (2009) analysed the data according to procedures proposed by Van Manen (1990). Beitz (2009) synthesised data into theme clusters and categories. Savard and Woodgate (2009) identified the essence of the experience, themes and associated subthemes. Notter and Bernard (2006) analysed the data following procedures described by Giorgi (1985) to identify themes and categories. Sinclair (2009) used Clandinin and Connolly's (2000) framework describing four directions (looking backward, looking forward, looking inward and looking outward) guiding research into human experience to analyse the participants' stories. Common and divergent themes from the stories were identified within the biophysical, psychological and social components.

2.8.6. Findings

Findings in all studies were presented as interpretive and narrative accounts under the themes, categories and frameworks described above. All the studies provided rich description with the discussion supported by quotes from the data and by reference to the published literature. Beitz (1999) described ten thematic categories that emerged from the data, with 39 subsumed theme clusters. The thematic clusters were then grouped into Van Manen's (1990) four existential concepts: lived body, lived space, lived time and lived other (relationships). Notter and Bernard (2006) identified four key issues that emerged: pain and shock, body image and sexuality, the loop ileostomy, and the roles of the general and specialist nurses. Savard and Woodgate (2009) identified the essence of the lived experience as concealing and revealing the self, with subthemes of uneasy feelings, 'It's hard' and renewed sense of self, and 10 subthemes within those. Sinclair (2009) organised the findings within the four directions of Clandinin and Connolly's (2000) narrative knowing framework, and identified twelve major themes.

2.8.7. Ethical Issues

One study (Notter and Bernard, 1999) did not include any information pertaining to ethical issues. The remaining three studies all stated that the research had been approved by an ethical committee. In addition, Beitz (1999) provided verbal information about the study to participants and obtained their written consent to participate. They were informed that consent could be withdrawn and were assured of confidentiality and anonymity as their information would not be linked to their identities. Savard and Woodgate (1999) stated that process informed consent was obtained. Sinclair (2009) provided written information concerning the study, voluntary nature of participation, the right to withdraw at any stage, confidentiality and offered counselling if the interview triggered emotional distress.

2.8.8. Self Reflexivity

Three studies considered aspects of self reflexivity. Beitz (1999) described the need for bracketing assumptions and attempted to identify how professional and life experiences influenced her thoughts. Assumptions stated included: common experiences occur in patients who had IAP, they have lived in a world of fear and/or pain and anxiety, that the major surgery would affect personal relationships and that interpersonal relationships within the health care system can affect the person's lived experience. Notter and Bernard (2006) stated that bracketing was an essential first stage, but provided no further information. Sinclair (2009) acknowledged the researcher's role and relationship with participants in shaping the narrative and patient stories.

2.8.9. Credibility Of Findings

Although there are no universally agreed criteria by which the rigour of qualitative studies can be judged (Ring et al, 2010), all the studies described some measures that were taken to ensure study quality. Beitz (1999) followed guidelines developed by Lincoln and Guba (1985) and Sandelowski (1986) in terms of auditability by providing sample data to another researcher for review, credibility by making results available to nurse scholars and wound and ostomy specialists and applicability by careful selection of participants. Confirmability was considered to have been achieved when the previous three criteria had been met. She also referred to the literature to support the study findings. Notter and Bernard (2006) stated that they assessed the rigour of the study through the criteria of trustworthiness and authenticity and an audit trail. In data analysis they avoided forcing or transforming the data to the extent that meanings were ascribed by the researcher. In Savard and Woodgate's (2009) study, two interviews were carried out, the second to allow participants to expand on their thoughts and ideas and to clarify information previously provided. Two researchers analysed the data. Sinclair (2009) used member checking, returning scripts to five of the seven participants who could be contacted to verify their accuracy.

2.8.10. Value

These studies all used methods and procedures that achieved the stated goals of the research. Although there are some omissions in information provided, this could partly be explained by word restriction in some selected publications. The qualitative literature identified was limited in that only one study included participants in the same age group as the current study (Sinclair, 2009), the number of male participants was small, and in most studies the participants were not culturally or educationally diverse. In addition, the previous qualitative research focussed on the experience of having a temporary stoma as part of IAP surgery and not at all on the patients, mainly with CD, who experience other abdominal operations or perianal surgery. All of the included studies contributed interesting, useful, rich and detailed findings which described the experiences of adults undergoing surgery for IBD, with direct quotes from participants to support the findings and findings supported by reference to current literature. One study did not discuss any limitations (Notter and Bernard, 2006). One study did not suggest any implications for practice (Savard and Woodgate, 2009). Two studies did not make any suggestions for further research (Notter and Bernard, 2006, Sinclair, 2009).

Methodologically, Sinclair's (2009) narrative inquiry study illuminated directional changes (forwards, backwards, inwards and outwards) in participants' experiences which are of particular relevance to this study of transition in young adults with IBD undergoing surgery for their condition.

2.9. QUALITATIVE FINDINGS

Qualitative findings identified in the four studies (Sinclair, 2009, Beitz, 1999, Notter and Bernard, 2006, Savard and Woodgate, 2009) were analysed using Schlossberg's 4S framework (Goodman et al, 2006) (Appendix 7, figures 2.2, 2.3, 2.4, 2.5). According to this theory, aspects of the self (patient), situation, support, and coping strategies influence the transition experience. There is evidence from the four qualitative studies that patients do undergo a transition which provides support for Schlossberg's theory (Goodman et al, 2006) as an organising framework for the present study.

Key themes that emerged included the extreme difficulties that patients experienced with living before surgery; the key need for information to help them in decision-making and to adapt after surgery; profound changes that occurred with having a stoma; the positive impact of surgery on quality of life and wellbeing, and body image issues relating to cleanliness and intimacy. They also highlighted the important role of the specialist nurse, partners and family and other people who have had similar surgery in helping patients transition through surgery.

Notably, the language used by the researcher in these publications was catastrophizing, which may be intended to highlight the difficult experience for patients, but such dramatic language can reduce credibility of the interpretation.

2.9.1.Situation

2.9.1.1.Control

Preoperatively, participants described a situation before surgery where the illness was out of control; because of the unpredictability of symptoms, they stayed at home and people came to see them (Savard and Woodgate, 2009). The desire to escape steroid therapy and its side effects and for control of body functions and freedom from pain and urgency were primary motivators for surgery (Beitz, 1999).

2.9.1.2.Assessment

Decision making, preparing and self education were seen as efforts to regain control of the situation (Beitz, 1999). The need for emergency surgery took away choice, but for others the decision to have a permanent stoma could be a struggle which could take years (Sinclair, 2009). The surgical option of IAP sphincter saving surgery was chosen particularly by those who wanted to avoid a stoma for the rest of their lives (Beitz, 1999). IAP surgery was perceived as returning them to normal (Savard and Woodgate, 2009). Even so, having this operation meant for some that their dream of a full recovery from disease was now gone (Notter and Bernard, 2006).

Potoperatively, IAP was perceived as a major positive change in participants' lives, releasing them from vicious cycles of UC (Beitz, 1999). A permanent stoma cured the disease and put them 'back on track' so they could live again, and having a period with a temporary stoma prior to this made adjustment to a permanent one easier (Sinclair, 2009). Perceptions of a temporary stoma were mixed. For some, it changed life for the better, with perceived benefits of feeling healthy, a renewed sense of self, no pain, no frequency and less restriction (Savard and Woodgate, 2009). Others were appalled at the impact of the surgery on the body (Notter and Bernard, 2006). In two studies, nobody wanted the temporary stoma (Beitz, 1999, Savard and Woodgate, 2009) and some were in dread of the IAP failing and despite complications, were determined to keep it at all costs and avoid a permanent stoma (Notter and Bernard, 2006).

Those with an IAP were pleased with their improved bowel function, but it was not perfect; where symptoms had been mild before the operation, participants were less satisfied as the prolonged recovery was perceived as worse than the illness and there was a lack of closure because of the awareness of worsening symptoms. In contrast, those with bad UC symptoms before the operation were very pleased with the outcome (Beitz, 1999).

The physical effects of the surgery were profound. Pain could be severe and prolonged and not adequately controlled because of insufficient analgesia (Notter and Bernard, 2006, Savard and Woodgate, 2009). Stoma surgery was traumatic and debilitating with overwhelming fatigue and there was frustration, distress and disappointment at the prolonged recovery time (Notter and Bernard, 2006, Savard and Woodgate, 2009). The stoma was a burden; it was perceived as decreasing attractiveness and increasing the stress of recuperation (Beitz, 1999). Participants felt not ready to care for the stoma themselves and were terrified of discharge and coping with the stoma alone (Savard and Woodgate, 2009, Sinclair, 2009). In addition, they experienced appliance leakage that left them feeling ‘dirty’ and stoma function could also be erratic, with bad odours, frequency, incontinence, skin irritation and altered pelvic sensation (Beitz, 1999). Time was seen as a significant factor in adjustment (Sinclair, 2009).

2.9.2. Self

2.9.2.1. Changed Lives After Surgery

Participants described a restricted life world, with enforced proximity to the bathroom, the need for concealment of ‘dirty’ parts of the body, and they wished for freedom from the strain of UC and the cycle of relapse and remission (Beitz, 1999). UC led to feelings of difference resulting from a life of staying home, hospital appointments and medication; because of lost energy, they lacked the desire to engage socially with family and friends (Sinclair, 2009).

After surgery, participants resumed former activities, education and careers despite concerns about participating in social activities and returning to work with a permanent stoma (Sinclair, 2009). Those with a temporary stoma expressed a desire to return to a normal life (Notter and Bernard, 2006). With an IAP, after the stoma had been closed, they had freedom from illness, felt healthy, more like themselves, had more freedom to do things and acted like a normal person (Beitz, 1999, Savard and Woodgate, 2009).

2.9.2.2. Anxiety And Uncertainty

Participants worried about many things throughout the experience of surgery; of dying from UC, dying from major surgery, the effect of complications on quality of life, of cancer due to degeneration of the IAP as the small intestine was not designed to store faeces and of pouch leakage which led to humiliation and embarrassment (Beitz, 1999, Savard and Woodgate, 2009).

They also expressed uncertainty about the outcome of surgery, because there were no guarantees that the IAP would not deteriorate in years to come and they would later need a permanent stoma (Beitz, 1999)

2.9.2.3. Body Image

Preoperatively, participants were embarrassed by the body changes consequent to steroid therapy (Savard and Woodgate, 2009). However, the change in body function and appearance with a temporary or permanent stoma had a huge negative effect on all participants. There was shock and emotional distress at seeing the stoma for the first time, from which some never fully recovered (Sinclair, 2009, Notter and Bernard, 2006). The majority objectified the stoma and referred to it in the third person (Beitz, 1999, Notter and Bernard, 2006, Sinclair, 2009). With a stoma, they felt disfigured and different– ‘a freak’, ‘damaged goods’, less feminine, and had decreased self respect and self confidence (Beitz, 1999, Notter and Bernard, 2006, Savard and Woodgate, 2009, Sinclair, 2009).

The stoma was perceived as a stigma (Savard and Woodgate, 2009). The stoma bag and its associated care was a great strain, offensive and induced disgust and the thought of never being clean (Beitz, 1999, Notter and Bernard, 2006, Savard and Woodgate, 2009). Feelings of difference persisted as clothing changes were made to hide the stoma and activities were restricted (Savard and Woodgate, 2009). There was an expressed need for increased privacy, but it was not given and participants found it humiliating to have to deal with the stoma ‘in public’ on the ward (Notter and Bernard, 2006). For the few male participants, the possibility of impotence following surgery was also a threat to body image (Beitz, 1999).

2.9.2.4. Better Self After Surgery

Some participants felt that they had become a better person or had matured as a human being from the experience of surgery (Savard and Woodgate, 2009)

2.9.3. Support

2.9.3.1. Partner And Family

Preoperatively, some participants reported that partners had not been offered support by health professionals so that although they tried to be supportive they could be unprepared and lack full understanding (Beitz, 1999, Notter and Bernard, 2006). Close relationships could also be under strain preoperatively due to the restrictions imposed by the disease, with reversal of parent/child roles and feelings of inadequacy regarding parenting, spousal relationships and intimacy (Beitz, 1999).

Postoperatively, partners and family were described as the best support system, and relationships unaffected by those with a permanent stoma; however, single patients avoided dating and the risk of forming a new relationship (Sinclair, 2009). Others described variation in the amount of reassurance and support from partners, although some helped with stoma care (Notter and Bernard, 2006). Those with a temporary stoma felt embarrassment which interfered with intimacy (Beitz, 1999, Savard and Woodgate, 2009). However, once the stoma was closed, and they were living with an IAP, significant relationships and intimacy returned to normal (Savard and Woodgate, 2009).

2.9.3.2. Friends

Details of the illness and surgery were sometimes not disclosed to friends (Savard and Woodgate, 2009). Others felt that if friends reacted negatively to the stoma, they would question whether they still wanted them in their lives (Sinclair, 2009).

2.9.3.3. Patient Support Group

These people were described as the only ones who truly understood; as a consequence of this experience, some participants also wanted to advocate for and advise others in a similar situation. Some became IAP Visitors, and described how this gave them ‘more than they gave’ (Beitz, 1999).

2.9.3.4. Health Professionals

Experiences with health professionals were mixed. Opinions of ward nurses ranged from excellent, compassionate and caring to lacking in quality, lacking respect, non-caring, insensitive and showing negative attitudes towards a stoma (Sinclair, 2009). Sometimes they appeared to lack confidence, lack knowledge and be unsure of what to do (Beitz, 1999, Notter and Bernard, 2006).

The specialist nurse was universally perceived positively, being described as: very supportive (Sinclair, 2009), a lifeline, helping with adaptation to the stoma (Beitz, 1999) and providing open access, very supportive and the key to ongoing high quality care (Notter and Bernard, 2006).

2.9.4. Strategies

2.9.4.1. Active Coping

In all studies, participants mainly described using active coping strategies (Beitz, 1999, Notter and Bernard, 2006, Savard and Woodgate, 2009, Sinclair, 2009). Regardless of whether a stoma was temporary or permanent, they prepared themselves for surgery and coped postoperatively through obtaining information and self education. Such information could be hard to find and some considered that inadequate information was provided before and after the operation (Beitz, 1999, Notter and Bernard, 2006). Some wanted written information to refer to (Notter and Bernard, 2006). Other participants most highly valued talking to someone who had previously had surgery, such as members of a stoma organisation, and felt that this most helped their postoperative adjustment (Sinclair, 2009). Patients also described educating themselves through phoning manufacturers of stoma supplies, searching the Internet, website chat rooms and the public library (Sinclair, 2009).

Other practical strategies used were dietary modification (Beitz, 1999) and preparing a pack of spare supplies that could be used to change the appliance when away from home (Notter and Bernard, 1999).

2.9.4.2. Acceptance

Some participants described accepting that the early postoperative period was a phase that they had to get through (Beitz, 1999). Others accepted that some pain would be inevitable after the operation and tried to cope by using ‘mind over matter’ but found that it could not be ignored or forgotten (Notter and Bernard, 2006).

2.9.4.3. Self Protective Strategies

Knowing that their stoma was temporary, some participants took steps to avoid having to reveal it to others by hiding it (Savard and Woodgate, 2009). They also withdrew during the time that it was there by limiting their social life and staying indoors (Notter and Bernard, 2006). Others used prayer and their relationship with God to help them to cope, or humour (Beitz, 1999).

2.9.5. Summary Of Qualitative Findings

Significantly, only one study primarily investigated the experience of having an IAP (Beitz, 1999). Two further studies explored patients’ experiences of a temporary stoma, but this was a necessary first stage of a multiple stage IAP procedure (Notter and Bernard, 2006, Savard and Woodgate, 2009). IAP surgery is usually chosen because patients are keen to avoid having a long term stoma and so it is possible that their perceptions of having to live with a temporary one for any period of time will be quite negative. Only one study (Sinclair, 2009) included participants who had actually chosen to have a permanent stoma as a primary procedure.

The qualitative findings indicate that health professionals, patients and their families need to be mindful that IBD patients need time to recover not just from the physical trauma of surgery, but also the major emotional trauma. The journey through surgery had highs and lows, and it took time to recover and adapt to the consequences. Provision of information and education was one thing that health professionals needed to improve. Quality of nursing care was variable, and the specialist nurse was seen as the key resource. The surgery could be a success, but there were many other factors which affected preparation, recovery and adjustment of patients, such as the provision of information, helping patients to cope with difficult emotions, pain management, post-operative self-care, effective communication, appropriate support and effective coping. A limitation of the qualitative studies is a lack of detail regarding what patients did to cope on a daily basis, and what helped. There is a need to capture the transition perspective while still retaining important contextual details, which the present study addresses.

2.10. RATIONALE FOR THE PRESENT STUDY

From this review it is clear that there is scope for a further study investigating the experience of young adults with IBD who undergo surgery for their condition. The literature addressed quality of life and specific outcome indicators and mainly focussed on patients with UC who had had particular procedures that could not be done for patients with CD. Surgery is more frequent in patients with CD, so there are obvious gaps in the literature. The key messages of the literature review relate to the impact of surgery on quality of life and physical function outcomes- urinary, bowel and sexual. The focus of previous literature is mainly on quality of life as an indicator of positive adjustment to surgery and less on the psychosocial and transition aspects of the surgery experience such as surgical decision-making, body image, adjustment, quality of care and patient satisfaction.

In the majority of both quantitative and qualitative studies, most of the participants were older adults. Only two purported to investigate the experiences of young adults (Savard and Woodgate, 2009) and Sinclair (2009). However, Sinclair (2009) recruited only one participant under the age of 30. Therefore the experiences of young adults aged 18 – 25 are underrepresented in the existing literature. Eighteen of the quantitative studies incorporated small patient samples in single centre cross sectional retrospective questionnaire surveys. However, the studies which investigated outcomes at different points in time after surgery reported changes in quality of life, sexual function, body image, self esteem and physical recovery in UC and CD patients following IAP, bowel resection and stoma formation (da Silva et al, 2008, Davies et al, (2008), Thirlby et al, 2001, Tillinger et al, 1999, Weinryb et al, 2003). There is evidence from the qualitative studies that the journey through surgery for IBD patients had highs and lows. It took time to recover and adapt after the operation. However, there is a lack of detail in those studies concerning what patients did to cope, how they adjusted and what helped them. These findings suggest that further research which increases our understanding of the patient experience of IBD surgery including how their perceptions change over time and what factors influence those changes is warranted. This study is intended to fill the gap in existing knowledge by investigating the experience of surgery in young adults with IBD through the framework of transition.

CHAPTER 3: THEORETICAL FRAMEWORK

The literature review revealed that there were only a few studies (mainly qualitative) which investigated patients' experience of IBD surgery, and only one of these looked at the surgical experience as a journey (using narrative inquiry) (Sinclair, 2009). In most of these studies, there was no underlying philosophical or theoretical framework, which would link together, and make empirically testable, all possible factors and determinants of a patients' surgery experience (see Chapter 2: Systematic Review). Therefore, in Phase 1, patient narratives were sought to obtain a detailed description of the experiences of young adults with IBD undergoing surgery. Early analysis of the detailed narratives of the experiences of young adults with IBD undergoing surgery in Phase 1 revealed that they were describing a process, or 'journey' through surgery. To try and place this within the context of a theoretical framework, the researcher read the wider psychosocial literature pertaining to the experience of surgery. Concepts and theories such as biographical disruption, recovery, adjustment and adaptation were considered for their applicability to the present study. However, none served to explain the stories told by participants until the researcher came across Schlossberg's Transition Theory (Schlossberg, 1981a, Goodman et al, 2006). This had an immediate resonance as it incorporated elements and issues that were evident in previous research and the data and provided a framework for assessing, exploring and making sense of the data without any forcing. The researcher continued to explore the transition literature, most particularly Meleis' (2010) work on transition as a nursing theory. However, although Meleis' theory did provide some insight and explanation of the data it was not as compatible as Schlossberg's Theory, and so was rejected as an appropriate theoretical framework for this study. The researcher analysed successive narratives to determine whether the experience of surgery could be described as a process of transition. During this process it became evident that the stages and key components in Schlossberg's theory: situation, self, support and strategies incorporated the key variables within the narratives. Thus the thesis focussed on the process of transition as the organising framework for the study and the researcher decided to adopt Schlossberg's Transition Theory (Goodman et al, 2006) as the potential underlying theoretical framework for this study, to see if the stages, factors, assets and liabilities in this model could be used to explain young adult IBD patients' experiences of surgery.

This chapter first describes the concept of transition then discusses Schlossberg's Transition Theory (Goodman et al, 2006) in more detail. It then briefly outlines Meleis' theory of transition which is most used in nursing research and explains why Schlossberg's theory was preferred for this study. The chapter then considers how transition is viewed in current colorectal surgical practice and how the concept of transition is implicit in previous nursing research that has investigated the experiences of patients undergoing colorectal surgery. These studies used other terms but show there is a consciousness among both nurse researchers and patients that the experience of surgery is a transition. The chapter ends by justifying Schlossberg's theory as the theoretical framework for this study.

3.1 THE CONCEPT OF TRANSITION

Transition occurs when a person's current reality is disrupted, causing a forced or chosen change that results in the need to construct a new reality (Selder 1989). This disruption is caused by stressful events or nonevents that alter a person's roles, relationships, routines, and assumptions (Chickering & Schlossberg, 2001; Schlossberg, 1984; Schlossberg et al, 1989). Such events were categorised by Schlossberg (1984) as anticipated, for which preparation can be made; unanticipated, which typically involve crisis; chronic hassles, such as concerns with health and difficult relationships; or non events, which are anticipated transitions that do not occur, such as expecting but avoiding stoma formation as a consequence of surgery (Schlossberg, 1984). A health related personal transition may be experienced simultaneously with other expected or unexpected transitions that occur in life, such as moving from adolescence to young adulthood, changes in relationships or new roles such as motherhood (Meleis, et al 2000). An alternative way of identifying types of transitions is in relation to their effects: personal transitions include those involving physical (changes in symptoms and functioning), emotional (psychological upheaval and adjustment), and social (shifts in family and functioning and routines or roles) effects (Shulman-Green et al, 2012). Care transitions involve shifts in treatment or approach (hospital to home, paediatric to adult clinics) and may not actually bring about any personal transition if the patient considers that they have relatively little personal impact.

Transition is a dynamic process, which has no uniform trajectory and duration and outcomes that are different for each individual (Kralik and van Loon, 2009). It involves the key elements of process, movement, variability, perception, and time span (Meleis, 2010), and also transformative learning whereby people acquire knowledge to make meaning of their lives and find new ways to locate themselves in an altered world (Cranton, 1996, Bridges, 2004).

Transition differs from change in that not all changes result in transition. Transition is not simply change, but rather the process that people go through to incorporate the change or disruption into their lives (Kralik et al, 2005). A key feature of transition is awareness of the changes that are taking place, followed by some engagement in the transition process whereby the person involved undertakes activities such as seeking information or support, identifying new ways of living and being, modifying former activities, making sense of the circumstances and changing the definition of self (Chick & Meleis, 1986, Elmberger et al, 2002). Transition is also not synonymous with adjustment, a term which is commonly used to imply the completion of change from one state to another, without addressing the processes of change and adaptation that occur within an individual (Brennan, 2001).

Variability in the transition process is related to the impact of the event, the individual's perception of it, and the personal and supportive resources available to cope with the transition (Goodman et al, 2006). When different people experience similar events, these factors determine differences in perceived impact, reactions and subsequent experience of and movement through the transition process. The role of time is important in transition; the process of disengaging from previous roles, modifying behaviour, making psychological and interpersonal changes and acquiring new learning and abilities takes time; multiple stressful events within a short space of time may make it difficult to complete the tasks necessary to negotiate each transition, the perception that a situation is life threatening may force people to confront, engage and negotiate their way through the transition process sooner (Shulman-Green et al, 2012).

There is no consensus among researchers or theorists about the nature of the transition process. Bridges (2004) conceptualised transition as linear, commencing with an ending of disengagement and ceasing to identify with previous roles, through a neutral zone of suspension in time between old and new roles and a final beginning phase of renewal and a new sense of normalcy. Similarly, Selder (1989) describes a state of disrupted reality leading to uncertainty and then to restructuring of reality. However, although Meleis and Trangenstein (2010) consider transition to consist of three phases: entry, passage and exit and Schlossberg (1984) identified similar phases: Moving In, Moving Through and Moving Out, they considered the transition process to be more complex. Schlossberg (1984) acknowledged that a person could move forward and backwards through these phases at different times and also that Moving Out often signals the start of something new, rather than simply an ending, with the question being asked: what comes next? She also perceived that not all transitions will end with a positive outcome. From the literature, Meleis et al (2000) identified specific outcomes associated with a positive or healthy transition and that these outcomes may occur at differing points in the transition process. However, besides differences in the depiction of the transition process, there is actually no agreement on how, and if, a transition ends. In particular, there may be difficulty in establishing a definite ending to a health related transition; Glacken et al

(2002) and Shaul (1997) found that transitions for people with chronic illness may never be complete due to ongoing changes in their condition.

Despite their differences, transition frameworks all acknowledge it to be a process with movement and phases and are useful in attempting to facilitate an understanding of 'the extraordinarily complex reality that accompanies and defines the human capacity to cope with change' (Goodman et al, 2006, p55).

3.2 SCHLOSSBERG'S THEORY OF TRANSITION

Schlossberg's (1981a) first depiction of a model to understand adaptation to transition started from the premise that all adults experience change and that often these changes require a new network of relationships and a new way of seeing oneself. This model drew from the theories of adult development and work on adaptation and transition in identifying three main determinants affecting an individual's adaptation to transition: their perception of the particular transition, the characteristics of the pretransition and posttransition environments and characteristics of the individual. She then attempted to categorise the many factors that seemed to affect the outcome of a transition on the individual within this broad framework.

Describing her first attempt at developing a framework to understand the transition process as exploratory and tentative, one of the strengths of Schlossberg's current theory is that it was subjected to peer review at an early stage and reformulated as a consequence (Hopson, 1981, Gould, 1981, Schlossberg, 1981b) and has been periodically refined since. She reconceptualized her model as dealing with the "response to transition" because "adaptation" might not always be achieved (Schlossberg, 1984).

The theory (Goodman et al, 2006, Anderson et al, 2011) is based on three premises; adults continuously experience transition; an individual's reactions to a transition depend on the type of transition, the context in which it occurs and its impact on their lives; a transition has no end points but is a process over time that includes phases of assimilation and continuous reappraisal as people move in, through and out of it.

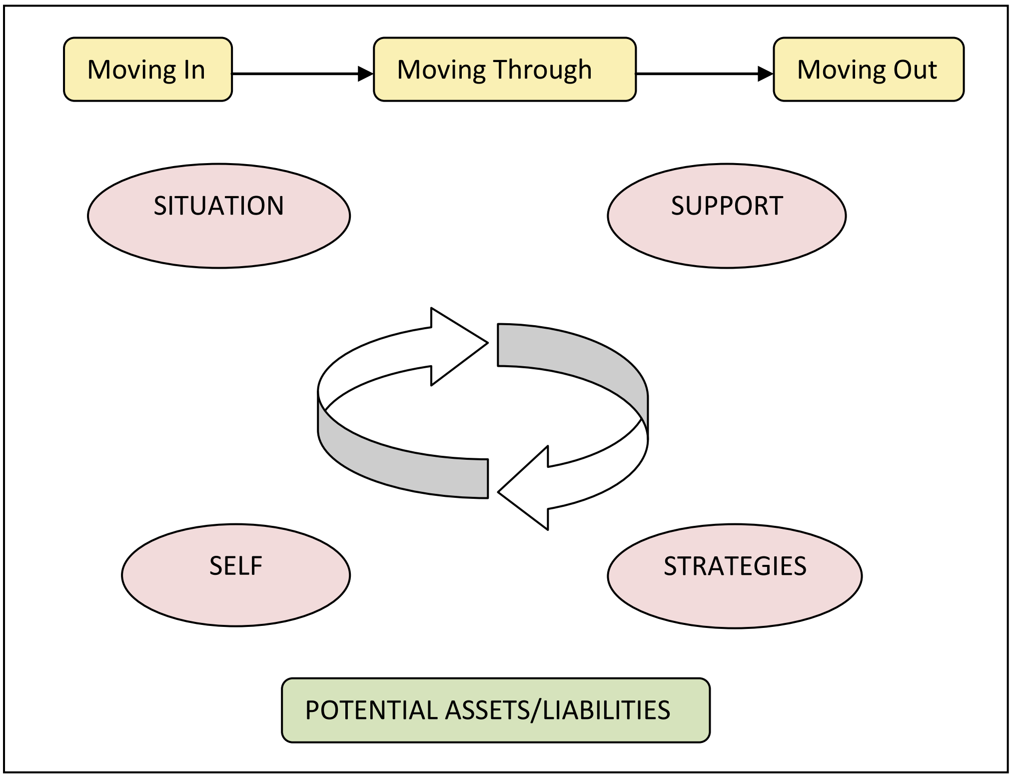
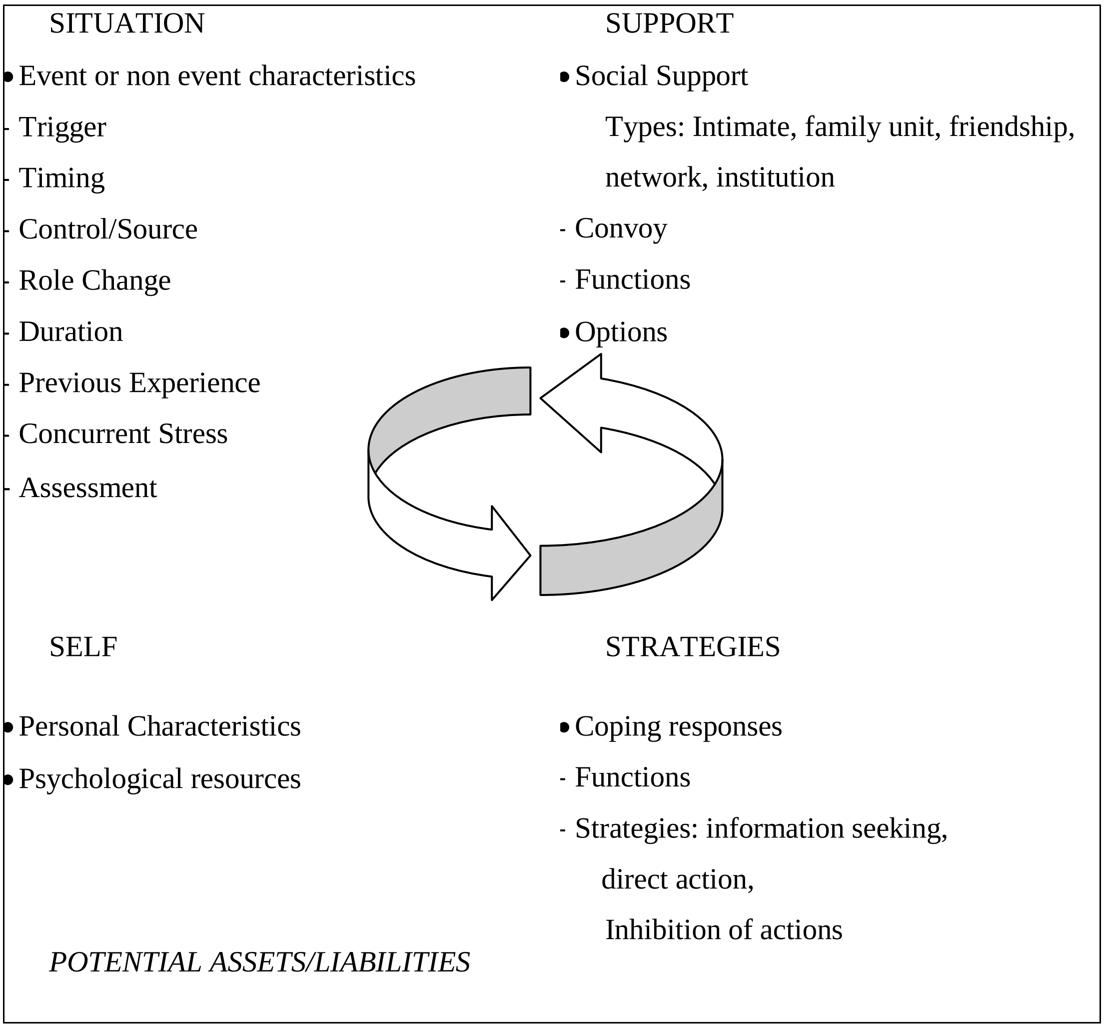


Figure 3.1: Key Elements of Schlossberg's Transition Framework
(adapted from Goodman et al, 2006)

Schlossberg (1981a) also described transition as a dynamic process with movement through various stages of a transition. As the model was further refined (Schlossberg et al, 1989, Chickering and Schlossberg, 2001), the transition process was presented as having three components: approaching change, taking stock, and taking charge. Within the section on taking stock, the 4S system was introduced (Situation, Self, Support and Strategies) as a reframing of her previous discussion of coping resources characterized by the transition, individual, and environment. This provided a guide to analyzing personal and environmental assets and deficits in any given transition. Additionally, the taking charge section introduced the terminology of "Moving In," "Moving Through," and "Moving Out" (Figure 3.1). When Moving In, an individual orientates themselves to the new situation and becomes familiar with new norms, routines and expectations; Moving Through, they discard past roles, relationships, routines and assumptions, and this may involve a period of liminality or disruption while new ones evolve; when Moving Out these changes have been integrated and assimilated and one is no longer sharply aware of and consumed by them (Goodman, et al, 2006). Schlossberg et al, (1989) observed that a person could move forward and backwards through these phases and that the Moving Out phase could signal an end to a particular transition and a new beginning.

The 4S system identifies four major sets of factors which influence the individual's ability to cope during a transition, which can be viewed as assets (resources) or liabilities (limitations). These refer to a person's Situation (what is happening?), Self (to whom is it happening?), Support (what help is available?) and Strategies (how does the person cope?)



SITUATION

- Event or non event characteristics
  - Trigger
  - Timing
  - Control/Source
  - Role Change
  - Duration
  - Previous Experience
  - Concurrent Stress
  - Assessment

SUPPORT

- Social Support
  Types: Intimate, family unit, friendship, network, institution
  - Convoy
  - Functions
- Options

SELF

- Personal Characteristics
- Psychological resources

STRATEGIES

- Coping responses
  - Functions
  - Strategies: information seeking,
    direct action,
    Inhibition of actions

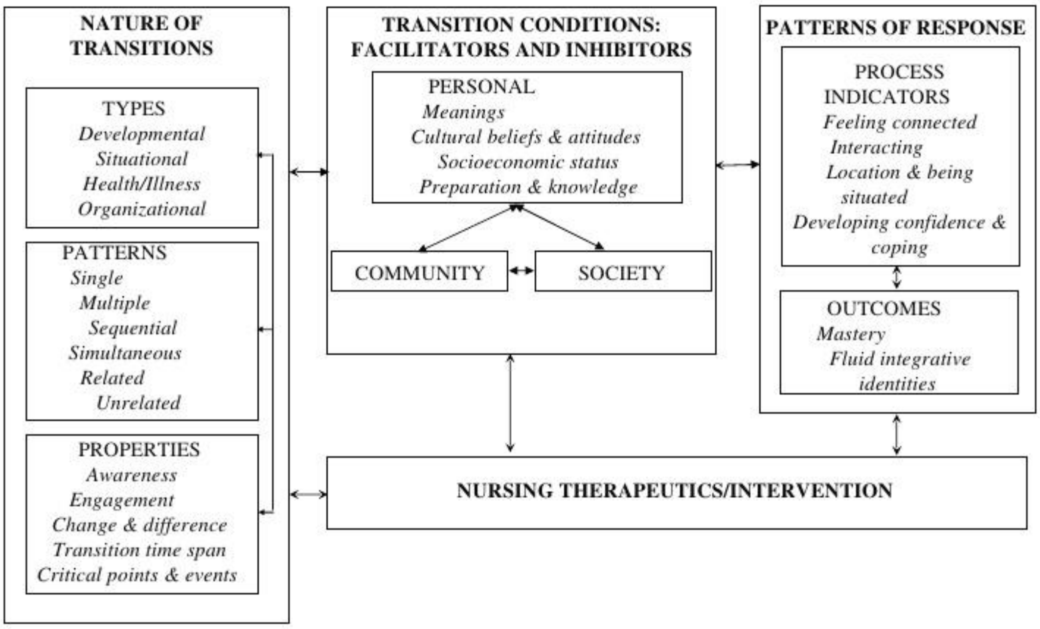
POTENTIAL ASSETS/LIABILITIES

Figure 3.2: Coping Resources: the 4S's (adapted from Goodman et al, 2006)

Each of the four major variables has specific interrelated dimensions which are likely to have particular impact on and will make a difference to an individual's ability to cope with change, and which can be viewed as assets or liabilities (Sugarman, 2001) (figure 3.2). The transition framework recognises that the balance of assets and liabilities can change as an individual moves through the transition and can help to explain why different people react differently to the same type of transition and why a person can react differently at different times (Goodman et al, 2006). Therefore it is particularly pertinent to this study which is seeking to identify how people respond and adjust to the experience of surgery which may involve more than one operation.

3.3. MELEIS’ THEORY OF TRANSITION

The concept of transition was introduced to nursing by Meleis (1975), who proposed that transition was central to nursing practice and research and refined her theory in 2000.
She argued that, although other disciplines focus on transition, nursing’s unique contribution is its ability to facilitate transitions toward health and well-being and identified 310 citations with the word ‘transition’ in the nursing literature between 1986 and 1992 which covered multiple specialty areas and professional roles. Given its focus, it is not surprising that Meleis’ theory is the most widely used in nursing research on patient transition, with multiple studies investigating diverse groups of patients (Meleis, 2010, Davies, 2005, Shulman-Green et al, 2012, Marnocha et al, 2011).



From Meleis, A.I., Sawyer, L.M., Im, E-O., Hilfinger Messias, D.K., & Schumacher, K. (2000). Experiencing transitions: An emerging middle-range theory. *Advances in Nursing Science, 23,* 12-28. (Figure 1)

FIGURE 3.3: Meleis’ (2000) Transition Theory

From a review of the literature, Meleis (2010) later modified the outcomes which were indicative of a positive or healthy transition, substituting a subjective sense of well being, mastery of new behaviours and the well being of personal relationships. She considered the goal of a sense of well being was nursing’s unique contribution. She also made explicit three nursing measures applicable to nursing intervention during transition: assessment of readiness, preparation for transition and role supplementation.

The two theories of Meleis (2010) and Schlossberg (Goodman et al, 2006) have commonalities and shared key elements, such as the nature of the transition, facilitators and inhibitors of transition and coping. Each identifies three phases of the transition process: Moving in, Moving Through and Moving Out (Schlossberg) and Entry, Passage and Exit (Meleis). However, Meleis' (2010) focus was on transition as an organising framework for nursing knowledge and practice, assessing and devising nursing therapeutics.Although Meleis' (2010) work has been widely used in nursing research, its focus on the role of the nurse renders it less appropriate for use in this study that that of Schlossberg (Goodman et al, 2006), with its focus on the individual undergoing the transition.

3.4 TRANSITION IN COLORECTAL PRACTICE AND RESEARCH

In contrast to other areas of healthcare practice, transition has not been well studied in colorectal surgical patients. In the medical literature, IBD is the only specialty in which transition has been specifically discussed. However, in this field, the concept of transition has been limited to a change in the delivery of care for adolescents, who may or may not have had surgery, as they move from paediatric clinics to adult services. This recognition of their changing needs and development has led to recommendations for good practice in managing the transition and the establishment of 'Young Adult' IBD clinics but the actual impact of this change has not been investigated from the patients' perspective (Hait et al, 2006, Escher, 2009, Goodhand et al, 2011, Leung et al, 2011, Philpot, 2011, Sebastian et al, 2012).

While not explicitly referring to transition theory, there are nursing studies, predominantly qualitative, that recognise that patients undergoing colorectal surgery do undergo changes over time akin to transition. For example, seminal work by Wade in 1989 identified factors related to the eventual adaptation of patients undergoing stoma formation. These were associated with the event itself (brief or longstanding illness, emergency or elective surgery, temporary or permanent stoma), attributes of the self (younger or older, male or female, dissatisfaction or satisfaction with the appliance) and support (satisfaction or dissatisfaction with information, the presence or absence of a stoma nurse, single or married status). Thorpe et al (2009) explored the experiences of patients following stoma formation. They identified three major themes of healthcare experiences: relationships with health care professionals; being prepared; and regaining autonomy. Patients revealed how building a new sense of embodied self and increasing social confidence was facilitated by regaining physical capacity, mastering stoma function, purposeful care, and acceptance and support of others. These key elements can be categorised within the 4S system outlined by Schlossberg (Goodman et al, 2006). Sinclair (2009) used a framework of narrative knowing to investigate the experiences of young adult ileostomists. She described a temporal process of moving forwards and backwards, inward struggles with self, the need for support and challenges in coming to terms with the impact of the surgery and adjusting to the presence of a permanent stoma. Beech et al (2012) conducted a longitudinal study to explore the individual's experiences and perspective of the emotional, social and cultural aspects of recovery following surgery for colorectal cancer. Their grounded theory study described the process of recovery in three phases: disrupting the self, repairing the self and restoring the self, which are remarkably similar to the phases recognised by Schlossberg (Goodman et al, 2006) and other transition theorists.

3.5 RATIONALE FOR USING SCHLOSSBERG'S TRANSITION THEORYAS THE THEORETICAL FRAMEWORK FOR THIS STUDY

Previous research demonstrates that a study to investigate transition in young adults who undergo IBD surgery is both timely and necessary to obtain a clearer understanding of their experiences. Clearly, the factors identified by Schlossberg (Goodman et al, 2006) as important in facilitating or hindering transition are present in the findings of these existing colorectal surgical studies. Information which adds to this small body of knowledge by focussing explicitly on the transition process will increase awareness of patients' needs during their journey and provide practitioners with an opportunity for questioning and improving current practice.

Schlossberg's Transition Theory incorporates all the variables- the nature of the event, the self, resources and liabilities and social support, which interplay to influence the transition process. Unless we understand all aspects of an experience that promote or hinder recovery from IBD surgery, we cannot make appropriate and timely interventions. Transition is more than a sequence of stages, or a physical move from one hospital department to another, or home; Schlossberg's Transition Theory (Goodman et al, 2006) provides a way of understanding the reality patients experience, and how they, health care professionals, and their social networks can be assets and/or liabilities at all stages of the surgical journey: preoperatively (Approaching the Transition, Moving In stages) to acute postoperative and recovery at home (Moving Through stage), and the resumption of normal life (Moving Out stage). This particular theory was adopted for use in this study because of its potential to assist in organising, describing and analysing the experiences of young adults with IBD undergoing surgery and facilitating a better understanding of those experiences and the important factors that influence them.

CHAPTER 4: METHODS

The methods chapter is divided into four main sections. The first section justifies the overall approach selected. The following two sections discuss separately the sequential phases of the study: Phase 1 – qualitative narrative, Phase 2 – quantitative survey. Sections pertaining to trustworthiness, ethical considerations and limitations complete the chapter.

4.1. STUDY DESIGN

This study used a mixed methods approach to investigate the experience of surgery as a transition in the lives of young adults who faced the prospect of, or had experienced, an operation for IBD. It was designed as a sequential 2 phase design in which a quantitative phase chronologically followed a qualitative component. This design was appropriate for the study, since little was known about the area of investigation; the first phase explored and described their experiences in depth and the findings were then tested in the quantitative phase (Teddlie and Tashakkori, 2009).

4.1.1 Rationale For Using Mixed Methods

Mixed methods studies are informed by a pragmatic ontology which places the research problem as central to the research and applies appropriate approaches to its investigation and understanding (Cresswell, 2003); this permits the selection and use of data collection and analysis techniques most likely to provide insights into the question with no philosophical constraints or adherence to any particular paradigm (Mackenzie and Knipe, 2006). Mixed methods research thus recognises the importance and usefulness of both quantitative and qualitative methods and data and utilises them in combination to bring their different strengths together in the same research project (Morgan, 1998); the central premise is that the use of quantitative and qualitative approaches in combination provides a better understanding of research problems than either approach alone (Cresswell and Plano Clark, 2007). Rather than restricting or constraining researchers’ choices, mixed method research permits an eclectic approach to thinking about and conducting research; methods and research techniques can be selected that best address the research question and are most likely to produce the strongest evidence to fully answer it (Johnson and Onwuegbuzie, 2004, Connelly, 2009).

The mixed methods design provided a more comprehensive answer to the research questions than would have been possible with either a qualitative or quantitative study alone (Cresswell and Plano Clark, 2007). The qualitative narrative approach in the first phase enabled the researcher to identify key factors which had been influential in deciding whether and when to have surgery, how they perceived their surgery and prepared for it, and those which affected patients' postoperative adjustment and experiences in an area where there had been little previous research. This phase provided the foundation for Phase two, as key issues and themes identified through analysis of the qualitative data were used to generate the content and inform the design of the questionnaire in Phase 2. The quantitative survey in Phase 2 was conducted to establish that the initial findings from qualitative investigation were corroborated and generalisable beyond that population thereby increasing confidence in the inferences that could be drawn from them. In addition, Phase 2 provided quantitative data that could be read by medical colleagues and policy makers.

4.1.2. Study Phases

This mixed methods study had two sequential phases as follows:

Phase1 was a qualitative exploratory phase which used narratives to discover the process of transition as it was experienced by young adults with IBD in one NHS Trust who faced the prospect of, or had undergone surgery, for their condition. Little was known about this area so it was anticipated that this investigation would reveal in depth information about perceptions, concerns, motivations, needs and responses and thus provide the descriptive data necessary for a better understanding of these young people's experiences. This phase provided the foundation for Phase two, as key issues and themes identified through analysis of the qualitative data were used to generate the content and inform the design of the questionnaire in the second phase.

Phase 2 was a quantitative survey undertaken to establish whether the views of the young adults in Phase 1 were generalisable beyond the population studied for the qualitative data. A questionnaire was designed using data provided in Phase 1 to generate specific items pertaining to the experience of surgery in young adults with IBD. These were then tested using a closed and open response questionnaire. After piloting and appropriate revision, the questionnaire was administered to a sample of 120 similar young adults attending IBD clinics at 7 NHS centres in England. The sample was obtained by sequentially selecting patients as they attended the IBD clinic at 5 centres and by sending a postal questionnaire to all patients who met the selection criteria identified from patient databases at 2 centres.

4.2. PHASE 1

4.2.1. Participants

4.2.1.1. Sample Characteristics

Purposive sampling (Lincoln and Guba, 1985) was used to select 24 participants in the age range 18 – 25 who had been diagnosed with IBD who either faced the prospect of surgery or had previously undergone surgery for this condition. Selection criteria were deliberately broad so that participants in young adulthood, of both sexes, from different cultures and backgrounds and at different stages in their experience of surgery are included. This heterogenous, maximum variation sample provided two types of data – individual narratives yielding rich data about unique individuals, and identification of shared themes and concerns across participants (Morse, 1994); the intention was to capture the full range of opinion and draw out not only 'typical views' but ensure that minority perspectives were included.

4.2.1.2. Sample Size

The purpose of Phase 1 was not to produce generalisable findings but to develop theory which could be tested in subsequent investigation (Flick, 2009), therefore a sample size calculation was not appropriate (Boswell and Cannon, 2013). Qualitative studies reported in high impact peer reviewed journals typically report data from 20 – 40 respondents (Benson and Britten, 2006, Everitt et al, 2003, Davies 2005). Therefore young adults with IBD, drawn from the 250 who attend the Adolescent and Young Adult IBD clinic at one NHS Trust who had either had or were about to undergo surgery were invited for interview until no new information was obtained. The sample size of 24 was determined during the process of data analysis; when no new information emerged, sample selection and data collection stopped (Smith and Biley, 1997). This sample provided a sufficient variety of participants to adequately capture the data required.

4.2.1.3. Recruitment

Potential participants who met the eligibility criteria were identified by a Consultant Gastroenterologist from among those attending the Adolescent and Young Adult IBD clinic at one hospital site. At their visit they were given information verbally about the study and a patient information sheet (Appendix 8). Those who expressed an initial interest in participating were asked their permission for the researcher to have their telephone details so that she could contact them to provide further information and make interview arrangements if they chose to participate. To minimise the risk that they might feel pressured to agree to participate, and allow time for them to familiarise themselves with the study information, the researcher only introduced herself, gave a brief verbal overview of the study and provided a written information sheet during the clinic visit, and then telephoned potential participants one week later. During this telephone conversation, the researcher further explained the nature of the study and how confidentiality would be assured. Each potential participant was informed that participation in the study was entirely voluntary, and that their decision would not affect their ongoing treatment and management in any way. They were also told that consent meant that they would be volunteering to participate in an audiotaped interview. A date and time for the interview was then set with those who agreed to be included in the study, which was most often at their next clinic visit.

4.2.2. Data Collection

4.2.2.1. Interviews

In depth interviews encourage participants to tell their stories in their own words and are therefore an appropriate strategy for collecting the type of data required in this study. They provide the opportunity for narrators to tell about their experiences and proceed on the assumption that the perspective of others is meaningful, knowable and able to be made explicit (Patton, 2002, Albright et al, (2008). One of the significant ways that individuals make sense of and give meaning to their experience is to organise them in narrative form (Mishler, 1986a). Young adults, the participants in this study, have the necessary skills, including recall, insight, interest, attention span and life experiences to recount their personal stories related to surgery and IBD (Haglund, 2004).

Careful consideration was given to the research aims and Phase 1 questions and how these could be transformed into suitable questions that would elicit sustainable stories that enabled participants to give free responses and to control the content and manner of their telling (Wengraf, 2001, Mishler, 1986b). The researcher asked them to talk about their experiences of surgery, beginning with the request to describe what surgery they had had. This was then followed by ‘what did you feel when you were first told that you needed to have surgery’ and interviews proceeded in an individual manner from there.

4.2.2.2. Interview Guide

It has been found that young people often expect that an interviewer will ask them questions, to which they respond, and leave out emotional responses and interpretations (Haglund, 2004). Therefore, a flexible semi structured approach was adopted. With advice from an academic supervisor experienced in conducting health care research with adolescents and young adults, an interview guide with open questions was developed; similar guides have effectively been used previously in adolescent interviews (Kyngäs, 2003) to help to focus their thoughts, aid the flow of the narrative and facilitate a comprehensive exploration of their experiences. This guide contained a range of broad questions such as ‘how do you feel about your body after (type of surgery)’ and ‘some young people feel ... after this surgery. Has this happened to you?’ Questions in the guide were introduced when the researcher needed to explore additional issues, or to develop an area about which the participant had already been speaking.

As the interviews proceeded, data was concurrently analysed. This led to some reframing of questions after the study was reconceptualised, the purpose of which was twofold - to find out more about particular issues emerging from the data and to clarify aspects of the theoretical model. Such questions were introduced in a broad manner to avoid forcing participants to discuss issues in a specific way. For instance, if a participant stated ‘I couldn’t have got through it without...’ which relates to the support factor, the researcher’s response would be: ’in what ways did they help you’.

4.2.2.3. Interview Process

The main role of the narrative interviewer is to initially request a story, then to remain a listener, abstaining from interruptions, posing questions for clarification, and assisting the interviewee to continue to tell the story (Kvale and Brinkman, 2009). In most instances, apart from the opening questions, there is no predetermined and fixed sequence of questions and participants freely select what subjective experiences and interpretations they include.

As the early interviews took place, the researcher was concerned that participants might be inhibited from talking about issues of intimacy and sexuality to a white, middle aged female. The stories that were being told covered many elements of their experiences in detail; they talked about intimate relationships but did not devote much time to sexuality and intimacy within those relationships. The researcher brought this issue for discussion with her supervisor. As a consequence, additional questions were added and used in the interviews. Subsequently six interviews were completed and preliminary analysis underway. At this point, it finally became clear that sexual concerns were not a major issue for these young people as they faced surgery: *‘I think that’s the least of your worries, really’* (quote from interview with James).

The decision was made to refocus the study and the interview guide that was finally used was developed (Appendix 9). Subsequent interviews were as open and non directive as possible, with pre prepared questions (prompts) used only as necessary. Interviews ranged in length from about 30 minutes to 90 minutes. In practice many became like an extended conversation, and the techniques that the researcher mainly used were expressions of interest (‘oh really’, ‘that’s interesting'), requests for more information ('can you tell me more about that'), expressions of empathy ('that must have been difficult', 'I can imagine', 'I can understand') and reflecting or summarising statements for clarification. Third person questions were also quite commonly asked, framed as 'Some young people find/think...how about you', which served to introduce some topics of interest to the researcher that had not previously been addressed.

4.2.2.4. Recording And Transcribing Data

All interviews were recorded using a Dictaphone and microphone and then transcribed verbatim by the researcher as soon as possible after each interview. This provided an accurate account of the questions asked by the researcher and participants' responses. An example of a transcript is in Appendix 10. Although time consuming, this process was extremely valuable in that it provided the first opportunity to become familiarised with the interview content and facilitated critical scrutiny of the process. This process assisted the researcher to determine her effectiveness as a questioner, listener and co-participant in the interview (Mishler, 1986a) and consider what changes could be made to improve the quality of the experience and the information obtained in subsequent interviews. The completed transcriptions constituted the raw data for analysis.

4.2.2.5. Field Notes

In some instances, participants also provided additional relevant information as they chatted with the researcher after recording stopped. With their permission, this was written down, which were read alongside the finished transcript but not included in the analysis.

4.2.2.6. The Role Of The Researcher

The primary role of the researcher was to develop rapport and facilitate open discussion with participants. Before each interview commenced, the researcher discussed why they had been selected, the value of their contribution to the research project, that anything they said would be of interest and then assured confidentiality in the manner described in section 4.5.2. These young people were interesting and enjoyable to talk to, and very open and accepting in their attitudes towards the researcher. There usually appeared to be an atmosphere of trust in that stories were shared about themselves which were not directly related to the research, and some disclosed highly personal and what could be considered to be 'risky' information at times, about non compliance with medication, opinions of the medical team, difficulties in relationships and with sex and illicit drug taking. There was also humour and laughter.

The researcher was most careful to try not to stray into a clinical role with participants as she was a qualified nurse but on one occasion a participant made a statement which expressed anxiety or uncertainty about himself in relation to his recovery and she deemed it appropriate to step out of the researcher role to respond with information for reassurance. The participant spoke of his dietary improvements but expressed concern that he was not gaining weight in the early months after his operation. The researcher responded with factual information about how in the early period after surgery he was using nutrition for healing and he might put on weight later. He said that was what he had been thinking and the reasons why, which the researcher reinforced and when she had confirmed he was happy to continue, the interview moved on.

4.2.3. Data Analysis

4.2.3.1. Data Organisation

To familiarise herself with and begin to understand the content of the interviews, the researcher used two methods to organise and reduce the raw data in the transcripts. The first was story mapping (Richmond, 2002). This was selected as a means of understanding changes in participants' lives over time and was instrumental in identifying the process they were describing. A grid was developed, the vertical axis of which was labelled with 10 themes which were broad enough to capture all the aspects of their lives participants had discussed such as 'the surgery', 'disease', 'self', 'family'. The horixontal axis was divided into 'past experiences', 'present experiences' and 'future intentions' (Table 4.1). Related items in the participants' own words were placed in the grid. An example of a storymap is in Appendix 11. This revealed changing thoughts, feelings and behaviour for each participant over time in relation to key areas of their lives, including the operation and their illness.

Table 4.1: Storymap to Organise Transcript Data (Richmond, 2002)

	Past experiences	Present experiences	Future intentions
Self			
Disease			
The surgery			
Health professionals			
Family			
Friends/other people			
Intimate relationships			
Appearance			
College/Work			
Activities			

The data were then further reduced and organised by 'restorying' (Cresswell, 2008) . In this process, repetition was removed, and what had been said by each participant within each theme was synthesised into a story that told their experience of surgery and its effect on their lives, again using their own words. These processes reduced the many pages of individual transcripts, and gave form and clarity to the data. This enabled the researcher to see the process of transition as it was experienced by each participant and to document changes in themselves and their lives in relation to their surgery. An example, Ruhana's story, is in Appendix 12.

4.2.3.2. Data Analysis

Schlossberg's model of transition (Goodman et al, 2006) was used as the organising framework for data analysis. The 4S system (Situation, Support, Self and Strategies) and the 3 stages (Moving in, Moving through and Moving out) provided the main categories for analysis.

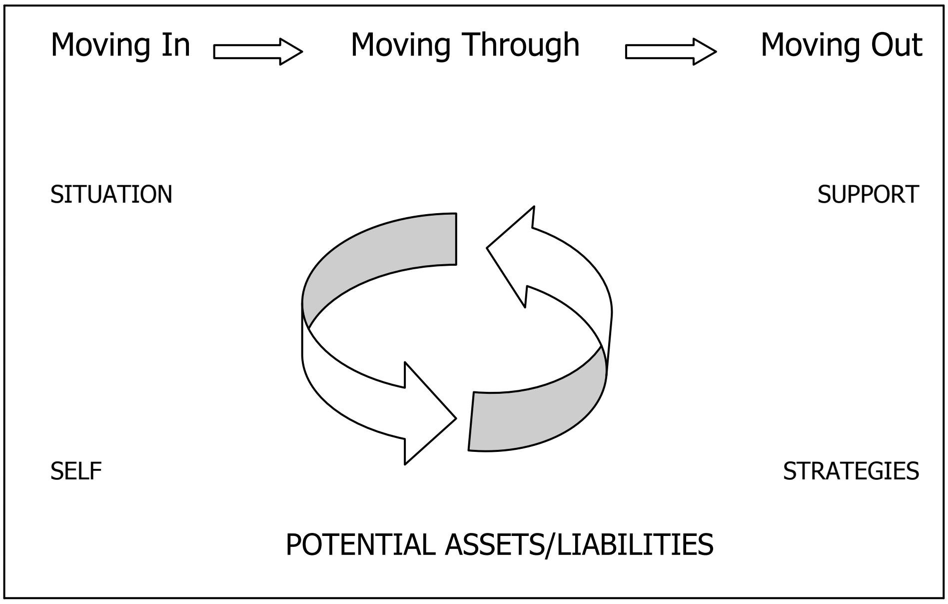


Figure 4.1: The Three Stages of the Transition Model (adapted from Goodman et al, 2006)

The Situational dimension, which encompasses the surgery (event) itself, has specific dimensions assigned to it, which were directly used as themes. Factors pertaining to the other three dimensions related to individual differences and were at a broader level of conception. Each participant's story was examined and quotes from individual stories that fitted into these dimensions were assigned to and grouped within themes which were then appropriately labelled as data analysis proceeded (Table 4.2: Appendix 13). All the data provided could be accommodated within this framework.

Information considered to generally ‘help’ or ‘hinder’ transition was assigned to the developing themes from which a descriptive account was then constructed of factors that affected the process of transition as it was experienced by young adults with IBD who undergo surgery. Trends and agreements were highlighted as well as areas of divergence and notable exceptions of opinion.

A separate analysis was carried out to identify stages in the process of transition as they were experienced by participants undergoing surgery, using the categories of Moving In, Moving Through and Moving Out. Analysis was undertaken in two ways: each transcript was reviewed to identify ways of thinking, feeling and behaving that indicated particular stages, and a more holistic analysis considered individual participants’ stories to determine those that were at different stages of transition (see Chapter 5: Patient Portraits).

4.2.4. Trustworthiness

In the qualitative phase of the study, trustworthiness refers to the efforts made by the researcher to address the more traditional quantitative issues of validity and reliability and establish the quality and robustness of the research findings (Bloomberg and Volpe, 2008, Tobin and Begley, 2004). The researcher took the following steps to ensure that the qualitative investigation in its conduct, findings and analysis could be trusted to provide a plausible and credible answer to the research question: an audit trail, member checks and Steering Committee Member review.

4.2.4.1. Audit Trail

The documentation pertaining to data collection and analysis for Phase 1 commenced with the interview guide. The transcripts, storymaps, restoried narratives and results which were used to organise and analyse the data all used the participants’ own phrases. This ensured that the process by which the data was transformed was clearly visible. In addition, the researcher maintained records which could be reviewed that provided an account of the actual course of the research process, including the need for reconceptualisation of the study and which outlined the changing decisions and rationales for action which were taken as the investigation proceeded.

4.2.4.2. Member checks

At the end of each interview participants were asked if they would like a copy of their story to be sent to them, so that they could check that they were happy about the content that was included and revise this if necessary. Most declined this, commonly with comments such as ‘I have said everything that I’d like to say’ or ‘that about sums it up really’. The five that did receive a copy were provided with a stamped addressed envelope to return the document but advised in a covering letter that they need take no action if they did not want to make any changes. No transcripts of stories were returned. This strategy was deemed not entirely successful in establishing the veracity of the data; those who declined to check it appeared to trust that an honest account would be given of their information, and those who received it did not send anything back, so it could be assumed that they, too, were satisfied. However, it may simply be that none of the participants wanted to devote any more time to the project.

4.2.4.3. Steering Committee Member Review

This strategy was chosen in addition to member checking so that a sample of the transcript data, the restoried data and the study findings from several participants could be scrutinised by an independent person familiar with the research to determine that what was said by participants was accurately reflected in the analysis. The Professor in Cancer and Palliative Care, who was an expert in qualitative research methods, undertook this. It was intended that this procedure would prevent biased results and a reliable description of the participants' experiences be assured.

4.2.4.4. Reflexive Research Diary

Throughout the study, the researcher kept a reflexive diary that provided a record of thinking and responses to what was happening, and account of issues that arose. This provided a research "trail" of how the study progressed (Ortlipp, 2008) and was of particular value during the early interviews and analysis and the search for identifying and understanding the process which the participants were describing, which eventually led to the identification of surgery as a transition and the reconceptualisation of the study.

4.3. PHASE 2

4.3.1. Participants

4.3.1.1. Sample characteristics

The characteristics of the national sample were the same as for Phase 1. Thus, the sample consisted of participants in the age range 18 – 25 who had been diagnosed with IBD who either faced the prospect of surgery or had previously undergone surgery for this condition. Participants in young adulthood, of both sexes, from different backgrounds and at different stages in their experience of surgery were included.

4.3.1.2. Sample size

Statistical advice was taken from the statistician at City University to determine the appropriate number of participants for Phase 2. Existing literature does not provide any information on the outcomes of primary interest in this study, as research in this area has not been done before. Therefore it was not possible to do a sample size calculation.

The sample size was determined from an estimate of what would be a realistic number of participants to recruit to the study in a period of six months of data collection, on the basis of clinical experience and discussion. It was thought feasible to recruit 5 participants a month from each of 6 centres that have regular adult IBD clinics and 10 patients a month from each of two centres that hold regular Young Adult clinics. This would yield a total of 300 participants (180 from the adult clinic centres and 120 from the Young Adult clinics).

In practice, this proved impossible to achieve, and recruiting sufficient participants to the study was one of its most challenging aspects. Recruitment was dependent on the voluntary cooperation of other health professionals and the characteristics of the participants, and was slower than estimated from the outset. After six months of attempted data collection, at a discussion meeting with the Steering Group during which recruitment difficulties were explored, it was agreed that a pragmatic approach had to be taken. After 15 months recruitment stopped and at that time there were 120 participants.

4.3.1.3. Recruitment

The Consultant Gastroenterologists at eight centres in England who were known to have appropriate clinics were approached and asked to consider participating in the study. All agreed, and submissions were made for approval to conduct the study at each identified local Research and Development department. One centre withdrew before approval was given and one afterwards and before any recruitment took place, due to lack of sufficient staff to participate. At the remainder, gaining approval to commence the study was often a lengthy process; although one centre granted approval within a month most took between 6 and 9 months to approve the study. One centre took 14 months. Eventually 6 centres and the researcher’s own participated.

4.3.2. Data Collection

4.3.2.1. Questionnaire Development

The design and content of the questionnaire was developed from the findings of Phase 1 with a structure that reflected the 4S system of the transition model- Surgery, Support, Self and Strategies (Goodman et al, 2006). Individual items included were those identified as most important in facilitating or hindering transition. The nine main questions were arranged sequentially to take participants through their surgical journey: how long before it took place that they knew they needed an operation, their reaction to first hearing they would need an operation, preoperative concerns, what they did to prepare for surgery, what they did that was helpful, things they did to help them to cope after surgery, things parents, partner and friends did to try to help them after surgery, how they feel now after surgery and best and worst things about the operation. Most questions required participants to tick item boxes for easy completion. The questions about their reaction to hearing they would need an operation and best and worst things about the operation were free response questions. The researcher tried to ensure the questionnaire was free of technical language, had simple instructions, a logical progression from preoperative to postoperative experiences and provided signposts indicating how much of it had been completed. A front sheet (Appendix 14) was also devised to obtain information about the participant's disease, age, gender and operation details.

4.3.2.2. Questionnaire Testing

Once the questionnaire was drafted, opinion was sought from IBD health care team members at all sites and the Steering Committee on its appropriateness and content. Comments and suggestions for improvement were considered by the researcher and steering committee and it was revised accordingly. Ten young adults who attended the IBD clinic at the researcher's centre were asked to complete the questionnaire and were then interviewed by the researcher using a pretesting questionnaire (Appendix 15) to elicit their opinions on the clarity of questions, ease of completion, and the time it took to do so. All their responses were reviewed. Further minor amendments were made, after which it was considered ready for use.

4.3.2.3. Pilot Study

A pilot study was conducted with 20 participants who met the eligibility criteria to determine that it was feasible to administer the questionnaire in clinic. The target number was reached in five clinic visits, so the rate of recruitment was slightly lower than target. However, the pilot took place at the end of the academic year (early summer), and this is a time when clinic non attendance is usually higher than normal as it is when major examinations take place at college and university. Taking this into account the researcher did not anticipate problems in recruiting to target. The researcher planned to code the pilot study data and devised an Excel spreadsheet for the purpose. On beginning to enter this data it was discovered that one item was missing from one question in the questionnaire, so this error was corrected and a final version of the survey questionnaire created (Appendix 16). None of the pilot study questionnaires were included in the main study analysis.

4.3.2.4. Data Collection Strategy At Participating Centres

Initially it was planned that Consultants and IBD Clinical Nurse Specialists at participating centres would be responsible for recruiting patients who were attending IBD clinics to the study. All patients who attended the clinic and fitted the eligibility criteria would be asked if they would agree to participate. Those who did were to be given a brief information sheet, the questionnaire to complete in clinic and an envelope into which the questionnaire could be placed so that it remained confidential and anonymous. The envelope was prepaid and addressed for its return and the Clinical Nurse Specialist would be responsible for posting the envelope back to the researcher. She would also be contacted by the researcher at the end of each month to record the number of participants who had completed the questionnaire so that progress in recruitment could be monitored. This process was to continue until the required number of participants was acquired. If required numbers were obtained before the end of six months, recruitment would stop at that centre but continue in others until that time.

This decision was based on experience of conducting interviews in Phase 1 and member checking in the qualitative phase, and following discussion with an Adolescent and Young Adult IBD nurse specialist, about the most appropriate way to survey young adults. In Phase 1 it was found that young adults are willing to participate in research, provided it does not involve making specific arrangements that impact on their normal lives, or involve much time. Questionnaire completion in clinic was considered to be the most feasible strategy. Because of this, a postal survey was thought to be likely to have a low response rate and was initially rejected as an alternative.

Following approval, the researcher visited each centre to explain the procedure for administering and returning the questionnaires. However, when visiting two centres to explain the requirements of staff in recruiting and administering the questionnaires it transpired that, although they were supportive of the study, low staffing levels and high clinic activity would prevent them from recruiting patients and administering the questionnaire as planned. It was not feasible for the researcher to attend the clinics at these centres to undertake this task herself so it was decided after consultation with the Steering Committee that postal questionnaires would be sent out. The researcher visited these centres again and with the assistance of the clinical nurse specialist at that site, obtained the details of all patients now aged 18 – 25 who had had surgery for IBD and sent out questionnaires to them all. A summary of recruitment strategies and numbers appears in Table 4.2. below.

Table 4.3: Participating Centres, Methods Of Recruitment And Sample Size

Centre number	Recruitment in clinic	Recruitment by post	Response at first posting	Response at second post	Total participants
2	23				23
3	14				14
4	46				46
5	11				11
6		27	6	3	9
7	3				3
8		34	9	5	14
	Total participants				120

4.3.3. Validation

To determine the quality of the newly developed survey instrument, reliability testing was carried out using Cronbach's alpha to assess the internal consistency of the items within the Brief Cope scale, and the newly developed psychosocial measures Preop Concerns about Surgery scale, Preparation for Surgery (What they Did) scale, Preparation for Surgery (What Helped) scale and Post-Surgery Perceptions scale (see Chapter 6: Scale Validation).

4.3.4. Data Analysis

The plan for analysis of the questionnaire data proceeded sequentially to reflect the transition experience. Specific questions were asked of the data that grew out of the qualitative analysis. These provided the foundation for quantitative analysis of the questionnaire to determine if the phase 1 findings could be corroborated. Using SPSS for Windows, descriptive statistics were used to analyse the participants' demographic data: gender, disease type, surgical history (type of operation, frequency and recency). A one way analysis of variance (ANOVA) test was used to generate mean scores and rankings for the items in the psychosocial scales. Gender, age and disease differences were compared using independent t tests. Relationships between coping and Post-operative Perceptions, Pre-operative Concerns about Surgery and Post-operative Perceptions, and Preparation for Surgery (What they Did) and Post-opeerative Perceptions were analysed using Pearson's correlation coefficient. Content analysis (Krippendorff, 2013) was used to identify and code themes in the data from the free response questions; how you reacted when you first heard you needed to have an operation and Best things and Worst Things about surgery, and then frequency of mention counted to determine their prevalence. Multivariate analysis was then undertaken to understand the interrelationships among multiple transition factors and post-operative perceptions of surgery.

4.4. PROJECT MANAGEMENT TEAM

The project management team consisted of the Steering Group and a staff member from Crohn's and Colitis UK, a national charity that also funded the research. Steering Group members were a Consultant in Gastroenterology, Professor of Healthcare Research and Professor in Cancer and Palliative Care who supervised, guided and advised on this research project from its inception to completion. They met with the researcher at approximately 3 monthly intervals to review progress and critically appraised decisions and actions of the researcher at all stages of the study to ensure they were sound and could be justified. In addition they offered helpful advice to ensure the integrity and coherence of the study and that the schedule for completion was adhered to. As the research study was funded by a grant from the charity Crohn's and Colitis UK, the Steering Group and researcher also met regularly with staff members from this organisation, to provide information and discuss progress. Additional advice was provided by a Consultant in Colorectal Surgery.

4.5. ETHICAL CONSIDERATIONS

4.5.1. Ethical Approval

This study received ethical approval from the Research Ethics Committee in May 2009. When the application was submitted, the Committee had concerns about the settings in which it was planned to conduct the interviews, as they included the participants' own homes. The Committee considered that there might be some personal risk to the researcher when discussing sexual issues in that environment and also that the discussion might be overheard. Therefore it was decided that all interviews would take place on neutral ground. Once this amendment had been made, final approval was given. In practice, all but one interview took place before or after a scheduled clinic appointment in a private consulting room in a separate building from the clinic. The remaining interview took place in a park.

4.5.2. Confidentiality and Anonymity

It is important in any study to ensure that participants can be confident that their information will remain private so that they can discuss personal and sensitive issues in the knowledge that it will not be disclosed to others (Israel and Hay, 2006). The researcher outlined to the participants the steps that were taken to guarantee confidentiality:

They were assured that no information they shared would be disclosed to any other person without their permission, and that the final report or any publications would not include any information about them in a form in which they could be identified.

Paper documents and interview cassette tapes when not in use were locked in a filing cabinet in the researcher's office for which only she had the key. Participants' electronic data, results and records were stored and worked with on one password protected laptop and one similarly protected USB memory stick.

Patient names and other identifiers were removed from any documents shared with Steering Committee members and pseudonyms were assigned in the final report.

At the end of the study the records are to be retained for 10 years, kept in the approved repository for long-term storage as required by Trust research governance policy.

4.5.3. Facilitating Choice In The Decision To Participate

Since participants in Phase 1 were being recruited from a clinic setting, and introduced to the idea of the study by their medical consultant, it was important to ensure that they did not feel obligated to become involved. Therefore, away from the consulting room, a short verbal description of the study was provided at the end of the outpatient visit by the researcher. At this point it was stressed that participation was entirely the young person's choice, a decision not to take part would not affect their treatment and that any information they provided would not be disclosed to members of their medical and nursing team without their consent. They were then given detailed written information describing the purpose of the study, why it was being done, and explicitly stating what they would be required to do. At least a week later, the researcher telephoned each potential participant, provided further information as required, and ascertained whether they would be willing to be interviewed. Where feasible, a date was then set for those who agreed or arrangements made to telephone them at a future time to do this. These strategies were designed to enable participants to give informed consent and to make a free decision about participation.

4.5.4. Managing Participants' Well Being

This research study focussed on personal experiences relating to illness and surgery in young people. When being asked about or recounting these experiences, it was possible that they might experience a range of emotions including discomfort or distress. Therefore steps were taken to try to avoid this happening and to manage the situation appropriately if it did.

Before the interview took place, each participant was told that they could refuse to answer any question if they were not comfortable doing so. This occurred only once. (Chapter 5, section 5.1. The Experience Of Interviewing Participants).

CHAPTER 5: PHASE 1 FINDINGS

This chapter first describes the experience of interviewing participants. This is followed by a description of participant characteristics and their experience of surgery. The Phase 1 results are then presented using the 4S system (Situation, Self, Support and Strategies) as an organising framework. Three Patient Portraits complete the chapter.

5.1. THE EXPERIENCE OF INTERVIEWING PARTICIPANTS

Participant interviews that provided the qualitative data were sometimes challenging but always interesting. The most difficult aspect involved arranging a venue and time for interviews, as they could not be carried out in participants' homes. The pragmatic solution was to conduct twenty three interviews before or after a scheduled clinic appointment. One further interview took place at the participant's request in a park. However, some participants would agree to be interviewed and then not attend their outpatient appointment, which was a common experience in this clinic. Therefore some interviews had to be rescheduled, sometimes more than once, so data collection in Phase 1 extended over more than a year. In practice twenty two of those who agreed to be interviewed were able to tell their stories and provided information pertaining to many of the issues within the interview schedule often without directly being asked. Only two interviews with younger participants were predominantly led by the interviewer, where they provided answers and then waited politely for the next question. Participants were also told at the outset that if they were asked any questions they did not want to answer, they could say 'I don't want to answer that'. Only one participant did so; when asked if he had a girlfriend before he started having surgery, he replied, 'That's complicated. I wouldn't really put that on the tape', although he was willing to answer questions about plans for a girlfriend in future.

On two occasions shortly before an interview, the researcher sensed from the potential participants' manner and speech that they were at that time reluctant to proceed, although this was not explicitly stated. She made the observation to them that she thought they may have changed their minds and also stated that it was acceptable to withdraw from the interview without giving a reason. One participant withdrew completely, the other wanted to reschedule for another day and this went ahead.

During one interview, the participant became overtly distressed as she recounted her story. The researcher offered to terminate the interview but the participant wanted to continue, although she sobbed all the way through. At the end, with the tape off, the researcher asked the participant if she felt she needed help with managing this distress. Informed that the clinical nurse specialist had provided help and support in the past, the researcher suggested that the participant contacted her again and asked her permission to contact the nurse so that the nurse would be aware that she would be doing this, which was given. In this way the researcher ensured that the nurse specialist knew of the need for assistance, without breaching confidentiality.

When walking away after another interview a participant with a recent stoma chatted about her reluctance to start dating, and if the researcher felt that was a normal thing at this stage after surgery. Based on what she had previously said in her interview, the researcher provided reassurance that this was a reasonable thing to do.

5.2. PARTICIPANT CHARACTERISTICS

From March 2010 to May 2011, 24 young people were interviewed (Table 5.1 Appendix 17). Eleven were male and thirteen female. At the time of interview, participants were aged from 18 to 25. The majority were in their early twenties. Eighteen had CD and six UC. Twelve were working, eight were at college or university, of whom two had part time jobs. Four had no occupation at the time of interview, although two of these had definite plans for the future. Fourteen were in steady heterosexual relationships, and four of these had plans to marry. Ten were currently single, including four who had not had a close relationship since surgery. Three female participants were parents.

5.3. EXPERIENCE OF SURGERY

One participant was waiting for his first operation. One had refused surgery. Of the remaining twenty two, three participants had first had surgery as a child, all of whom now had a permanent stoma. Three were interviewed when they were in hospital recovering from a surgical procedure. The remainder were interviewed between several months and two years after a surgical procedure.

Eight of the nine male participants who had been operated on had undergone major abdominal surgery. One had 3 operations and 5 had had two operations. Most of these were open procedures, but Sam had both his operations, and Jack his second operation, laparoscopically. The remaining male participants each had one operation; Paul had laparoscopic surgery and Fazeel underwent an open procedure. Two (Humza and Rayhanul) were living with a stoma at the time of interview, although a further three had had stomas reversed. Two of these were now living with a functioning ileoanal pouch (James and Dave). Krish had had perianal surgery.

All 13 female participants had had surgery. The ten who had abdominal surgery all had open procedures. Six had undergone more than one abdominal operation, of whom five were currently living with a stoma (Lesley, Daisy, Helen, Yasmin, Bernice) and one had an IAP (Anne). Four had had a single abdominal procedure (Ruby, Sadie, Victoria, Mariam). Mariam and Victoria were living with a stoma. Victoria was scheduled for a further operation. Six females in total had had perianal surgery, of whom three had also had major abdominal surgery (Sadie, Lesley, Daisy). One had had one perianal operation (Sadie), four had undergone 2 - 3 perianal procedures (Ruhana, Daisy, Mia, Rania). The remaining participant (Lesley) had had so many perianal procedures in the last 10 years that she had lost count.

5.4. ANALYSING RESULTS: THE 4 S SYSTEM

Analysis of data involved examining the data for patterns and themes within stories, then assigning them to relevant categories within the 4S system- (figure 5.1, below) - Situation, Self, Support and Strategies (Goodman et al 2006) to reveal the factors which influenced transition through surgery and adjustment to an operation.

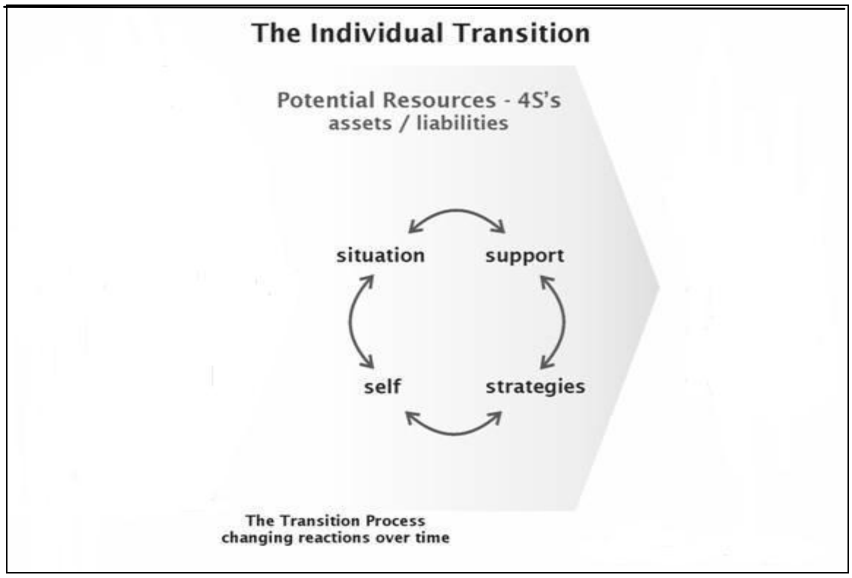


Figure 5.1: 4 S System (Goodman et al, 2006)

5.5. THE SITUATION

The Situation variable consists of eight interrelated categories or dimensions (control, trigger, timing, duration, role change, previous experience with a similar transition, assessment and concurrent stress) that affect how participants view and respond to the impact of a transition on their lives (Goodman et al, 2006). These eight dimensions relate to the surgery itself.

SITUATION	An uncontrolled illness (Control)
	Decision making (Control)
	Turning points (Control, Triggers)
	Timing (Control, Timing)
	Positive and negative appraisal of surgery (Assessment, Role Change, Previous Similar Experience)
	Different perceptions about surgery among participants with CD and UC (Duration)

(Situational dimensions in brackets)

Figure 5.2: Major Themes Related to Schlossberg's Situational Dimensions

This section identifies the range of comments in participants' stories about the operation, before and after it took place. Figure 5.2 summarises the major themes identified which incorporate Schlossberg's Situational dimensions.

Several of the factors identified by Schlossberg were closely related in participants' accounts, such as control (or lack of it), turning points (triggers) and timing. Role change, assessment and duration were factors related to the theme of participants' appraisal of surgery, and duration was a factor that affected perceptions of surgery. Issues related to control also appeared to be an element of several other themes; decision making, timing and appraisal of surgery. Concurrent stress was not a major factor for the majority of these young people, although it is evident from their interviews that the two participants who did encounter multiple concurrent stressors (Mia and Helen), had a difficult time and a pessimistic view of the future (see below 5.6.2.2. and 5.6.6.2.)

5.5.1. Control

5.5.1.1. An illness out of control

All the participants who had surgery were in a situation where the disease and its symptoms could no longer be controlled by medication. Some showed determined resistance to a disease perceived as an adversary:

> *'I'm not gonna let it trap me'* (Daisy)
>
> *'I'm not gonna let it beat me...I'm gonna ignore the Crohn's pain...You can never ignore it and when it wants to bring you down it does'* (Fazeel)

However, when medical treatment failed, there was little control or choice about whether to have an operation or not as surgery was the only option left. Yasmin said:

> *'(I realised) there's nothing I can do to stop this. I was on the prednisolone. I was on the Azathioprine. I was on so many medications. I went through the whole medications that was there'.*

Lesley had a proctectomy and formation of a permanent ileostomy when she was 12:

> *'...the doctor said if I didn't have it then I...wouldn't be here today...my illness had got so bad...I do remember him saying that...There wasn't any medication for me to take so I had no options'*

James spent two months in hospital when he was 17, during which time he could see he wasn't getting any better. He worried about himself a great deal and thought he might not survive:

> *'I was very poorly and they tried medication after medication and nothing was helping me. I was just deteriorating...I was really terminal...and in the end I just said yea I'll have the operation to get well and get on with life'*

5.5.1.2. Turning Points (Triggers)

Six participants had experienced emergency surgery, when acute complications of disease (perianal abscess formation, sepsis and toxic megacolon) precipitated an emergency admission closely followed by an operation. These overwhelming symptoms proved a turning point in the management of the illness and triggered an operation.

> *'As the day went on...I was really really sick ...I was sent straight here and...that was when I had the first surgery. They said...you've definitely got Crohn's and you've got these perianal abscesses as well and I was on the verge of getting septicaemia...So they had to stop it quite quickly'* (Mia)

> *'I was in a very bad state at that time. I would have agreed to anything. I didn't think that anything could make it worse...Any decision anyone made I was willing to go along with it'.* (Rania)

Uncontrolled pain also proved a turning point for others. Ruhana described taking antibiotics for a few days prescribed by her GP for the pain in her bottom, but then:

> *‘I couldn’t handle the pain and then I got myself admitted to A and E and as soon as they look at it, it’s called a abscess and they said it needs to be treated straight away...Surgery took place the next day and I had a seton put in’*

Both Fazeel and Daisy had spent a considerable time trying to avoid an operation, trying to live normal lives and ignoring their symptoms. A cluster of events in rapid succession led Fazeel to reappraise his attitude towards surgery:

> *‘Last year I just come home from uni, just got off the bus and...it was like someone’s pressing a knife against my stomach...the ambulance people found me crawling...I stayed in hospital about a week, left, I was back again within a month and I stayed another week. That’s when I knew...I can’t fight this anymore. I’m gonna go for surgery...I want that thing removed now’*

Daisy coped with worsening symptoms from a perianal fistula for two years, during which she had steadfastly refused surgery. She reached a turning point when she could endure no more and told the doctor she wanted to proceed with surgery. She perceived this as having no choice, as she could not continue any longer as she was:

> *‘The following year it just got awful...It was like poo used to leak down and it was just so painful...and then I sat there and I thought...I’ve got to have it done...I can’t go on like this...If I had a choice I wouldn’t have had it but I didn’t have a choice, otherwise I probably wouldn’t have been here now it had got so bad’*

5.5.1.3. Decision Making

Participants exercised ultimate control over surgery, because no operation could take place without consent, but in emergency situations or in the presence of overwhelming symptoms, as Daisy previously pointed out, choice was effectively taken away because surgery was the only option. Others came to the decision that they wanted an operation over the course of time:

> *‘At the start I didn’t really want to have it done...After a couple of weeks...I turned around and said d’you know what, I feel like absolute crap. Just go on and do it’* (Dave)

> *‘When I (got) back (from Pakistan) my life is still as bad as it was before...I thought you know what, let me do it’* (Yasmin)

Sam had known that he might need an operation for some time, so felt that he was mentally prepared, even though he was admitted for an emergency colectomy and temporary stoma:

> *'I always had it in the back of my mind...when push came to shove...I'd come to accept it and I feel OK with it...definitely more accepting of it'*

Decision making could be easier if the experience of previous surgery had been positive, even if the proposed surgery was for symptom recurrence. Participants knew what to expect, were older, and had seen how the surgery had benefitted them. As Jack stated:

> *'I've had two surgeries...the second time round was a lot easier. I think being older and having surgery before. I'd seen how the surgery before had helped me...and it seemed the logical step'*

However, previous difficult experiences gave rise to anxiety and concern that this time would be the same. Ruhana recalled her fear on hearing that she would have to consent to further surgery:

> *'I felt very scared...Oh trust me, I didn't want to. I was just so upset for days when I found out they wanted to do it again'*

The responsibility for making the decision to go ahead with surgery rested with the young person, but they relied on their parents to support that decision:

> *'I talked to my family a lot of the time (about the decision to have surgery)* (Sam).

> *'My parents were just like well that's what you want to do, do it. They were pretty supportive...I guess they...wanted it as much as I did'* (Paul).

> *'If it was left to my parents they'd probably say to treat it medically...but because I'm now of age...I can decide'* (Fazeel).

Most participants were dependent on the expert opinion, clinical experience and advice of their physicians and surgeons about the right course of action:

> *'It came to the point where...surgery looked like it was the most appropriate option...for dealing with it...so I was told by consultants'* (Jack).

> *'It was kind of them saying right we'll get rid of everything. When Dr _ suggested it to me...he thought it was gonna happen anyway...whether I liked it or not'* (Paul).

However, being advised that an operation is needed may not make it easier to commit to having surgery. Five participants exercised control by refusing to have an operation. Two of these decided against surgery on the basis of reasoned judgement, using their knowledge of themselves and the illness, that it was not the best course of action for them. Olu had clinically extensive disease, but he had never thought that an operation was necessary: *'I sort of agreed to have surgery next summer and by January...I felt a lot better so I knew in my mind I wasn't going to have it anyway'.* Besides feeling better he knew, but had not told his doctors, that at the time they were planning surgery he had not been compliant with his medication. Lesley, with a long history of previous surgery, had refused any further surgical procedures. She trusted her own experience more than the advice of her doctors:

> *'I feel like anything I've had before, like this biopsy...just made it all worse... I've had various debridements...A couple of them have just made the wound bigger...which has then put me back to square one...I'm dubious now to go for any sort of surgery... It could work but then it couldn't'*

Yasmin had the most extreme reaction:

> *'Before my first surgery I ran away. I went back to Pakistan because I was afraid to have my surgery...The night before I (went) to Heathrow...I didn't tell anyone that day. I just told my mum and dad I'm going to see friends'*

The two remaining patients were younger teenagers when their surgery was first suggested and the distress they felt at the time was evident in the way they recalled what happened on being told they needed it. Both described situations of conflict where they argued with doctors and neither could be persuaded. Daisy's biggest fear was having a stoma. Her doctors set a date for her surgery anyway:

> *'I'm not having it. I'm not having it. I'm not having it. No. I just kept saying...and they were well, it's not if you're having it, it's when you're having it. It's just a matter of time. I was like no. It ain't a matter of time. I'm not having it. I'm making a decision now but I mean that was the November of 2004 and they booked me in to have it done in the December. I went you're joking. I ain't having it and I didn't. Obviously I didn't go'*

Rob refused a permanent stoma, left his appointment with the surgeon in frustration and was lost to follow up for several years.

> *'They mentioned it when I was younger...and I told him I wasn't having it and he was saying no no cause he told me the bag would be permanent. So I said no and he was like you've gotta and I said I'm not having it and he said you've gotta and in the end I ended up throwing the chair and walking out...He wasn't listening at all'*

Four years later, Rob returned to clinic where the surgeon understood his fear of a permanent stoma, and his reassurance that this would not happen was sufficient for Rob to consent to the surgery he had previously refused:

> *'I was just thinking no no no the whole time and then I just decided just get on and do it and that was cause he said he'd reverse it. Even if it was that bad he'd reverse it anyway'*

5.5.1.4. Timing

Participants wanted to control the timing of the operation so that it would least interfere with work and college commitments. Jack's surgery had been planned to take place so that he could be well during a time when he was taking exams and studying, events which would provide the foundation for his career in adult life.

> *'It's given me some years ... without having to worry about... the Crohn's...so I've been able to get on with studying at school and at uni without really much problem...For the future that's helped me, because I've done better than I probably would have done if I'd been ill.'*

Whilst Dave had a temporary stoma which could have been closed earlier, he elected to keep it for several years and delay his reconstructive surgery. He felt he could live with the effects of the stoma on his confidence, social life and developing romantic relationships while he studied and began a career but when the right moment arrived, he had a reversal.

> *'I wanted to get the rest of my school done cause I'd missed a lot of that. Then I thought well I want to go to college. Then as I came out of college I went into full time work...I got made redundant so I thought OK, now I've got that gap I'll have a reversal...Five years was enough. I didn't want it for the rest of my life '.*

Two more participants described how they negotiated the date of their operation with the medical team. Paul described how he deferred for several months until the time was right in his college year.

> *'I decided I wanted surgery...but cause I was at university I needed to find x amount of weeks to cover it and if it didn't go well I'd need x amount more'*.

Mariam's surgery was more urgent, but she still managed negotiate a delay so that her nurse training was not interrupted:

> *'I said to them I just want to finish my placement and then we can do this. They wanted to do it straight away but I just (said) no I need to finish what I'm doing and then arrange to have the time off'*.

Mia, who had negative perceptions of surgery, referred to multiple reasons why she wanted to defer another operation. She had previously lost her job because she needed time off for surgery so this was a legitimate concern, but her language about that and the effect of an admission for surgery on her partner indicated that she saw surgery as catastrophic:

> *'I knew I had to come in but I was putting it off...because...it was my partner's birthday that was coming up...I was like, I really don't wanna ruin it. I will at least hold off past that...Another reason...I can't afford it. It means I lose everything. It means I lose my home'*

5.5.2. Positive and Negative Appraisal of Surgery (Assessment)

5.5.2.1.Positive Perceptions (Role Change)

The majority of participants had an improvement in physical health and experienced release from a role as a sick person after recovering from surgery. They no longer felt life was dominated by considerations and disruptions related to their illness and its treatment and also felt able to do the same things as their healthy peers without the constraints that their IBD imposed. They could also make plans for the future, which with illness-dominated lives, they had been unable to do. Fazeel commented:

> *'I didn't anticipate how much better I'd feel...The consultants told me you'll feel a lot better...Some days you'll feel like a new person.'*

> *'It's so good just to go out and have nothing to worry about'* (Anne)

> *'To be honest, I've just tried to live my life like...anyone else would do...I don't really think about Crohn's that much nowadays. I just take it in my stride...because I haven't got symptoms I'm not thinking about it'* (Jack)

> *'I'm fine and healthy. You know when they weighed me before the operation, I weighed 14 Kg...I see myself now...I still can't believe I'd be at this stage, cause I still can't believe my eyes... it's just that confidence, so I can now literally do everything myself...Work's going good for me. Got my education. The future looks bright for me right now...It's just normal life I'm living now'* (Humza)

One participant was different in that surgery appeared to have changed his values in life. Fazeel said *'surgery did kind of put perspective in me'.* He had reappraised his situation and decided that he needed to put his education above everything else. Three months after the operation he had changed his sleeping habits, ate a healthier diet, stopped partying, stopped drinking alcohol, limited the time he spent with his friends, prioritised his studies and used every opportunity to catch up on his university work. He was the participant who, more than all others, had made no concessions to his illness and tried to maintain a normal life in the face of severe disease, which involved doing all the things that his healthy peers did. He had also resisted surgery until he could avoid it no longer. Now he was healthy, he did not want to maintain that lifestyle and decided to change.

5.5.2.2. Negative Perceptions (Previous Similar Experience)

Some CD participants developed complications after surgery that prolonged their hospital stay or necessitated readmission and gave rise to feelings of anxiety and depression. The following three quotes summarise the impact of those complications and their effect on participants:

> *'I found it quite hard cause both times I haven't been out of hospital as soon as I'd have liked to have been...and I've felt quite horrible after it...and um there's just been like not huge complications but little complications that've kept me in a bit longer* (Jack).

> *'Instead of being in hospital for like for a week, two weeks I was in hospital for...five weeks. It wasn't expected and I thought great this is supposed to be the cure for me and all of a sudden I'm in hospital for longer. I was a bit...emotionally quite low then'* (Mariam).

> *'They admitted me because my temperature was really high...that's when they said my pelvis broke down and I'd got a collection (of pus)...I would say don't expect anything that good to come out of (surgery)* (Bernice)

Participants with CD who experienced multiple surgeries for recurrent perianal disease expressed frustration related to the uncertain and unpredictable course of recovery, which meant that they had to live with a seton stitch for years, and a perceived lack of definitive treatment:

> *'I thought maximum six months and it'll be gone and then I was told that like they could stay in there for really long...now I've got two setons put in and the drainage still hasn't stopped and it's been like two years now and I'm thinking like is this going to go in time. I've been told that it never goes away… (I feel) like very very upset. '* (Ruhana)

> *'This is the third time I was in recently and I've had another surgery where now I've got abscess on this side, on my left side as well as on my right side. So I've now got a seton that runs from both of them, goes through the both of them...It's been six years of having abscesses and like never being normal, having setons and what not...I want it sorted. I'd rather get some bathroom filler and fill it all up that way'* (Mia)

Surgery for CD may also bring additional and long lasting problems to cope with as CD can infiltrate the operative site and compromise healing. Although the initial surgery saved her life, Lesley has never known what it is like to be completely well, as in ten years since her surgery for CD, she has never healed. At the time of the operation, she and her parents were not told by health professionals that the disease could affect the skin and interfere with wound healing.

> *'Removing the rectum we thought basically that would be alright but... it's like ten years eleven years later and I've still got the wound from that... I then developed Crohn's of the skin... within that wound but also...into my labia and places like that and it's just caused a lot of pain...a lot of discomfort...a lot of upset....'* (Lesley)

> *'Six weeks after I had it done I was back in hospital again even iller than I was before...I went home... I was still leaking stuff and I was in such pain and I just got so down about everything and then I didn't eat and I weren't drinking and I basically got so malnourished I was like five stone. My hair was dropping out...They took me down to theatre to find out what was going on. They basically said the stoma was hanging on by a thread. It weren't even healed to my skin'* (Daisy).

The effect of these complications made some participants question whether they would have the same experience when there was the need for further surgery:

> *'It's just I have fears this time round...I've had a lot of problems post surgery'* (Sam)

> *'When you don't know what you're in for, it doesn't scare you that much but when you know what's gonna happen, it's scary knowing you are gonna put yourself in that situation'* (Ruhana)

Although the majority of participants had positive perceptions of surgery, all the young women (Lesley, Mia and Ruhana) who had had multiple operations for perianal disease due to recurrent fistulas and abscesses had negative perceptions. These young women had all had the standard treatment which is to drain abscesses and insert a seton stitch into a fistula track. The seton is intended to prevent further sepsis by allowing fistulas and abscesses to drain. This means that pus and faecal matter leak out. They may stay in for months or longer. Ruhana described typically what it is like to live with a seton:

> *'I've got two setons put in and the drainage still hasn't stopped and it's been like two years now... wearing them sanitary towels every day...even though it's not noticeable, it really makes you feel unattractive'.*

Surgery for perianal fistula also resulted in continuing distress because of intense pain. These young women experienced similar problems before and after surgery: pain and constant malodorous leakage which could only be contained with pads.

> *'That area of my bottom was on fire basically...I couldn't sit down. I had to lie in certain positions. Going to the toilet was just dreadful. I dreaded that every time. It was the kind of pain you wouldn't wish on your worst enemy'* (Sadie)

> *'It was like just awful, the pain...every time I stood up, and you'd always have to wear sanitary towels every day'* (Daisy).

> 'W*hen you need to go toilet that pain it just hurts so much... it's not even pain. It burns for like an hour and a half. I would sit there and cry in pain until that soreness goes away...You are taking painkillers and it's still not enough for that pain'* (Ruhana).

> ‘W*ith going to the toilet just going for a wee...I’m coming out of the toilet in floods of tears because it’s just been so painful because of the wounds’* (Lesley).

Both Daisy and Lesley now have a stoma, which for Daisy has improved her perianal symptoms. However, Lesley has continuing problems with additional labial Crohn’s disease and wounds that have never healed. Participants stuck in a cycle of recurrent perineal disease and multiple operations, as described previously (5.5.1.3.) had negative experiences of surgery; these young women were all anxious about the prospect of further surgery, and Lesley had refused it, saying that her many previous operations *‘haven’t really worked’.*

5.5.2.3. Different Perceptions about Surgery among Participants with UC and CD (Duration)

The key finding here about improvement after surgery, in relation to what Schlossberg describes as duration, is that there were differences in the way that participants with UC and CD perceived the outcomes of their surgery.

Those with UC (Dave, James and Anne) who underwent IAP operations, knew at the outset that their surgery was curative and that their stomas were temporary. Once they had adjusted to the ileoanal pouch, they could go on to live their lives free from illness:

> *‘After I had the (stoma reversal) I was out bandaged up and out sunbathing and out with friends...shortly after I came out of hospital I got with my girlfriend...I had the operation on the fifteenth and my birthday was April 11th and I was out with my mates drinking....It’s made a huge difference’* (Dave)

> *‘It took me time to get used to the J pouch cause you had to adapt and get used to...the holding in the early stages. The different feelings. The going to the toilet a lot more than normal but I managed to get used to it quite fast...I was over the moon really cause I was able to do most of everything. I could go out with friends, go to college’* (James)

> *‘I had to get used to going to the toilet again...It took me a couple of months...No problems with the pouch now....It don’t stop you from doing nothing...so I’m on top of the world’* (Anne)

By contrast, participants with Crohn’s disease appreciated their improvement after surgery, but had concerns about whether it would last. They hoped the disease would not return and were vigilant about any symptoms, such as abdominal pain that might signal a recurrence. There was uncertainty about being able to maintain their wellness, as two CD patients stated:

> *'Initially I kind of thought it was gonna be they did it and I was fixed, magically fixed and I was a brand new me...and then...they told me that 50% of people have a relapse within - I can't remember whether it's two years or five years... I'm not entirely sure if I'm starting a cycle of having the operation, five years later it comes back...then need another one...Then on the other hand it might not come back and this might be me done, done with this...so I guess you can't really tell what the future's gonna hold can you.'* (Paul)

> *'I just hope it won't come any time soon, cause people say oh like that means it's gone forever but it's not...It's not gone for good. That's the scary thing, cause you don't know when it's going to appear...When I have stomach pains sometimes, then I worry in case that...is it'* (Ruby)

SITUATION	
HELPED	**HINDERED**
Perception of disease out of control	
Turning point leading to reappraisal of situation	
Control over decision making	
Empathic doctors	Conflict with doctors
Control over timing	
Improvement in physical health	Continuing distressing symptoms after surgery
	Surgical complications
Previous positive experiences of surgery	Previous negative experiences of surgery
Curative surgery	Uncertainty about duration of improvement
	Lack of definitive treatment

Table 5.2: Summary of Factors Related to Situation that Helped or Hindered Transition

Table 5.2 summarises the key factors related to the surgery itself that could be identified as assets or liabilities (helping or hindering) in the process of transition. Multiple factors concerned actual or perceived control. Uncontrolled disease and ineffective treatment could precipitate a turning point in participants' thinking and make the decision to have an operation. Participation in decision making, with support from health professionals, previous positive experiences and timing the procedure so that it fitted in with patients' lives were also helpful factors. Positive appraisal of surgery- the perception that it would relieve symptoms and make them feel better- was also an asset. Uncertainty about how long the beneficial effects of surgery would last was expressed by participants with CD whose surgery is never curative. Negative appraisal of surgery, and a reluctance to undergo further operations, was seen in those young women who had had recurrent surgery for perianal disease with no improvement in distressing symptoms.

5.6 SELF

SELF	Surgery as a benefit: Getting my life back
	Worries and concerns before and after surgery
	Uncertainty
	Body image
	Feelings after surgery

Figure 5.3: Major Themes in This Study Related to Schlossberg's Dimension Self

Self is described as the characteristics that are relevant to the individual as they experience a transition (Goodman et al, 2006). The authors define these characteristics on a broader scale than those in the previous section and they can include: demographic characteristics, gender, age and stage of life, state of health, ethnicity, culture, psychological resources, outlook, commitment and values and spirituality and resilience. Figure 5.3 shows the major themes that emerged related to the dimension of Self. In addition gender differences in concerns and responses were identified.

5.6.1. Surgery as a benefit: Getting my life back

Recognising the positive changes that surgery had made to their lives was a key factor enabling participants to adjust to surgery. Several participants described their restricted lives dominated by illness symptoms before surgery, and how their operations had enabled them to regain a sense of wellbeing and normality:

> '*It used to be I'd have to go to the toilet so frequently there was no point me going out of the house. I had to stay by the toilet and there was so much pain'* (Sam)
>
> *'Before I had* (the operation) *I had no life. I really felt I was living day by day...couldn't really plan anything. Lying on the sofa and my whole family was going in and out of the house, my sister and my brother doing stuff, and I was just sort of sitting there saying OK I'll be here...when you come back'* (Mariam)

Those with UC also took the adjustments necessary for living with an IAP in their stride and, once they had physically recovered from the surgery to close the stoma, they described lives similar to those of healthy peers. Both Dave and James had a really positive reaction to getting the pouch, as they now could ‘do’ all the things they had dreamed of:

> *‘I’m really over the moon about the pouch and what it has done for me. It enabled me to do all the things I couldn’t do with the ileostomy...There’s still restrictions with going to the toilet a lot more but...you can get on with life...It’s basically living normal again. Getting on with things’* (James)

> *‘(I wanted) just to get rid of it. Just to have my confidence back, really...I was quite happy to have it removed. As soon as I had this operation my confidence came back like that and away I went... It was hard, I must admit...I did have to wear these huge sized nappies...I did have to have pads on the bed but it didn’t get to me...It was hard but after two weeks I got control of everything’* (Dave)

A major finding from this study is that many participants described positive changes as a result of having the stoma, everything from getting their life back, to eating well, less medication, less frequent need to use toilets, and more control over bowel function, and their lives. This perception of the stoma as a benefit was influential in enabling them to adapt to the stoma, even while at times continuing to express antipathy towards it:

> *‘I wasn’t in that much pain any more...Not having to run to the toilet (with) that urgency...I was constantly late for anywhere because no matter how early I left unless there was (a toilet) on the train...I’d just have to get off...Not having to worry about that...sort of gave me my confidence back...Definitely the medicine was a big thing...It was now only like three tablets a day. For a long time it was much more than that...I was having to take...lots of Build up drinks which now I don’t have to...Being...tube fed- I don’t have to do that anymore. It’s nice...My arthritis doesn’t really play up any more. I just have more energy now, which I never, never thought I was going to have...Two years ago I thought (it) was never going to happen. Now I just feel really, really good... Before I had it, I had no life* (Mariam)

> *‘If it wasn’t for my...ileostomy then I wouldn’t be here. It’s definitely given me a better quality of life than what I had before...and it allows you to do more things rather than feeling lethargic and just lie on the sofa...It allows you to get out with friends...it’s definitely worthwhile’* (Lesley)

> *'I tend to not think about it. As much as it's turned my life around completely... It's not something I like to look at or I enjoy having. It's just the change it's made to my life...I would never go back and not have it, because it's made such a massive difference to my life... Even now, much as I hate it, in a lot of senses I would never ever change it...There's a chance I wouldn't be here now without it'.* (Victoria)

> *'I do get down about it and I do get really pissed off. I just get to a point where I think I can't be bothered with this (stoma) any more…Having the bag has given me my life back, whereas before I didn't really have much of a life...because it got to a point where I couldn't really do anything myself. It has given me that...I never thought I'd be able to pass my driving test. I never thought I'd...get a job, things like that and I've done it all...Having a bag gives you a future...It is worth it otherwise you ain't gonna have a life. You're not gonna have nothing. You'll just get worse and worse and worse.* (Daisy)

Although she had the opportunity, Helen decided not to have her stoma closed. *'*

> *When I first had it done, they said it'll just be temporary...but as the years went on...I felt so well. At one point I was in remission for maybe three years...I felt so much better. I didn't want to get rid of the bag, cause I thought if I did I'd be unwell again...I'd got used to it...I wasn't bothered about it anymore'*

Humza also looked at the possibility of reconstructive surgery, but decided against it. He didn't want to risk the life he had with a stoma for the uncertain outcome of another operation.

> *'Back then I was having a lot of problems...My bag used to keep leaking a lot...and I just got really sick of it...Mr _...told me, most of the people I have done the (reversal) operation to, it was 80%...chance...it's worse...It's better not to do it. You won't be able to control everything that...comes out...I thought about it. I was really sad that day... After that I just calmed myself down. It's life, just take out what you can...It's better to be safe than sorry...It's just not worth it'.*

5.6.2. Worries and Concerns about Surgery

Fears and concerns preoperatively related to the surgery itself, especially where this was a new and unknown experience. Young women described far greater concerns and difficulties about sexual issues and parenthood, than young men, only two of whom described any concerns about their sexual function.

5.6.2.1. Worries about the Operation

Rayhanul had been diagnosed with CD six years prior to this study and the prospect of surgery had first been raised in his teens. He described why, until he had been left with no option, he had refused to consider it:

> *'I was actually petrified, I mean just the thought of being cut up and just having surgery done petrified it just basically scared me. I've always been scared of ... operations'.*

> Ruby, Yasmin and Fazeel were also frightened of being cut:

> '*I was scared when they were saying oh you're going to have to have an operation cos like they're...gonna have to cut out so much stuff in your stomach'.* (Ruby)

> *'I was afraid to have my surgery. I thought what is this...They'll cut me open'* (Yasmin)

> *'Even thinking about it...I was thinking oh going under the knife, what are they going to remove from me and I was... very nervous actually... how would I feel afterwards..., I thought I'd...feel kind of disabled because some part of me is missing.'* (Fazeel)

For Rob (see 5.5.1.3.), Jack and Daisy, the possibility of having a stoma was the biggest concern.

> *'I think the most worrying thing was ...they talked about...possibly putting a stoma if they couldn't join it back together. I was quite worried because I ... didn't like the thought of that'* (Jack).

> *'I come up from theatre and...Mr _ was talking to my mum and...I just got that vibe. I was like "have I got to have a bag done" It was like my worst fea.r'* (Daisy).

5.6.2.2. Worries due to Uncertainty about the Surgical Experience

Worries due to uncertainty about what was going to happen, what had been done, or how they would feel after surgery affected seven participants.

> *'The surgeon's not really sure what he's going to do which is a bit more difficult for me'* (Victoria).

> '*I don't quite know what's gone on with this one'* (Mia).

'I was thinking like I didn't know what to expect really cause I'd never had surgery' (Anne).

'I wasn't really sure what I was expecting from the bag and from the state of having a stoma. I only got to see a stoma on my preadmission clinic...and I think then it really hit me that it was happening... I felt a bit rushed...it was the last minute to call the nurse to show it to me...I can't really remember having that much prep for what it was going to be like afterwards.' (Mariam)

Jack and Sadie made the point that they feel health professionals give less consideration to explaining what to expect after surgery.

'I think they're good at explaining what's happening before hand and during the operation what they're doing but I think that the aftercare isn't perhaps as well explained'. (Jack)

'It was very brief. I'd go to see them for an appointment and like two minutes and out. After surgery I felt very low and you know I've got the seton and they don't explain things properly. I think they should spend more time explaining with their patients what's actually happened, things like after care' (Sadie)

Lack of appropriate information led Sadie and other participants to underestimate how they would be affected in the early postoperative period:

'This is the part that really saddens me because I wasn't told how it would be after this operation...It was impossible for me to actually care for myself and my young son...I had to go back home to my parents so I could be looked after properly. I'd been told after you have the seton you can get on with things and that wasn't the case.' (Sadie)

'Cause I never had previous experience of surgery... I was thinking yep after the operation I would wake up I'll be normal yeah. I'll be bedridden but I could use my laptop to do my work. I couldn't even do that. I couldn't even lift my hands.' (Fazeel)

'I was like yea everything would be fine after the operation like I could walk and everything... I couldn't even sit up or nothing like at the start. Obviously you had to wait for it to heal but I didn't think it was gonna be that bad' (Daisy)

5.6.2.3. Concerns about Surgery and Motherhood

All four females who wanted to have a baby described multiple concerns relating to conception, pregnancy, delivery and raising a child. Mia was still grieving over the loss of her unborn baby (which was a medical termination). She had become pregnant but then developed septicaemia, from untreated abscesses.

> *'I had to have an abortion but I didn't want to and neither did (my partner)… (The doctor) said to me look the likelihood is that I wouldn't be able to carry the baby as I am if I didn't have the surgery, because I wouldn't have made it and the baby wouldn't have made it either...There's loads of obstacles in the way of me having children'*

Also with CD, Ruhana was concerned that she might have difficulty conceiving and with her pregnancy.

> *'Ever since I was young I've always wanted to have loads of kids. I always wanted to be a young mother…After I had the operation...I thought is this gonna affect me in the future, whether I'm gonna have babies, cause the affected area's the whole stomach and my womb's near there'*

Because they both had perianal disease, Ruhana and Mia had been told that they would have to deliver their babies by caesarean section but neither wanted to deliver a baby that way:

> *'Because of the amount of surgeries I've had...round my back passage and...around my front as well I can't...have a baby naturally...I'd love to have that option...So it's literally I'm booked in and come in and get sliced open and it's done. It just doesn't feel like you've achieved anything'* (Mia)
>
> *'They've said that because of what's going on inside my stomach...if I do plan to have kids in the future it may be best to have a caesarean but I'm really unhappy to hear that… when they cut your baby out of you...It's not natural and you have to live with the pain'* (Ruhana)

Anne had a positive experience of pregnancy: *'My pouch function got better. My life was absolutely amazing. The best.'* However, because of the risk to her pouch with a vaginal birth, she had delivered her baby by caesarean section and expressed similar feelings about that as Mia and Ruhana:

> *‘I did want a natural birth because (that) is a whole part of being a mum. I wanted to do it all properly but it’s one of the things you’ve gotta deal with I suppose’.*

With systemic CD and a badly affected perineum, the normal processes of partner intimacy, conception, pregnancy and delivery were impossible for Lesley because of the pain and the wound, and were affecting her relationship deeply, and causing concerns about her fertility and having children. Despite her partner’s understanding, there is just total uncertainty:

> *‘We can’t have sex because of the pain it causes me, because of my wound...It’s hard on him, so we have to find other ways...but...he is very good with that...If ever we have tried and it is too painful... and we have to stop then he’s fine…He doesn’t make a big thing about it like some blokes would...I haven’t had a period for...at least three years...I was on the (contraceptive) injection...to stop them because each time I had a period each month...my symptoms, my Crohn’s, would get worse...Then that...got me thinking about my fertility and having children...’*

In regard to helping her ovulate again, a gynaecologist told her and her partner:

> *‘At the minute we probably couldn’t have children in the way of me carrying the baby and then having it at the end, because the doctors have always said that I could never have a natural birth. Because of the wounds and everything it would have to be a caesarean which then obviously...makes me worry as well because it’s...quite close to where my problems are, so what if, even if...my wounds had healed and I did have a caesarean...that’s an open wound so would the Crohn’s then attack that and cause problems’*

Amidst the difficulties, they considered two alternative ways to become parents:

> *‘if the doctor can do...egg freezing....we’d still...be able to have our own child...but in a different way... surrogacy or something...We’d still end up with our own baby’*

Even if achievable, there are concerns about her ability to look after a child, due to on-going health problems:

> *‘I keep having these funny episodes where I keep going into hospital...keep getting unwell, not having enough energy and things like that...If we want a family then... we’ve*

> *got to make sure that I'm...OK to be able to look after the baby...It is a big issue and I do worry about it a lot...We just try to look on the bright side'*

Helen described a difficult entry into motherhood and the concerns that Lesley, Mia and Ruhana had were borne out by her experience. Her baby was born prematurely and at the time of delivery her disease worsened, resulting in the need for two operations in the first two months after his delivery, which affected her profoundly:

> *'It just went downhill for me… (he) came home for a week then...I was in hospital for eight weeks..I missed everything...He sort of squashed everything and I had a massive abscess on my back...on the inside...I had major surgery on my back...and… an ileostomy...I suffered from depression. I (saw) a psychiatrist...I was really upset...just felt so low. Lowest I've probably felt in the whole time I've had Crohn's'*

In contrast, young men expressed very few concerns about sexual issues. When considering this issue, James said: *'I think that's the least of your problems really'*

Rayhanul felt that his illness was jeopardising the things in life he valued and saw his surgery as a benefit in this respect:

> *'I would love to have kids in the future and I don't want to take these medications all my life and lower the chances of stuff like that happening'*

Only one young man, Humza, had concerns about sexual function. He described how meeting a male adult with a stoma after his own surgery, when they both volunteered at doctors' examinations, had allayed his fears about having a normal sexual relationship, by answering questions he could not discuss with health professionals:

> *'When I was at college…I was thinking would they [relationships] work out or they just wouldn't work out, so I was stressed a lot but...there was a person who was helping out. He goes 'I've got a bag and I've got a wife'…I was only sixteen. So…I had a little chat to him. Does it work all right, like properly and he goes 'yea everything works'. I don't have a problem anymore'*

5.6.2.4. Worries about Personal Relationships: Disclosing Hidden Differences

A key issue for participants with a new stoma was that it shouldn't be seen or disclosed to other people. Young women, (5.6.4.1. below), altered their clothing to achieve this and all the young men with temporary stomas reduced their dating to avoid revealing that they had one.

Rob and Bernice had the most extreme reactions following stoma formation, in that not only did they choose not to date, but restricted their lives until it was reversed; only once did Rob venture out further than the end of his road in the eight months that it was there. Bernice said:

> *'I don't really go out much...I will wait till the stoma is gone'.*

Dave did have a couple of girlfriends in two and a half years, but *'I kept it very much to myself'*. After his reversal of his stoma in the last stage of his IAP surgery, *'my confidence came back like that and away I went'*. He was interested in a particular girl five months before his stoma was closed, and started getting to know her, but waited until it was reversed before he asked her out:

> *'I must admit I did wait until all the operations had cleared up...I thought it would be easier. I explained to her what I'd had and she was absolutely fine with it.'*

Sam had an emergency operation which resulted in a temporary stoma. He has decided he will not date again until after his IAP surgery and stoma reversal. He has a traditional background; his family is concerned that he is at an age when he should be looking for a partner, but he stated:

> *'I haven't been really actively searching for a girlfriend since I got (the stoma). When I first got it I did have a girlfriend...but I ended the relationship...I felt...if I can't look after myself there's no point in trying to look after someone else. Lonely, lonely, that's the word I think...I've coped OK but obviously everybody likes a companion to talk to'*

He looks forward to going back to the person he used to be, being '*socially more open'* when his surgery is finished. However, stoma reversal was not an option for any of the young women in the foreseeable future, and they all described concerns about revealing they had one to a potential partner. The risk of rejection and the damage she felt this might have for her confidence was sufficient to prevent Mariam from contemplating a relationship, two years after she had her stoma raised. Still coming to terms with its impact on her appearance, she said:

> *'At the moment only I see myself. Only I really see my bag so it's OK but it might all change if I'm in...a relationship...It scares me having to bring it up and bringing it into the equation. I'd rather not find out whether it would actually be all right or not...I don't think I'd feel comfortable being in a relationship with it which does worry me a bit. I'm trying to work over that...I haven't spoken to many (boys) but I wouldn't go any further. It stops me from pursuing anything else because...I...think he likes me now, but what happens if I tell you I've got Crohn's and I've got a bag'.*

Victoria had grown up with a stoma and had one steady relationship for a long time. When this ended, she had to face disclosure for the first time.

> *'I only really came across this issue a couple of years ago because I had a boyfriend from when I was fifteen...and never ever had to deal with the problem of having it in relationships...When we broke up it was oh God now what am I gonna do...because I feel such a normal person and because I don't let it take over my life and don't even really consider (the stoma) at all. It's now become...quite a big issue... because everybody looks at me and thinks I'm perfectly normal...I know that one day I will probably have a negative reaction and I really don't think that's going to be easy to cope with at all.*

Mariam and Victoria both worried about rejection once the presence of a stoma became known to existing and potential boyfriends. However, the responses most of the young women recounted were actually positive. Yasmin feared:

> *'When (my boyfriend) sees me he's going to think (the stoma) is disgusting...and he's going to be put off but he's nothing like that. He is the complete opposite...I do get emotional. I have days when I say you don't love me because of the stoma bag. He says don't be stupid'.*

Anne had problems with an unsupportive boyfriend:

> *'The baby's dad...used to go you're fat and look at your bag and your scars...but the boy I'm with now is really nice and he never puts me down. I'm getting a bit more confident because I've got him telling me they're nothing to be ashamed of, you're lucky to be here'.*

Victoria had had two casual and two more serious relationships in recent years. The boyfriends with whom she became intimate were both accepting of her stoma, but she also revealed that one had known of it before she told him.

> *'The two guys that I've been with were brilliant...The first, the dentist guy...already knew before I even told him, because he was like- you know I'm not stupid and I'm not blind. So I thought oh OK then, and he was like look, I don't care. It's fine. The other guy...looked it all up on You Tube and was more interested than I think I've ever been. So...with those guys I've never had a problem'*

Daisy recalled that when she first learned she would have to have a stoma, the first thing she said was *'no one's gonna want to be my boyfriend'*. After her surgery she met someone, but described how she kept finishing the relationship because she thought he didn't know of the stoma and she couldn't bring herself to tell him. However, somebody else informed him:

> *'Then my sister and her big mouth told someone and they told him… and he doesn't even care at all...I think if you really found out something about me like that and you took the piss then you're not really a...good person'*

Disclosure was made easier for Helen because her new boyfriend worked with her. He already had some knowledge about a stoma, because a colleague had one:

> *'When we got together I just said to him...you know what Vs got. He said yea. I said well I've got it too. He said oh OK. So it was really easy cause...(my boyfriend) knew basically what it was all about. I didn't have to go into detail, explain everything...That was seven years ago and still together'*

Humza, with a stoma raised in childhood, was Asian and the only male participant with a permanent stoma. With strong religious beliefs, his first girlfriend would probably become his wife. He thought he would have no difficulty telling a partner he had a stoma. Like Daisy, he felt that the stoma did not determine his desirability or his worth as a person. They both thought that if the stoma was a problem for somebody else, this reflected that person negatively rather than themselves.

> '*It's in our religion...not to have a girl because it leads to...sex and all that stuff and that's not allowed...We can have a sexual relationship with a woman...after getting*

> *married...If I was to find a partner now obviously I would tell them this is the problem...I'm just a normal human being, just like you, so the only thing is I've got this bag and you haven't... If the person loves you that much then that's not gonna be a problem'*

5.6.3. Body Image

Surgery for IBD results in changes in bodily appearance. The interviews highlighted how these changes upset young women most, who described concerns about their physical attractiveness, their reactions to scars and, with a stoma, how their clothing choices were affected as they made various adjustments to hide the stoma.

5.6.3.1. A Changed Appearance: Having a Stoma

Two males and seven females had a stoma, and three males and two females had had stomas that were subsequently reversed. All the young women with a stoma expressed concern about their appearance and being fashion conscious, just like healthy peers. They spoke negatively of their changing images as they looked in the mirror:

> *'I used to hate it when I first had the bag. I remember being stood there and looking in the mirror... at myself and thinking, oh my God am I ever gonna actually...change and not be like this'.* (Daisy)

Most of these young women did overcome their fears about their appearance over time. Helen had her stoma aged thirteen and describes how she gradually adjusted.

> *'When I first had the stoma I used to look in the mirror and cry, cause I'd just think look at all these girls. They've got bikinis on and wear nice clothes and I thought the rest of my life I'd have to wear track suit bottoms and big T shirts...and I thought that for a good few years...As I got older I just tried different things, tried new clothes and, to be honest, you just look in the mirror and it's part of you. I don't look in the mirror now and go oh my God.'*

Outward appearance was very important to these young women, and all described issues related to clothing, especially beach-wear. None of them would contemplate wearing a bikini, because this would expose the bag.

The following three women describe very different reactions to adapting their clothing choices to the stoma. The first participant very self-conscious, the second adapting and the third defying the limitations that the stoma has imposed on her clothing choices:

With a fairly new stoma, Mariam was still consciously considering her stoma when making clothing choices:

> '*I don't think there's any way you can wear these really nice dresses...If your bag gets full you can see it. I try...to stop it keeping me from wearing too many of the things I'd normally wear'.*

Having had her stoma for longer, Victoria said:

> 'Y*ou do have to make exceptions but then you forget that you're doing it because it becomes just like normal, like clothes and swimming costumes'*.

In contrast, Daisy makes no concessions to her stoma when she chooses clothes and takes risks. She finds that by doing this and not being perceived to be different, the stoma is more acceptable to her:

> *'I always wear leggings and jeans and I wear everything I want to...I go out in the skimpiest outfits, like in the night, and no one would look at me and think there's anything wrong with me and I think that makes it a lot easier.'*

5.6.3.2. A Changed Appearance: Healthy Body

It can also be hard to adjust to a body which, after years of illness, now changes on regaining health. Mariam has adjusted to having her stoma, and has a positive image of herself, but describes her ambivalence about regaining weight. She used to be the envy of her friends because she was slight and she now looks the same as them, because she can eat everything she wants and no longer ill, as the disease keeps patients thin:

> *'If I stand in front of the mirror with just...my underwear on...I see my bag and I think, oh this isn't great looking but everything else looks good to me. I think I'm looking great at the moment...It's not normal, a bag and having a bit of your bowel sticking out, but as soon as you put something on you can't see it...I have definitely gained a lot of weight and that's something I've got to get used to... I keep remembering*

> *that's...normal and what I was before wasn't normal. I still...find that hard to grasp, because to a certain extent being slim was the only thing I had when I was ill'*

Yasmin has also gained weight after surgery but, unlike Mariam, is not accepting of it:

> *'I am most looking forward to going on a diet to lose this weight because I can't with a stoma...I never used to put on weight but after the first surgery I was gaining weight so I am very into that, lose weight, go back to my old clothing'.*

5.6.3.3. A Changed Appearance: Scarring

There were major gender differences over scarring as well. Men didn't pay them much regard, but women were very concerned by them. For example, for Rayhanul, anticipating surgery, a scar was not one of his main concerns:

> *'I'm not really worried about having a scar as long as...the disease goes away and a scar is just a scar…That doesn't trouble me at all'.*

Dave described how initially during the first stage of his IAP surgery, he kept the stoma hidden, but as he got used to it and then had a reversal, he views his scar with pride:

> *'First surgery, me confidence went really downhill...Always had my clothes on. Always hid everything...but over...the four or five years I had it I...just like grew above that and now I've had it reversed I'm the biggest tart...I'm always in the gym...I've always got me top off. Always showing off me scar'.*

Whilst not proud to show them off, other male participants did not pay them much regard. Rob had had two open abdominal operations:

> '*I ain't really bothered. They're just scars. No one's really gonna say anything...Where I come from mind your own business'.*

Even in the early postoperative period scarring didn't seem to be a problem for Paul. *'I've seen them and they didn't seem too bad'*. Jack, following one open and one laparoscopic operation, commented, *'As a guy, guys aren't as worried about scarring as girls are...I wasn't too bothered about it'.*

None of the young women who underwent abdominal surgery had a laparoscopic procedure, where scarring is minimal. Bernice and Ruby were told they would have keyhole surgery, but Bernice was told just before her operation that she would have a conventional incision and Ruby woke up after surgery with a traditional abdominal wound, which she hadn't wanted. '*They just had to make big cuts...I was like no cause...I didn't want to have big scars'.* She described her reaction when she saw the wounds in the early days after her operation. *'I was like oh that's so disgusting...every single morning when the nurses were changing the dressing'.* Anne was also anxious about scarring: *'I didn't really want a scar on my body'.* Victoria was concerned about prospective surgery for a parastomal hernia which had developed after fourteen years. She had been told the stoma might have to be moved to another place on her abdomen:

> *'I have a scar, a long scar through my abdomen and then I have a scar here and I have my ileostomy here...My frustration is...because I'm not particularly big either, this bit of me here is the only bit of me that's not got anything on it...The thought of having it moved is horrendous... It's a completely vain reason...When I'm with a guy it's the only bit of my stomach he could hold that's not got anything on it.'*

Yasmin was the only female participant who was unconcerned about her scars:

> *'They don't bother me because I feel unique...I feel like no-one's got these...they don't have my scars that's made me better today. You look at them so be it, they're there but those are the things that helped you'.*

5.6.3.4. Malodour and Leakage: Surgery for Perianal Crohns' Disease

The female participants who had had multiple operations for perianal fistulae all described the difficulties of having to cope with a body experiencing prolonged periods with similar symptoms before and after the operation- malodorous leakage and continuing pain. These have been fully described in 5.5.1.4.2. Ruhana summed up what effect this has on her psychologically:

> *'I've got two setons put in and the drainage still hasn't stopped and it's been like two years now...It becomes a part of you. It is off putting...Your confidence is down and your esteem goes down and (it) kind of brings you down'*

The results in this section suggest that surgery for IBD results in major body image issues for young women women aesthetically and can affect their self-confidence and feelings of attractiveness.

5.6.4. Feelings after Surgery

Participants described different feelings at different times after surgery. When things were not going so well, they described feeling low. Despite this, they could recognise an increase in self confidence following all types of surgery.

5.6.4.1. Feeling Low

Several participants described feeling low periods with the illness, during surgery or at times of crisis, but for most these feelings were transient. Dave described how his confidence dropped when he had his stoma. Daisy also became frustrated with her stoma:

> *'I do get down about it and I do get really pissed off. I just get to a point where I think I can't be bothered with this anymore...I love my life. I do love my life I just don't love that side of my life, that's what gets me down... I just feel like I haven't got time to be ill'.*

James found dealing with the stoma and uncertainty about his future surgery difficult:

> *'I got really upset sometimes. I was thinking I'm missing out. I want to do this, I want to do that, I can't...I did go through a stage where I was mentally down and depressed'.*

5.6.4.2. Regaining Confidence

Despite feeling low at times, many quickly regained their confidence in themselves. Dave (5.6.1.) described his confidence returning after IAP surgery. Hamza's confidence was linked to his ability to manage a permanent stoma effectively:

> *'One thing I haven't been called in my life is someone with a disability. That's the main thing... If someone said I had a disability from the start, I would be really discouraged...cause I wouldn't feel the same as everyone else'.*

Ruby also discovered her happiness and confidence returning after her operation:

> *'When I had Crohn's I was more...stroppy and stuff and...not in a good mood...but I feel now I'm much more better cause I'm...more healthier now... I feel much more happier with myself...cause I feel ...OK, really, really good...I've been more confident and interacting with other people as well, but if I did not have the surgery I don't think I'd be as I am now'* (Ruby)

5.6.4.3. Feeling 'Normal'

Participants used the word 'normal' in several different ways. Some felt normal after the operation; and then some looked normal, but still felt they were different; others just expressed a wish to be normal but this group were not actually doing anything to help themselves to achieve that. All but four of the participants used the word normal in relation to themselves, and some referred to it multiple times.

Some were sensitive that they looked normal to other people, but had a hidden, physical difference in the disease *'They'll think I'm a normal person...no one will ever tell that you've got Crohn's disease'* (Ruhana) or with a stoma: *'I can pass as normal'* (Victoria).

Others either expressed the wish to 'be normal' or to live a normal life, unaffected by their illness and improved by surgery, or felt that surgery had returned them to normal. Ruhana perceived herself as not normal because of her illness:

> *'If I'd have been normal, I'd have been more able to get up to speed with things, try and think about how I'm gonna build my life... It's always holding you back'*

The perception for some was that, either because of the consequences of surgery, or their illness, normality was not something that they had not yet attained:

> *'I'll be normal. I'll be fixed'* (Paul)

> *'It's been six years of having abscesses and like never being normal...I'd love to be normal'* (Mia).

James described his time with a stoma as *'not normal'* but now that he is living with an IAP, *'It's basically living normal again'*

5.6.4.4. Developing Personal Strength

A major positive finding post-surgery is young people felt that their experience of surgery had either helped them to develop personal strength or they had found that they already possessed an inner determination which enabled them to cope well with these difficult times. As five patients stated:

> *'I think being brave and being determined...that's what kind of helped me a lot. Just my mindset...I was just born with it, to be honest, brave and committed, determined so...from the start that helped me a lot.'* (Humza)
>
> *'I think it's more mental than anything, to be honest...If you want to live a normal life, you live a normal life'* (Olu).
>
> *'I never just feel like I can't do anything and if I feel like that then I just work a way round it'.* (Daisy).
>
> *'I'm really strong inside...I don't show a lot of emotion...I've always been really strong minded about things so if I say...I'm gonna do it, I'll do it...Going through all this has made me strong'* (James)
>
> *'I try to be strong...From a young age I did used to cry a lot and I think I just said to myself, you know there's no point crying any more. Might just as well be strong and get through things yourself... It makes me think more clearly a lot of the time'* (Sam)

Participants demonstrated their inner strength in a variety of situations- in the length of time that they carried on with uncontrolled disease before surgery (Fazeel and Daisy, 5.5.1.2.) in living with longstanding and painful complications following surgery (Lesley 5.7.4.4) and in doing the things they had to do following surgery, such as learn how to look after a stoma, to be able to adapt .

In addition to Lesley, participants demonstrated stoicism in the presence of pain:

> *'(I) don't want to make a fuss about anything...unless it's something really really bad...I don't really make a big deal of it'* (Olu).

> *'I never really took painkillers if ever I was in pain. I just kind of grunted and got on with it'* (Paul).

Following major surgery, sometimes prescribed analgesia failed and they coped with that as well:

> *'They put the epidural in the wrong place so I woke up and no pain relief whatsoever...Once I had that sorted I was fine'* (Dave).

> *'It hurt a bit when I woke up cause there weren't a battery in the pain thing, so I was like shouting...it's not working. They went, oh you should have been like crying and everything. I went why'd I wanna cry...It hurts. That's what I been telling you'* (Rob)

5.6.5. Outlook on Life

After their surgery, participants described mixed thoughts about the future. A positive approach was evident in many interviews, but some women with CD expressed pessimism about the future.

5.6.5.1. Positive Approach

In general, participants described taking a positive approach to life and considered that this was important in helping them through surgery. This positive approach consisted of carrying on with things, not worrying excessively and not letting their lives be circumscribed by illness:

> *'I just take each day as it comes. I carried on with life...just have fun and...just getting on with life'* (James).

> *'I just crack on. I live life to the max. You only live once* (Dave).

> *'The more you are mentally positive towards it the more better you'll recover...You could sit there crying all day long or you could go out there thinking let me just forget about it and enjoy myself'* (Yasmin)

> *'I just tend to get on with something, you know, if something happens, it happens and if it's good, then it's good and if it's rubbish then so be it.'* (Paul).

> *‘I’ve just tried to live my life like as anyone else would do um I don’t really think about Crohn’s that much nowadays I just take it in my stride’*(Jack).

> *‘I have so much more to look forward to in life rather than just thinking about an illness’* (Daisy)

Lesley, who was affected most by her disease and surgery, described a positive future for herself, which involved marriage and having a child despite immense difficulties:

‘Hopefully in a year’s time before the wedding...I’ll be healed...just have the wedding and then look more into having a family and having children’

5.6.5.2. Pessimism

Men didn’t express any pessimism, whereas women with CD did and it appeared to be related to their previous experiences. Helen, Bernice and Mia had had multiple surgery and on-going health problems, and all expressed a negative attitude towards the future

> *‘I always say to...my boyfriend that no doubt I’ll be back in hospital again. He says no you mustn’t talk like that. I said I’m being realistic...It’s not just going to go away’* (Helen)

> *‘They told me surgery would be in three months but I am going to double that and think it will be six months’* (Bernice)

> *‘There’s no point getting my hopes up about something to be let down, because I know how much it will upset me if I can’t do something... (My boyfriend) says why do you think you’re so old...I don’t think I’m old I’m just realistic about things’* (Mia)

SELF	
HELPED	**HINDERED**
Recognising positive changes surgery has made to life	
Perception of a stoma as a benefit	Fear of a stoma
	Fear of being cut
	Complications
	Non healing
	Concerns about conception, birth and motherhood (F)
	Concerns about sexual function (M)
	Fear of rejection on disclosing stoma to potential partner
	Uncertainty about what is to happen
	Uncertainty about what has been done
	Uncertainty about how it will feel after surgery
	Negative feelings about changes in appearance
	Negative feelings about changes in body appearance
Self confidence	Lack of confidence
Feeling normal	Not feeling normal
Personal strength	
Stoicism	
Positive approach to life	Pessimism about the future

Table 5.3: Summary of Factors Related to Self that Helped or Hindered Transition

Table 5.3 summarises the factors related to Self that helped or hindered transition. Recognising the positive changes that surgery, including stoma formation, had made to their lives was a key factor in enabling participants to adjust to surgery. Participants worried about the operation itself and what would happen to them. Young women had concerns about the effects of surgery on having a baby and motherhood and those who already had a child described mixed experiences. Those with a stoma also had concerns about the effects of disclosure on relationships but in most instances partners were very understanding and supportive. Uncertainty affected participants at all stages of their surgery. This was often related to lack of information and knowledge about the experience and what constituted a normal recovery which led to unrealistic expectations and disappointment. Changes in bodily appearance – the stoma, scarring, weight gain- affected young women most. Some felt low at difficult times, but confidence did return. The importance of a positive approach to life and the development of inner strength through the surgical experience were seen as important factors in adjustment and recovery, although some did not feel they were completely ‘normal’. A minority expressed pessimism about the future which appeared to be linked to the experience of previous surgery and multiple ongoing problems.

5.7. SUPPORT

Social support is the third of the four dimensions of Schlossberg's transition theory, which she classifies according to their sources: intimate relationships, family units, networks of friends and the institutions/communities of which they are a part. She further states that the right support is a facilitating factor, but inappropriate support or lack of it can hinder transition, so it is the perception of the support that is really important. Key themes that emerged in relation to the dimension of Support are summarised in Figure 5.4.

SUPPORT	Parents and family support
	Friends
	Partners
	Health professionals
	School
	College
	Work

Figure 5.4: Key Themes Related To Types Of Perceived Support

5.7.1 Parent and Family Support

All participants appreciated the care and support given by their family, especially parents, during their illness, before and after surgery with many references such as *'always there for me', really supportive'* and *'brilliant!'*.

5.7.1.1. Being There

Before, during the hospital stay and in the early stages of recovery, families provided a constant and reassuring presence and helped participants to cope when they were psychologically fragile.

> *'My parents helped me a lot because they're...the ones supported me all the way through'* (Humza).

James said:

> *'My mum and my nan were there for 100% of the way. My mum...was always there, bless her, and without her I wouldn't have got through it...because I did go through a mental stage where I was quite down and depressed...she helped me through it...always reassuring me.'*

After a difficult postoperative recovery, Mariam reflected:

> *'I don't feel I'd have got through...unless I'd had the support from my sister and parents the first month...this is just a little set back...don't worry it's only going to start getting better...they wouldn't give up hope, made sure I wasn't going to give up hope as well'* .

Sam also had a difficult time after his operation, and appreciated his family's support, but also felt some guilt:

> *'They've been here every day and at the same time I do feel bad because I've had to put them through it as well. Doctors...can't really support me on an emotional level so it really comes down to...family...coming to visit me.'*

Sam, in common with other participants felt that doctors can't offer the kind of emotional support that a family can (see 5.7.4.1.)

The whole family rallied round to support many participants, before the surgery:

> *'My family have said really supportive stuff...they'll help me all the way through...if I have to have a bag'* (Rayhanul)
>
> *'I had me friends and family round me...so supportive'* (Dave).
>
> *'Family being around you's the best possible thing...just talking to you'* (Ruhana).
>
> *'Me mum dad and sister. They was always there for me'* (Rob).
>
> *'My parents were brilliant. My brothers and sister were brilliant'* (Victoria)

Jack had an extended network of close relations and a community family to sustain him:

> *'I've grown up in a Christian home so I think my parents and my faith have helped a lot...in dealing with...suffering and the grief of it...I was...really, really ill and in hospital for about a month and for that whole time my mum stayed in the hospital with me... and the rest of my family visited and ...my wider family as well...a lot of them are Christians so all of them were praying and their churches were praying and it's...really encouraging and uplifting to know that'*

However, not all patients received the consistent support that they needed. Mia, living with chronic disease, thought that family should actively support her more than just when she was admitted to hospital for surgery. This participant who was particularly negative throughout said:

> *'I know my mum cares...and she wants to be there all the time but...I'm ill all year round and nobody comes and sees me but as soon as I'm in hospital it seems to be like a family gathering...I don't need the sympathy vote'.*

5.7.1.2. Practical Help

Mothers and fathers also did practical things to help. For example, after she had her stoma formed, Daisy developed complications and needed enteral feeds. The tube blocked. *'My mum tried everything to get it unblocked. She was trying to shove coke down it, she was trying like to do all fizzy drinks'.* These attempts were not successful and, to avoid having the nasogastric tube reinserted, she promised she would drink the required amount of 14 cups of Modulen (nutritional drink) every day. She kept it up for the full six weeks with the help of her parents and grandmother:

> '*I went on holiday and I still did it and my nan made them for me ...my dad made me a little chart I could tick off every day that I had it. And I did it'.* (Daisy)

> *'(The stoma) took some getting used to...changing it and everything. My mum was really helpful'* (Dave)

> *'My mum's a nurse too. She was brilliant (with the stoma)...With university...we managed to get...accommodation with en suite bathrooms instead of having to have a communal bathroom which we managed to sort out'* (Victoria)

However, one participant did not appreciate his parents' efforts to help:

> *'Since the operation I've had my parents on my case. They'll be up in the morning, making my breakfast, make sure I wake up on time, now have my lunch on time, and even my dinner on time... I've got my mother saying this. I've got my grandmother saying this...they think they know the illness better than me* (Fazeel)

The above shows there is a fine line between support and engulfment, particularly at an age, when young people want to assert their independence and cope on their own.

5.7.1.3. Parental Attitudes

Several participants described their parents' attitude towards their surgery. Paul and Fazeel have been quoted previously (5.5.1.3.) Ruby said:

> *'I think my mum and dad were really worried. I think my mum more. They were OK with it then when it started getting closer to the time they got scared.'*
>
> *'They didn't want to see me having surgery so often and disappointed when I didn't stay connected'.* (Bernice)
>
> *'My mum was more uptight than I was...she's very emotional...I was like Mum and Dad don't come into the hospital if you're gonna be like this...you're just bringing me down'* (Yasmin)

Parents who had a supportive rather than over protective attitude were perceived as helpful. Victoria, with a permanent stoma since she was 11, feels she benefitted from parents who encouraged her, even with extensive CD, to live life to the full:

> *'They just wanted me to have as normal a life as possible...I had a school trip to the Isle of Wight and...I really wanted to go, so my consultant upped my steroids and sent me with my pump. I had a gastrostomy with a pump and I was on 24 hour feeds and I did all that...You can do it, if your teachers are willing and if you're willing...you can do it'.*

She now talks to other young people about her experiences of surgery, and notes the difference between her parents' attitudes and those she sometimes sees in others. '*Some parents, they just make these scared little children because they're scared for them...I don't think it's good, especially when it then comes to having surgery and you've got these scared adults and scared children'*. She sometimes finds these visits difficult as she tries to set a realistic but positive example; *'It is frustrating. It's not enough that your kid's in bed all sick and I'm fine. Not enough'.*

'*Tough love*' or straight talking by parents was also perceived positively by participants. Sometimes Humza used to be careless with his stoma:

> *'I didn't used to really care about it leaking so my mum used to tell me off a lot so...cause of that I've learnt now'.*

Other parents stopped their children from feeling sorry for themselves.

> *'I think it helps with my mum because she's one of these people...if I'm moaning about it, it's just like get on with it. She don't give no one sympathy.'* (Daisy)

> *'My mum...made me a bit stronger...she used to, not in a horrible way...say to me there's people worse off than you'* (Helen)

5.7.1.4. Sharing Experiences

Three parents supported their children by sharing their experiences. Following his major bowel surgery as a child, Humza said:

> *'My dad...used to be with me all the time and cause I couldn't eat, he didn't used to eat as well...When he used to go...home...then he used to have something to eat'*

Rob's father gave up the activity he used to share with his son when he was recovering after surgery and unable to participate.

> *'We used to do weights. I used to go with my dad. He used to do weights with me...He wouldn't go without me. He'd rather go with me'.*

In contrast to the previous two participants Fazeel, recovering at home, was not so appreciative of his parents' overprotective efforts to help although, as described in section 5.7.3.1., he accepted his girlfriend modifying her diet to mirror his:

> *'They wouldn't eat certain things which I would want, I would crave...I'm Asian, we love our curry but curry and my stomach don't actually go hand in hand so...my parents, they try to maintain their diet but they'd be very careful as in where I am I tell them, you can eat whatever you like...It does get to me.'*

5.7.1.5. Not Knowing How to Help

Some participants were also aware that their parents found it difficult when they did not know how to make things better:

> *‘I think they’re just happy that I’m well to be honest and they don’t have to worry cause I know that it... really upset them when I was ill and they like didn’t know what to do some of the time’.* (Jack)

> *‘They didn’t like it cause of how I was. I was upset all the time’* (Rob)

> *‘My family it’s the first they’ve heard of anything like this...they’d just be like oh, it’s cause she doesn’t eat..They think you don’t eat properly all the illnesses come to you...if you eat properly all this is gonna go away...They don’t feel there’s nothing they can do to help me’.* (Ruhana)

Despite this study not specifically addressing culture, there were some notable cultural differences in how certain families coped and supported their child through surgery, for example, traditional beliefs could lead to a more passive way of dealing with things, or type and amount of support offered, accepted, and perceived.

5.7.1.6. Regaining a Normal Family Life

Participants reported that as parents and siblings perceived improvements following surgery, vigilance and assistance tended to diminish and normal family relationships could resume. These changing relationships were at times the source of some parental regret. Mariam recalled the changes in her family in detail:

> *’They don’t really have to do much now...My mum keeps saying you know you were really like my baby even when you were growing up...whereas now you’re sort of leave me alone...You’re just independent...you don’t need me to do anything’.*

Her parents now treat her as though there is nothing wrong with her, assigning house-hold chores: *‘It’s your turn to wash the dishes, put the clothes out’* and the concessions made to her illness have gone. *‘I don’t get let off as easily any more’.*

> *‘If I call them up, can you come and take me home...it depends what mood they’re in... If I say I’m too tired, I don’t have enough energy, they’re like well, you were out last night that’s why, not because of your Crohn’s’*

She also recognises that it is no longer possible to use her illness as an excuse to avoid things or to get her own way.

> *'To a certain extent it would be really easy if I didn't want to go and see other family to say, "I don't feel well, Mum".. I wouldn't have to do things and if I didn't like the food someone was making, "Oh, I just don't want to eat that"."What do you want to eat, as long as you eat something that would be great". Whereas now, "if you don't want to eat, make your own food, you know it's your choice"...I can't really use that anymore.'*

Becoming normal comes at a price. No more special treatment, treated like everyone else. Like other young people, she enjoys pushing boundaries *'I test how far I can get...see how far I can use it...it's fun'.*

Daisy described a normal sibling relationship with her healthy sister:

> *'She don't say anything, actually. She just takes the piss out of me but I just laugh about it... She has said some hurtful things to me before but that's just sisters being sisters, ain't it, because I call her a fat cow.'*

5.7.1.7. Parents Letting Go

As their children recovered health, parents also became less vigilant and allowed participants more freedom. Ruby noticed that her parents were less protective and allowed her to do things that other teenagers do:

> *'My mum doesn't mind me going to see bands and stuff like that but... now...allows me to do more stuff than before.. I've a favourite band and... they said that they'd allow me this time to go and see them in Brighton and Birmingham so that's a big change there'*
>
> *'My parents...they're a lot more relaxed now about me going out. They're not worried that I'm...gonna be calling them to come and pick me up at any hour or...that all of a sudden I'm not gonna be well...so they're much more confident with me just doing what I want to do'* (Mariam)

Sometimes it is harder for parents to adjust:

> *'I'm older now doing my own thing, college and the driving. It's mad because she still treats me as a baby when I'm well. Mum, I'm alright now...and she's slowly starting to let me have my leeway now and knows I've got to get on with me own life'* (James)

But that is part of the transition for parents as well. Once he had a stoma and became healthy, Humza discovered a love of sport. This was important in helping him to feel 'normal'. He described how in the beginning his parents were reluctant for him to do this, because they were concerned it would be too much for him:

> *'My parents used to discourage me a lot but it was kind of serious then, cause I didn't know what can I do. Now I've found out, this is what I can do, this is what I can't do.'*

5.7.2. Friends

5.7.2.1. Support and Disclosure Before Surgery

When they spoke about their lives with illness before surgery, most of the young women expected and received support from their female friends. Ruhana relied on a close network of friends for emotional support and told them everything.

> *They come with me to the hospital all the time. That's what (specialist nurse) says, I have my army with me...Yea, they all come. It's always someone different, someone's always here...I feel they're really supportive...sometimes the closeness you find in a friend, you can't always get with your family'.*

> *'I spoke to my close friends about it and they gave me all the support they could possibly give. Also they would place a bag on themselves just so I could feel like she's not alone doing this'.* (Yasmin)

With systemic Crohn's disease, Mariam relied on her friends to understand her restricted life, but also sometimes needed practical help:

> *'They just accepted I didn't want to go out...They were worried that you're not actually going to be well enough to carry on...(and) have to figure out how to get home for you.'*

One male participant described help of this nature from his friends and didn't particularly welcome it:

> *'My close friends, they know... I've got Crohn's and everything. They're just a bit surprised that I don't tend to look after myself...and so they used to- these are just a handful of close friends- they used to actually refrain me from doing anything I*

> *shouldn't be doing...which was irritating in some ways, but you could actually see why they were doing it'* (Fazeel)

Young men who made new friends at university tended not to disclose their illness to them until it could no longer be avoided. So the role of friends differed for men at college:

> *'I didn't really tell anyone for the best part of two thirds of the first year and then I kind of sort of said oh you know I've got this thing... and I just get on with it...My friends... forgot that I don't eat or they kind of... would go off and eat and I'd just be sitting there'* (Paul)

> *'Friends I made at university, I didn't tell them I've got Crohn's...There was no need to tell them. They did start wondering earlier this year how comes I'm missing uni...I had to (tell them) because...they obviously noticed suddenly I'm not out and about as much these days and...they hear it from other people oh Fazeel's in hospital. So they'll start phoning me up, what's wrong...so obviously can't hide that'*. (Fazeel)

> *'Three particular friends I value. They really are the ones that know more about my condition than anyone else. It's only recently that a couple of other friends have known more...but generally I don't like to speak about my condition to many friends'* (Sam)

5.7.2.2. Friends and Disclosing the Need for Surgery

When it came to disclosing they might to have an operation, friends were encouraging. Ruhana and Mariam told everyone:

> *'What everyone kept telling me, it's gonna benefit you after and they were...really supportive'.* (Ruhana)

> *'My friends welcomed it'*. (Mariam).

Other participants were more selective. When disclosing she had to have a stoma, Daisy said:

> '*I didn't feel like I could tell my friends...I've got two best friends that I've been friends with since I was in nursery...I told them obviously before I had it done'.*

Similarly, Rob told just a few people about his proposed surgery.

> *'A few of them that come down...knew about it. They was alright about it. They was like well just go in. If that's what you need to do, just do it'.*

Although his friends said the right things, Rayhanul was not certain if they would actually give him support after surgery if he had to have a stoma.

> *'Friends have told me that it's completely normal. If you are ill and you need to have something then you might as well go for it...They said they'd try and protect me from everything. So they have reassured me and that made me feel a little bit better...Maybe if I had it done, afterwards they might not be as supportive as they say they're gonna be'.*

5.7.2.3. Friendships After the Operation

After surgery, Rob refused to socialise outside his home while he had the stoma, but *'(my friends) were the same apart from I didn't go out with them...for quite a while messing about'.* Instead, they came to his house with their dogs, and interacted with him and his puppy there.

Ruhana and Mariam continued to have the same expectations of their friends:

> *'All my friends know I've had an operation in my bottom... if you get the right support then it doesn't feel as bad'* (Ruhana)

She relied on them to visit her and help her through difficult times as described in 5.8.2.1. Mariam's friends also helped her to cope with the stoma:

> *'Sometimes if I go out to a club or something...the toilets don't flush very well. That really worries me (if) I have to empty my bag. I end up saying to my friends...you go first and don't use the flush and I'll come along, cause then I've more chance of the flush actually working'.*

She has also noticed a change in her friends' attitudes towards her in that they are less solicitous after her operation.

> *'I think everyone challenges me more. Now they don't feel guilty about asking me out and I know if I say I don't want to come out, they're what are you talking about...My friends say that... I just dwelled on my Crohn's a bit whereas now I don't think I do. It's*

> *not a huge part of my life any more...It doesn't come up as often. It's nice because it makes me feel normal. There's no difference between us'.*

Victoria described how her school friends accepted her after her surgery:

> *'I was lucky with my friends, cause we went to a school where we all met each other when we were five and stayed together until we were sixteen...Everybody knew already that I was ill and so (the stoma) wasn't a big deal and everybody knew what was wrong with me'*

However, Bernice chose to withdraw from her friends once she had the stoma:

> *'I don't really go out much...That's what my friends notice...My friends come round when they're not at uni or college...They don't really know or understand much. It's my choice not to tell many friends. They're the same as if I didn't have anything wrong. I just see them less'.*

None of the young men disclosed their illness or the details of their surgery as openly as the young women to their friends.

> *'I'm quite a quiet person with my friends. I have a good bunch of friends with me all the time. They don't really know the full extent of my illness but they knew I was in hospital really unwell and had to have operations. They've always been really understanding. Never really asked too much about it, but they've always been there. They've not known the full extent of it. There's a few that know and they've always been there'* (James)

> *'When I...moved my schools to another one...I told a couple of people, cause I didn't feel comfortable being with them and stuff like that...but they were fine with it. They didn't say anything nasty to me... I just found good friends...they're just like good human beings'* (Humza)

5.7.2.4. The Unique Role of Friends After Surgery

Importantly, there were three factors that differentiated peer friendships from other relationships in participants' lives. Friends provided them with opportunities to do the things that other young people of their age were doing; sometimes friends forgot that they had had surgery; and they behaved as if they were the same as them – they treated them as normal.

> *'They sort of call up every day asking do you want to come out yea I'll come out...Before...my friends were very much there for me but I don't think I have many memories of actually doing stuff together. Our stuff would be them coming round to my house and watching a film. That was all I could handle. Now it's like...we're going on holiday together. We go shopping together...Now I'm no longer going oh what's this joke all you guys are saying about. I'm actually involved in the joke...I remember the memories now whereas before I was always trying to catch up'* (Mariam)

> *'They just see me as any other mate. They don't treat me no different...and I like that, cause it's the best way to be...I don't like people to feel sorry for me in any way. I like to be treated the same and they do. I've got a good bunch of friends...they understand and if I said oh I've been unwell or I've been in hospital, they're like are you alright and we catch up and go out and do things together. Good bunch of friends'* (James)

> *'Most of my friends know about it and they all forget...They just forget and...sometimes they go have you still got it and I go like yea ...They don't treat me any differently...They don't even think any different of me. They just think of me as being normal... I just feel normal now. I feel if somebody saw me standing next to my friends they wouldn't see anything different'* (Helen)

> *'My friends they encouraged me and I think if they hadn't done I would not have gone back to uni'* (Raina)

Besides Bernice, only Rayhanul described significantly less interaction with his friends after the operation but for different reasons. He had previously had what he described as a *'hectic'* social life, which was one of the ways he minimised the effects of his illness. Now well, and having to catch up with his university work, he had other priorities:

> *'Where my friends invited me to come to this party or let's go out tonight or anything, I'd actually have to think twice now...It is a big change very different now.'* (Fazeel)

5.7.3. Partners

Fourteen of the 24 participants were in steady heterosexual relationships and four of these had plans to marry. Not all of them discussed details of the support their partners provided, or that they wanted from them. However, the following section considers the nature of the support in relation to intimate partners that was described by those who did.

5.7.3.1. Support Sought by Young Men

In intimate relationships male participants looked for and received practical support. Where there was the possibility of a stoma, reassurance was also sought.

Rayhanul worried most preoperatively about having a stoma. There was a very small chance that this would happen but he thought his fiancé would find this off putting, even though she had reassured him that she wouldn't. When he reasoned about it, he knew it was unlikely, but still he had doubts. He was also concerned about the practicalities of managing a stoma, and was relying on his fiancé to help with that:

> *'I've been with my fiancé for a long time and we are going to get married... She's completely fine with (the stoma) so that does make me feel a little bit better but... She's just saying...she won't see me as any different. She will still love me for who I am. She'll help me with everything she can...but she might...be off towards me... I can't really let stuff like that come in the way, because my health comes first and my well being comes first and so that's the first thing I've got to prioritise in my life, but it does worry me a little bit'*

His fiancé had already demonstrated her support during his illness, and they had discussed the help she could give after his operation.

> *'She's very supportive, comes to every single appointment. The last five years she's never missed out a single appointment...She's a nurse herself, she takes time off work. I think that is another helpful thing because she's nursing and if I was at all ill or if I need a bag she's experienced with stuff like that'.*

Fazeel also looked for practical support following his operation. Before he had surgery, he was sometimes non compliant with his medication so his fiancé took over, ensuring he did the things that would help him to keep well.

> *'She knew I had my illness. She'd be careful...She'd make sure I'd take my medication ...and I'm really forgetful as well, so it was my girlfriend telling me things to do, keeping an eye on my diet...She's the one that actually knows my appointments, what time I've got it, what date I've got it...She even bought me a phone...so I would actually remember'.*

She continued to do the same things for him after the operation, but he noticed she was more vigilant and careful, sometimes too much so, in his opinion.

> *'After the operation the only way it's changed...it's like now I've got my mother with me twenty four seven so whatever I'm doing now she keeps an eye out...Before the surgery I could just tell a white lie oh I'm alright, so we'd be able to go out have fun, something like that but now she does actually think twice- oh I don't actually think you should be doing this... I've told her off a few times really you know I don't need (all that)...She's a bit more glued on. I guess she's a bit more worrying which is understandable because I forget myself, it's only been...three months since the surgery...And food, whatever we eat outside...She changed her diet as well which was quite nice'*

5.7.3.2. Support Sought by Young Women

Ruhana's partner helped her by dissipating her worries with reassurance and humour, particularly about the effects of her illness on her ability to be a good wife.

> *'He's like oh you need to get better as soon as possible, so he was always nagging me like make sure you don't miss hospital like make sure you go...Coming from my background...it's another worry that I want to get married… because they hold a lot of expectations from you. Where we come from, when you get married you kind of go over and take over the responsibilities of the mother in the house as a daughter in law...I don't feel as active as a normal person…and if I'm falling ill all the time...I don't want my husband to be disappointed in me...He's just like, oh don't worry it's gonna be OK I'm sure. He's supportive and he's like to me oh don't worry. He just makes me laugh thinking, he just turns everything into a joke...He just makes everything seem not so serious...I don't want it to be that serious in my face'*
>
> Yasmin's boyfriend was also supportive and encouraging:
>
> *'He says to me looks change but the personality won't...He was telling me to do it for a long time from when my condition was first bad...That support was always there'.* (Yasmin)

Rayhanul, Fazeel, Ruhana and Yasmin were all from an Asian background. All but Yasmin had partners of the same culture. None of them lived together. Fazeel was the least traditional, with an independent lifestyle which also included alcohol consumption. Ruhana was the most traditional in her expression of cultural values and neither she nor her fiancé expected that he would accompany her to appointments – her female friends had this role- although he encouraged her to attend. Lesley, who is white, sometimes spent time in a wheelchair due to the debility and pain of her illness, and was living with her partner:

> *'I have found...my fiancé and he just doesn't care...In the last four years since we've been together ...he's supported me through a lot and he's actually stopped by me, whereas a lot of people I know wouldn't...Having him there, he's just sort of he manages to make me laugh about things if I'm down or just...lightens the mood and that...It really helps having someone like that to get you through things. If you're not...having a great day or whatever then he comes home from work and...just makes me laugh and that, just gives me a cuddle or whatever and it really helps'*

While most participants described supportive relationships Mia, who had to contend with multiple social difficulties, as well as recurrent disease and surgery also had problems in her relationship. Although she described her partner as 'really good' and 'always there' for her, she related a critical time, when she was in hospital, undergoing a termination of pregnancy, when both physically and emotionally he was not:

> *'When...it all started he...didn't want to come near me.. He couldn't even look at me. I just laid in bed in pain and he couldn't even come in and talk to me and when he did ...he couldn't even hug me... cause he was scared... I think he was. He wanted to help but he didn't know what to do...At the same time he was losing something and not just I was, and it's affected us a lot over the years'*

He was also critical of her and not understanding of the effect of the disease and its treatment on her life:

> *'My boyfriend.. says I'm really negative but it's because I don't get my hopes up about anything cause I never know what's coming...he hates the fact that I can't turn round and say yea well we're gonna have kids in a year or we can start thinking about having them now or it's even like going on holiday and things like that. I know how much it frustrates him but there's so much more that I've got to think about and I don't think he quite understands...It's easier for me to not have high expectations because then I won't get hurt as much...My boyfriend says that I'm too old. He keeps saying that. He keeps saying...you're only twenty two...I don't think I'm old. I'm just realistic about things*

> *and...when he says well we can do this and we can do that,...I'm like we can't. We can't do that, so it is difficult'*

She accepted responsibility for the problems that beset them (see 5.8.3.1. below), even those over which she clearly had no control:

> *'It didn't help that last time when we came in (hospital) it was his birthday...He came to visit me on his birthday and I told him not to but the woman in the bed opposite me died while he was sitting with me. That's not nice. That's never nice for someone. I just feel like...I'm a burden'*

In dealing with the loss of her baby, the effects of surgery and the threat of unemployment, Mia described a couple together but essentially alone when dealing with crises in life.

> *'If I went into hospital...(my employer) just didn't pay me. Statutory sick pay isn't much to get by on...nowadays...especially because me and my partner live together.. He always says to me...you can move back to your mum's and I'll go stay with a friend...but I don't want that'*

5.7.4. Health Professionals

Participants had differing expectations of the support that could be provided by members of the health care team.

5.7.4.1 Gastroenterologists/Medical Doctors

These young people were prepared to follow their doctors' advice and undergo medical treatments, despite the effects on their lifestyle and appearance and appreciated the difficulties associated with managing IBD medically.

> *'The doctors are great...but if you're seeing the doctor especially for something like Crohn's it tends to be for the long haul and you don't know what's going to happen but neither do they...They're just doing trial and error- this might happen, this might work. If it doesn't try this, if it doesn't try this'* (Victoria)

However, they did not tend to seek emotional support from medical staff although it was appreciated when it was given: *'My doctor...over here he supported me as well...When I was in the hospital he used to come to me every time. Even if he was going past, he used to ask how are* *you doing'* (Humza), but these young people did not seem to consider this type of support to be the doctor's role.

> *'Doctors...can't really support me on an emotional level'* (Sam)

What they did expect was that doctors would support them by continuing to treat them, no matter what happened. Fazeel described how he let his situation deteriorate, not taking medication and avoiding seeking treatment for his condition:

> *'I've had all my consultants...saying quit smoking but I'm still struggling with that...I was out and about three weeks after the surgery...when...doctors advised me against that...Sometimes I might ignore (my symptoms) ...but where it comes to a point I know this is serious I usually end up running back to Dr _'*

> *'I get angry at like Dr - and Professor – and I have no right to cause they're all very good...and to be honest they've put themselves out for me a lot...whenever there's a problem'.* (Mia)

However, some participants it difficult and frustrating when they felt that there was no definitive plan for treatment:

> *'Last year I was like what's the plan then. What is the plan. Well the plan is just to carry on as you are and hopefully things will calm down, but I don't really see that as a plan. That's not a plan to me. A plan would be like right we'll do this, we'll do that and if this happens, we'll do this, we'll do that and give me all these options, but it's not. It's like I'm just expected to waddle along'* (Daisy)

> *'(Last time...) they took the drains out and they took me off the Infiximab and it just healed over and the infection was still inside (and) got worse...This time they're determined not to...take them out unless I've had an MRI but at the same time I think they're reluctant to give me an MRI to see if it's getting any better. They want to keep me on (the medication) as long as possible but at the same time I wanna get off it'* (Mia)

5.7.4.2. Surgeons

Participants also commented that surgeons had a different approach from their physicians:

> *'If you go to see a surgeon they have something that they're going to do and they're such straightforward people. They...don't make anything seem nice or flowery or everything's going to be fine. They say this is what we're gonna do. Unfortunately we might have to do this and we might have to do this but only in x per cent of cases'* (Victoria)

> *'Mr _...told me, most of the people I have done the operation to, it was 80%...chance...it's worse...It's better not to do it. You won't be able to control everything that...comes out...It's just not worth it'* (Humza)

James also appreciated this direct approach.

> *'I was always told straight really and I quite like that because I'm quite a smart kid. I know what's going on and throughout all that you wanna be told straight. You don't want to be fussed around'*

Participants also appreciated surgeons who responded to their individual concerns:

> *'As soon as I heard about the operation I was like oh no and I was wondering like what if it goes wrong and stuff like that... I was like oh would you be able to cure it like...if anything bad happens...The guy was like yea. It felt much more better...cause I could understand more. Like before...they always used massive big words and stuff and it's like you don't understand...Then after they explained it like in young people's terms I could understand'* (Ruby)

Rob finally committed to having a bowel resection and temporary stoma after his second surgeon reassured him that his biggest fear, of having a permanent stoma, would not be realised:

> *'He always talked about reversing it cause see he's a better surgeon. Cause the other one said you can't and he said yea I'll do it....'* (Rob)

However, other participants expressed disappointment about communication with the surgical team:

> *'I was told it would be a simple operation and they're gonna drain the fistula abscess and put a seton there...I wake up now and I find yes they did that but they cut open another part...I've got a hole in my bottom the size of a trench and I kind of wish I'd been informed...I still have the seton in now...I feel like I haven't been kept up to date...They didn't tell me I would have it in for about a year...The last time the surgeon saw me he dismissed me for six months... I feel I should be seen like not so distant so i can know what's actually going on'.* (Sadie)

> *'I didn't know there was a possibility of the pelvis break down and all of that and feeling so ill after the surgery. I just didn't think that would happen. The stoma they always mentioned...they just brushed that off as if I wasn't going to have it...They say things. I know now they say things and it don't necessarily happen'.* (Bernice)

5.7.4.3. The Specialist Nurse

The member of the health care team who did provide emotional support was the specialist nurse. She provided continuity of care when participants attended outpatients, in hospital and in the community and it was to her that they first turned for reassurance and help.

> *'She's excellent...I'd be lost without her she's amazing whenever there's a problem literally I ring her and she meets me straight away'* (Mia)

> *'I was very worried when I first went home whether I was doing things correctly. My parents were very worried. We were on the phone to the stoma nurse a good few times a day'* (Mariam)

> *'I wasn't well not long ago...I was panicking cause I thought it was my Crohn's and everything runs through your head... I phoned (specialist nurse) straight away...To be honest, when I was in hospital... if it wasn't for (specialist nurse) I don't think I would have got through it cause she just came up to the ward...once even twice a day just to see if I was OK...I know it sounds silly but when I see her my face just lit up because I feel like I can talk to her'* (Helen)

> *'The stoma nurses... helped me quite a lot. If it wasn't for them I would still be having a nervous breakdown even till now...I talked to (IBD specialist nurse)...Oh thank God ever since I was diagnosed (IBD specialist nurse) was there for me. You just need that support'.* (Yasmin)

5.7.4.4 The Patient as Expert: Inclusion in Decision Making

Participants needed their feelings and opinions to be acknowledged by health professionals. When they were ignored, there could be open conflict, as described with Rob and Daisy previously (5.5.1.3. Decision making). Because they have lived with the illness for a long time, some participants also feel that they are the experts on their own condition and that they therefore have a valid contribution to make to decision making:

> *'I've lived with this and...I'm actually the best judge to know what's wrong in my body and what's good for me even though sometimes I might ignore it'* (Fazeel)

Lesley, with the most experience of surgery, also said *'People should listen to the person who lives with the illness every day'.* She described several occasions where health professionals ignored her wishes. Admitted for an examination under anaesthesia to investigate two pinhole wounds which had appeared on her right vulva, she specifically asked the surgeon only to look and not to do anything. When she returned from theatre this had been opened and drained, because there was sepsis. This wound has subsequently not healed. When she told her gynaecologist about the incident, she said that she would have done the same thing. *'I felt dismissed'.*

She had also undergone multiple debridements in an effort to help the wounds to heal. In the early days after surgery, she was always seen by the consultant but later they devolved her care to the ward nurses. She described how this resulted in a lack of continuity of care – a different nurse did her dressing each day- and the ward nurses did not always listen to Lesley about the least painful way to clean the wound, for example letting her change position to drain irrigation fluid rather than swabbing. She preferred to leave hospital and go to the Day Centre where the staff knew her and listened.

Pain relief could also be a problem when she had surgery. Because she took strong painkillers all the time- Oromorph, Diamorphine and Tramadol, dosages needed to be higher than usual to control her postoperative pain. Commonly doctors were resistant to doing this and queried her need for this amount. In contrast, the Pain Team at one hospital did listen to her and manipulated the regime for her until she was pain free.

There were also other occasions when participants felt they had not been treated in an appropriate manner by their doctors:

> *'I came in and the registrar that spoke to me on the phone kicked my mum and my boyfriend out of the room and had a go at me about being pregnant and having the surgery...He really upset me and I complained because...that's not right...'*(Mia)

> *'After I had my three operations with (surgeon) he went private and he didn't let me know and...while I was ill this year there was big confusion about...what surgeon I was with and I wasn't really handled properly...and it was quite a shock really cause I didn't hear from him and he didn't let us know he had left'* (James)

Such negative experiences as recounted by Lesley, Mia and James will obviously add to the stress of surgery, and emphasise the need to involve young adults in their care decisions and to communicate effectively with them.

5.7.5. School and College

Victoria, who had surgery as a child, described her teachers as '*brilliant*'. They had worked with her parents before and after stoma surgery to ensure that she was able to do the same things as her healthy peers and so wasn't excluded or made to feel different. Ruby found school life difficult. Her teachers didn't appear to understand her condition, she had to manage several episodes of tube feeding, and found it difficult to integrate because she left her new classmates to have surgery. Nevertheless, because she wanted to do well, she went back to college at the earliest opportunity.

> *'I was only there for about a week or so and then I had to go to the operation... (I) went to college faster than anyone else (after) that. Some people like might just take the mick and stay there for months, stay at home. I wanted just to go back'*

Dave also described peers at school as immature. Both Dave and Helen found school life difficult after they had had a stoma raised in their teens – Dave because of bullying and Helen because she found it difficult to cope with a new stoma amongst fellow pupils she did not know well. Both had been able to receive home tutoring. Anne described taunting by her school fellows but reacted in a different way:

> *'One day in school I just lifted up my skirt and I showed everyone exactly what I was going through and since that day no-one said anything to me...I think they were shocked what it actually was'.*

Victoria and her mother had been able to acquire a separate bathroom for her in her university accommodation so that she could manage her stoma more easily. The young men at university did not disclose their illness to their friends but they did have to tell their university tutors. Paul arranged to have his surgery in the university vacation but Fazeel, who minimised the effects of his illness, surprised his tutors when he had to ask for time off for his operation:

> *'I used to miss a lot of uni a few weeks at a time, falling behind most of the lectures...I just had to tell them...about this and...they were all amazed. They said you don't look it and you don't act it and now you're just telling us you're suddenly going for surgery where they're gonna be removing this much of your bowels. They were a bit shocked'*

Fazeel, Paul and Sam all recognised the effect of the stress associated with studying on their illness. IBD symptoms and their treatment interfered with their ability to study and examinations exacerbated their disease.

> *'It really did slow me down at university... I used to get all my work...top level...but as the stress kicked in I had to slow down and didn't think I was achieving what I could potentially achieve...I've graduated now and I...feel...because of it I've lost out on a lot of achievements'* .(Sam)

However, none of them described approaching their tutors for support or advice, or asking for concessions to be made because of their illness and its treatment. Now that he has had his surgery, Fazeel is more focussed on his academic life and the need to make up the time he has lost.

> *'When I was at hospital, I missed a lot of university work so I'm trying to catch up with that...which means a lot of late nights...It is stressing me out in a different way, because I have to worry about meeting deadlines plus doing the work which I've missed already plus the exams'.*

He continues to try to manage on his own, not asking for help from within the university.

5.7.6. Work

Having a career and being able to work were very important to participants. Those who were coping well or whose surgery had cured them were just like their healthy peers and did not require support in the workplace.

5.7.6.1. Normal Working Life After Surgery

Some, whose surgery had made them well, were able to have a working life that was exactly the same as other young people. Mariam felt that her stoma had not interfered with her career as a nurse at all and that she was living a normal life in this respect. Following closure of his temporary stoma and adjusting to life with an IAP, Dave described the difference his surgery had made:

> *'I started work in November...I started in a warehouse which probably wasn't the best idea to do but now I'm working in a pub so it's just bar work. It's just work for me until I find something a bit better. (The operation's) made a huge difference...because I haven't got to worry about (the stoma) leaking. I haven't got to worry about going to the toilet and emptying it. I haven't got to worry about noises and everything and obviously just me confidence as well'*

5.7.6.2. Absence From Work

Intelligent and ambitious, Rayhanul described his frustration at the disruption that frequent illness relapses caused in his working life:

> *'It's trying to hold onto jobs, that is the problem...Because of the Crohn's and my absence I never get kept on the job... I've had jobs in investment banks and they've taken me...Then I've had the managers come up to me...Whatever work you do is great but we can't have someone that's coming in, taking a day off every week or a day off every two weeks. We need someone that can be in here at least five days a week and a fit and healthy person and I'm sorry but...we can't keep you on'*

Participants frequently stressed how important it was for them to work and more than one commented about the difference in their attitudes to work related absence from those of healthy peers:

> *'When my friends are ill, they've got a cold or a cough and they're off work...I go into work and I've got really bad...diarrhoea...a relapse, like having hot sweats. I've got a temperature. I feel like I'm going to be sick. I have to keep running backwards and forwards to the toilet and I'm in pain...If I have a cough or a cold it's nothing to me. It's nothing. I don't even think I'm ill when I get things like that...Bloody hell everything's just the Crohn's'* (Daisy)

Similarly, Mia did not take sick leave, other than for her CD or for surgery:

> *'It's not like I'm off, going off sick, with...silly things like I've got a cold or ...I've got this, I've got that. It's literally because I've got a Crohn's flare up'*

5.7.6.3. Supportive work environments

Participants gave examples of employers' and colleagues supportive attitudes following their surgery. Helen went to work for a small company:

> *'My first job after leaving school and funnily enough one of the blokes who worked there, he had a colostomy bag, so everyone knew he had a bag...and when I started I told the two managers. I just said, look I've got a colostomy bag. They said yea, so has V and I was like oh my God'*

Ruhana described how her colleagues and managers gave her consideration and support when her illness flared and she had to have surgery. However, she is concerned that other employers may not be the same and worries about the future.

> *I've got an apprenticeship in business and administration...and they're so understanding but I know I won't get that everywhere...They're always telling me...if you ever feel like you've got any sort of pain, anything, just let us know immediately... My biggest fear, even today, right now, about getting another job is once I have another operation I'm going to have to go back off work. Because...after my last operation...I couldn't move for days'.*

With IBD, absences may not just be frequent and short, but of long duration. Like Ruhana, Sam worried about absence from work. He described his managers as understanding about his prolonged sick leave due to illness exacerbation followed by emergency surgery. However, he also worried about his career prospects and hoped with his temporary stoma that things would settle down.

> *'Since I got seriously ill this time round...I haven't actually been working at my part time job for a couple of months now. They've been OK with it, quite understanding, but obviously...I've been apologising sincerely for not being able to work a lot.'*

5.7.6.4. Lack of Support in the Workplace

Unfortunately, not all workplaces were understanding about the illness or supportive to participants. Mia worked in an unsupportive environment with multiple stressors. She made a huge effort to attend, even when she was sick. However, she could only find temporary employment which meant that she was not paid when she did not go to work. Her manager did not understand her illness and the stress of the situation contributed to her difficulties. She wanted to leave and find a job in a different field, with a smaller company but because the pay would be less, felt she had to stay.

> *'The first time I came in for the surgery here I lost my job...I'd just started there. I'd been there about three weeks then I was off...for a long period of time...In the end they turned round and said to me we can't keep you on...We hired you because we need the staff...We can't afford for you not to be here with the workload that we've got...Jobs aren't understanding at all'.*

Table 5.4 summarises the factors related to support that helped or hindered the transition for participants in the study.

SUPPORT		
SOURCE	**HELPED**	**HINDERED**
Parents and family	Nurturing in early phases: loving presence	
		Parents who show they are upset
	Supportive	Overprotective
	Practical help	
	Sharing experiences	
	'Tough love'	
		Not knowing how to help
	Less vigilance with recovery	
	Permitting more freedom with recovery	Not letting go
Friends	Encouragement	Uncertainty of actually receiving support
	Normalising role	
Partners	Practical support (M)	
	Reassurance (M)	
	Comfort (F)	
	Emotional support (F)	
	Humour (F)	
Health professionals:		
Medical doctor	Continuing to treat no matter what	
		Lack of a definite plan
Surgeon	Responding to individual concerns	Ignoring individual concerns
	Feelings and opinions listened to	Ignoring feelings and opinions
	Clear straightforward explanations	Lack of information
Specialist nurse	Emotional support and reassurance	
	Continuity of care	
	Being available	
School	Not being excluded	
	Not being made to feel different	
		Immature peers
		Bullying
		Teachers not understanding illness and its effects
		Non disclosure (M)
	Private facilities for dealing with stoma	
		Stress of studying inducing flares
Work	Supportive colleagues	
	Supportive employers	Managers who do not understand the illness
		Absence due to illness flares

(M=described by male participants; F= described by female participants)

Table 5.4: Summary of Factors In This Study Related To Support That Help Or Hinder Transition

Parental and family support were mainly nurturing in the acute phases of illness and surgery, as just being there as a loving and caring presence, was perceived as helpful. Parents also played a facilitative role in assisting their children to cope with the surgery and its effects, by offering practical help, sharing experiences, having a positive attitude and responding appropriately to recovery and wellness, to help them to move out of the sick role, and bestow the freedom which their recovering children desired. On the other hand, parents sometimes found it difficult when they couldn't actively help their children and also to let go. Parental overprotection was perceived negatively by some participants, in contrast with helping them to live their normal lives, so parents need to adjust as their children change as well.

Most participants who talked about their friendships all described positive experiences. There were some differences in the type of support sought from and given by young men and young women. Before surgery, young women were more open in their disclosures to friends about the illness and their surgery and expected and received support before and after the operation. Young men were more selective in telling friends about their illness, disclosing only partial information, sometimes only when they had to. Friends were encouraging when told about impending surgery. After the operation, friends appeared to play a unique role in participant's lives that appeared to be a normalising one. In the company of supportive friends, young people could do normal things and think of themselves as normal people. They could do so because their friends didn't treat them any differently; they didn't ask much about or dwell on their surgery, sometimes because they simply forgot.

Male participants who talked about support in their relationships looked for, and received different support from female participants. Female participants wanted and received comfort and emotional support and also appreciated the efforts of partners to make things better by using humour.

With the uncertain nature of their illness, participants perceived the main role of their medical doctors to be providing support through continuing to work with them to provide appropriate treatment whatever their attitude or situation. They did not expect doctors to provide emotional support. They had difficulty when their expressed concerns and needs were not appreciated and wanted to be listened to and for their experiences to count in decision making. They needed surgeons to explain things directly and honestly so that they could understand. The specialist nurse was appreciated for her availability and it was she that they turned to after surgery for help and advice with their concerns and sought for emotional support.

Participants had mixed experiences in relation to school and college. Some participants experienced support from their educational institutions which included withdrawing them from a difficult situation and making alternative arrangements for schooling. The disease and an operation could interfere with progress at school and college and other participants described a lack of understanding of the illness and its effects by their tutors and a consequent lack of support. Those in tertiary education appeared to try to manage the situation before and after surgery on their own with minimal disclosure, and did not ask for help, even when their studies were affected.

Some participants found that, despite exacerbations or the need for absence for surgery, their employers were caring and sympathetic. Nevertheless, they were part of a workforce and even a sympathetic employer had to consider the demands of the job and required an employee who was be able to do this. Unsupportive colleagues, who did not understand the condition, together with the disruption caused by the disease and its treatment, could make it extremely difficult for those affected by IBD to have a stable and productive working life.

5.8. STRATEGIES

Strategies are the skills and behaviours that people use to help them to cope with transitions (Goodman et al, 2006). The young people in this study mainly used a variety of positive and active strategies to help them to cope with surgery, but they also used some strategies that could be considered to be protective in that they were directed towards helping them to coping with the stress but did not actually change the situation; some of these were helpful, but avoidance and wishful thinking gave them no benefit. Only one participant (Mia) used self blame among several strategies which appeared to be directed more towards decreasing emotional distress, rather than actively working to resolve it. The other strategies she used were: ignoring, emotional release, distraction, and wishful thinking. She used direct action only in relation to diet if her disease was flaring, and even though she compared herself favourably to others with CD, she said doing so annoyed her as she wanted to feel sorry for herself. Mia had been through an extremely difficult time, with multiple operations, and sobbed as she spoke of her grief at the loss of her unborn child. Figure 5.5 shows the key themes that emerged related to Strategies.

STRATEGIES	‘Getting on with it’
	Information seeking and advice
	Positive comparisons
	Self assertion
	Maintaining the right attitude towards surgery
	‘Dress to impress’
	Distraction
	Putting on a brave face
	Emotional release
	Resignation
	Ignoring and avoiding
	Wishful thinking
	Self blame

Figure 5.5: Key Themes Related to Strategies

5.8.1. Active Coping Strategies

5.8.1.1. ‘Getting On With It’

This phrase was the commonest strategy, described by over half the participants, as a way of try dealing with the situations in which they found themselves such as coping with pain, adjusting to symptoms, learning how to live with an IAP and a stoma. Even though emotionally they could find things tough, ‘getting on with it’ was something they felt they had to do. Similar strategies were expressed as ‘dealing with it and ‘sorting it out’.

The presence of a stoma often elicited this approach. Faced with a new stoma that required attention, Dave described how he managed:

> *‘It took some getting used to like changing it and everything but after a week or so I was alright. I just got on with it’*.

Having a stoma also required specific routines that sometimes interfered with normal life.

> *‘If I wanted to go out with friends, sometimes I couldn’t cause of leakages or supplies...I was quite bounded in that way. I couldn’t really go out and stay overnight at places, always had to be home of a night to sort myself out with supplies and that...but I understood. I just got on with it’* (James)

Having lived with a stoma for a couple of years, Mariam described how she coped with accidents:

> *'Now that I don't have the leaks as often, I might have a little cry for two or three minutes, but then say right let's get another one on, it's fine'.*

Daisy is desperate to have her stoma closed, but until that happens, she also recognises she has to carry on:

> *'It gets me down but I just get on with it... 'I don't like looking in mirrors thinking like I've got a bag but at the moment that's just something that I've got to deal with.'*

She was one of two participants who recounted specific incidents in which problems with the stoma occurred in the presence of other people and how they managed. When with her friends on holiday:

> *'We went on the banana boat when we went Egypt last year... the second time we fell off...I hit the water so hard the bag just ripped from my skin and I just...went, I'm swimming to shore.. I just swam straight in...back to the hotel, sorted myself out and just come back but I do panic about things like that, especially when I'm at work and stuff but I just get on with it'.*
>
> *'I was doing this coaching course...and the...volleyball nets...have a hole this big, so...when I jumped, my bag got stuck in there, flew off...Everyone was looking, but I couldn't do anything, so I just took the bag and went to the toilet cause I had to sort it out'* (Humza).

'Getting on with it' for participants with a stoma encompassed three elements- self reliance, direct action and not dwelling on, or making an issue of things, whether they were part of everyday experience or an unexpected problem. This strategy was also used by participants with Crohn's disease who also had to cope with recurrence and the knowledge that this was something that they couldn't influence.

Paul described how he dealt with his disease and the pain of a flare:

> *'I've got this thing...and I have to take these drugs for it and I just get on with it...If ever I was in pain I just kind of grunted and got on with it'.*

Daisy had problems with nutrition and decided to take matters into her own hands:

> *'I said to them look can you just take (the nasogastric tube) out and I'll drink the drinks...Trust me I will drink the drinks...I just got on with it...it is hard. It's not easy for everybody just to do that but I thought well, I'm bloody doing it. I ain't putting up with this anymore'.*

Living with active disease, a stoma and a perineal wound that has remained unhealed for 10 years Lesley said

> *'I've had to deal with it for a long time I suppose...It is...my life so I just go on with it every day...I can't...change it at the minute so...I just deal with it'.*

Similar feelings were expressed by Helen.

> *'I have my days when I feel not brilliant and I get a bit upset about it cause I think if I didn't have Crohn's maybe I'd feel well all the time...Nothing's gonna take it away is it, so just get on with it really' .*

5.8.1.2. Information Seeking and Advice

Most participants sought and obtained information from a variety of sources and for a number of reasons- to help them to understand the situation, to reduce anxiety, for reassurance and to assist in decision making before an operation.

However, two participants simply looked forward to the operation and did not actively prepare. They subsequently described difficult postoperative experiences as they did not know what to expect.

> *'I didn't really have too many concerns about it at all. It was all pretty cool. The kind of main aspect was just getting fixed....I was kind of looking forward to what it would be like after the operation rather than the actual – you know...the whole thing itself'.*
> (Paul)

Mariam, who underwent stoma formation had relatively little time to prepare because she was so ill, but had a similar approach. As she stated:

> *'I didn't really think about it...I was literally pleased that was going to be the day when everything was going to be so much better...that was my goal'*

With a lack of time to prepare, a focus on the outcome and the preparation she was given insufficient (see 5.6.3.1.), Mariam's postoperative hospital stay was stormy- physically and emotionally difficult; she developed fits, for which no organic cause could be found, and appeared psychosomatic. In total, she remained in hospital for five weeks after surgery, which is much longer than normal.

Paul described his first postoperative days as *'pretty horrible'* and with hindsight felt that it would have been good to know:

> *'...the grim reality of it. It's good to know what the low is going to be- you are sitting there and you can't move and you're boiling hot and this morphine's making me throw up and your stomach muscles are in tatters, so it really hurts'.*

Before an operation was the time when participants felt a need to find out about a situation they had not previously experienced, so that they could know what was going to happen to them.

> *'I was a bit worried about it and everything...I started reading about the operation on the Internet, finding out a bit more plus watching the videos as well... just go to You Tube and type in a right hemicolectomy it comes up... it shows the procedure very well...what they're gonna do to you...because pictures only explain a certain amount...'* (Rayhanul)

Other participants had mixed experiences with Internet information:

> *'I would advise everybody not to go on the Internet because that's the worst place. People on the Internet they only tell you the worst part about it and that will put you off'.* (Yasmin)

> *'I went on this web CD Forum...reading what other people are going through gives you that calmness. OK it could be much worse...They are going through the same things you are going through and some of them are strong'.* (Raina)

Rayhanul used the Internet, but also sought information from people who had previously had surgery:

> *'The main things that stopped me being afraid of it was just doing research on the operation itself and just reading all testimonials about people that have had it done in the past...Mostly it's 80% positive things that people say about it and their lifestyle after the operation...so that has made me feel very reassured... I was speaking to someone today in the clinic and they had it done recently and they just looked so happy. They said look, I used to be so scared but it's...the best thing that I've done. I feel so much better. Everyone has noticed a change in me...They've got the bag. They say it's only five minutes more in the bathroom...just nothing significant. I understand it doesn't really bother them and their lifestyle, so they made me feel a bit...better'*

Ruby, Yasmin and Humza (described in 5.6.1.2.) also valued the opportunity to talk to people who had similar experiences:

> *'They gave me some like internet interaction thing with other people that had Crohn's disease and I was like speaking to one girl on it...Speaking to someone who has exactly the same thing as you, that helps'* (Ruby)

> *'I met people in clinic and they just said to go ahead and get it done...you speak to doctors about it and you speak to people who have actually gone through it is two different things'.* (Yasmin)

Health professionals provided information about intended surgery (see also 5.7.4.2), worrying symptoms and treatment:

> *'If you have any questions you should ask them and you'll get them answered. Even if they're ridiculous questions you know someone will answer them for you and that should be sufficient for you...to stop worrying. That always helps. So long as you know what's going to happen'.* (Victoria)

> *'When you go to see any doctors write down what you want to ask because you hear a lot of things you don't want to hear...but there's more you need to know...When they say BUT that scares me and IF...(The surgeon) should break it down into little pieces'.* (Yasmin)

With recurrent disease and multiple previous operations, Helen is often anxious if she becomes ill and vigilant in case this marks the beginning of a flare.

> *'I'm always get scared it's gonna come back...and you're more cautious now. You look out for signs and stuff...I phone (specialist nurse) straight away...I want to check'*.

5.8.1.3. Positive Comparisons

These were widely used. Participants made comparisons between their state of health and what they could do before and after surgery, and between themselves and other people that they perceived as worse off than them.

Positive comparisons related to adjusting to a stoma have previously been described. In considering life before and after surgery, participants thought of it as having saved their lives, restored their health and improved the quality of their lives (see sections 5.5.1.4.1. and 5.6.1.) This affirmation can be a continuing process. Two years after surgery, Mariam says:

> *'At night I still think about it...I go through what happened and whether it was worth it. That's the only way I can keep myself confident that I did make the right decision to have it done...When I think about what I was able to do before and now it's a huge difference, a lot to do with me having this operation, and I'm so grateful for it because I think it's definitely given me my life back...I had my birthday a few months afterwards, and actually being able to go out with my friends...I think that was the turning point for me'*

Positive comparisons were also made between themselves and people with and without the disease. With her Crohn's confined to the perianal area, Mia says:

> *'I've not even got it as bad as what most people have. Some people are a lot worse off...That annoys you as well, cause sometimes you just want to feel sorry for yourself, and people keep saying other people have got it worse than you...I know that and I feel sorry for them'*

Two participants compared themselves to other family members. With a stoma, Humza felt he had an advantage over his brother:

> *'I've felt much better like this although some people have diarrhoea* problems... *especially my brother. He has a lot of that stuff so I can go ha ha ha. In that way I'm better than him'*.

Helen described two family events in close succession which led her to reappraise her situation.

> *'My dad...had a heart attack...my granddad died...There's a lot of people worse off than me. That's what I think all the time...You've got (a stoma) for life basically but there's still people worse off than me. I can do things still, still have children...Once my dad had the heart attack...I thought...anything could have happened really and I would have still been here...still would have had (my child)'.*

However, in contrast, Bernice made negative comparisons between herself and her friends:

> *'They have an easy going time of it. They don't have any problems'.*

5.8.1.4. Self Assertion

Two female participants related examples of self assertive behaviour when they took charge to help them to cope. Daisy was self assertive with meeting her nutritional needs (see section 5.8.1.1.) Victoria told of her experiences when she was eleven and her stoma was constructed. There was no paediatric stoma nurse and one who saw her preoperatively:

> *'...was used to speaking with...old men. I was asked to speak to this stoma nurse afterwards and they ask you to speak to a psychologist and all that kind of thing and I just turned round and said that...I was fine, that I would cope with it myself'.*

5.8.1.5. Maintaining the Right Attitude Towards Surgery

Having lived through the experience, participants identified how a positive attitude helped them through sometimes difficult times. Many of these comments related to the work they had to do inside themselves to cope with their experiences, and demonstrate an emotional maturity that had either developed before surgery, or that they developed as a result of it.

> *'It was very nerve wracking but I dealt with it quite well...they said I adapted really well to it...I've been quite chuffed really...At the beginning I was very fragile. The first operation made me a lot stronger in myself after getting used to (the stoma) and it made me the person I am today...I was always positive'* (James)

Dave found his confidence diminished when he had his stoma. He described how he responded to this:

> *'As long as you don't let it get to you and you just work on it you recover so much quicker...Don't worry about it. Just take it as it comes. Don't panic about it and it'll all go fine. Just push yourself forwards. The more you worry about it, the more you get stressed out over it. Just don't. Just crack on with it and you'll be fine'*.

Keeping rational thoughts, avoiding panic and stress were themes repeated by other participants. Victoria said:

> *'You have to depend on yourself a lot but...as long as you're pragmatic you help yourself. If you get more stressed about things that are possibly never gonna happen you make yourself more (so).'*

Sam, who had had a difficult and uncertain time following surgery summarised how he coped with this:

> *'Be prepared for anything that happens...Try to keep your hopes up...Just keep thinking positively...If you think about things rationally, you'll get through a lot faster'*

5.8.2. Helpful Self Protective Strategies

5.8.2.1. 'Dress to Impress'

Although other female participants talked about appearance and clothing, Daisy appeared to use dress and appearance as a strategy to improve her self esteem and reduce the psychological impact of her stoma. While some other participants worried about people finding out they had a stoma, she appeared to view this almost as a challenge, especially in places like nightclubs, where she was among her peers.

> '*I wear anything I want....I go out in the skimpiest outfits like in the night and no one would look at me and think there's anything wrong with me and I think that makes it a lot easier...people look at me and speak to me and think I'm normal'*.

5.8.2.2. Distraction

Distraction served to help some participants to cope when they were feeling low. This was sometimes provided as an extension of the support given by family and friends described previously.

Having had two operations for perianal problems and postoperative pain uncontrolled by medication, Ruhana said:

> *'What you need is people distracting you, people in front of your face, people talking to you about other things going on. I think the biggest thing to have is people around you, cause once you're alone the pain's just gonna be there and that's all you're gonna feel'.*

Daisy found that socialising with her friends helps when she is feeling low.

> *'I get down. I can be crying one second and up the next and that's why I go out with my friends on a night out and we dance and we... have drinks and like some shot that we do...that's when I just...feel normal'*

In almost a year spent at home with a stoma, Rob described how his parents worried about how upset he was. They came up with a solution which helped him.

> *'We got a dog...That was the only time I went out. Went and got my dog for my eighteenth birthday... You have to focus on him...You have to look after him. You still thought about it but you think about him more'.*

He still didn't go out much, just with his father to the end of the road when he exercised the dog, but he got involved in house training and looking after the puppy and it took his mind off his situation.

Distraction became a form of displacement activity for the grief of one participant who was going through a distressing time in many areas of her life, with multiple surgery, the loss of her unborn baby, relationship and work problems.

> *'I don't like being left on my own because if I'm left on my own I get tearful and I start thinking about things...I've become like an obsessive compulsive about cleaning...I've got to clean to keep myself occupied. I know it drives (my partner) nuts...My mum usually rings me if I'm on the train but if nobody rings me or...people that I talk to...they're not on the train I've been getting really tearful, cause I just keep thinking about what I've lost'* (Mia)

5.8.2.3. Putting on a Brave Face

Lesley described her life, with a stoma, multiple operations and chronic wounds as '*hard'.* However, she often didn't disclose this to other people:

> *'I'm quite able to cover up how I'm feeling ...If someone says how are you and I'm not so great I'll say yea I'm fine anyway...so I'm pretty good at putting on a face'.*

5.8.2.4. Resignation

Two participants described how they were resigned to certain things they experienced, about which there was nothing they could do. Ruhana talked about the inevitability of pain after an operation.

> *'The thing is, the things that happen to you after are things that have to happen. There's nothing that can ease it. It's just that- be ready for the pain and having to know be ready...after the operation'.*

Paul talked of the first days after his operation.

> '*I just didn't really feel great at all. Just kind of sitting there waiting for it to be over'.*

5.8.2.5. Emotional Release

Participants used emotional release when they felt overwhelmed by their feelings. There was a difference in the way that male and female participants used this strategy. Young men described single episodes associated with specific events, such as when Rob threw a chair and stormed out of a consultation in frustration (see 5.5.1.3. above). The young women who described emotional outbursts used them repeatedly and although they occurred mainly with family and friends, they could also do this in the presence of health professionals.

After emergency surgery, postoperative complications and a slow recovery, Sam said:

> *'Most recovery's about five days so that was what I was expecting...but because of how weak I was prior to the surgery it took a lot longer than that. (It) frustrated me really really badly...did affect me emotionally as well...so I did get a bit upset about not being able to recover fast enough. I feel a bit embarrassed about feeling so emotional about it but there was that one night that...it really did get to me and I let out a lot of emotions which is a new experience for me'.*

A combination of physical symptoms and negative thoughts give rise to Ruhana’s emotional outbursts.

> *‘All this pain. All this slowing down, it can make you feel depressed...you think there’s people out there and there’s nothing wrong with them...and then you kind of sit there thinking that there is something wrong with me...It can affect you. You can have those feelings where you’re going through a lot of pain and...you start taking it out on other people like I do’.*

Daisy described how she used to be:

> *‘I had an attitude when I was younger...I didn’t care what I said to people. I used to have a go at my mum all the time...my nan used to come and see me, I’d be like what are you doing here. Don’t want you here. Just want to be left on my own’.*

Now, with a life that has been interrupted by the need for frequent treatment and multiple previous operations, she feels frustration and this gradually accumulates. She expresses this frustration to family members and to health professionals.

> *‘I’ve had so many surgeries. I’ve...had the colostomy bag. I’ve had that redone again...It prolapsed so I had to have it restitched back to my skin. It gets me down all the time coming in and having my throat stretched cause I’m the only person has that in the whole of bloody England...There is times probably about once a month or once every couple of months I get really down and have...a massive outburst like I did today.’*

Mia uses this strategy with her partner and mother when they try to give her advice and get her to seek treatment.

> *‘I know they mean well and I understand that they are right in the sense that I do need to get on with it and...I do need to go in hospital and if it means having surgery...I’ve gotta do it. So I know they’re right but that doesn’t stop me getting frustrated with them...I think that they do help...but most of the time I’m just shouting and screaming telling them both go away’.*

5.8.3. Unhelpful Self Protective Strategies

5.8.3.1. Ignoring and Avoiding

Participants used these strategies to avoid recognising symptoms and/or the need for surgery, or to deal with difficult circumstances afterwards. Some acknowledged that this may have given rise to more difficulties that they had to contend with later.

Not wanting surgery and convinced he didn't need it, Olu would not think about it.

> *'Briefly it kind of crossed my mind but I didn't really think about it too much... I never really thought of surgery that was something that was going to happen to me anyway. I just put it to the back of my mind...Ain't gonna go. Not gonna have it'.*

Olu was fortunate that his condition did improve so that an operation was not necessary. Rob coped with his temporary stoma by never going out. *'I just stayed in till it went that was about it'*. Using this strategy with symptoms, however, can result in worsening disease and a more difficult operation. Mia has had three operations for perianal disease. With the second, she ignored the need for surgery so long that she developed septicaemia . With the third, she was so ill that without an operation she would have died, but she still says:

> *'I try to ignore it. It's like this recent one. I knew I had to come in, but I was putting it off... My partner does tell me off for that and my mum... cause they're like come to terms with it. I know they're right but you still think it's not you that's going through it. It's me and if you was in my position you'd be doing the exact same thing. Be ignoring it as much as I am because you don't wanna go in...It'll go away. It'll disappear'.*

Fazeel could also recognise the signs that he was relapsing and delayed seeking medical help, but had sufficient knowledge of his illness to know when to face up to it.

> *'Sometimes I might ignore it...feign ignorance...but when it comes to a point where I know this is serious, I usually end up running back to Dr _'.*

Daisy developed perianal disease as a young teenager. Looking back, she said:

> *'I went on for two years not showing them my bum not talking about anything and it didn't get me anywhere. I think it got me into a situation that I couldn't get out of'.*

In the end, she knew her disease had progressed so much that she had no choice other than an operation.

Ignoring was also a strategy used by some participants before the operation and to cope with an unpleasant situation afterwards.

> *'I didn't really think about what it would be like. I kind of...thought about the actual operation itself...That's all I really thought about'.* (Paul)

Victoria and Yasmin recollected their reactions to a newly formed stoma:

> *'It was a good three weeks before I looked at anything, cause I didn't want to see what it looked like'.* (Victoria)

> *'When I first had my stoma it was a bit difficult for me...I didn't look at it. I didn't want to touch it'.* (Yasmin)

Avoiding could lead to more physical problems, but not dealing with the situation also resulted in emotional difficulties for Lesley:

> *'I got to a certain point and just ended up...not sort of being able to cope quite every day and I think it was just because it was the emotion that ...I should have had when I was little...just catching up, me realising certain things'*

5.8.3.2 Behavioural Disengagement

Both Rob (see 5.8.2.2.) and Bernice demonstrated this behaviour. Bernice saw her friends less than usual, went out very little, didn't talk very much about her situation to anyone and did not do very much while she had the stoma:

> *'I don't have nothing to do...I stay in my house most of the time...I can't really do anything anyway because I have to consider the stoma bag...I watch TV or browse the Internet...I am just trying to pass the time'.* (Bernice)

5.8.3.3. Wishful Thinking

Three participants described wishing that things were different. Paul was interviewed in the early postoperative period following major abdominal surgery. He had not given any thought to what his postoperative experience would be like and described what had happened to him:

> *'The first couple of days after the operation, they were pretty horrible...I was in a...fair bit of pain... I've been strapped up to...drips and the morphine drip and I had a catheter in as well and that's a bit psychological, it's like...ball and chain...they're trying to get me to drink water and I didn't want to and yesterday they wanted me to eat food and I...had no appetite so really want to hibernate for three weeks and wake up brand spanking new but obviously I can't '*

Two other participants expressed the desire to be other than they were, although their desires were not congruent with the reality of their situation. Daisy has been told that further surgery isn't an option as she has active disease that is not well controlled but she still wants to have her stoma reversed and will not recognise that, for the foreseeable future, it has to remain.

> *'I just wanna keep going on, get all these little problems sorted out and then, hopefully, eventually get the bag off... even if it is just for a year...If I can just keep myself well and everything just clears up then I'll just be so much happier... I've got more disease there but it does go and then it comes back...I just feel like isn't there anything else they can do. There must be something else'*

Mia is non compliant with her diet and medical treatment, and avoids having surgery. These actions are incompatible with her greatest wishes.

> *'My biggest thing is that I just wanna be normal. I just wanna get on with my life... I'd love to be normal and I think that's why it puts me off coming in here...I'd...just love to have a normal life. I'd love to get better'*

5.8.3.4. Self Blame

Only one participant used this strategy and she repeatedly attributed the cause of unhappy events in her life to herself. Describing how she had to have surgery when she was pregnant, Mia was told that if she had an operation the baby would probably not survive but she would not survive without it. She was advised to think about the options, which involved terminating her pregnancy.

> *'So me and my boyfriend had to come to a decision on what to do...I blame myself for that because it's my fault and I know how much he wanted to have a baby...but I know it wasn't the right time but that's my fault because I don't...do as I'm told, and I could have got better a long time ago. We've not been the same together ever since it happened and I put that on me... I know he's really depressed at the moment...and that's partly my fault as well'*

Table 5.5 summarises the factors that helped and hindered transition related to Strategies.

STRATEGIES			
HELPED		**HINDERED**	
Active	'Getting on with it'		
Active	Information seeking and advice		
Active	Positive comparisons		
Active	Self assertion		
Active	Maintaining the right attitude towards surgery		
Self protective	'Dress to impress'		
Self protective	Distraction		
Self protective	Putting on a brave face		
Self protective	Emotional release		
Self protective	Resignation		
		Self protective	Ignoring and avoiding
		Self protective	Behavioural disengagement
		Self protective	Wishful thinking
		Ineffective	Self blame

<u>Table 5.5: Summary of Factors Related to Strategies that Helped or Hindered Transition</u>

There was a wide variety of strategies that participants used to prevent, or cope with the experience of having an operation and living with the consequences. Some participants described multiple things that they did to help them to cope. 'Getting on with it' a combination of direct action, self reliance and not making an issue of things was the coping response most commonly used. This and information seeking and advice were very practical strategies which acted to directly alter the situation. They also frequently did cognitive work in the form of making positive comparisons and maintaining the right attitude towards surgery. This included thinking positively, not panicking and maintaining rationality when things got difficult. Ignoring and avoiding which sometimes extended to non compliance, was the most frequently used strategy to manage stress which involved not directly engaging with the problem and was a form of self protection but for the participants in this study who used it, it tended to result in a worsening of their problems. Emotional release was a strategy used differently by male and female participants, but in both genders was usually cathartic. Other self protective strategies, which appeared to be used when the situation could not be changed were distraction, behavioural disengagement, wishful thinking, resignation and putting on a brave face. Very positive strategies, used predominantly by one participant, were self assertion and 'dressing to impress'. Most participants used a combination of active and self protective strategies.

5.9. PATIENT PORTRAITS

The following section summarises the stories of three participants, their individual transitions through surgery and the stage each participant was at in the surgical transition at the time of interview. The patient portraits demonstrate the effectiveness of the Transition framework (Goodman et al, 2006) in tracing a patient's individual surgical experience, determining the stage they have reached in the transition process and the factors that helped or hindered them in that transition. Each has been chosen to illustrate contrasting experiences and to highlight the effect of multiple influencing factors on the patient's journey through surgery.

5.9.1. Rania: Example Of A Patient Moving Out

Now aged 24, diagnosed with CD, this young woman had two perianal operations when she was 23, the first to drain a perianal fistula and insert a seton, and the second a few months later to replace the seton.

She described a situation where her symptoms worsened until her life was greatly affected:

> *'It kind of got worse and then I got a fistula and I needed to have surgery done. I was in a lot of pain I couldn't really go out or walk that well. The thing is I was in a very bad state at that time. I would have agreed to anything'.*

Rania prepared herself by learning about the operation and visiting a website where other young people with IBD shared their experiences. The website helped her to realise that other young people had more severe problems and coped with them:

> *'I did a lot of research myself so I knew there were like two types of seton and I knew that mine was going to permanently be in there because it wasn't the tight type of seton. ...You realise these people (on the Website) have a lot serious problems, much worse than yours and that kind of gives you relief. Because in real life you may not meet anybody with CD but reading (that) other people are going through the same things you are going through and some of them are strong'.*

She recovered from her surgery but the seton was difficult to live with:

> *'Unfortunately the first one they put in it was a different material and it wasn't very comfortable at all and then I had to have surgery again and a new string in... I'd had improvement but it didn't feel comfortable. I told myself it was normal but it wasn't. The thing is I took time out of my studies and everything so I wasn't doing anything anyway. The second one was better. After the first week when I wasn't doing very much I was more comfortable. The pain was a lot better. It was easier to handle'.*

She had a lot of support to help her through the experience and enable her to resume a normal life:

> *'I think my family were more strong for me, so they never really showed any worry. They were always very positive and encouraging. I talk about my surgery with my close friends... my family they said we're not going to push you to anything whereas with my friends they encouraged me and I think if they hadn't done that I would have not have gone back to uni'.*

The surgery has made positive changes to her life and she perceives it as beneficial:

> *'I don't know if it is the seton but generally my health has been a lot better. The thing is I couldn't eat anything ...but now... cause I'm well I'm going out more and when I go out I eat whatever's on the menu. A year down the line, it doesn't affect me as a person because I see it as relief because I knew how bad it was a year ago. I see it as a good thing. Definitely. I don't really know if I would be happy to have it there forever but for now I am cool with it'.*

INFLUENCING FACTORS FOR RANIA	
HELPED	**HINDERED**
Disease out of control before surgery	Complications
Surgery perceived as positive	
Better life after surgery	
Previous experience of surgery	
Appropriate preoperative preparation	
Preoperative information	
Parental and friends' support	
Positive attitude	
Positive comparisons	

Table 5.6 Factors that Influenced Rania's Transition through Surgery

Table 5.6 summarises the multiple helpful factors that facilitated Rania's transition through surgery; she prepared for it in ways that were helpful to her, could perceive the positive changes her operations had made to her life, received positive support from multiple sources and had a positive attitude that helped her to cope. Although she had to have further surgery, she saw her operations as beneficial. She knows that her CD is not cured but she is no longer controlled by her illness and, feeling well, is able to live normally, having successfully completed the transition.

5.9.2. Bernice: Example of a Patient Moving Through

Bernice is 19 years old and has had three abdominal operations. Diagnosed with CD, she underwent an ileocolic resection and end ileostomy with a mucous fistula in 2010 when she was 18. Later that same year, she underwent an anastomosis to join the two ends of the remaining bowel together, but because the operation was difficult her stoma was not closed. Shortly after her discharge she was readmitted after developing an anastomotic leak with an abscess, which required drainage.

Although none of the medication Bernice had been taking was effective, she and her mother were reluctant to consider surgery at first, but gradually accepted that this was the only solution for her symptoms:

> *'My Mum didn't want me to do it at all. She wanted further scans to confirm that I definitely needed surgery and I agreed with the same thing cause I didn't want surgery myself... I didn't want to but it was something to make me feel better really. In the long run I'll be better so I thought I have to do it. My Mum came around as well. It was the only solution. The Infliximab wasn't working. Nothing was working...I had to take days off and they became weeks and months... I didn't finish college because of (my disease) and I didn't get to go to uni or anything.*
>
> *'I didn't really want a scar on my body. A nurse informed us it was going to be a keyhole (operation) but ... the day they did come and speak to me they was telling me how they was going to open me up... Me and my Mum was very shocked but we had no choice really just to do it'.*

However, her first operation was very difficult and she was given a stoma to allow the bowel to heal which she was not expecting:

> *'Even after it I was really bad. I was sick all the time. I couldn't get out of my bed. I couldn't do nothing for myself and it took a long time to recover... (Before my first operation) I didn't like the thought of a stoma at all...I still don't like the thought. I was expecting not to have it. I see the nurses changing it but I didn't know what it was really. And then eventually I asked the stoma nurse who came in what is that... Then I realised they obviously gave it to me and the doctors said to me it won't be as long as six months so I was thinking to myself six months is not a long time...and you'll be better afterwards. I didn't know there was a possibility of me having the pelvis break down and all of that and feeling so ill after the surgery. I just didn't think that would happen. I didn't think I would be having the stoma for so long. I've had it for longer than they told me I was going to have it. Nearly a year'.*

Several months later, Bernice looked forward to her second operation which was to reverse the stoma:

> *'(When I came in for my second operation) I had thought the stoma was going to be gone so I had planned things like going back to work again and I was going to go on holiday early next year. That surgery was meant to be the happiest. Then I realised the stoma is still on me. They said I had to have it. After that I felt ill in hospital before I went home but I don't think they thought anything of it... Then I phoned the IBD nurse and she said come into A and E and then they admitted me...They said my pelvis broke down and I'd got a collection and I had to stay in hospital for that. Many things I wanted to do got put back and the wait again. It ...delayed everything again. The doctor was telling me its only two months. But the stoma nurse said, don't expect anything this time. Don't have your hopes up because it could be the case where I have to have the stoma bag for six months'.*

Bernice has found life with a stoma hard:

> *'It kind of interferes in work life, social life, stuff like that because there's a lot of care you need to do really. There may be leaking, it needs changing a lot and there's time when there's nothing in it but too much air so you have too much caring. It takes a while to do. I don't like my appearance. I'm not a person that likes being skinny... I look in the mirror and I go oh my God I look ill... I don't like (the) big scar. My clothes don't fit me and stuff like that. (The stoma) limits my clothes as well'.*

Her parents also found the situation difficult:

> *'Surgery didn't turn out as expected. Shocking for (my parents) ... They had high hopes and it was just like crashed down. They prepared food for me and stuff and asked me if I needed any help. General care basically when I came out of hospital. They know I am just irritated with the stoma and I don't like it and I am saying I wish I didn't have the stoma bag'.*

Bernice describes a life of uncertainty and now she has lost some trust in the surgeons:

> *'I don't have a plan of what's going to happen.. They say things. I know that now they say things and it don't necessarily happen. I can't do anything that I want to do but I'll just have to get over it... I keep things to myself. I will wait till the stoma is gone. Stay in the house. I prefer that'.*

Her past experiences have left her feeling negative about the surgery and she has low expectations:

> *'Every time I've had surgery I've come back with something I don't want. I would say don't expect anything that good to come out of it. Obviously in the long run it will be good for you but certain things that you might not want you might get'.*

INFLUENCING FACTORS FOR BERNICE	
HELPED	**HINDERED**
Disease out of control before surgery	Complications
Surgery initially perceived as positive	Negative experience of previous surgery
Specialist nurse	Stoma
	Negative body image
	Lack of information
	Uncertainty
	Lack of trust in doctors
	Parental attitudes
	Behavioural disengagement

Table 5.7. Factors that Influenced Bernice's Transition through Surgery

Table 5.7 shows the factors that affected Bernice's transition through surgery. Most particularly, the development of surgical complications hindered her progress. Her life continued to be restricted as she waited out the time until she could have the stoma closed, feeling unhappy about the stoma, her scars and her body. Although her parents gave her practical help, she felt their concern and disappointment and kept her feelings to herself. Her surgical experience was one of continuing uncertainty. She began not to believe what she was told by the surgeons because they appeared to give her false hope, but the specialist nurse appeared to be more honest. Not surprisingly, Bernice was stuck in the transition, dealing with the aftermath of two unsuccessful operations and unable to Move Through until her stoma was reversed.

Bernice eventually had her stoma closed five months after the second operation. Four months after her last operation, her bowel function was normal, she was asymptomatic, had gained weight and was beginning to resume a normal life.

5.9.3. Yasmin: Example of a Patient Moving Out

Yasmin is aged 20 and has UC. She had a subtotal colectomy aged 18 and several months later had the stoma refashioned because of complications.

She did not want to have the first operation, but with worsening symptoms decided to have it with the help of her specialist nurse:

> *'Before my first surgery I ran away. I went back to Pakistan because I was afraid to have my surgery...When I got back my life is still as bad as it was before. There's nothing I can do to stop this...I said Mum and Dad it's time that I just do it... I said I know it is going to be difficult for you as well but it is more difficult for me but if I have that support and I have that love ...then I'll be so grateful about it'.*

She described how she felt after she had had the operation:

> *'I was in hospital for two weeks... I knew afterwards it's going to be difficult. It's not just jumping out of bed...it's going to be painful... Then the physio came round the second or third day and I'm up on the fourth day. The more you are mentally positive towards it, the more better you will recover. If you keep thinking I can't do this or I don't want to do this that's how you're going to be...so you must think positive... When I first had my first stoma it was a bit difficult for me. I didn't look at it. I didn't want to touch it. And then I saw...the stoma nurses and they helped me quite a lot...If it wasn't for them I think I would still be having a nervous breakdown even till now'.*

The experience was different and much more positive than her expectations:

> *'Honestly I thought I would be an emotional wreck. I actually thought until the last stage is done I wouldn't go out of my house...but it was nothing like that. It was the complete opposite. Everyone has that bit of hope but they've just got to find it within themselves...I went away on holiday because my sister was getting married. I went away with the stoma and no problems...That's the life I wanted'.*

Even though she had a stoma and scars, she remained positive:

> *'After I had my stoma I started to wear loose clothing but only one size bigger with the dresses and the tops...I used to get so paranoid that you can see it or you can feel it. I don't know what to do for the first few months...but after that it was so much better. I don't care if no one sees it...(The) scars...don't bother me...So what if you've got a stoma, so what if you've had UC. There's so many people out there that's got cancer... they've got that limited time and that's it but whereas with us we can change it'.*

She received lots of support to help her to cope:

> *'My partner he was lovely... (He said) from the day you was diagnosed to today nothing's gonna change... (I was) Oh my God what's he gonna think when he sees me... I used to think what if he hugs me is it going to hurt... and I thought if we do go and have sex... he is going to see it and he is going to be put off, but he is nothing like that... At first I thought I didn't want to talk to nobody about it and I thought people were going to think it's disgusting...nasty. I spoke to my close friends about it and they gave me all the support they could possibly give'.*

Her experience with the second operation was very different from the first time. She also looked forward to having the next operation when she would have an IAP formed, but felt that her life was good even while she waited for that to happen:

> *'This time I think I recovered a whole lot better because I was prepared for it. The night before my surgery I'm all packed now ready to go... (With my ileoanal pouch) I will be looking forward to going through my back passage again if you like. I think that's all anyone with UC or CD would want- a life not living on the toilet, just puking up all the time ...that's all it used to be whereas now you feel alive, you feel more woken up, more energy...I just wake up wash my face and I'm out again, just do whatever I want to do'.*

INFLUENCING FACTORS FOR YASMIN	
HELPED	**HINDERED**
Disease out of control before surgery	Fear of surgery
Surgery perceived as positive	Complications
Better life after surgery	Lack of appropriate preoperative preparation
Specialist nurse	Lack of knowledge
Positive body image	
Previous experience of surgery	
Parental, partner and friends' support	
Positive attitude	
Positive comparisons	

Table 5.8. Factors that Influenced Yasmin's Transition through Surgery

Table 5.8 shows the factors that influenced Yasmin's transition through surgery. She was initially very fearful of an operation and actually tried to avoid it by leaving the country. However, her specialist nurse and partner helped her to come to terms with it. She found life with a stoma difficult at first but had a very positive attitude. The benefits she could see from the operation together with support from the specialist nurses, her partner and friends all helped her to adjust to the stoma. She maintained her positive attitude even though she developed complications with the stoma and had to have it refashioned. She felt that her previous experience of an operation had helped her to cope with the second. She even considered keeping the stoma and not having her IAP operation. She had a positive image of herself and was the only young woman with a stoma who was not bothered by body image issues.

Although Yasmin faces a further operation she has clearly Moved Out of her previous surgery, feeling well and happy and living a normal life.

The patient portraits demonstrate the influence of significant factors in helping or hindering the transition through surgery. Rania's portrait, in contrast to other young women in Phase 1 who had more than one operation for perianal Crohn's disease, shows that it is possible to have a positive experience, if multiple helpful influencing factors outweigh those that are negative. Bernice provides an example of a patient who had a difficult time transitioning through surgery. She underwent multiple operations, including stoma formation, with negative outcomes combined with numerous hindering factors. In contrast, Yasmin, who also had to adjust to a new stoma, perceived her surgery positively and was helped in her transition by multiple positive factors. The contrasting experiences illustrate the usefulness of Schlossberg's framework in assessing individual patients using the 4s system.

CHAPTER 6 – PSYCHOMETRIC SCALE VALIDATION

This chapter defines the constructs of pre-operative concerns, preparation for surgery, post-operative coping, and post-operative perceptions of surgery and describes the development of the Pre-operative Concerns Scale, the Preparation for Surgery Scale, and the Post-operative Perceptions of Surgery Scale. Evidence for the reliability of these four new scales as well as the standardised Brief COPE Scale (developed by Carver, 1997) is presented.

6.1. DETERMINING RELIABILITY

Reliability was determined using Cronbach's coefficient alpha (Cronbach, 1951), to assess the internal consistency of all measures used in this study.

High Cronbach's alpha coefficients between .70 and .90 indicate that the question items within a particular scale are internally consistent and accurately measure their intended construct. Low Cronbach's alpha coefficients between .10 and .60 indicate that there is a problem with the question items in that scale (for example, some question items may need to be revised or deleted to improve the reliability of the scale). Alpha coefficients ≥ .70 are the accepted minimum threshold for adequate scale reliability (Gliem & Gliem, 2003, Nunnally and Bernstein, 1994). However, to some extent .60 levels are acceptable for new scales (Robinson et al, 1991; Sekaran, 2000).

6.2 RESULTS

Table 6.1 (below) shows the internal consistency (i.e., alpha coefficients) for the quantitative measurement scales used in this study.

6.2.1. Pre-operative Concerns About Surgery Scale.

Internal consistency reliability for the Pre-operative Concerns about Surgery scale ranged from .37 to .76. The pre-operative anxiety, fear of surgery, and isolation in hospital subscales demonstrated adequate scale reliability. However, the post-surgery physical after-effects and post-surgery body image scales demonstrated low reliability, which may be explained by the small number of items (three items) in each scale. Statisticians recommend at least three question items for a valid scale as reliability tends to increase with more items in a scale (Jonason & Webster, 2010).

6.2.2. Preparation for Surgery Scales.

Internal consistency reliability for the preparation for surgery scales was reasonably adequate. The What Patients Did Scale yielded reliabilities ranging from .60 to .78; and the What Patients Did That Helped Scale, had reliabilities ranging from .52 to .77. Therefore, these two scales appear to measure their intended constructs, though in future research, revising or increasing the number of items in each scale might increase alpha to .80 or .90.

Table 6.1: Reliability of New Measurement Instruments

Constructs	N	Number of Items	Cronbach's Alpha (α)	Type of Reliability[3]
Pre-operative Concerns about surgery				
Fear of Surgery	120	3	.68	Adequate
Fear/Uncertainty	120	3	.62	Adequate
Isolation	120	6	.76	Adequate
Post-operative Physical After-Effects	120	3	.55	Low
Post-operative Body Image	120	3	.37	Low
What Patients Did To Prepare				
Conducted Personal Research	120	3	.75	Adequate
Spoke to Health Professionals	120	3	.78	Adequate
Spoke to Friends & Family About It	120	2	.60	Adequate
What Patients Did to Prepare That Helped				
Conducted Personal Research	120	3	.76	Adequate
Spoke to Health Professionals	120	3	.52	Low
Spoke to Friends & Family About It	120	3	.77	Adequate
Post-Operative Perceptions of Surgery				
Positive perception of surgery	120	6	.76	Adequate
Recovery of physical health	120	4	.78	Adequate
Psychological recovery	120	6	.79	Adequate
Body image perception	120	4	.81	Good

N=Sample Size

[3] Source: Gliem & Gliem, 2003 (p.88)

6.2.3. Post-Operative Perceptions of Surgery Scale.

Internal consistency reliability for the Post-operative Perceptions of Surgery Scale ranged from .76 (adequate) to .81 (good), with the highest reliability observed for post-operative body image perception. Considering this was exploratory research, these represent high alphas for a new scale, and indicate that the items within each scale accurately measured their intended construct. Nevertheless, this scale would also benefit from further revision in future research to increase alphas to .80 or .90, as is typically found for well-validated scales.

6.2.4. Brief COPE Scale (Carver, 1997).

Table 2 presents the reliabilities for the 14-item Brief COPE Scale (Carver, 1997). Internal consistency reliability of this scale for this study ranged from low (for acceptance, self-distraction, use of emotional support, and venting) to excellent (for religion). The low reliability of the self-distraction subscale (α =0.27) may be explained by the fact that those two question items appear to measure different things. For example, question 1 measured: 'turning to work or other activities;' whereas question 19 measured: 'going out, shopping, watching TV, reading, sleeping, etc.', to think about it less. The mean values for these items suggest that patients might have used more question 19 coping strategies (e.g., more leisure/rest) than question 1 coping strategies (e.g., less work-related activities). Finally, the negative alpha for acceptance subscale (α = -0.12) suggests those two questions did not accurately measure the construct of acceptance for respondents. Question 20 measured: 'accepted the reality of the fact that it had happened;' whereas question 24 measured: 'learned to live with it.' These coping responses are not necessarily the same thing, as one can learn to live with it, but not necessarily accept it.

Table 6.2: Reliability of Standardized Measurements

Constructs	**N**	**Number of Items**	**Cronbach's Alpha (α)**	**Type of Reliability**[3]
Brief COPE Scale				
Religion	120	2	.90	Excellent
Humour	120	2	.83	Good
Self-blame	120	2	.86	Good
Active coping	120	2	.68	Adequate
Denial	120	2	.73	Adequate
Substance use	120	2	.73	Adequate
Use of instrumental support	120	2	.73	Adequate
Behavioural disengagement	120	2	.68	Adequate
Positive reframing	120	2	.68	Adequate
Planning	120	2	.65	Adequate
Acceptance	120	2	-.12	Low
Self-distraction	120	2	.27	Low
Use of emotional support	120	2	.58	Low
Venting	120	2	.58	Low

Carver (1997) initially reported alpha reliabilities for all the new two item scales as acceptable, with an alpha value of 0.60, excepting Venting, Denial and Acceptance, which equalled or exceeded 0.50. Although the reliability of the Brief COPE scale has sometimes been questioned (Cooper et al, 2008, Hankins et al, 2013), it continues to be widely used in health care research, including with surgical patients (Schwartzer et al, 2005), those with CD (Knowles et al, 2011) and IBD patients with a stoma (Knowles et al, 2013a).

CHAPTER 7: CROSS-SECTIONAL SURVEY RESULTS

This chapter presents the results of the cross-sectional survey, which aimed to examine young adult IBD patients' perceptions of their transition through bowel surgery including initial reactions to needing the surgery, preoperative concerns, preparation activities for surgery, post-operative coping strategies, and post-operative support received. In addition, the chapter explores the best and worst things about the surgery, and IBD patients' post-operative perceptions of surgery. For clarity, the chapter is organised into nine main sections. Section 7.1 describes the response rate and sample characteristics. Section 7.2 reports respondents' initial reactions to knowing they needed surgery, 7.3 their main preoperative concerns and 7.4 preparation for surgery. Section 7.5 reports the main coping strategies used after surgery. Section 7.6 reports respondents' perceived social support. Section 7.7 describes the best and worst things about the surgery; and section 7.8 reports respondents' post-operative perceptions of surgery. Finally, Section 7.9 portrays the process of transition for three IBD patients as they move through the phases Moving in, Moving Through and Moving Out (Goodman et al, 2006).

7.1 SAMPLE CHARACTERISTICS

7.1.1 Patient Characteristics

Questionnaires were distributed to 158 young adult IBD patients who underwent bowel surgery in the NHS. One hundred and twenty completed questionnaires were returned (76% response rate). Table 7.1 (Appendix 18) profiles respondents by their patient characteristics, and Table 7.2 (Appendix 19) by their bowel surgery history. Fifty respondents were male (42%), and 70 were female (58%). Their ages ranged from 18 to 25 years; with 47% (n=56) aged 18 to 21 years, and 53% (n=64) aged 22 to 25 years. A young adult patient sample was recruited for this study, as no previous research has investigated young adult IBD patients' transition through surgery. All respondents had undergone bowel surgery for IBD, 6 months or less to 5 years ago, with or without a stoma. 82% (n=99) had a confirmed diagnosis of Crohn's Disease, and 18% (n=21) had a confirmed diagnosis of ulcerative colitis.

7.1.2. Surgical History

7.1.2.1 Number Of Operations

A total of 196 bowel surgery operations had been carried out on respondents, including 159 operations (81%) for CD and 37 operations (19%) for UC. Hence, the majority of operations were related to Crohn's disease. Most respondents had only one operation (60CD, 9UC) (58%), 35 had two operations (28CD, 7UC) (29%), and 11 had three operations (6CD, 5UC) (9%). No participant with UC had more than three procedures, but among those with CD, three participants had four operations (2.5%), one had 5 operations (0.8%) and one had 7 operations (0.8%). Therefore, on average, participants had 1-2 operations, with little variation in number of procedures (M=1.63, Mdn=1.00, SD=.961, range: 1-7).

7.1.2.2. Timing Of Operations

Most operations took place more than 2 years ago (*n* = 143; 74%), with 41 operations (20%) between 7 and 24 months ago, and 12 operations (6%) 6 months ago or less. Less than half the participants (n=52: 44%) knew they would need an operation more than a month before it took place (i.e., planned surgery). About one-third knew less than a week before (*n*=36; 30%) (i.e., emergency surgery), and the remaining 25% (n=30) knew from a week to less than a month (i.e., urgent surgery). Two types of operation were carried out only on patients with CD. These were small bowel resections with anastomosis (n=34; 17%) and perianal operations (n=43; 22%). However, the majority of large bowel resections with anastomosis were also undertaken for CD (*n*=25; 13%), as only 1 was done on a patient with UC. These operations accounted for 52% of all procedures. There were 65 (33%) operations involving stoma formation, 36 of which were in women and 29 in men. The most common operation was subtotal colectomy with temporary ileostomy (*n*=13UC, 6CD). Ten further procedures, all in CD participants, also involved a bowel resection with a covering stoma.

Fifteen procedures, all in CD participants, raised a temporary stoma only. Six procedures resulted in a permanent stoma (4CD, 2UC), and there were two stoma revisions. Twelve stomas were integral to an ileoanal pouch procedure (n = 9UC; 3CD). Only 3 ileoanal pouch procedures were carried out in UC participants without a covering stoma. Twenty seven other abdominal procedures were done, with the most common procedure stoma reversal (7UC, 13CD). Additional data revealed that nine participants (4M, 5F) had each had two stoma operations and four participants with a stoma also had a seton inserted to drain the fistula. There were 36 participants (30%) in total currently living with a stoma, 29 of which (11UC, 18CD) were intended to be temporary. Twenty nine of the perianal procedures involved seton insertion. 19 participants (4M, 15F) had one seton operation, three (1M, 2F) had 2 and one (F) had had 3. Of the 14 remaining procedures, 11 involved abscess drainage

7.2. PRE-SURGERY INITIAL REACTIONS

7.2.1. Initial Reactions To Surgery

Participants were presented with seven survey statements and asked to complete those which they felt corresponded to their initial reactions on hearing that they needed to have an operation.

Table 7.3. Initial Reaction To Surgery: Responses to Each Question

	Statement	No. of Responses	Per Cent
1	I welcomed it because....	54	23%
2	I thought it was the right thing for me because....	54	23%
3	I tried not to think about it because....	44	18%
4	I didn't want it because....	32	13%
5	I refused to have it because....	3	1%
6	I had no choice because....	46	19%
7	Other reaction	8	3%
	Total	241	100%

Table 7.3 shows the percentage of responses to each statement. Content analysis of the responses identified nine themes, which described their initial positive and negative reactions to needing surgery. Content analysis was chosen over other methods, as it is a very fast, theory-neutral method of coding open-ended question responses, and can be used to organise and reduce multiple statements into fewer content categories (Gray and Densten, 1998; Stemler, 2001), as Figure 7.1 shows. The table shows frequency of mention by respondents in percentages out of the total number of respondents (n=120) in each theme. The total is greater than 100% as many participants made multiple comments.

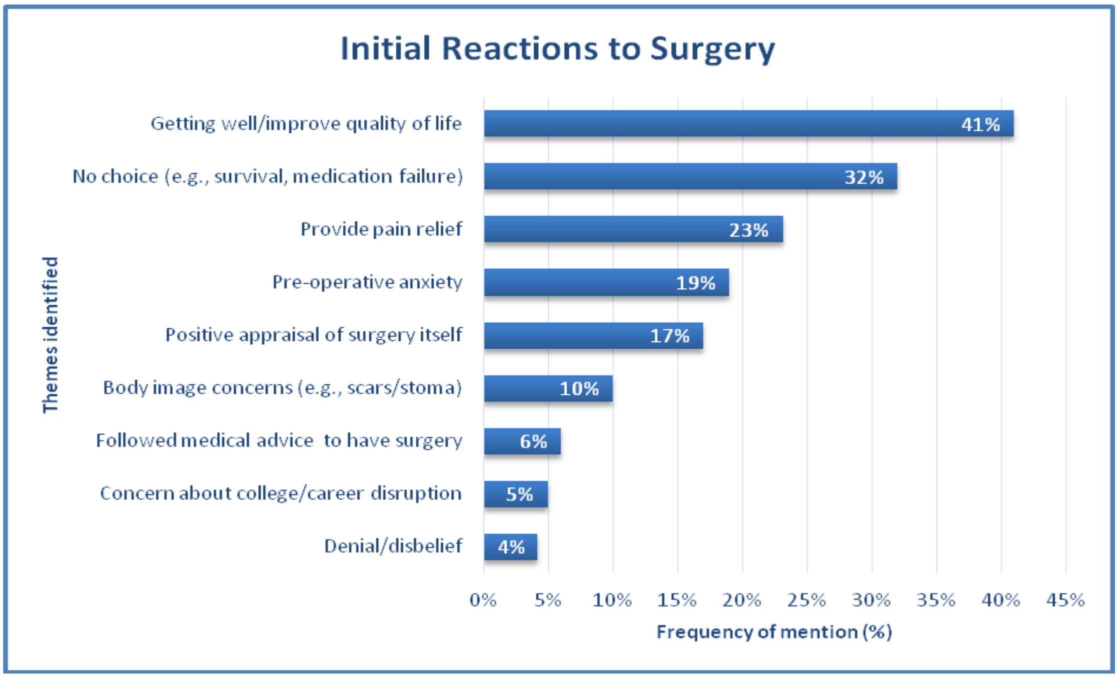


Figure 7.1: Content Analysis Themes for Initial Reactions to Surgery (n=120)

7.2.1.1. Initial Positive Reactions

The most common positive reaction was an expectation that patients would get well and improve their quality of life by having the surgerymentioned by 41% (n=50); as one respondent stated: '*I would be able to live a relatively normal life*.' Thirty two percent (n=39) of respondents felt they had 'No Choice.' As one respondent stated: '*They said I wouldn't survive without it.'*; these patients were either very sick or medication had failed. 23% of respondents' (n=28) indicated they expected that the surgery would provide the pain relief that they needed. Many had unbearable pain, for example: '*I was in a lot of pain and on a lot of drugs and they said it would make the pain stop,'* and *'I was in such pain it was unbearable.'* 17% of respondents described a positive appraisal of the surgery itself, for example: *'This promised an end to the medical drama that had been going on for more than a year*.' 6% of respondents described following doctors' medical advice to have the surgery, as the right thing to do: *'I was so ill the doctors said I had to have it immediately*'.

7.2.1.2. Initial Negative Reactions

Preoperative anxiety was the most frequent negative initial reaction for 19% of respondents. For example, they stated: '*I wasn't sure what it is exactly and I was really scared,' 'The potential complications were frightening,' 'They asked me for a decision but to be honest I didn't really understand what I was agreeing to.'* Surprisingly, at this stage, only 10% of respondents indicated worries about body image (e.g., getting the stoma bag, or having scars), as two stated: '*I was only twenty one and I thought the stoma wouldn't be well hidden,' 'I wasn't ready to have such a big change in my personal appearance.'* 5% of respondents described worries about possible career or college disruption, for example: *'I was worried about the impact it would have on my university studies as I had essays and exams coming up*,' and *'I was worried about time off work*.' Finally, the least frequent reaction was denial or disbelief in 4% of respondents, among those who felt they had to conceal their IBD illness, or believed that a stoma was for an old person. As two respondents stated: '*I didn't want to admit I had IBD*,' and '*I thought only old people had this operation and I thought it was disgusting*.'

Some participants expressed both negative and positive reactions. Table 7.4 (Appendix 20) summarises the nine initial reactions with definitions of codes and example quotations from the survey respondents.

7.3. PREOPERATIVE CONCERNS ABOUT THE SURGERY

7.3.1. Issues that give rise to patient concern

According to Pritchard (2009), just the initial idea of having surgical procedures can bring about very high levels of anxiety in patients. Figure 7.2 illustrates their main preoperative concerns.

Post-Surgery Body Image was the highest preoperative concern and included having a stoma. This finding suggests that practically every patient worried about getting a stoma, even though the risk of getting a stoma might be very low. It also shows that while body image was only the sixth initial reaction to surgery, once patients engage with what surgery really means to them, post-surgery body image comes right to the top.

Post-Surgery Physical After Effects was the second highest concern, which relates to patient concerns about how long it would take for them to recover, or about having complications, and being in pain after surgery.

The third highest preoperative concern was **Preoperative Anxiety.** Such worry and apprehension about the surgery may have arisen from both the present situation and personality traits (Tluczek, Henriques and Brown, 2009).

The fourth highest preoperative concern was **Fear of Surgery** itself. This rating is interesting because it suggests that patients are not really concerned about having an anaesthetic, or a part of them removed. It suggests their major fear is body image concerns.

Finally, **isolation in hospital** was the lowest preoperative concern, which suggests that having to spend time in hospital, missing college, work, family, partner or friends least worried respondents, who worried more about their body image, physical after-effects, and the surgery itself.

What is interesting about these results is that body image and preoperative anxiety were both common initial reactions and were still high concerns moving into surgery. However, there was a shift in patients' focus from the long term after effects of surgery, which dominated their initial reactions (e.g., pain relief, getting well), to their focus on the event itself, with new concerns emerging such as fear of the surgery itself, physical after-effects, and isolation.

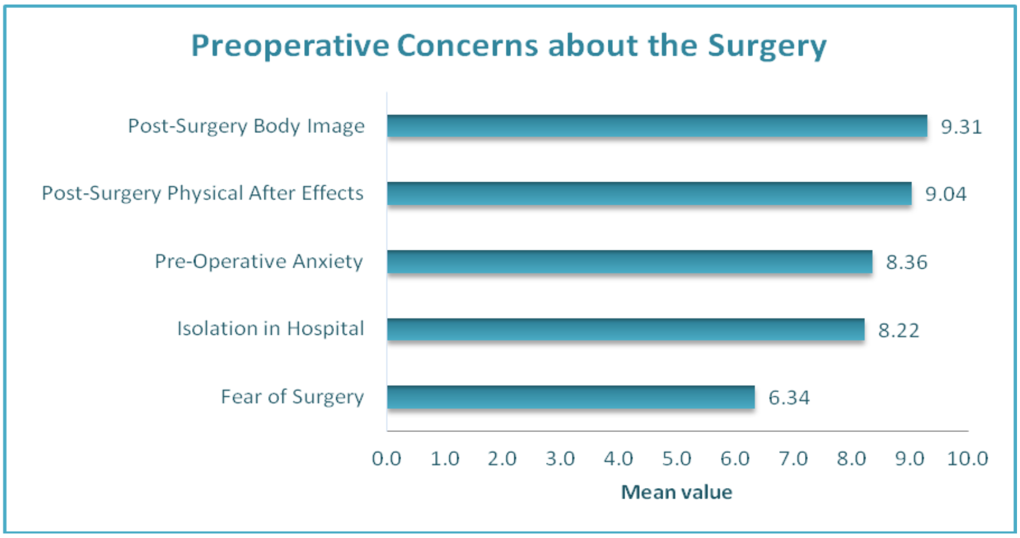


Figure 7.2. Mean Preoperative Concerns About the Surgery, by IBD patients, n=120.

7.3.1.1.Comparing responses across subgroups

Table 7.5 (Appendix 21) shows the mean preoperative concerns for the full sample and separately for subgroups (including gender, stoma groups, disease type, and timing of surgery). Post-surgery body image concern was significantly higher among females (p<0.01), patients who had a stoma (p<0.01), and approached significance for emergency surgery patients (p=0.064). Concern about post-surgery physical after-effects was significantly higher among females (p<0.05) and emergency surgery patients (p<0.05). Preoperative anxiety was significantly higher among females (p<0.01), and emergency surgery patients (p<0.05). Fear of surgery was significantly higher among emergency surgery patients (p<0.05). Finally, concern about isolation during hospital stay was significantly higher among females (p<0.05) and emergency surgery patients (p<0.05). These findings clearly show that preoperative concerns about the surgery vary based on the self and situation characteristics of the patient, with most significant differences observed between males and females, and between emergency vs. non-emergency patients.

7.3.1.2. Testing Association between Preoperative Concerns and Post-Operative Perception of Surgery

A logistic regression analysis was carried out using preoperative concerns as predictor variables and whether or not patients had a high overall post-operative perception of surgery as the dependent variable. A test of the full model using all predictors against a constant only model (Block 0) was borderline statistically reliable, $\chi 2$ (5, N=120) df= 9.62, p = .087, indicating that the predictor variables reliably predicted whether or not a patient had a high overall post-op perception of surgery. Nagelkerke’s R square is .109. The model correctly predicted 33.3% of respondents who had a low post-operative perception of surgery and 84.3% of respondents who had a high post-operative perception of surgery. Table 6 shows the regression coefficients, Wald statistics, odds ratios and the 95 per cent confidence intervals for the odds ratios.

Table 7.6: Logistic regression results in which whether or not a patient has a high overall post-op perception of surgery is predicted with preoperative concerns about the surgery

Variable	B	Wald	Sig.	Odds Ratio	95% confidence interval of odds ratio	
					Lower	Upper
Fear of surgery	-.010	.020	.886	.990	.860	1.14
Post-surgery physical after-effects	.070	.638	.424	1.07	.903	1.27
Post-surgery body image	.071	.729	.393	1.07	.912	1.26
Preoperative anxiety	**-.259**	**7.98***	**.005****	**.772**	**.645**	**.924**
Isolation	.063	.577	.447	1.07	.906	1.25
Constant	.893	1.615	.204	2.44		

* *p*<.05, ** *p*<.01. *N*=120.

The results in table 7.6 show that high preoperative anxiety was a significant predictor of having a low post-operative perception of surgery (p<0.05); with every one-unit increase in preoperative anxiety, the likelihood of having a high post-operative perception of surgery decreased by 33% (i.e., 1 – OR .772) [OR = .772, *p* < .01]. No other preoperative concerns significantly predicted whether a patient had a high post-operative perception of surgery. This result suggests that young adult IBD patients with high preoperative anxiety are much more likely to have a low perception of their surgery afterwards, than patients with low preoperative anxiety.

7.4. PREPARATION FOR SURGERY

Nine participants were unable to undertake any preparation because surgery was carried out as an emergency procedure. Two further participants undertook no preparation, recording in the free response section of the questionnaire: *'Just told myself it would be worth it to get it over and done with'* and *'Didn't even try to think. Wanted it over with'*.Table 7.7 shows the respondents' mean scores for the preparation activities that they did to prepare for surgery; and the preparation activities that helped.

Table 7.7: What Patients Did to Prepare and What They Did that Helped

	Mean (SD)	Mean (SD)	Scale Range
Preparation Activities	*What Patients Did*	*What Helped*	
Spoke to health professionals	**8.79 (3.58)**	**10.38 (3.48)**	3-15
Spoke to family/friends	5.93 (2.34)	6.35 (2.17)	2-10
Researched operation	8.22 (3.85)	9.83 (4.14)	4-20
Prepared yourself in other ways	3.19 (1.72)	4.00 (1.34)	1-5
Prayed about it	2.15 (1.60)	2.35 (1.51)	1-5

Table 7.7 shows the most frequent preparation activity was speaking to health professionals, which respondents also rated as their most helpful activity. The next most frequent activity was speaking to family/friends, which respondents also rated as the second most helpful activity. This was followed by researching the operation, rated third most helpful activity. The less helpful activities included preparing in other ways (surgeon drew a diagram, kept a diary, tried to gain weight) and praying about it. This finding is really interesting as it shows that what patients did to prepare was also what helped them most; and it shows that speaking to health professionals was the top preparation activity for most young adult IBD patients, and was the activity that helped them the most. Figure 7.3 illustrates what patients did to prepare versus what they did that helped.

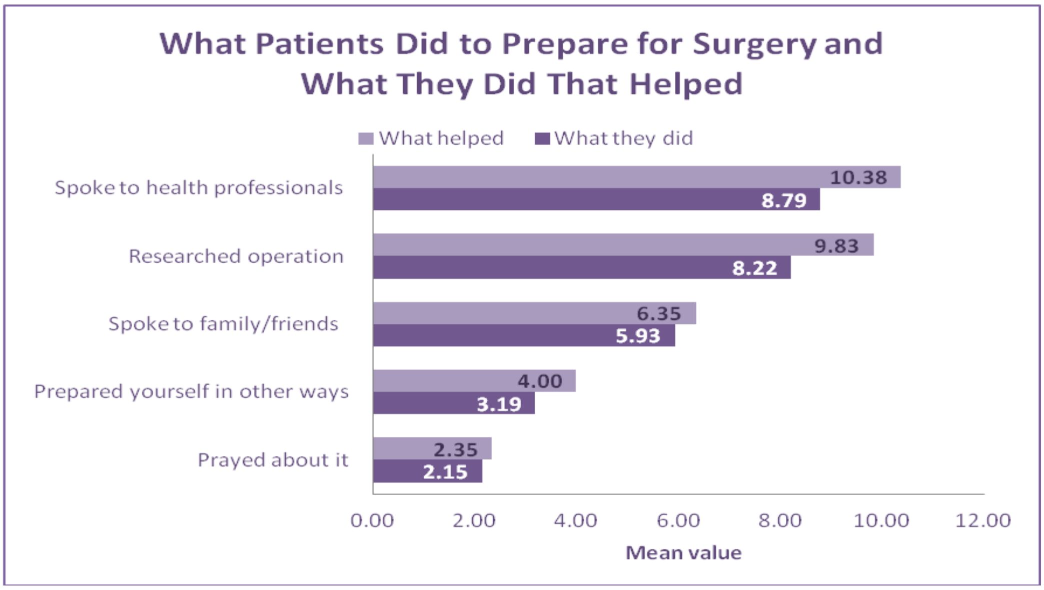


Figure 7.3: Mean Scores For What IBD Patients Did To Prepare Versus What They Did That Helped

7.4.1. The Top Five Most Helpful Activities That Patients Did To Prepare

Table 7.8 shows the top five most helpful activities that patients did to prepare for bowel surgery. The most helpful activity was speaking to the doctor, followed by speaking to family (not including friends), then speaking to the specialist nurse, reading written information about it, and speaking to the nurses on the ward. These results confirm that speaking to health professionals, particularly doctor and specialist nurse really helped young adult IBD patients.

Table 7.8: Top Five Most Helpful Activities to Prepare for Bowel Surgery, *N*=120

Specific Activities[1]	Mean	SD
Spoke to the doctor about it	3.89	1.25
Spoke to my family about it	3.72	1.23
Spoke to the specialist IBD and/or stoma care nurse about it	3.62	1.50
Read written information about it	3.15	1.34
Spoke to the nurses on ward about it	3.14	1.42

[1] Individual question items are derived from the 12-item ‘Preparation for Surgery: What Helped’ scale. Scale range: 1-5. Higher scores reflect more use of each preparation activity.

7.4.2. Testing the Effect of Preoperative Anxiety on Preparation for Surgery

The level of preoperative anxiety that patients experience might play a role in the preparation activities that they do to prepare for surgery. To test this, a median split independent t-test compared respondents with high preoperative anxiety (≥ median 8, n=64) and low preoperative anxiety (< median 8, n=51) in their mean preparation activities. Table 7.9 (Appendix 22) shows the mean preparation activities between high and low preoperative anxiety groups. Respondents with high preoperative anxiety were significantly more likely to speak to their family about it, and to pray about it, and to speak to the doctors about it at the $p<0.05$ to $p<0.06$ level.

7.4.3. Testing the Effect of Fear of Surgery on Preparation for Surgery

The fear of surgery that patients might experience may also play a role in the preparation activities that patients do to prepare for surgery**.** To test this, another median split independent t-test was performed to compare high fear of surgery (≥ median 5, n=69) and low fear of surgery (< median 5, n=47) groups. Table 7.10 (Appendix 23) shows the mean preparation activities between high and low fear of surgery groups. Respondents who experienced high fear of surgery were significantly more likely to speak to health professionals about it (p<0.01) including the doctor (p<0.001) and the nurses on the ward (p<0.01), and their family (p<0.01), and were significantly more likely to pray (p<0.001), as compared with patients who experienced low fear of surgery. These findings suggest that fear of surgery really does influence what preparation activities young adult IBD patients use to prepare for surgery. Overall, IBD patients with high fear of surgery tend to pray more, speak to the health professionals, and their family more to help them prepare for the surgery.

7.4.4. Testing the Effect of Surgery Timing on Preparation for Surgery

An independent samples t-test was performed to compare the mean preparation activities between respondents who had emergency surgery and respondents who had non-emergency surgery, as the timing of surgery may play a role in which preparation activities IBD patients use most. There was no significant difference in the preparation activities that emergency versus non-emergency surgery respondents did; and there was no significant difference in each groups' ratings of how helpful their preparation activities were. Hence, the timing of surgery does not influence the preparation activities that most young adult IBD patients do.

7.5. POST-SURGERY COPING

Table 7.11 shows the average use of 14 coping strategies from the Brief COPE scale. Carver (1997) states none of these coping strategies represent positive or negative ways of coping in themselves; that depends on the situation. For example, self-distraction could be viewed as a positive coping strategy immediately after bowel surgery, to help IBD patients take their minds off the pain. Table 7.10 shows that, on average, respondents used acceptance most to cope after surgery. This was followed by self-distraction, positive reframing, use of emotional support, humour, active coping, planning, and use of instrumental support, which can all be viewed as positive coping strategies that tend to reduce stress. Respondents used venting, behavioural disengagement, self-blame, religion, denial, or substance use less frequently. Overall, these results suggest that most young IBD patients used very positive coping strategies to help them move through their surgery and get well again.

Table 7.11: Mean Ranking of 14 Coping Strategies Used After Surgery, by IBD patients, *N*=120

Coping Strategies	**Mean**	**SD**
Acceptance	**8.45**	4.91
Self-distraction	6.60	2.20
Use of emotional support	6.56	2.46
Positive reframing	6.56	2.70
Humour	6.32	2.91
Active coping	6.02	2.46
Planning	5.57	2.50
Use of instrumental support	5.12	2.44
Venting	4.70	2.42
Behavioural disengagement	4.48	2.04
Self-blame	4.00	2.40
Religion	3.96	2.89
Denial	2.96	1.80
Substance use	2.63	1.64

Note. Higher scores on the Brief COPE Scale reflect higher use of each coping strategy.

7.6. PERCEIVED SOCIAL SUPPORT AFTER SURGERY

Social support is another very important factor for helping patients to move through and out of surgery (Moskovitz, 2000a). Table 7.12 (Appendix 24) shows the frequency percentage of perceived social support that respondents received from their parents, partner and friends after their surgery. In this study, the social support scale measured positive support (i.e., I received the type of support that I needed), and negative support (i.e., I did not receive the type of support that I needed). Table 7.12 shows that, on average, 81% to 91% of the respondents received positive support from the three support groups; although 9% to 16% of the respondents received negative support, suggesting that approximately 1 in every 7 respondents lacked support. The highest positive support, on average, came from friends (99%), followed by partner (91%), and then parents (84%). Notably, those respondents who lacked one source of positive support (e.g., from a parent), tended to also lack positive support from a partner and/or friends.

For further insight, Table 7.13 ranks respondents' perceived social support (based on the mean). This shows that parental support was lower, on average, than support from partner or friends, across all six social support categories. **Appraisal normalising** was the highest perceived social support, which helped IBD patients to feel normal about their surgery, and this was highest among friends. This was followed by **tangible practical** support, which was highest from partner and friends, and then **emotional distraction**, which was highest from the partner. **Emotional encouragement** and **informational advice** came next and mostly from friends who provided the highest encouragement, advice and information to help patients not to dwell on their feelings about surgery. Finally, partners provided the highest **emotional listening**, although this was the lowest type of support from all support groups.

Table 7.13. Mean Ranking Of Social Support From Parents, Partner And Friends Post-Surgery, *N*=120

Rank Type of Social Support	Parent Mean (SD)	Partner Support (SD)	Friends Support (SD)
1. Appraisal Normalising	7.52 (2.39)	8.10 (2.54)	**8.22 (2.42)**
2. Tangible Practical	6.50 (1.74)	**6.76 (1.85)**	**6.75 (1.77)**
3. Emotional Distraction	5.06 (1.45)	**5.62 (1.02)**	5.47 (1.18)
4. Emotional Encouraging	4.97 (1.36)	4.98 (1.46)	**5.07 (1.39)**
5. Informational Advice	4.82 (1.28)	4.98 (1.67)	**5.13 (1.29)**
6. Emotional Listening	3.67 (.743)	**3.80 (.558)**	3.66 (.738)

Note. Higher scores reflect more positive support. Figures in parentheses are standard deviations (SD).

Figure 7.4 clearly illustrates that the types of support are extremely similar from parents, partner and friends; though notably, perceptions of appraisal normalising from parents were lowest, suggesting that IBD patients turned more to their partner and friends after surgery, to feel normal and 'get their life back;' which is a positive sign that they were 'Moving out'.

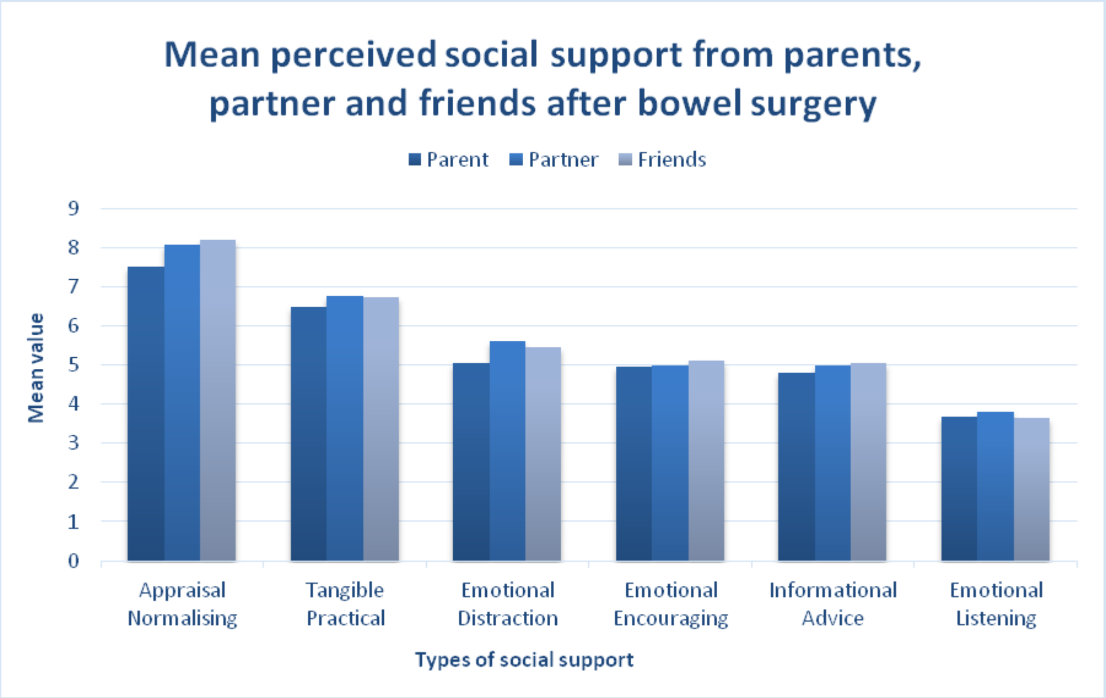


Figure 7.4: Mean Social Support Received From Parents, Partner, And Friends, N=120

7.6.1. Coping Strategies Used By Those Who Had And Those Who Lacked Support

The support variables were median split and three independent samples *t*-tests were performed to compare the coping strategies between those with high and low parent, partner and friends support, respectively. The results for coping strategies based on levels of parental support are shown in Table 7.14 (Appendix 25), as differences in parental support produced the most significant differences in coping strategies used.

Respondents with **high parental support** tended to use significantly more positive reframing, emotional and instrumental support, humour, and venting to cope after surgery; whereas respondents with **low parental support** tended to use more behavioural disengagement to cope after surgery.

Respondents with **high partner support** tended to use significantly more religion to cope after surgery (M=4.35, SD=2.87), than respondents with **low partner support** (M=2.71, SD=1.93), $t(33) = 2.13$, $p<0.05$.

There were no significant differences in respondents' use of 14 coping strategies between those respondents with **high versus low friends** support. This result suggests that the level of friends' support really does not influence IBD patients' use of particular coping strategies after surgery.

7.7. PERCEPTIONS OF THE WORST AND BEST THINGS ABOUT BOWEL SURGERY

Respondents were asked to describe what the three WORST and three BEST things about their surgery were. Content analysis was used to analyse these responses, which identified nine worst things, and ten best things about the surgery, as shown in Figure 7.5 and Figure 7.6. The percentages indicate the percentage of respondents out of the total number of respondents (n=120) in each category.

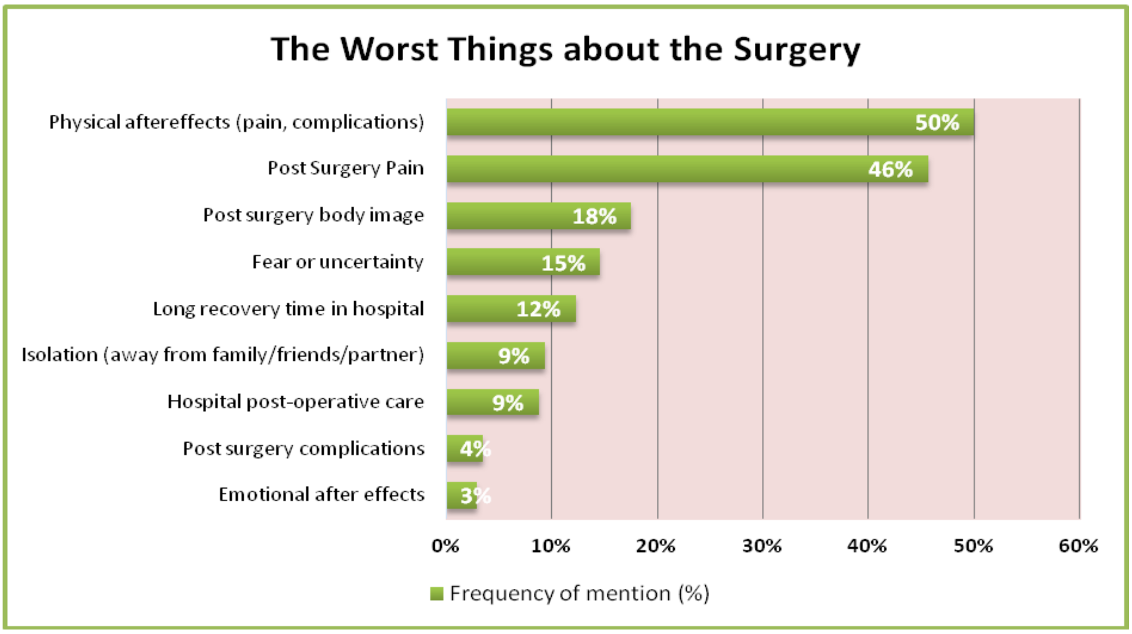


Figure 7.5: Worst Things About The Surgery, By Young Adult IBD Patients, n=120.

7.7.1.The Worst Things About the Surgery

Figure 7.5 shows the worst thing about respondents surgery was the physical after effects of surgery, mentioned by 50% of respondents, with references to:

> *'Having the drain in the abscess for a long period'*(Respondent 2.5)
> *'Loss of anal muscle control'* (Respondent 2.25)
> *'The amount of time it took to begin putting weight back on'* (Respondent 3.12).

This category included the second theme of post-surgery pain (46%), and the majority of respondents comments in this category related to that. As two respondents commented:

> *'Having to deal with more pain'* (Respondent 5.5)
> *'The pain was unbearable'* (Respondent 3.10).

The remainder of the comments in this category related to complications of surgery (4% of responses) and respondents wrote:

> *'The surgery in itself was not successful as in six months I was feeling unwell again'* (Respondent 5.51)
> *'Getting infection in wound caused prolonged recovery'* (Respondent 2.23).

The third worst thing about surgery was post-surgery body image for18% of respondents. Typical were references to:

> *'Adapting to how my body looks now and having to hide bag under my clothes.'*(Respondent 6.9)
> *'Adapting to having a stoma bag* - *ongoing problems, leakage etc.'* (Respondent 6.11)
> *'Scars. The way my body looks'* (Respondent 4.15)
> *'My scar being far bigger than normal due to complications'* (Respondent 8.28).

The fourth worst thing about surgery was the fear or uncertainty in 15% of respondents, which was also the third highest preoperative concern. Respondent scommented:

> *'Feeling scared about what was going to happen and what was happening'* (Respondent 3.9)
> *'ITU was horrible, dark, frightening'* (Respondent 8.2)
> *'Not knowing exactly what was involved'* (Respondent 7.3)
> *'Not having the procedure fully explained to me'* (Respondent 2.25)
> *'Being left not knowing what would happen next'* (Respondent 4.31).

The fifth worst thing about surgery was the long recovery time in hospital, for 12% of respondents. They wrote:

> *'Spent 6 weeks in hospital'* (Respondent 6.14)
> *'I was in hospital for such a long time – 6 months)* (Respondent 6.1)
> *'Feeling frustrated at the slow rate of recovery*' (Respondent 3.9).

The sixth worst thing about surgery was the isolation for 9% of respondents, and this also the fourth highest preoperative concern. For example, they stated:

> '*I felt lonely a lot*' (Respondent 4.9)
> '*Missing out on school, education and work form being ill'* (Respondent 4.20)
> *'It's hard watching your friends have lives while you're stuck trying to heal and get used to new plumbing'* (Respondent 3.4).

The seventh worst thing about surgery was the hospital post-operative care for 9% of respondents who stated:

> *'The nurses in the hospital didn't listen or understand'* (Respondent 2.9)
> *'Lack of help with the stoma from regular ward staff'* (Respondent 5.13)
> *'The aftercare wasn't great at the hospital I was in as they didn't have the expertise'* (Respondent 3.13)
> *'Some of the nurses weren't kind or helpful'* (Respondent 8.9)..

The least frequently mentioned worst thing about surgery was emotional affects for 4% of respondents, who described:

> '*Feeling down'* (Respondent 4.1)
> *'Recovery was emotionally painful'* (Respondent 6.9).

One of the most significant findings is the amount of pain that patients recall immediately after surgery, as it is the strongest aspect of post-surgery physical after-effects; complications were only experienced by a minority of patients. In addition, references to fear and/or uncertainty were a feature right throughout their surgical experience, which related to many things, including: (a) their body image concerns, for example:

> '*The possibility of living with a stoma for the rest of my life, or any amount of time, is something I feared'* (Respondent 4.40)
> *'Possibility of having a stoma as I had struggled previously to deal psychologically with it'* (Respondent 3.7)

(b) a lack of medical information and help in hospital, which increased their fear and uncertainty, for example:

> *'Not knowing the outcome of operations/being confused'* (Respondent 4.40)
> *'The lack of updates and information about my op whilst on the ward'* (Respondent 5.1)

> *'I wasn't prepared or told I could reject the surgery and feel sick for days'* (Respondent 8.9)

(c) isolation in hospital, for example*:*

> *'I felt scared and alone a lot'* (Respondent 3.10)
> *'Staying in hospital far from home'* (Respondent 8.11).

As expected, 12% of the respondents' commented on a long hospital stay, which links with the theme of isolation:

> *'Longer recovery time than I expected'* (Respondent 2.10)*'*
> *'Feeling permanently sick for six weeks in hospital'* (Respondent 8.17)
> *'Months in hospital, missing out on things my friends got to do e.g uni, date, summer ball, holidays'* (Respondent 2.19).

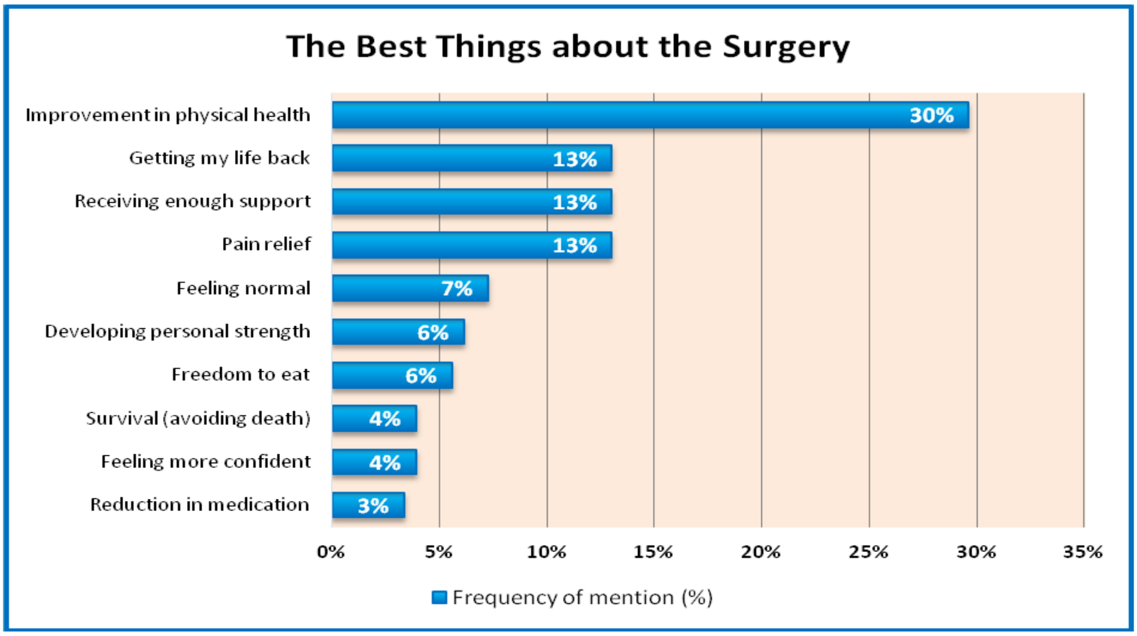


Figure 7.6: Best Things About The Surgery, By Young Adult IBD Patients, N=120.

7.7.2. The Best Things About the Surgery

Figure 7.6 shows the best thing about surgery was the improvement in physical health for 30% of respondents, who described:

> *'I feel a lot better'* (Respondent 3.11)
> *'Having more energy'* (Respondent 3.5)
> *'No flare ups'* (Respondent 8.28)
> *'I look healthier and am no longer in pain. I can do all the physical activities I want to'* (Respondent 4.24)
> *'Not going to the loo every five minutes'* (Respondent 2.11)
> *'Feeling so much better almost straight away'* (Respondent 5.11)
> *'Symptom free for three years'* (Respondent 2.11)
> *'My symptoms of Crohn's have disappeared practically'* (Respondent 2.12).

Improvement in physical health was related to the second best thing about surgery, 'getting my life back' for 13% of respondents, who wrote:

> '*Getting my life back, less hospital visits, socialising normally'* (Respondent 2.7)
> *'Quality of life improved'* (Respondent 3.7)
> *'It improved my lifestyle massively'* (Respondent 4.36)
> *'Able to go out/on holiday etc. without being sick and looking pregnant all the time. Able to have a career now and not be off sick most of the time'* (Respondent 5.13).

Pain relief was the best thing about surgery for 13% of respondents, which is what the patients really hoped for. For example:

> *'No more constant pain on my left side'* (Respondent 3.13)
> *'I did not have to worry about pain while going to the toilet'* (Respondent 5.5)
> *'After a few weeks I was pain free from tummy aches'* (Respondent 8.25).

Getting enough support was the best thing for 13% of respondents, which comprised two subthemes of: (1) getting support from health professionals, and (2) getting support from family, partner, and friends. In terms of getting health professionals' support, the very negative perceptions described in worst things about surgery, contrast sharply with the overwhelmingly positive perceptions of health professional support identified in best things about surgery. For example, patients often described in glowing terms the support they received from doctors and nurses:

> *'The doctors and surgeons were really helpful and supportive'* (Respondent 2.6)

> *‘The nurses were wonderful both in the hospital and the district nurses. They were very caring and understanding and went out of their way to help’* (Respondent 2.16)
> *‘The care I received from the doctors and nurses (especially the nurses) was unbelievable. Very grateful to all. My stoma nurse was amazing. Very informative and helpful’* (Respondent 3.4)
> *‘Nurses and consultant were great at explaining my condition and taking care of me’* (Respondent 3.9)
> *‘The amount of care and support I received from the surgeons, consultants, IBD nurses and stoma nurses has helped me get to where I am now’* (Respondent 5.2)
> *‘Being in a place where all the care I needed was easily accessible’* (Respondent 3.9)
> *‘The IBD nurses were very helpful and supportive before and after surgery with continued contact via e mail’* (Respondent 3.10).

The responses in best things come across as very genuine and really express appreciation for all the care, help and support of health professionals.

Respondents also showed much appreciation for family, partner and friends’ support, for example:

> *‘Getting lots of positive attention and support from friends and family’* (Respondent 3.2)
> *‘My family are closer and we appreciate the little things’* (Respondent 2.19)
> *‘I felt my partner and I grew closer as he shared the experience with me by supporting and caring for me’* (Respondent 2.16).

The fifth best thing was feeling normal for 7% of respondents, who wrote:

> *‘Feel like a normal person’* (P Respondent 4.44)
> *‘Made me feel 'normal' again’* (Respondent 7.1).

The sixth best thing was developing personal strength for 6% of respondents, who commented:

> *‘Feel stronger mentally and emotionally’* (Respondent 4.46)
> *‘The experience has made me mentally stronger’*(Respondent 3.6)

> *'I feel that my experiences have made me a stronger person. I got some awesome looking scars, which are a reminder of what I went through and each a part of my s*tory' (Respondent 8.13).

For 6% of respondents, freedom to eat was the best thing about surgery. They described:

> *'Being able to eat what I want'* (Respondent 8.28)
> *'I had no pain after eating which I hadn't experienced for almost a year before'* (Respondent 3.10)
> *'Not suffering ill effects when I eat. I can now eat a lot more foods that I like except cucumber, eggs and curry'* (Respondent 2.12).

For 4% of respondents, survival (avoiding death) was the best thing about surgery:

> *'It saved my life'* (Respondent 8.31)
> *'I survived and have excellent health without a useless colon'* (Respondent 8.2)
> *'I could have died so was glad it was done'* (Respondent 6.14).

For another 4% of respondents, the best thing was gaining confidence, for example:

> *'It gave me a confidence boost'* (Respondent 4.36)
> *'I feel more confident and able to do whatever I want'* (Respondent 2.12).

Finally, only 3% of respondents mentioned the best thing about surgery being a reduction in medication. They commented:

> *'No more steroids!!! that drug is evil!'* (Respondent 3.4)
> *'The side effects of these such as difficulty sleeping were greatly reduced'* (Respondent 8.14).

On reflection, perhaps reduced medication is a very small issue in comparison with the post-surgery transition to feeling well, getting their lives back, having less pain, feeling normal, and the freedom to eat.

7.7.3. Summary Of Best And Worst Things About The Surgery

Patients' different perceptions of the worst and best things about surgery suggest they had very different experiences, possibly because they came from different centres. For instance, one of the worst perceptions was lack of medical information which increased patients' fear/uncertainty, yet in thinking about the best things, the respondents describe health professionals as '*very informative and helpful'* (Respondent 3.2) and *'great at explaining my condition'* (Respondent 3.9). Alternatively, their perceptions of surgery could have changed at different stages of their transition (i.e., Moving In, Moving Through, Moving Out). An example of this might be in relation to pain; nine participants made references both to pain as one of the worst things and to pain relief as one of the best things. Statements such as *'The pain was unbearable'* (Respondent 4.27) were most likely to be an early postoperative experience, whereas *'After a few weeks I was pain free from tummy aches'* (Respondent 8.25) probably indicates a participant further along the road to recovery.

7.8. POST-OPERATIVE PERCEPTIONS OF SURGERY

Table 7.15: Post-operative Perceptions of Surgery, *N*=120

Post-operative Perceptions of Surgery	**Mean**	**SD**	**Scale Range**
Overall Perception of Surgery	58.02	15.28	20-90
Positive Perception of Surgery	22.02	6.18	5-25
Psychological Recovery	20.97	6.33	5-25
Recovery of Physical Health	15.21	3.86	6-30
Body Image Perception	12.62	4.74	4-20

Table 7.15 shows the mean ratings for post-operative perceptions of surgery. The highest rating was given for positive perception of surgery, indicating that most patients perceived their surgery to be successful and now felt positive about the future. This was followed by psychological recovery, indicating that most respondents felt happier, more self-confident, more outgoing, or felt stronger as a person after their surgery. The third rating was recovery of physical health, indicating that most respondents experienced a moderately good recovery of physical health.

It is worth noting that most of these patients had their surgery over two years prior to this study, so this scale measures how they feel now, which is moderately well, and suggests they have experienced an increase in physical health, but not complete recovery.

The lowest rating was for post-operative body image perception, indicating that body image was respondents’ least positive post-operative perception of their surgery. Notably, a larger majority of these respondents were women (i.e., 70 women versus 50 men). An independent samples *t*-test found there was no significant difference in post-op body image perception between male and female respondents, (t (116) = 1.36, p=.176). However, men were found to be more bothered by their scars than female patients (t (111) = 2.76, p<0.01). Overall, the generally low body image perception for most respondents suggests that they still felt concerned about their physical attractiveness, but had somewhat adapted to the changes in the way their body looked after their surgery.

7.9. PATIENT PORTRAITS

7.9.1. Participant 27. Esther: Example of a Patient Moving Through

This 20 year old young woman had IAP formation with a temporary stoma for UC followed by a stoma reversal, both surgeries within the last 7 – 24 months.

She had less than a week to prepare for the first operation and had many concerns about the operation itself: the anaesthetic, pain, complications, scarring, the stoma, and her ability to have children, and related to isolation- being in hospital, being away from her partner, missing her friends and socialising with them, which were typical concerns for the full sample. She was told that ‘*they had to operate’* and had ambivalent feelings about the surgery. She didn’t want it because ‘*It's a major operation and I had a hard road ahead with two more ops. It's daunting*’. At the same time, she recognised the potential benefits: ‘*I wouldn't have UC anymore and I could start to enjoy things that I was too tired to do or too ill to eat’*. In the short time she had before the first operation, she mainly prepared by speaking to health professionals – the doctors, specialist and ward nurses, and her family and friends and read a little. She found the reading and the specialist nurses of most help.

After the operation, she received lots of support from her family, friends and partner, which again was typical of most patients in the sample. She would have liked her parents to have given her more emotional support. She used lots of positive coping strategies including active coping, acceptance, planning and seeking social support, although she also used alcohol/drugs from time to time. However, the results of her surgery were not good:

> ‘*Even though I had no choice in the surgery there was a high chance that I could lead a normal life afterwards. Unfortunately, I now have chronic pouchitis so the surgery feels pointless. The recovery time was so long and painful. It's hard watching your friends live lives while you're still trying to heal and get used to new plumbing! There isn't enough support for the 18 - 25 bracket. It's hard trying to juggle finding out who you are, establishing a career when you're recovering from ops*’.

Now she doesn’t feel happier or healthier, that her daily life has improved or that she can physically do anything she wants. She has also not adapted to the changes in the way that her bowel works or feel like a normal person. Despite all these negative feelings, she still recognises that there were some positive things about her operation:

> ‘*No more steroids!!! (that drug is evil!). The care I received from the doctors and nurses (especially the nurses) was unbelievable. Very grateful to all. My stoma nurse was amazing. Very informative and helpful*’.

Unfortunately, complications following major surgery prevented improvement in this young woman’s health, and interfered with her living a normal life. She was still ‘Moving Through’ - having to cope with continuing bowel symptoms and to deal psychologically with a poor surgical outcome.

7.8.2. Participant 2. Joseph: Example of a Patient Moving Out

Now aged 22, in 2013 this young man underwent a small bowel resection and anastomosis for CD between 7 and 24 months ago.

This operation was an emergency procedure as *‘I had become that ill that it was the only option left’*. He had ambivalent feelings about the operation, writing

> *‘It worried me quite a lot, in case something went wrong or if I had to have a stoma bag, not being able to do normal things again, interact with friends in public’* but *‘ultimately if it made me feel even the slightest bit better and in less pain then it was worth it’*.

His main preoperative concerns related to how he would cope emotionally, his scars and the possibility of a stoma, but he also worried about pain, his physical recovery, if his ability to have children would be affected and being isolated from his family, partner and friends. He prepared for the operation by talking to the doctor and specialist nurse, his family, friends and partner and praying. He found the doctor, specialist nurse and his partner of most help.

Following the operation he used mainly positive coping strategies: acceptance, planning, active coping, instrumental and emotional support, prayed a lot and blamed himself a little. His parents, partner and friends provided lots of support, the first two also assisting with his dietary changes. He would have liked even more emotional support, but also thought that they could all be overprotective at times.

Looking back, now his operation is over, he thought the worst things were:

> *'The worry about having to have a stoma bag and how it would affect my life, friends and especially my partner. Worrying about how my bowels would operate after the surgery. Weight loss while recovering and the scar after'*.

He was very appreciative of all the health professionals who cared for him. He is still adjusting to the changes in the way his body looks. Apart from that:

> *'It improved my lifestyle massively (i.e. more outgoing). It gave me a confidence boost. The relief of not going to the loo every five minutes.' 'I feel so much better on a daily basis and that the pain has been taken away. Gained weight and feel better about my body. Getting back to normality with friends and family and partner.'*

This young man has had a successful operation and felt well afterwards. With a much improved lifestyle, he has 'Moved Out' and is resuming a normal lifestyle.

7.3. Participant 113. Steve: Example of a Patient Moving Out

This 21 year old young man with CD had two operations, the first a subtotal colectomy with formation of a temporary ileostomy more than two years ago in 2011, followed by a segmental resection of his sigmoid colon and reversal of the end ileostomy within the last 7 – 24 months.

The first operation was an emergency procedure:

> *'so I didn't have any time to prepare for it. Wasn't diagnosed until after surgery when they tested the part of bowel they removed... I was pretty sick when they told me I*

> *needed surgery. I don't remember much about it. I do remember being upset about missing a West-life concert though'.*

He described his postoperative period as:

> *'a scary time because it happened so fast. I didn't like having to stay in hospital. I missed my family loads. The stoma bag took a bit of getting used to (I named the stoma Shane because I was due to go to a West-life concert on the day of my op'.*

However, he received lots of positive support from his parents and friends.

> *'My mum did loads of research to help me understand my diagnosis. I also joined Teen IBD, an online Forum where I could discuss everyday things with people that understood the situation'.*

He also used only positive coping strategies, including acceptance, active coping, planning and humour.

He scored highly across all domains of perception of surgery, with no regrets about having the operation. He also felt like a normal person whose day to day life had improved, who had adapted to changes in the way his body looks. With the stoma now closed, he wrote:

> *'I feel much healthier and happier now and am much more positive about the future. I feel that my experiences have made me a stronger person. I got some awesome looking scars which are a reminder of what I went through and each a part of my story'.*

He did not regret having his surgery at all, although he does not wish he had it earlier. With his health now restored, and the stoma closed, this young man felt normal, psychologically strong, was forward thinking, and had clearly moved out of the phase of his life that included surgery.

CHAPTER 8 – MULTIVARIATE ANALYSIS

Multivariate methods were required to understand the interrelationships among multiple transition factors and post-operative perceptions of surgery. This chapter examines post-operative perceptions of surgery according to patient characteristics, identifies patient subtypes using hierarchical cluster analysis, and examines interrelationships among explanatory and outcome variables.

8.1. OVERALL POST-OPERATIVE PERCEPTIONS OF SURGERY

An overall post-operative perceptions of surgery variable was created by summing the four post-operative perception variables, and splitting patients into positive (n=71) and negative (n=48) groups (using a median split of 58.0). Table 8.1 shows 60% of respondents had a positive perception and 40% had a negative perception. A Chi-square analysis found there was no significant difference in overall post-operative perceptions of surgery by gender ($\chi2$ (1) = .088, p=1.000); surgery timing ($\chi2$(1) =0.433, *p*=0.687); disease type ($\chi2$ (1) =.562, p=0.472); or stoma groups ($\chi2$ (1) = 2.88, p=0.05). Figure 8.1 shows that regardless of patient characteristics, respondents were more likely to have positive overall perceptions of surgery. Notably, patients who did not receive a stoma had the most positive perception (76%).

Table 8.1: Overall Post-operative Perception of Surgery Categories by Patient Characteristics

Characteristic	**Category**	**Negative**	**Positive**
Full Sample		40%	60%
Gender	Male	41%	59%
	Female	40%	60%
Timing	Emergency Surgery	36%	64%
	Planned Surgery	43%	57%
Disease Type	Crohn's Disease	39%	61%
	Ulcerative Colitis	48%	52%
Stoma Groups	With Stoma	42%	58%
	Without Stoma	24%	76%

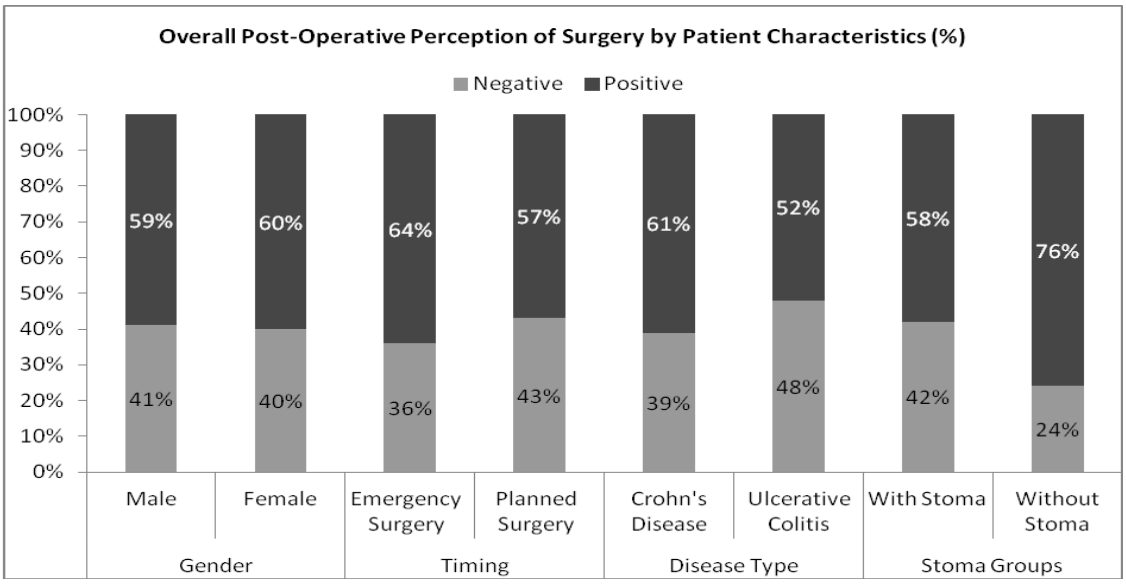


Figure 8.1. Overall Post-Operative Perception of Surgery by Patient Characteristics (%)

8.2. USING CLUSTER ANALYSIS TO IDENTIFY SUBTYPES OF IBD PATIENTS

The findings from the patient interviews (n=24) suggested that IBD patients could experience the transition through surgery in different ways, which prompted the exploration of patient clusters to understand the co-occurring features of patients who transitioned well, versus those who did not. Cluster analysis offered a way to partition a dataset into subtypes that share common patterns, and identify subgroups of individuals with different profiles, across multiple dimensions of interest (Clatworthy et al., 2005, Eisenbarth, 2012, Henry et al, 2005). The potential usefulness of identifying patient clusters lay in prioritising information and support for patients at risk of difficult transition. This could result in better treatment efficiencies and surgical outcomes. Additionally, the cluster analysis profiles might help to identify the underlying causes of why some IBD patients transitioned well while others did not. These underlying causes could then be verified by assessing the interrelationships between potential explanatory variables and the outcome variables.

8.2.1. Analysis

To determine the patient subtypes in the sample of 120 IBD patients, hierarchical cluster analysis was performed on the four Post-Operative Perceptions of Surgery scales by means of the Ward's minimum variance method and squared Euclidean distance as the combined measure of distance across all of the variables (Gore, 2000; Leonard and Droege, 2008). Ward's method was selected as it outperforms most other clustering techniques for identifying cluster structures in known data (Lorr, 1983). To profile the obtained cluster solution, Chi-square and independent samples *t*-tests were performed to differentiate the clusters by patient characteristics, pre-operative concerns, preparation activities, post-operative coping, support, and post-operative perceptions of surgery outcomes.

8.2.2. Results: Patient Subtypes

The cluster analysis agglomeration schedule and dendogram revealed that a two-cluster solution fitted the data best. Table 8.2 (Appendix 26) presents the frequency percentages and mean continuous variable scores for the two subtypes in the total sample. The significant factors that differentiated the two clusters were pre-operative anxiety, speaking to the specialist nurse to prepare for surgery, rating of preparation activities that helped, use of five coping strategies, and ratings on all four post-op perceptions of surgery.

The first subtype (Cluster 1) was characterised by a positive overall perception of surgery (91%), lower pre-operative anxiety, more frequently speaking to the specialist nurse about the surgery, and the following activities helped more: researching the operation, speaking to health professionals, speaking to family, friends, and other people who had had the surgery. Respondents used more acceptance, active coping and less self-blame, denial and substance to cope, and had significantly better postoperative perceptions of surgery outcomes.

By contrast, the second subtype (Cluster 2) was characterised by a negative overall perception of surgery (100%), higher pre-operative anxiety, less frequency in speaking to the specialist nurse, and rated the following activities as less helpful: researching the operation, speaking to health professionals, family, friends, and other people who had had the surgery. Respondents also used less acceptance and active coping and more self-blame, denial and substance use, and had significantly more negative post-operative perceptions of surgery. This subtype also included 72% of stoma patients versus 56% of stoma patients in the first subtype suggesting that negative perceptions were somewhat associated with having a stoma.

8.3. CORRELATION ANALYSIS

8.3.1. Intercorrelations between Support, Coping and Post-operative Perceptions of Surgery

Table 8.3 (Appendix 27) presents the Pearson correlation coefficients among the post-operative independent variables which were the support and coping factors and the dependent variables which were the four post-operative perceptions of surgery outcomes (body image/positive perception/physical recovery/psychological recovery). Cohen (1988) describes the strength of a correlation as: “small: $r = .10$ to $.29$, medium: $r = .30$ to $.49$ and large: $r = .50$ to 1.0”. Most of the relationships observed were small. As Table 8.2 shows, the factors that were associated with reduced post-operative perceptions of surgery were pre-operative anxiety, denial, substance use, and self-blame coping strategies. In contrast, the factors that were associated with increased post-operative perceptions were researching the operation, speaking to health professionals about it, speaking to family and friends about it, using humour, self-distraction, active coping, and positive reframing coping strategies, and having high parental support. High partner support was also associated with increased psychological recovery, but had no relationship with other surgery outcomes. No other factors were identified that were associated with perceptions of surgery outcomes.

8.3.2. Correlation Analysis by Patient Characteristics Subgroups

8.3.2.1. Intercorrelations Between Pre-Operative Concerns About Surgery And Post-Operative Perceptions Of Surgery By Disease Type

Table 8.4 (Appendix 28) shows seven significant intercorrelations between pre-operative concerns and post-operative perceptions for CD patients, but only two significant intercorrelations for UC patients.

For Crohn's disease patients, high pre-operative anxiety was associated with lower positive perception of surgery (r = -.242, $p<0.05$), lower recovery of physical health (r = -.208, $p<0.05$), lower psychological recovery (r = -.223, $p<0.05$) and lower post-operative body image perception (r = -.347, $p<0.01$). In addition, low post-operative body image perception was associated with higher pre-operative concerns about fear of surgery (r = -.224, $p<0.05$), post-surgery physical after effects (r = -.251, $p<0.05$), post-surgery body image (r = -.330, $p<0.01$) and pre-operative anxiety (r = -.347, $p<0.01$).

For Ulcerative Colitis patients, high pre-operative fear of surgery was associated with lower recovery of physical health (r = -.539, $p<0.05$) and a high pre-operative concern about post-surgery body image was associated with psychological recovery (r = -.458, $p<0.05$).

8.3.2.2. Intercorrelations Between Pre-Operative Concerns About Surgery And Post-Operative Perceptions Of Surgery By Stoma Groups

Table 8.5 (Appendix 29) shows significant intercorrelations for patients with a stoma but not for those without stoma.

For patients who had stoma forming surgery, high fear of surgery was associated with lower recovery of physical health (r = -.293, $p<0.05$). High pre-operative concern about post-surgery body image was associated with lower post-operative body image perception (r = -.393,

$p<0.01$). In addition, high pre-operative anxiety was associated with lower post-operative body image perception ($r = -.343$, $p<0.05$).
Among patients who did not have a stoma, there were no significant relationships found between pre-operative concerns about surgery and post-operative perceptions of surgery. These results suggest that the pre-operative concerns about surgery may be almost entirely related to patients' concerns about having a stoma; when they do not have one, there are no relationships with post-operative perceptions of surgery.

8.3.2.3. Intercorrelations Between Pre-Operative Concerns About Surgery And Post-Operative Perceptions Of Surgery, By Gender

Table 8.6 (Appendix 30) shows a different pattern of intercorrelations among male and female patients.

For male patients, high fear of surgery was associated with lower positive perception of surgery ($r = -.358$, $p<0.05$), lower recovery of physical health ($r = -.358$, $p<0.01$) and lower psychological recovery ($r = -.358$, $p<0.05$). In addition, higher concerns about post-surgery body image were associated with having a lower post-operative body image perception ($r = -.358$, $p<0.01$).

For female patients, a low post-operative body image perception was significantly associated with high pre-operative concerns about post-surgery physical after-effects ($r = -.290$, $p<0.05$), post-surgery body image ($r = -.284$, $p<0.05$) and pre-operative anxiety ($r = -.372$, $p<0.01$) (most likely due to fear about having a stoma or scarring after the surgery).

Overall, for male patients, fear of surgery was related to post-operative perceptions, whereas for female patients' pre-operative concerns were mainly related to post-operative body image perception.

8.3.2.4. Intercorrelations Between What Patients Did To Prepare For Surgery And Post-Operative Perceptions Of Surgery By Disease Type

Table 8.7 (Appendix 31) shows the correlations between what patients did to prepare for their surgery and their post-operative perceptions, by disease type.

Patients with Crohn's disease who prepared passively for surgery (e.g., reading about it, praying) had lower post-operative perceptions of surgery. Reading written information about it was associated with a lower recovery of physical health ($r = -.237$, $p<0.05$) and praying about it was associated with lower body image perception ($r = -.234$, $p<0.05$). Patients with Crohn's disease who spoke to the specialist IBD and/or stoma care nurse about their surgery reported a more positive perception of surgery ($r = .302$, $p<0.01$), better recovery of physical health ($r = .228$, $p<0.01$) and better psychological recovery ($r = .223$, $p<0.05$). Speaking to the nurses on the ward was also associated with a positive perception of surgery ($r = .251$, $p<0.05$) and better psychological recovery ($r = .271$, $p<0.01$). Speaking to their friends about their surgery was associated with a more positive post-operative perception of surgery ($r = .246$, $p<0.05$) as was speaking to other people who had surgery ($r = .232$, $p<0.05$).

For UC patients, reading about other people's experiences of surgery on the Internet was associated with more positive perception of surgery ($r = .476$, $p<0.05$), better psychological recovery ($r = .452$, $p<0.05$) and positive post-operative body image perception ($r = .489$, $p<0.05$). This is the only activity that was significantly associated with a positive post-operative body image perception. Speaking to their friends about their surgery was associated with lower post-operative perception of surgery ($r = -.490$, $p<0.05$), lower recovery of physical health ($r = -.472$, $p<0.05$) and lower psychological recovery ($r = .583$, $p<0.01$).

8.3.2.5. Intercorrelations Between What Patients Did To Prepare For Surgery And Post-Operative Perceptions Of Surgery By Stoma Groups

Table 8.8 (Appendix 32) shows the correlations separately for patients with and without a stoma.

Stoma patients who spoke to the specialist IBD and/or stoma care nurse about their surgery experienced a more positive post-operative perception of surgery ($r = .308$, $p<0.05$), better recovery of physical health ($\mathrm{r} = .300$, $\mathrm{p}<0.05$) and better psychological recovery ($r = .403$, $p<0.01$). Patients who prayed to help them prepare experienced a negative post-operative body image perception ($r = -.332$, $p<0.05$).

Patients without a stoma who spoke to the specialist IBD and/or stoma care nurse about their surgery had a positive post-operative perception of surgery ($r = .469$, $p<0.01$) even greater than stoma patients who did this. Patients who spoke to their family about their surgery to help them prepare reported a lower post-operative body image perception ($r = .465$, $p<0.01$).

8.3.2.6. Intercorrelations Between What Patients Did To Prepare For Surgery And Post-Operative Perceptions Of Surgery By Gender

Table 8.9 (Appendix 33) shows the correlation coefficients between what patients did to prepare for surgery and their post-operative perceptions of surgery, for male and female patients separately.

For male patients, looking the operation up on the Internet/You Tube was associated with higher psychological recovery ($r = .309$, $p<0.05$) and speaking to the doctor was associated with a lower post-operative body image perception ($r = -.460$, $p<0.01$). In addition, male patients who prayed to help them prepare for surgery had a lower post-operative body image perception ($r = -.332$, $p<0.05$).

Female patients who spoke to the specialist IBD and/or stoma care nurse had a more positive perception of surgery ($r = .260$, $p<0.05$) and better recovery of physical health ($r = .249$, $p<0.05$). Female patients who spoke to the nurses on the ward about their surgery experienced a better post-operative psychological recovery ($r = -.328$, $p<0.01$).

CHAPTER 9: DISCUSSION

The aim of this study was to investigate the process of transition through surgery as it was experienced by young adults with IBD who faced the prospect of, or had undergone, surgery. The research was achieved through a two phase exploratory mixed methods design (Teddlie and Tashakkori, 2009) with a qualitative phase informing a later quantitative phase of the study. This study fills a gap in the literature because it is the first to investigate the experience of surgery in a large group of young adults who have IBD, to conceptualise IBD surgery as a transition and to comprehensively explore the influence of contextual, situational and personal factors, support and coping strategies on that transition.

This chapter first summarises the study that was carried out. This is followed by a discussion of the study findings. The strengths and methodological limitations are next presented. Recommendations for research, practice and education follow. The chapter ends with the conclusion.

9.1. SUMMARY OF THE STUDY

The aim of the initial qualitative phase was to investigate the process of transition through surgery through semi structured interviews undertaken with 24 young people aged 18 – 25 who had IBD. The findings revealed the impact of an operation on their lives, factors and experiences that affected them as they tried to cope with and adjust to their operations and differing experiences of transition.

The sample of 18 young people with CD and 6 with UC reflected the reported higher incidence of surgery for this form of IBD (Gupta et al, 2006, Hyams et al, 1996). Similarly, the proportions of young women with CD and young men with UC in the qualitative sample were consistent with gender differences previously described in the literature (Lennard-Jones and Shivananda, 1997, Björnsson and Jóhannsson, 2000, Bernstein et al, 2006). Therefore the qualitative sample appeared representative of the numbers of young IBD patients in the general population that would be expected to have surgery for their condition, with CD patients more likely to have an operation. The qualitative phase demonstrated that most young people coped with their IBD symptoms even though they may have had a profound effect on their everyday life. They were also socialising into adulthood in ways that were similar to those of other young people described in the literature: establishing relationships with other adults as an equal adult, studying and beginning a career and developing a satisfying personal and social life (Strough, Berg and Sansone, 1996, Young, Stewart and Miner-Robino, 2001, Arnett, 2001).

The qualitative phase was exploratory and descriptive. It employed Schlossberg's Transition Theory (Goodman et al, 2006) to explore variability in the transition process in relation to the impact of the operation, the individual's perception of it, and the personal and supportive resources available to cope with it. Four key dimensions of Schlossberg's framework- situation, self, support and coping strategies provided a framework for analyzing reasons why certain patients may have positive or negative experiences and successfully or unsuccessfully negotiate their way through the transition of surgery. This theory has successfully been applied to transition research in other health related situations (Loveys, 1990, Young, 1990, Labrague et al, 2013) and with other young adults (Halasz, 2013, DeVilbiss, 2014). The unique contribution of this thesis is the application of Schlossberg's Theory to young people with IBD. Phase 1 identified specific factors associated with the operation, the young person, their support and coping strategies that helped or hindered transition in young adults undergoing surgery for their IBD. The key finding was that preoperatively most young people knew that their disease had been out of control and postoperatively they perceived that surgery improved their physical health and positively changed their lives. This perception, appropriate support and active coping helped these young people in the transition through surgery. Fear, worry and uncertainty, continuing symptoms, body image concerns, lack of or inappropriate support and ineffective coping strategies hindered the process of transition.

The aim of the quantitative phase was to investigate the process of transition through surgery through a quantitative survey to measure the views of a random national sample of 120 young adults with IBD in 7 NHS centres in England about their experiences of surgery. The findings from Phase 1 led into the second, quantitative phase of the study where they gave focus and direction by providing the basis for questionnaire design. The quantitative phase was undertaken to determine if the Phase 1 findings could be corroborated in a larger sample (Teddlie and Tashakkori, 2009).

The sample of 99 young people with CD and 21 with UC again reflected the reported higher incidence of surgery for CD (Gupta et al, 2006). Similarly, the higher number of operations undertaken in young women with CD and in young men than women with UC in the quantitative sample was consistent with gender differences previously described in the literature (Lennard-Jones and Shivananda, 1997, Björnsson and Jóhannsson, 2000, Bernstein et al, 2006). Therefore the quantitative sample was also representative of the numbers of young IBD patients in the general population that would be expected to have surgery for their condition and suggested that the results could be generalised to the wider population. The key finding from Phase 2 was that most young people had a positive perception of their surgery and experienced an improvement in physical health. Most received appropriate support and used positive coping strategies in the transition through surgery. Those who spoke to the specialist IBD or stoma nurse about their surgery reported a more positive perception of surgery, better recovery of physical health and better psychological recovery. However, high preoperative anxiety, fear and uncertainty, uncontrolled pain, body image concerns, the presence of a stoma and lack of social support were all factors that affected physical and psychological recovery and adjustment to surgery. Differences also emerged between sub groups of patients undergoing surgery- those with CD or UC, male and female, emergency and non emergency surgery and participants with and without a stoma.

The mixed methods design provided a more comprehensive answer to the research questions than would have been possible with either a qualitative or quantitative study alone (Cresswell and Plano Clark, 2007). The qualitative narrative approach in the first phase enabled the researcher to identify key factors which had been influential in deciding whether and when to have surgery, how they perceived their surgery and prepared for it, and those which affected patients' postoperative adjustment and experiences in an area where there had been little previous research. This phase provided the foundation for Phase two, as key issues and themes identified through analysis of the qualitative data were used to generate the content and inform the design of the questionnaire in Phase 2. The quantitative survey in Phase 2 was conducted to establish that the initial findings from qualitative investigation were corroborated and generalisable beyond that population thereby increasing confidence in the inferences that could be drawn from them. In addition, the researcher developed and validated new data collection instruments which were derived from the initial research findings. With further refinement these could provide researchers with alternative measures with which to investigate patients' experience of IBD surgery. At present this field of investigation is dominated by quality of life measures which do not fully capture the issues of importance to patients that were identified in this study.

9.2. DISCUSSION OF STUDY FINDINGS

9.2.1. Approaching The Transition

Schlossberg (Goodman et al, 2006) described how a transition begins with an individual's initial perceptions and appraisal of an impending event and how it will alter their lives (Goodman et al, 2006)

This study found that most participants thought of the operation in positive terms when they first learned of the need for surgery, despite it being a new experience for over half of them.

They perceived it as the means by which they would get well, improve their quality of life and relieve their pain. Surgery represented an opportunity for most participants to change a life that was dominated by illness and uncontrolled symptoms. These perceptions were consistent with earlier findings (Beitz, 1999, Savard and Woodgate, 2009). However, sometimes participants felt they had no choice about having an operation, because they were very sick, medication had failed, or they could not carry on with life as they were. A smaller number were afraid and uncertain about what was going to happen, or expressed disbelief and denial that an operation was necessary. Previous experience of surgery influenced perceptions. Those who had had four or more operations mostly perceived their surgery negatively. However, the key factor affecting reactions in other participants who had had previous surgery appeared to be whether previous experiences had been negative or positive. Those who had had a difficult time were anxious and upset, fearing that the next operation would be similar. Those who had seen benefits, or saw themselves as having coped well before, were optimistic, even if the surgery was for disease recurrence.

9.2.2. Moving In

9.2.2.1. Decision Making

A salutary finding from this study is that some participants recalled consenting to an operation with no clear understanding of what was being done to them. This may be related to the unanticipated finding that the majority of operations took place very soon after participants were initially told that there was a need for it. Due to the seriousness of their condition, nine patients had no choice and hardly any time to become informed or prepare as they needed an immediate operation. Less than half the remaining participants knew for over a month, a quarter of them knew from a week to a month in advance but about a third had emergency surgery that took place within a week. This suggests that a good number were either very sick by the time they met the surgeon, or that complications had arisen that required urgent surgery. This inference appears to be supported by previous epidemiological studies where it has been reported that childhood onset IBD appears to be more extensive and progressive than adult onset disease, with more extensive inflammation and complications (Van Limbergen et al, 2008, Vernier-Massouille et al, 2008).

It might reasonably be thought that less time to prepare would be a factor that negatively affected postoperative perceptions but those who had emergency operations actually had slightly more positive views of their surgery. An explanation for this may be found by referring back to respondents' first reactions to the news they would need an operation, such as *'I would have died without the surgery due to the extent of my illness'* and *'I was in such pain it was* *unbearable'*. These young people were fully aware of the seriousness of their situation, some dealing with almost unbearable symptoms, so that surgery was actually anticipated and viewed afterwards with relief. There is some qualitative evidence to support this; Beitz (1999) found that those with bad UC symptoms before their operation were very pleased with the outcome of IAP surgery, whereas those with mild symptoms were less satisfied as the prolonged recovery was perceived as worse than the illness and there was a lack of closure because of the awareness of worsening symptoms.

Although most of these young adults were not in a position that allowed prolonged decision making, they did have time to make a choice. The findings of this study were consistent with previous qualitative work which described decision making as sometimes being a difficult process, particularly when it involved a permanent stoma (Sinclair, 2009). However, this study identified key turning points and specific triggers related to decision making in IBD surgery, such as unmanageable symptoms or reaching the limits of endurance, which are new.

One previous study has explored the role and influence of close others in decision making, finding that there was less decisional conflict if partner, family and friends helped with understanding the decision (Rini et al, 2011). Generally, participants in the present study described helpful influences from family and partners, and none of the negative influences found by Rini et al's (2011) work to be associated with higher decisional conflict and less likelihood of choosing surgery. In that work, older adult patients were more likely to decide to have surgery if they perceived they were at greater risk of colorectal cancer. Of a young age and with shorter disease duration, the long term risk of cancer was not foremost in the minds of young adult participants, but severe symptoms and threats to survival were similar disease related factors which influenced the decision to have surgery.

The present study also identified the major influence that the doctor had on the decision to have surgery. Low referring physician trust has been related to greater decisional conflict in adult patients (Rini, 2011) but the findings in Phase 1 of this study demonstrated that low trust in surgeons could have greater consequences for younger adults in that the associated conflict could result in refusal to have surgery. The exploration of doctor influence has not extended to the surgeon in previous work. In this study participants had different expectations of the role of medical doctors and surgeons, with clear straightforward explanation by the surgeon seen as very helpful. However, it is the gastroenterologist or physician who actually makes the decision to refer the patient to the surgeon and acts as a 'gatekeeper'.

Findings from previous research comparing gastroenterologists' and surgeons' preferences for treatment (Byrne, 2007) and their degree of alignment with those of adult patients with CD have implications for the care of young adult patients with IBD. In that study, for the majority of surgical treatment options- ileocaecal resection, laparoscopic ileocolic resection, subtotal colectomy, patients preferences aligned with those of the colorectal surgeon and differed from those of gastroenterologists, and the opinions of gastroenterologists differed from those of surgeons. Gastroenterologists were generally more averse than surgeons or patients to most surgical treatment options. This raises the question of whether the higher number of emergency and urgent operations in the young adults in this study is more than just a consequence of the differing nature of young age onset IBD. Gastroenterological practice could be contributory; it may be that gastroenterologists continue to pursue medical options when an earlier referral to a surgeon might have led to more operations being done in less sick patients with less risk of complications and less acute admissions closely followed by surgery. Such a possibility highlights the need for the whole multidisciplinary team to be involved in decision making, so that objective decisions can be made about the best course of treatment.

In previous work, adult patients have expressed dissatisfaction with the opportunity to participate in decision making (Persson et al, 2005). In Phase 1 of this study participants described needing to have some control over when the operation would take place and this finding may be of particular significance at this stage of life. As young adults, participants were building a foundation for their future lives (Arnett, 2001) so attending college and university to gain qualifications and beginning a career were very important to them. As a consequence, they felt the need to negotiate when an operation took place so that it least interfered with this aspect of their lives. This is something that should be anticipated by surgeons and accommodated wherever possible.

9.2.2.2. Preparation For Surgery

An important part of moving into any transition is the need to get ready, 'learn the ropes' and become familiar with the norms and expectations of the new situation (Goodman et al, 2006). Once the decision to have surgery had been made, participants usually began to prepare for their operation. Appropriate preparation was found to be a key factor in helping participants with the surgical transition; participants in Phase 1 who did no preparation had a more difficult time after surgery. Only two participants in Phase 2 chose not to do any preparation for their operation, and only a quarter of the 36 participants who had emergency surgery described having no time for preparation. This suggests that although the actual time from being told that they would definitely need an operation to its taking place was often short, most participants were already aware that surgery was likely and had prepared in a similar way to those who had planned surgery.

The findings of this study demonstrated that participants carried out multiple preparatory activities before surgery as described in previous, mainly qualitative, studies (Beitz, 1999, Notter and Bernard, 2006, Sinclair, 1999). Findings from the present study are more detailed and also reveal the relative helpfulness of different activities for different groups of patients. One surprising omission in most previous studies is that health care professionals are rarely mentioned as key sources of support in assisting with preparation, together with the perception of patients that information could be difficult to find. Moskovitz (2000b) found that IBD patients who had individual attention from trained nurses, physicians or trained lay visitors preoperatively reported better quality of life, fewer systemic symptoms and emotional problems after their surgery than those who prepared with support groups/meetings, educational resources, magazines, speakers or charity days. The findings from this study were consistent with those of Moskovitz (2000b) as they showed that speaking to health professionals, particularly the doctor and the specialist nurse was the most frequent activity carried out and also the most helpful, whereas reading written information and researching the operation were less frequently done and less helpful.

One explanation for the positive effect of interaction with these key health professionals is that, unlike other resources, they can provide individualised preparation which takes account not only the proposed surgery but how it will affect each patient and it also enables the patient to have specific concerns and questions addressed. It is difficult to explain why the doctor was not mentioned in the qualitative work, especially as Rini (2011) identified the referring doctor as the most important influence on patients' decision making. However, the specialist nurse may not have been seen as an important preoperative resource in the American qualitative studies because such posts are less common there than in the UK. Another contributory factor from past personal clinical experience is that, through lack of communication, sometimes specialist nurses have limited opportunities to help patients prepare. It is not uncommon for them to be notified about these patients when the patient has already decided to have surgery and very close to the date of operation. With little time left, they are only able to deal with immediate issues, such as stoma siting. However, the findings from this study identified that positive postoperative perceptions were linked specifically to speaking to the specialist nurse for most of these young people, including young women, those with and without a stoma, and patients with CD.

Other interesting findings related to preparation and postoperative body image perception were that young adult males who spoke to the doctor had a lower body image perception, which may reflect their reluctance to talk about such issues generally, or possibly the doctor might not take the initiative in addressing them. Also UC patients who read about other people's experiences of surgery on the Internet reported a more positive perception of surgery, better psychological recovery and better postoperative body image perception. That this was the only activity that actually did improve postoperative body image perception for this group of patients may indicate that for them, positive role models and personal accounts of coping with and living life following (mainly IAP) surgery are the most helpful resources they can have access to preoperatively.

9.2.2.3. Preoperative Concerns, Anxiety And Fear

There is limited previous research that investigates preoperative worries, concerns and anxiety in IBD patients. In 2012, Bullen et al found that potential stoma patients did not differ in their level of anxiety from patients undergoing surgery without a stoma. The present study fills a gap in the literature as it is the first to comprehensively investigate the nature of preoperative concerns, anxiety and fear in relation to IBD surgery. The findings indicated that, in this group of patients, they were frequent and wide ranging. In addition, preoperative fear and uncertainty was related to lack of information and knowledge about the operation and its effects, and described by participants as one of the worst things about surgery. Although the majority of participants had positive initial reactions to surgery, concerns began to surface when they were actually preparing for it. At this stage, body image issues (having a scar, having a stoma and being less physically attractive after surgery) became their greatest concern. Even though the risk of a stoma was low (only about a quarter of operations involved one), practically every patient worried about having one in both study phases. They were also concerned about the after effects of surgery. Such concerns gave rise to anxiety about how they would cope emotionally. Fear of the operation itself was less common but also described, especially where surgery was a new and unknown experience, or they had had a difficult time after a previous operation.

Young women described much greater concerns and difficulties with sexual issues and parenthood than young men in Phase 1, only two of whom described any concerns about their sexual function. The need for women to be able to discuss sexual issues prior to surgery has been identified previously (da Silva et al, 2008). However, patients of both sexes with an ileostomy for UC have expressed dissatisfaction with the opportunity they had to talk about sexual issues with the stoma nurse (Persson et al, 2005). Previous research into this area has predominantly focussed on sexual function in patients having IAP or a stoma up to a year after surgery. Studies investigating this in men, mainly following IAP surgery where there is a higher potential risk of sexual dysfunction due to low pelvic dissection, found that they had good function preoperatively despite disease and that surgery did not reduce this (Davies et al, 2008). When sexual function was compared between men with and IAP and those with a permanent stoma, both had improvement in sexual function in the first six months after surgery, although this was greater in IAP patients (Wang et al, 2011).

In women, sexual function has been reported as hardly improving in the first 6 months after an operation for IBD (da Silva et al, 2008, Wang et al, 2011). Within the next 6 months, improvement in sexual function continues but is not as good as that of the general population (Davies et al, 2008, Larson et al, 2008). These results are not surprising; those with an IAP have had low pelvic dissection so may experience pain on intercourse whilst still healing. Those with a stoma are likely to be still coming to terms with body image changes. One study investigated long term sexual function in patients with CD who had had surgery for a perianal fistula (Riss et al, 2013). The findings revealed that sexual function was worse in women who had had multiple operations. In the long term, Cornish et al (2012) compared women who had IAP surgery and those with UC who had not, and found sexual function did not differ between the two groups. However, the patients with IAP were cured of their disease so a better comparison would have been with healthy women. That study has been the only one to investigate childbirth in IAP patients. The findings revealed that vaginal delivery adversely affected IAP function. The issues in this study that most concerned young women with IBD before surgery: ability to conceive, carry and deliver a baby safely, have not been addressed in previous research and need to be investigated further. In clinical practice, this is an issue that will affect many of these young people, so does need to be included in preoperative discussion.

The findings are interesting as they suggested that it is not the actual operaton itself which induced anxiety and concern but the effects of surgery in terms of how participants would be affected physically, socially and emotionally. It is not surprising that body image issues were a major concern, particularly for young women. They are exposed to media images relating to standards of appearance and attractiveness. Young people are also less likely to be in stable relationships and surgically induced changes to their bodies will naturally give rise to concerns about their desirability to existing or prospective partners. It also appeared that many young people who do not need to were worrying about a stoma. There are several possible explanations for this finding. In practice, almost every patient who has to have bowel surgery is concerned that a stoma may be raised, because of its negative associations. It is also sometimes difficult to give patients specific information about the relative risk and not uncommon for surgeons to ‘err on the side of caution’ and ask the stoma nurse to prepare the patient when a stoma is not part of planned surgery, but may need to be raised if problems arise during the operation. The Phase 1 findings also revealed that young men may need encouragement and opportunity to articulate their concerns as they were less likely to do so than women. Overall the findings related to concerns and anxiety indicated a need for information which is tailored to the individual and extends beyond explanation of the surgery itself.

An additional important finding was that high preoperative anxiety was a significant predictor of having a low postoperative perception of surgery. As the level of anxiety increased, perceptions of surgery became more negative. Highly anxious patients also had lower recovery of physical health and lower psychological recovery. High preoperative concerns about body image, fear/uncertainty and isolation in hospital also continued to have an effect afterwards; those participants also experienced more post surgical after effects (pain, complications) and lower post surgery body image as well as having lower postoperative perceptions of surgery. The level of preoperative anxiety and fear also affected the things that patients did to prepare for surgery. Participants with high anxiety and fear were more likely to speak to their family and the doctor about their surgery and to pray about it. Family members may not be in a position to provide information that the patient needs. As previously discussed, although participants found speaking to the doctor a very helpful activity, it was actually the specialist nurse who made a difference to their postoperative perceptions of surgery. The findings also showed that praying was the least used and least helpful preparative activity. Taken together the findings suggest that those participants who needed most help did not engage in the preparative activities most likely to help them and reduce their anxiety and fear.

9.2.3. Moving Through

Schlossberg (Goodman et al, 2006) describes the early phase of Moving Through as an ‘in between status’ or period of liminality. This is characterised by disengagement from old roles and routines and may involve disorientation and confusion between the old life and the new. Because the transition is a process that occurs over time, reactions change as individuals become more familiar with, and learn new roles and begin to adapt to the change. As this happens, gradually the initial sharp awareness and pervasiveness of the transition decreases as it becomes integrated into everyday life.

9.2.3.1. Early Postoperative Experiences

The findings revealed that early postoperative experiences could be difficult, most particularly in relation to unrelieved pain and uncertainty. Over half of participants’ comments on the worst things about surgery concerned physical after effects. The majority of comments in this category referred to pain, which could be more intense than that experienced with the disease. This finding supported previous research describing severe and prolonged postoperative pain that was not adequately controlled because of insufficient analgesia (Notter and Bernard, 2006, Savard and Woodgate, 2009). Fear and uncertainty also continued after the operation. They were often related to lack of information and knowledge about the experience and what constituted a normal recovery. In previous research patients with a stoma rated the provision of information as very important but often expressed dissatisfaction with the quality of this aspect of care, particularly about the surgical procedure and its results (Persson et al, 2005). Similarly, some participants in this study described not knowing the outcome of the operation and a lack of information and updates about their surgery when they were on the ward. The consequence was that they did not know whether their experiences were normal or if something had gone wrong.

If complications did develop, necessitating a longer stay in hospital, this gave rise to further fear and anxiety. Complications and slow recovery were cited by participants as some of the worst things about surgery. In previous work, complications and readmission also appeared to have a detrimental effect on quality of life (Delaney et al, 2003). A significant number of these young people were very sick before their surgery and underwent complex operations, so the risk of a delayed recovery would be greater; the increased needs of these patients for information and support need to be met by health professionals to help them to cope positively when such difficulties arise.

However, other participants described very positive experiences. Some felt better almost straight away and their pain was relieved. They were also very appreciative of good care from doctors and nurses, describing this as one of the best things about surgery with terms such as: *'caring', 'understanding', 'informative', 'helpful', 'easily accessible', 'great at explaining my condition'*. In accord with previous research (Sinclair, 2009), mixed experiences with ward nurses postoperatively were also described; opinions of them ranged from excellent, compassionate and caring to the complete opposite. Some ward nurses have previously been perceived to be lacking confidence, lacking knowledge and unsure of what to do (Beitz, 1999, Notter and Bernard, 2006).

Such variation in experiences suggests there may be very different practices in different centres at this early stage in recovery. At this point in the transition, patients are very vulnerable. For most participants in this study, surgery was a new experience so they were reliant on information to help them to understand what had happened and what to expect after the operation. These findings suggest that those needs are sometimes not met, and this may be due to lack of knowledge, particularly among ward nurses, who potentially have an important role in helping patients adjust as they have the most continuous contact.

9.2.4. Moving Through/Moving Out

9.2.4.1. Positive Coping: Assisting Transition

The most important finding to emerge in relation to coping strategies was that these young adults used a variety of mainly positive and active strategies before and after surgery to help them to cope. This finding is consistent with those of previous qualitative studies (Beitz, 1999, Notter and Bernard, 2006, Savard and Woodgate, 2009, Sinclair, 2009) and further supported by Carlsson et al (2003) who found that confronting the problem directly was the most frequently used coping strategy for patients with a stoma.

Participants in Phase 2 used acceptance most to cope after surgery, followed by self-distraction, positive reframing, use of emotional support, humour, active coping, planning, and use of instrumental support, which can all be viewed as positive coping strategies that tend to reduce stress. What is interesting about the findings from Phase 1 is that they provide an insight into how these strategies are integrated and used in everyday life to cope effectively; participants most often used a cluster of activities in multiple situations. They described them with the phrase ‘Getting on with it’ and this incorporated acceptance of the situation by not making an issue of things, self reliance and active coping, doing something to deal with it.

Overall participants used less helpful strategies, which tend not to directly reduce the stress of the situation, less frequently. These included behavioural disengagement, self-blame, religion, denial (ignoring or avoiding) or substance use. The relatively high use of similar strategies has been previously identified as contributing to a poorer quality of life after IBD surgery (Moskovitch, 2000a). This pattern of coping was seen in only one participant in Phase 1, but she stood out as the person who had the most difficult time adjusting to her situation.

Interestingly, the level of parental support had an effect on the coping strategies used by participants. Those with high parental support used more positive reframing, emotional and instrumental support, humour and venting to cope after surgery. Those with low parental support tended to use more behavioural disengagement. This finding suggests that when participants perceive that their parents are not meeting their needs for support, they may have a more difficult transition because they do not make the effort required to adapt to the changes resulting from surgery.

The findings also revealed the importance of adequate pain relief following surgery, so it was surprising that substance use was the lowest reported coping strategy. This category may have appeared to convey a specific and negative meaning to participants as alcohol and drug use were coupled together. One participant wrote a comment on the questionnaire to clarify that she was taking prescribed analgesia and not recreational drugs. This may provide an insight into the interpretation of the two items that made up this category by a larger number of participants; they appeared not to relate it to their need for pain relief. Therefore it is not possible to know the true extent to which participants used analgesia to cope after their operation.

9.2.4.2. Not Alone: Appropriate Family, Partner And Friends' Support Assisting Transition

Adequate social support has previously been found to be an important factor related to quality of life in IBD patients in the months following surgery (Moskovitz, 2000a). However, the findings from this study go further in identifying what types of support were perceived as most helpful and the role of parents, partners and friends in the provision of support. As only about a third of Phase 2 participants had a current partner, most were reliant on support provided by parents and friends. The majority of participants received positive support; what they wanted was what they received, but about 1 in every 7 lacked the support they wanted. These findings suggest that health professionals need to be mindful of the social support that these young people with IBD have around them, through observation and speaking to the patient, as additional support may need to be provided for those in whom this is lacking.

Participants described the support they received from family, partner and friends as one of the best things about their surgery. Previous studies have differed in their reports of the support provided by partners and family; patients with a permanent stoma described them as the best support system (Sinclair, 2009). Women with a temporary stoma varied in the amount of reassurance and support they received from partners, although some helped with stoma care (Notter and Bernard, 2006). Additionally, some patients felt that partners could be unprepared and lack understanding even though they tried to help, because of a lack of support preoperatively from health professionals (Beitz, 1999). Support from friends was not mentioned in the findings from those studies, but insufficient demographic data was provided to be able to determine whether this could be because most participants were older with a stable partner so less reliant on other support. In this study, friends and partners provided the highest levels of support across all six social support categories. Appraisal normalising was the highest perceived social support overall and provided most by friends, suggesting that participants turned more to them after surgery to feel normal and get their lives back; friends seemed to forget that they had had an operation and got less protective as they got better. Friends also said the most reassuring things, and encouraged participants to be independent and live life to the full. Interestingly, it was friends in Phase 2 who provided most straight talking and gave advice when participants were recovering, whereas these were identified by Phase 1 participants as parental roles. Partners provided the highest levels of emotional distraction and emotional listening; they helped participants not to dwell on the operation, distracted them when they were down, used humour to make them feel better and encouraged them to talk about their feelings. Interestingly, the perceived level of parental support was one factor that affected postoperative outcomes. Participants with high parental support had more positive postoperative perceptions of their surgery. This finding may be related to the effect of parental support on coping strategies discussed previously.

In Phase 1, parents had a nurturing role, especially in the early phases after surgery. That they were perceived to provide lower levels of support by Phase 2 participants might be because most had had surgery more than two years ago, so the normalising role of friends was more important in helping them to adapt in the longer term. These young people were also at a stage in their lives when they would naturally be becoming less dependent on their parents, but the severity of their illness before surgery meant that many would have been quite reliant on them for help in their daily lives and they were often too unwell to participate with their friends in social activities. After the operation, as they began to feel better, it is not surprising that they turned to peers to help them adjust and ‘make up for lost time’ as they moved away from the sick role and into living more independent lives.

9.2.4.3. The Role Of Health Professionals

Although this study focussed primarily on the social support that participants received, the findings also provided information on the support provided by health professionals. In Phase 1, participants described their expectations and experiences of the support provided by the physician, surgeon and specialist nurse. Whilst they wanted the physician to continue helping them and the surgeon to provide clear explanations, it was the specialist IBD and stoma nurses who provided emotional support and continuity of care throughout their experience. This contact and helpfulness was also evident in Phase 2 comments relating to the best things about surgery. These findings were similar but more positive than those of adult patients with a stoma in previous work; Persson et al (2005) found patients were satisfied with the attitudes of and treatment by the specialist nurse, but some felt that the dialogue they had in relation to sexual life was less satisfactory. The care provided by the specialist nurse postoperatively was perceived very positively in Phase 1, as previously described in Chapter 5. One omission from the present study was measurement of health professionals' support after the operation. Participants without a stoma or an IAP are reliant on the IBD nurse for specialist nursing care during their recovery. These nurses generally have a medical rather than surgical background, and their role during the patient's surgical journey has not been explored. It would be appropriate to undertake further work, focussing particularly on the role of specialist IBD, IAP and stoma care nurses, to try to identify the nature of their support after the operation and its relationship to patient outcomes.

9.2.4.4. Adjusting To Changes In Body Image: Scarring

The findings from this study revealed how important changes to the appearance of the body consequent to the operation were for these young people, particularly scarring and a stoma. These bodily changes were described as the third worst thing about surgery, after the physical after effects and pain.

Scarring was not found to be a major issue for the young men in Phase 1, but affected young women greatly. In Phase 2, there was no gender difference in post operative body image perception overall (feeling physically attractive, thinking their body looked OK and feeling they had adjusted to changes in the way the body looked) but more young men described being bothered by their scars. Few participants in this study had a laparoscopic procedure, which reduces scarring. Previous work demonstrates that this does not necessarily result in a better body image perception in older adults (Dunker et al, 2001, Larson et al, 2008). However, with their greater concerns about body image and appearance, laparoscopic techniques might have a more positive impact on young adults. Unfortunately, in clinical practice, conventional, 'open' IBD surgery is usually undertaken because disease is extensive, or emergency surgery is required. Many of the participants in this study were in that situation, so it may not be possible to increase markedly the proportion of laparoscopic procedures in this group of young people.

9.2.4.5. Adjusting To A Stoma

The findings showed that one third of all the operations carried out had involved a stoma. In Phase 2, thirty six participants were currently living with a stoma, of which the majority were intended to be temporary. Most of them had been living with a stoma for over two years, with only three participants having one within the previous six months.

In this study, the majority of participants in Phase 2 with a temporary stoma had CD. Twelve IAP procedures involving a temporary stoma had also been carried out, of which three were in CD patients. Previous findings reveal significantly higher anxiety three months after surgery in patients who had a stoma (Bullen et al, 2012). One previous study investigating patients with an established temporary stoma suggested that they experienced significant anxiety afterwards (Knowles et al, 2013b). However, only a minority of patients contacted were included so it is not known if they were representative of the population. The findings from this study also revealed that participants with a stoma did adjust and their feelings change over time. Sinclair (2009) also found that time was an important factor in adjustment for patients with a permanent stoma. Although the proportion of patients with a stoma who had a positive perception of surgery was lower than the proportion of those without, well over half the stoma patients did perceive their surgery positively.

Findings from previous qualitative studies where most participants had a temporary stoma raised as the first stage of an IAP procedure found that few described any adjustment to or acceptance of the stoma (Beitz, 1999, Notter and Bernard, 2006, Savard and Woodgate, 2009). One explanation for this might be that they would have chosen that surgery specifically because they did not want to live with a stoma, so it might be expected that they would have a greater aversion to it. In addition, they could reasonably expect that the stoma would be closed in a relatively short time, once healing had taken place after the initial surgery. Knowing this, they might make little attempt to adjust to its presence, but simply wait out the time until it was reversed. However, the experiences of participants in this study were more similar to those investigated by Weinryb et al (2003). Their patients had had a temporary stoma after first stage IAP surgery for an average of 6.5 months, had made a good psychosocial adjustment and also had a good subjective sense of well being.

In common with previous work, this study found that young women experienced greater distress at the presence of a stoma in the early months after surgery, making clothing changes to hide the stoma, feeling upset and with decreased self confidence (Beitz, 1999, Notter and Bernard, 2006, Savard and Woodgate, 2009). Bullen et al (2012) also reported that women with a stoma had higher body image disturbance than non stoma patients at 3 months after surgery. That finding probably indicates that adjustment to body image changes following stoma formation takes longer than 3 months. This was evident in the Phase 1 findings which were supported by the work of da Silva et al (2008) who found that body image in women improved slightly at 6 months following stoma formation and continued to rise in the following six months. The women in that study did not have a poorer body image than those who had surgery without one.

9.2.4.6. Adjusting To Operations That Restored Intestinal Continuity

All the small bowel resections and all but one of the large bowel resections were undertaken for CD and together these operations accounted for over a quarter of the operations carried out. Large bowel resections commonly involved removing either the right side of the colon or the sigmoid colon and restoring bowel continuity with an anastomosis. Operation on the small bowel usually employ a limited resection to remove a scarred, fibrosed or strictured bowel segment that was causing obstructive symptoms followed by anastomosis (Van Limbergen et al, 2008). The advantage of these procedures is that bowel continuity is restored, because defaecation can occur in the normal way. However, loss of any, or all, of the colon, will result in bowel function that is more frequent and less formed than that of a normal person. IAP surgery is more complex than a large bowel resection, as some small bowel is fashioned to create a pouch or reservoir to store faeces, with the intention of reducing frequency.

In this study, participants who had a bowel resection without a stoma had the highest overall perception of surgery, with over three quarters of them perceiving it positively. There was also no relationship between their preoperative concerns and positive perceptions following the operation. This finding suggests that much of the preoperative anxiety in this group of patients was related to the possibility of having a stoma. Once this fear was not realised, and with symptomatic improvement, they felt well and their lives improved. da Silva et al (2008) found that health status was better than baseline within the first six months after surgery but did not improve further after a year. Those patients who had abdominal surgery (small or large bowel resection) recovered faster physically than those who had a pelvic resection (IAP). This is not surprising, because the latter surgery is more extensive. Improvement in quality of life has also been found for this group of patients in previous studies and mainly appears to relate to the absence of disease. Delaney et al (2003) described an almost immediate improvement in energy level, happiness and quality of life a month after surgery, especially for those who had previously been on steroids. In the medium term, Thirlby et al (2001) also identified improvements in quality of life for CD patients 16 months after bowel resection although most were slight, and did not reach those of the general population, the exceptions being mental health and bodily pain. Compared with preoperative scores, patients in Tillinger et al’s (1999) study had early improvements in quality of life and these were sustained 2 years after surgery for those patients still in remission. However, CD patients are not cured. In the longer term it is possible their disease may return. Participants with CD in this study were aware of this and voiced concerns about whether the benefits of surgery would last. This was a realistic worry; Thaler et al (2005) reported that 38% of patients had recurrent disease at an average of 42 months after surgery and it was this that impacted on quality of life, which was lower than that of the general population. Similarly, Moskovitz et al (2000a) identified current IBD symptoms as a major factor affecting quality of life after bowel resection.

Interestingly, the study findings revealed that participants without a stoma, who had spoken to the specialist IBD or stoma nurse before surgery, had a much more positive perception of the operation. This effect was not seen when they spoke to their family. This suggests that specialist nurses provide the patient with something that families cannot- accurate information about their surgery, the relative risk of having a stoma, and also reassurance that they would be able to help them to cope if one was necessary.

In Phase 2, three patients had undergone IAP surgery as a single procedure. A further 12 had had staged IAP surgery, with two first stage operations carried out in the last 6 months. One IAP had been excised. There were therefore twelve patients living with a functioning IAP. The difference between these patients and those who have other operations to restore intestinal continuity is that the majority have UC, the whole of the colon is removed, the small intestine is used to create a ‘pouch’ to replace the excised rectum and store faeces and the operation is curative.

Participants in Phase 1 described a lack of bowel control in the early stages of living with a functioning IAP, and how they needed to adjust to changes in the way the bowel worked. Although an IAP enables the patient to defaecate in the normal manner, changes in stool consistency and frequency of defaecation result from this surgery so bowel function may never be ‘normal’ in these patients. In previous research, in the long term, slightly less than half IAP patients are reported to be more satisfied with their bowel function after the operation (Andersson et al, 2011). On average patients needed to open their bowels 6 times a day and once or twice at night (Dunker et al, 2001, Wuthrich et al, 2009). There can be varying degrees of faecal soiling and Loperamide may be needed to achieve better control and decrease frequency of bowel movements (Cornish et al, 2012, Andersson et al, 2011). Although the experiences of IAP participants were not analysed separately from those of those patients who had operations to restore intestinal continuity, overall perceptions of physical recovery for all participants were less positive than other outcomes, with the exception of body image. This outcome included perceptions of adjustment to changes in the way the bowel worked. Thirlby et al (2001) found that IAP patients had not fully recovered physical health 5 months after surgery even though other aspects of quality of life were by then very similar or better than those of the general population and similar findings were reported in female patients after pelvic surgery by da Silva et al (2008). It is reasonable to infer that IAP patients in Phase 2 of this study would have a similar pattern of recovery, affected by the changes in bowel function.

9.2.4.7. A Difficult Transition: Adjusting To Recurrent Perianal Fistula Surgery

One group of patients who had difficulty adjusting to surgery emerged from the findings in Phase 1. These were young women with CD who had multiple operations involving seton insertion for perianal fistulae. They expressed frustration at the uncertain and unpredictable course of recovery and lack of definitive treatment. They also experienced similar problems before and after surgery- intense pain, malodorous leakage of pus and faeces due to the inserted seton stitch which could only be contained by pads. In addition they felt stuck in a cycle of recurrent disease and multiple operations which were hard to adjust to. There were no young men in Phase 1 in a similar situation. It was also not possible to verify these findings in Phase 2 as respondents were asked only state how many operations they had had and to consider their last operation when completing the questionnaire.

Information from limited previous studies does support these findings and reveals that patients with recurrent perianal fistulae are less satisfied with the outcome of surgery. Anal incontinence and soiling of underwear affected satisfaction with physical, social and sexual activity and dissatisfaction increased with the severity of faecal incontinence (Garcia-Aguilar et al, 2000). Similarly, Mahadev et al (2011) found that quality of life was most adversely affected by anal pain, faecal incontinence and anal discharge associated with the presence of a seton. Women were also affected by emotional aspects such as feeling unclean, self image and confidence to go out. In the most recent study, although sexual behaviour and function were not affected in patients who had had surgery for a perianal fistula, Riss (2013) also found that women had a significantly decreased quality of life in comparison with healthy controls. Anal incontinence was the key factor affecting quality of life. Other factors that were related to a worse quality of life were loose seton drainage, a complex fistula, active disease and continuing perianal problems. The last three factors make it more likely that more than one operation will be required and it was found that overall satisfaction was lower in those patients who had had multiple operations. A good indication of the amount of distress these patients suffer was disclosed by Kasparek et al (2007). This study investigated quality of life in CD patients who underwent stoma formation for perianal fistulae. Eighty percent reported better quality of life after this surgery with few restrictions on everyday life and almost all indicated that they would opt for diversion again.

In comparison with abdominal surgery for CD, an operation for perianal fistulation is minor and usually carried out as a day case procedure. Patients return to their homes for recovery and can live with a seton for months or years with outpatient appointments at intervals of several months to check that the seton is still in place and draining freely. However, the consequence of successful surgery (free drainage of the fistula) results in the continuation of symptoms that most negatively impact quality of life, especially for women. Overall, these findings indicate that it is extremely unlikely that this group of patients will manage a successful transition through surgery; their symptoms have not resolved and their quality of life has not improved. This is an area that warrants further investigation and also consideration of current practice to see if additional professional support and better pain control can help to improve the situation for these patients.

9.2.5. Moving Out

Schlossberg (Goodman et al, 2006) describes Moving Out as the final phase of transition, in which new roles are established and the old ones left behind, but this phase can also constitute a new beginning. A new beginning was evident in the experience of most of the participants in this study as the hopes and expectations that they had before surgery were realised. The most important clinically relevant findings were that the majority of participants were no longer sick young people; they felt better after their operation and their daily life improved. Health professionals who care for young adults with IBD faced with the prospect of surgery need to share this information to help to allay some of their fears and concerns. These findings also demonstrate the importance of enabling young people to meet those who have had previous surgery, so they can benefit from authentic information based on personal experience.

9.2.5.1. Recovery Of Physical Health

Most participants stated that their improvement in physical health was the best thing about surgery: *'Having more energy.' 'No flare ups.' 'I look healthier' 'I can do all the physical activities I want to.'* A dramatic improvement in physical health early after surgery has previously been reported (Delaney et al, 2003). After the operation, CD patients are free from the symptoms of disease, and those with UC have been cured. One interesting finding from this study was that, in the longer term, physical recovery was not complete, even though most operations had taken place over two years ago; recovery of physical health was actually rated lower than perceptions of surgery and psychological recovery. This category included ratings for feeling better, feeling healthier, being able to do anything they wanted to and if they felt they had adapted to changes in the way that their bowel worked. The lower rating may in part be reflective of the high proportion of patients with CD in the study, where surgery is not curative.

Previous research has also found that CD patients have a lower quality of life in relation to physical function after surgery and this appears to be related to disease recurrence (Thaler et al, 2005). Abnormal bowel function can affect quality of life in the long term. For those patients with an IAP, as described earlier, bowel function will never be normal and a poorly functioning pouch can markedly affect the ability to lead life to the full; Andersson et al (2011) identified that frequency of night time defaecation, faecal incontinence and urgency continued to affect IAP patients several years after surgery and these were all related to poorer quality of life. Night time frequency also had a negative effect on social function, mental health, vitality, bodily pain and general health scores, particularly in women.

Pain relief was clearly related to health and lifestyle improvements and was described as the third best thing about surgery *'The pain has been taken away.' 'No more constant pain on my left side.'* Improvement in bodily pain following abdominal and pelvic IBD surgery has previously been reported for both UC and CD patients from the early months after surgery to long term (Thirlby et al, 2001, Kuruvilla et al, 2012). Men appeared to have less pain than women after their operations (Brandsborg et al, 2013). However, as described previously, after surgery for perianal fistula, pain continued for participants in this study and Mahadev (2011) identified this as the factor that most frequently impaired quality of life, particularly in women.

In common with previous qualitative findings (Savard and Woodgate, 2009. Beitz, 1999), participants in Phase 1 described lives before surgery which were dominated and restricted by their illness. After the operation, their improvement in physical health enabled them to start living normally again. Good health has previously been reported as the most important factor in contributing to postoperative quality of life in IAP patients (Berndtsson et al, 2011). 'Getting my life back' was described by participants in Phase 2 as the second best thing about surgery. This extended to all areas of their lives: *'Less hospital visits, socialising normally.' 'It improved my lifestyle massively.' 'Able to have a career now and not be off sick most of the time'.* This finding was supported by multiple previous studies in which quality of life in patients was compared before and after surgery; improvement was reported in IAP patients (da Silva et al, 2008, Davies et al, 2008, Wang et al, 2011, Weinryb et al, 2003), those with a stoma (Wang et al, 2011), patients who underwent bowel resection (Thirlby et al, 2001, Delaney et al, 2003, da Silva et al, 2008) and perianal fistula patients who had had a stoma (Kasparek et al, 2007). Similar findings were described for patients with a permanent stoma (Sinclair, 2009) and IAP patients (Beitz, 1999, Savard and Woodgate, 2009) in qualitative work.

9.2.5.2. Psychological Recovery

Not surprisingly, with these positive changes in health and lifestyle, the majority of participants also made a good psychological recovery. They described feeling like a normal person, felt they had adjusted well to the surgery and described themselves as happier, more self confident and outgoing. In the process of adjusting to their surgery, they went through changes in the way they thought about the operation and themselves.

Similar positive findings in relation to emotional and mental health have been found in multiple previous studies where older patients have had surgery for IBD. Most reported improvements in IAP patients in the short and medium term (Dunker et al, 2001, Thirlby et al, 2001, Wang et al, 2011, Wuthrich et al, 2009). However, mental health was not as good as that of the general population in those living with an IAP for an average of 12 years (Andersson et al, 2011). Men and women were found to have an increase in mental and emotional health (Wang et al, 2011) but male patients appeared to have a greater improvement (Brandsborg et al, 2013). Following stoma formation, both men and women experienced improvements in emotional and mental health 6 months after surgery (Wang et al, 2011). Patients were happier within 30 days of bowel resection (Delaney et al, 2003). Positive changes in emotional and mental health in UC patients following bowel resection have also been reported but these changes appear to be smaller for CD patients (Thirlby et al, 2001, Thaler et al, 2005. This may in part be due to continued worries about, or the recurrence of, disease. Women appeared to be more affected by the emotional aspects of perianal fistula surgery such as feeling unclean, emotional distress and lack of confidence to go out (Mahadev et al, 2011), as described by participants in Phase 1 of this study.

Participants tried to maintain a positive attitude and not let the after effects of the operation get them down, even when things went wrong. They also demonstrated resilience- they did have transient low points, but these did not last. In previous work, depression was shown to improve in the early months after bowel resection for CD and remained so for those in remission two years after the operation (Tillinger et al, 1999). However, in contrast to the participants in this study, Knowles et al (2013b) identified probable or severe depression in stoma patients who had surgery on average one year previously. Notably, most of them had ongoing problems with the stoma and strong memories of problems from the outset. It would be difficult for patients to feel positive in this situation. The young women in this study did describe emotional distress in the early months after stoma formation, in accord with Bullen et al’s (2012) findings; they reported more depression in stoma than non stoma patients at three months following surgery. However, with such a profound change to body function and appearance, it is to be expected that emotional recovery would take some time for these patients and not be achieved within this short time frame. This findings from Phase 1 of this study demonstrated that time was a significant factor in the transition towards stoma acceptance and they are supported by Sinclair (2009).

The findings from this study also provided information about the things young people do to help them to adjust mentally and emotionally to their operation and move through the transition. One important helpful factor was a perception of the positive changes the operation had made to their lives. Participants frequently did cognitive work, mainly in the form of positive reframing as also described in previous qualitative literature (Beitz, 1999, Notter and Bernard, 2006, Savard and Woodgate, 2009, Sinclair, 2009). Phase 1 participants described comparing their lives and state of health before and after surgery, and comparing themselves to others they perceived as less fortunate; they could perceive surgery as a benefit, even with a stoma. This positive perception of surgery is important because the findings in Phase 2 revealed it was associated with a more positive perception of body image, better recovery of physical health and better psychological recovery.

Participants' perceptions of themselves also could change, as they felt that their experience had helped them to gain personal strength, feel normal again or grow as a person. Similar findings, that participants felt that they had become a better person or had matured as a human being from the experience of surgery, were identified in previous research (Savard and Woodgate, 2009). In the present study, recognition of these positive changes helped participants to get through surgery as they knew they could draw on their determination and inner strength.

What is also evident from the study findings is that the young people who successfully transition through surgery do new learning that helps them to cope: they learn about the operation and what will happen to them, they learn from the experiences of others, they learn new ways of thinking about what has happened to them which help them to see the surgery in a positive light and they learn practical ways of dealing with new or difficult situations.

9.2.5.3. Body Image Perception

In this study, body image perception was the least positively rated outcome of surgery for all patients. Body image was a major concern for most of these young people through the whole of their surgical journey and their biggest concern before their operation. Concerns about body image and high levels of anxiety before surgery were related to a less positive body image perception afterwards among those with a stoma, indicating that this group of patients may need skilled intervention before their operation to help them cope with the changes subsequently imposed by surgery. In relation to this, participants who spoke to their family to help them prepare had a less positive body image perception postoperatively, suggesting that the family doesn't have the skills that the specialist nurse has, for specific interventions to help patients to adjust to their body image. Also, family may say comforting things to help make them feel better like 'we're going to love you, whatever you look like,' which don't actually acknowledge the depth of their concerns or help them to address the issue.

Although much anxiety centred on the prospect of a stoma, it was not limited to this and participants were also bothered by scarring. Body image changes were cited as the third worst thing about surgery, after pain and complications, with participants commenting: *'Adapting to how my body looks now.' 'Having to hide bag under my clothes.' 'Adapting to having a stoma* bag - *ongoing problems, leakage etc.' 'Scars. The way my body looks'. 'The permanent scars.'* After the operation, body image concern was higher among women and those who had a stoma, although young men were more bothered by their scars

Much adjustment to the effect of a stoma on body image necessarily takes place following discharge home. This is not surprising, as early after the operation, patients are trying to master the practical skills of stoma care. Competence in stoma management is a requirement before patients can be discharged; with reduced length of hospital stays, this learning occupies patients with a new stoma more than issues of psychological adjustment. Previous research has identified that 3 months after surgery patients with a stoma have a high body image disturbance (Bullen et al, 2012) and that this actually worsened over time. da Silva et al (2008) also reported that postoperatively, in women a more positive body image was associated with those over 40, who had better mental health and better sexual function.

An important issue related to altered body image in participants with a stoma emerged in the findings from Phase 1 that is probably more pertinent to young adults than older people. This involved dating and disclosing a stoma to potential partners. Young men with a temporary stoma put dating on hold until it was closed. Still adjusting to changes in the way their body looked, concerned about their physical attractiveness and making efforts to avoid revealing the presence of a stoma, women in particular were concerned about rejection. Although this fear was usually not realised, it is noticeable that only a third of all participants in Phase 2 actually had a current partner. It is possible that their focus could be on other aspects of their lives. However, the low rating for this particular outcome in Phase 2 suggests that for some time after surgery, participants may not be positive or confident enough about their bodies to risk developing close relationships with others, particularly where stoma disclosure is a possibility. As one young woman stated in Phase 1: '*I'd rather not find out whether it would actually be all right or not... I don't think I want to find out...I would hope...soon I will be ready but at the moment it scares me too much'.* Therefore, besides pre and postoperative intervention, stoma nurses should provide continuing care for some time after patients have physically recovered. Body image changes are probably harder to come to terms with in younger adult patients and without ongoing specialist nursing support they may have more difficulty adjusting to this aspect of surgery.

9.2.5.4. Perceptions of Surgery

Despite some continuing difficulties in adjusting to altered body image, most participants had a positive perception of the surgery itself and didn't regret having it. They also felt positive about, and felt that they could make plans for, the future. Regardless of patient characteristics (gender, timing of surgery, disease type, with or without a stoma) respondents were more likely to have positive overall perceptions of surgery although notably, patients who did not receive a stoma had the most positive perception. Participants with and without a stoma, particularly young women, who spoke to the specialist nurse before the operation had more positive perceptions of their surgery, demonstrating how important it is that for them to have this opportunity.

In Phase 1, there were disease specific differences in the way that participants with CD and UC perceived the outcome of their surgery; those with UC knew it was curative and any stoma was only temporary, so once they had recovered from surgery, the transition was complete and they could lead normal lives in relation to appearance, activity and function. In contrast, those with CD were more uncertain. They knew the disease could return, and might necessitate further surgery. Furthermore, they could have a 'temporary' stoma for a prolonged period of time, and disease infiltration could prolong wound healing indefinitely. Notably in Phase 2, most of the participants who had had four or more operations for CD had a negative perception of surgery indicating that some of these patients might never be able to put the experience of surgery behind them, because they continued to be affected by the consequences.

Interestingly, when differences between groups were examined, the findings revealed that patients with UC in Phase 2 had the lowest overall positive perceptions of their surgery. There is no simple explanation for this finding. However, previous research suggests that severity of symptoms before IAP surgery is related to postoperative perceptions; patients with very bad symptoms were very pleased with the outcome whereas those with less severe symptoms can view the prolonged recovery as worse that their previous situation (Beitz, 1999). Some in this group were living with a temporary stoma as part of an IAP procedure. Although their reactions to this were less negative than previously described in some of the literature (Beitz, 1999, Notter and Bernard, 2006, Savard and Woodgate, 2009), they were still ‘waiting out’ the time until it was closed. Also, the perceptions of surgery of those with a functioning pouch may be related to their altered bowel function. It has previously been reported that slightly less than half IAP patients are more satisfied with their bowel function after the operation (Andersson et al, 2011).

The study findings revealed specific factors in Phase 2 that differentiated participants with a negative or a positive overall perception of surgery. These were the level of pre-operative anxiety, speaking to the specialist nurse to prepare for surgery, the rating of preparation activities that helped, the use of five coping strategies, and ratings on all four post-operative perceptions of surgery.

Participants who had a negative perception of surgery had higher pre-operative anxiety and spoke less frequently to the specialist nurse. They found researching the operation, speaking to health professionals, family, friends, and other people who had had the surgery less helpful in preparing for their operation. These participants coped less well, using more self-blame, denial and substance use, less acceptance and less active coping. They also had significantly worse perceptions of the individual surgery outcomes. This group contained a higher proportion of participants with a stoma, which suggests that negative perceptions of surgery are more likely with this operation.

In contrast, most participants with an overall positive perception of surgery had lower pre-operative anxiety and spoke more to the specialist nurse about the surgery. They found it helpful to research the operation, and speak to health professionals, family, friends, and other people who had had the surgery. These participants used more acceptance and active coping and less self-blame, denial and substance use in coping postoperatively. They also had significantly better perceptions of the individual surgery outcomes.

These findings demonstrate how multiple factors can influence perceptions of the outcome of surgery. This information is useful because it can be used to help identify more vulnerable patients who might have particular difficulty adjusting to surgery and successfully completing the transition. The presence of more participants with a stoma in the group with negative perceptions suggests that health professionals, especially the specialist nurse, need to be aware of the associated factors that appear to contribute to a negative outcome and work with these young people to help them to prepare appropriately, engage the right support and implement helpful coping strategies to try to improve their experience of surgery.

9.3. THE STRENGTHS OF THIS STUDY

This study has added to our knowledge of the experience of surgery in patients with IBD by being the first to explore the perceptions and experiences of young adults. It is also the first to explore the experience of surgery as a transition, using Schlossberg's Transition Theory (Goodman et al, 2006) as an integrating framework that underpinned questionnaire development and the organisation and analysis of findings. This approach enabled the researcher to comprehensively explore the influence of contextual, situational and personal factors, support and coping strategies on young adults with IBD who had surgery for their condition. The study also explored multiple perspectives by revealing differences between sub groups of patients undergoing surgery- those with CD or UC, male and female, emergency and non emergency surgery and participants with and without a stoma, all of which had the potential to influence participant perceptions of their surgery and their transition through it.

The researcher's experience as a practitioner was also a strength as insights from practice helped to inform the study design and rapport was successfully established with participants to enhance the quality of the interviews. Experience as a practitioner also added credibility to the findings as analysis, interpretation, discussion and recommendations were grounded in knowledge of the real world of IBD patients and surgical practice.

Two further strengths of the study were, firstly, the supervision by a research management team from inception of the study to its completion which included two academics with expertise in both qualitative and quantitative methods and a consultant gastroenterologist. This team provided the researcher with guidance and support, particularly in the management of difficult issues such as reconceptualising the study and sample size in Phase two, to ensure that pragmatic decisions could be made by the researcher without compromising the integrity of the study. Secondly, the involvement and advice of medical and nursing gastroenterology specialists also assisted in the development of the survey questionnaire as they brought the benefit of their considerable experience to the consideration of its appropriateness, focus, scope and acceptability to their suggestions for improvement.

9.4. METHODOLOGICAL LIMITATIONS OF THE STUDY

Two limitations of this study are its complexity and the length of time it took to complete; the decision to carry out a multi centre survey required the researcher to obtain approval from the

Research and Development department at each individual centre, which in most cases took over 6 months, although one centre took 14 months before approval was given. Also, specialist nurses or IBD research nurses had the responsibility of recruiting patients to the study and administering the questionnaires, which meant that the researcher had no control over this aspect of the study. Mindful of the nurses' goodwill in undertaking these tasks in addition to their clinical commitments, although the researcher did keep in regular contact, she found it difficult to 'chase' but mainly offered encouragement and support. Data collection for Phase 2 was therefore protracted and the target sample size of 300 advised by the statistician was not achieved after 15 months of data collection. These difficulties make it likely that a replication study will not be possible.

Further limitations relate to the potential for bias in the sample selected and in sample responses. Participants were recruited from seven centres, but five of these were tertiary referral hospitals running adolescent/young adult clinics so it may be that these patients had more severe disease and complex operations than those treated in local hospitals whose experiences may not be comparable. The researcher instructed the recruiting nurses to invite sequential potential participants to complete the questionnaire when they attended clinic so that everybody who fitted the selection criteria within the time frame could participate until the target sample was reached to decrease the risk of bias in recruitment at each centre. However, further risk of a biased sample arose when, for pragmatic reasons, questionnaires at two participating sites were sent out by post. The response rate after a reminder and second posting was still low, and it is possible that those who responded had either very good or very bad experiences. The researcher attempted to identify any differences by comparing perceptions of surgery between this sub group of postal responders and the main sample but could not detect any difference. This study was also at risk of bias because it was retrospective, relying on the recall of participants, most of whom had had surgery more than two years ago. It is possible that recollections of difficult or distressing events would be more vivid, so their responses might not accurately reflect the whole of their experience but most of them did recount positive experiences, as was the case with the Phase 1 participants, so this would appear not to be the case.

9.5. RECOMMENDATIONS FOR FUTURE RESEARCH

A number of possible further research studies could be undertaken, to expand on the findings from this study:

1. Further refinement and testing of the measures used in this study would be appropriate; most of the new scales demonstrated adequate reliability, but several had only a few items, which

undoubtedly affected the rating (Jonason & Webster, 2010). Review of the findings from Phase 2 could generate appropriate additional items for inclusion and subsequent testing. Also, the Brief COPE (Carver, 1997) had originally been chosen in preference to other coping measures for its brevity and ease of completion as a subsection of a larger questionnaire. When it was in use, the ‘substance use’ items in the scale appeared to have been perceived by participants as negatively loaded (‘I've been using alcohol or other drugs to make myself feel better’, ‘I've been using alcohol or other drugs to help me get through it’). Most of them would have used analgesia to control pain, but most did not interpret the statement in that way and it was the lowest used of all the coping strategies. Because of this, a different measure of coping other than the Brief COPE could be evaluated for its suitability for inclusion, or a new scale developed and tested, based on this study’s findings.

2. There was no scale measuring the support of health professionals in this study. Its inclusion was considered, but as the researcher was concerned about the length of the questionnaire, only parent, partner and friends’ support scales were finally included. The study findings revealed how very important health professionals’ support was for these young people and this warrants further investigation, particularly into the role of the specialist nurse to try to identify the nature of their support after the operation and its relationship to patient outcomes.

3. It would be very difficult to conduct a replication study for the reasons outlined above, but further insight into the experience of transition in this patient group could be carried out to identify changes in self, support, coping strategies and perceptions over time in a prospective longitudinal study. Since the current study did not specifically reference ethnicity, but differences in perception were apparent, particularly in Asian patients, the sample should include participants from this and other ethnic groups.

4. The current study revealed an association between high levels of preoperative anxiety and fear and postoperative perceptions of surgery. In addition, participants reported uncertainty during the whole of their surgical experience and uncontrolled pain. There is scope here for a series of action research studies to address these issues, with the potential to improve clinical practice.

5. The findings from this study could be used to develop new informational resources specifically for young adult patients who have IBD surgery addressing common concerns, preparation for and adjustment to surgery to improve their experience. These could be piloted

among a group of young adult patients to evaluate their effectiveness using focus groups or one to one interviews.

9.6. PRACTICE RECOMMENDATIONS

1. The specialist nurse should be involved in outpatient clinics and MDT meetings at which treatment planning decisions are discussed as she is the health professional who is most likely to be aware of patients' concerns and provide emotional and practical support before surgery.

2. Patients should be offered contact with other people who had undergone similar surgery. Recovered patients matched by gender can act as positive role models and have a normalising effect, either meeting in person or talking by phone, Skype or the Internet. This could be facilitated by the specialist nurse, who should also prepare local volunteers and provide information on suitable and reliable Internet sites/blogs e.g Ostomystory, Inflamed and Untamed, J pouch life.

3. Strategies to reduce preoperative anxiety should be implemented. Information giving and teaching should include aspects such as pain, recovery time and possible complications, particularly for young women who worry more about possible after physical after effects of surgery.

4. The checklist of preoperative concerns could be easily adapted for all patients to provide a starting point to encourage discussion, especially with young adult male patients who tend not to articulate their concerns, so their anxiety is less visible. Kept in the patient's notes, this could be referred to by all MDT members to ensure individual concerns are being addressed.

4. The surgical IBD and Pain teams should consider auditing pain relief practices to identify if improvements are needed. On an individual level, assessment of pain and the effectiveness of pain relief strategies could include asking the patient to complete a simple assessment tool (such as noting pain intensity on a scale of 1 – 10). Where there is ineffective pain relief, a specific member of the surgical team should be identified as responsible on each occasion to liaise with the pain team to ensure they can act to remedy this.

5. Better communication about progress following surgery, whether everything is proceeding as planned and if the patient is meeting expectations for recovery could easily be incorporated into the morning ward round to reduce uncertainty. Information given should be documented in the

patient's notes so that the specialist nurse and ward nursing staff can follow this up with the patient to ensure it has been understood.

6. The boundaries between specialist nurse and ward nurse roles should be examined, as the specialist nurse cannot be available seven days a week, to ensure there is continuity of care, particularly in areas of new learning such as practical stoma management.

7. There is no specialist nurse with specific responsibility for patients with CD, who have the most surgery, unless it involves a stoma. The IBD nurse should have continuing involvement with this group of patients after surgery. Regular contact by telephone, to identify problems with pain relief and to offer support and reassurance may help them to cope better after the operation and have less negative perceptions.

9.7. RECOMMENDATIONS FOR EDUCATION

1. Ward nurses should be offered continuing informal education so that they can be fully involved in supporting patients after surgery. This should include the surgery itself and its effects, patients' needs for information and support and practical stoma care.

2. Information and education should be provided for parents and partners so they can help to promote recovery. This should include the need to decrease protection and encourage independence and practical ways to assist in recovery. The specialist nurse should offer individual guidance to families who find it difficult to 'let go'.

3. The specialist nurse should ensure young people are aware that they have to be actively involved in their own preparation and recovery to achieve a better outcome. She should also help them to identify their needs for information and learning, to locate appropriate resources and to explore and utilise the coping strategies that have been found to be most helpful in promoting adjustment to surgery.

4. The researcher should use the findings from this study to help young adults with IBD who face the prospect of surgery learn from the experiences of others by working with Crohn's and Colitis UK to produce a web based educational resource.

9.8. CONCLUSION

The purpose of this mixed methods study was to explore the experience of young adults with IBD who undergo surgery for their condition. The conclusions from this study follow the main research questions and the findings. This study aimed to fill a gap in the literature because it is the first to investigate the experience of surgery in a large group of young adults who have IBD, to conceptualise IBD surgery as a transition and to comprehensively explore the influence of contextual, situational and personal factors, support and coping strategies on that transition.

It appeared that the study achieved the primary aim of identifying the factors and experiences that affected these young adults as they tried to cope with and adjust to their operations and differing experiences of transition. More specifically, Schlossberg's (Goodman et al, 2006) Transition Theory acted as an effective organising framework through which to understand their experience; the 4S system (Situation, Self, Support, Strategies) facilitated the identification of specific factors that helped and hindered the transition. The framework's phases (Approaching the Transition, Moving In, Moving Through, Moving Out) captured the changes that occurred in participants and in their lives as they moved through the surgical journey and adjusted to their operations. This provided a new way of understanding IBD surgery and its effects in a patient group that has not before been specifically investigated.

From the findings it can be concluded that whatever the type of operation, most participants viewed their surgery positively. They moved out of a life that was dominated by illness and became well. With the return of physical health, they started to live normally again. Normal life was more difficult to resume for some participants than others, most particularly those who had to adjust to a stoma. Most participants thought positively about their surgery when they first heard of it because they knew that their disease was out of control. However, they had many worries and concerns before the operation, which mainly centred on body image and particularly the prospect of a stoma. They were also often anxious and this was made worse by lack of information. They generally actively prepared for their operation in ways they perceived as helpful. Participants also usually received positive support from family, friends and partners and used appropriate coping strategies after the operation. However, fear, worry and uncertainty, continuing symptoms, body image concerns, lack of or inappropriate support and ineffective coping strategies hindered the process of transition. Throughout their experience, the specialist IBD or stoma nurse was the key health professional who helped participants to adjust to and cope with their surgery.

The findings from this study should lead to a better understanding of the surgical experience in young adults with IBD as it reveals their specific concerns, perceptions and needs. This information can inform health care practitioners and enable them to provide appropriate information, care and support for young IBD patients who have surgery in the future.

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APPENDIX 1. Table 2.1: PIO INCLUSION AND EXCLUSION CRITERIA MODIFIED FOR THIS STUDY

	Inclusion criteria	**Exclusion criteria**
Population	Adults aged 18 years and over Confirmed IBD: Ulcerative colitis OR Crohn's Disease Pre or post IBD surgery Surgical Intervention: Any type of surgery for IBD symptoms (bowel resection, ileoanal pouch, perianal surgery, rectal surgery, stoma formation Male and female Any ethnicity	Children and adolescents (< 18 years of age) Over 50% of participants are older adults, aged 60+ years Underlying condition of patient is not stated Type of stoma not stated Over 50% of patients have a cancer diagnosis Age of sample is not specified Mixed samples (e.g., combined IBD/non IBD patients) with less than 50% IBD patients Studies on urostomists
Study Design/Publication	Qualitative studies Questionnaire surveys Educational, psychosocial Intervention studies Comparative studies Prospective cohort studies Pre-post studies Cross-sectional and longitudinal study designs English language Peer-reviewed journal Dated 1999 to 2014 (last 15 years)	Pre-post intervention studies that evaluated only surgical techniques and technical outcomes Comparison of surgical techniques Narrative review Assessment of surgical safety Validation of a new instrument
Outcomes	Qualitative Outcomes Experiences of IBD surgery Experiences of Stoma Experiences of ileoanal pouch Quantitative/Qualitative Outcomes Experience; quality of life; patient concerns; pre-operative anxiety; illness perceptions; preparation for surgery; outcome; follow up; satisfaction; recovery; adjustment; adaptation; satisfaction; social support ; coping; physical and mental function: sexual function; body image; quality of care; decision making	Results for urostomists and bowel stomas analysed together Results for IBD and non IBD patients analysed together

APPENDIX 2 . SEARCH STRATEGY

PUBMED		Search 1: 3.4.2010	Search 2: 8.3.2014
Limiters - English Language; **Expanders** - Also search within all fields of the articles. **Search modes** - Boolean/Phrase		Publication dates	Publication dates
SEARCHES		1.1.1999 – 3.4.2010	4.4.2010 – 8.5.2014
1	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND experience[All Fields]	192	94
2	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND ("perception"[MeSH Terms] OR "perception"[All Fields])	18	11
3	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND ("social adjustment"[MeSH Terms] OR ("social"[All Fields] AND "adjustment"[All Fields]) OR "social adjustment"[All Fields] OR "adjustment"[All Fields] OR "adaptation, psychological"[MeSH Terms] OR ("adaptation"[All Fields] AND "psychological"[All Fields]) OR "psychological adaptation"[All Fields])	23	20
4	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND outcome[All Fields]	824	503
5	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND follow up[All Fields]	677	332
6	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND concerns[All Fields]	33	11
7	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND ("anxiety"[MeSH Terms] OR "anxiety"[All Fields])	11	6
8	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND ("personal satisfaction"[MeSH Terms] OR ("personal"[All Fields] AND "satisfaction"[All Fields]) OR "personal satisfaction"[All Fields] OR "satisfaction"[All Fields])	73	19
9	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND recovery[All Fields]	86	40
10	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND ("physiology"[Subheading] OR "physiology"[All Fields] OR "function"[All Fields] OR "physiology"[MeSH Terms] OR "function"[All Fields])	642	291

PUBMED		Search 1: 3.4.2010	Search 2: 8.3.2014
Limiters - English Language; **Expanders** - Also search within the full text of the articles. **Search modes** - Boolean/Phrase		Publication dates	Publication dates
SEARCHES		1.1.1999 – 3.4.2010	4.4.2010 – 8.5.2014
11	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND ("quality of life"[MeSH Terms] OR ("quality"[All Fields] AND "life"[All Fields]) OR "quality of life"[All Fields])	246	115
12	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND ("body image"[MeSH Terms] OR ("body"[All Fields] AND "image"[All Fields]) OR "body image"[All Fields])	15	10
13	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND "coping"[All Fields]	7	0
14	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND support[All Fields]	447	296
15	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND (ileoanal[All Fields] AND pouch[All Fields]) OR ("proctocolectomy, restorative"[MeSH Terms] OR ("proctocolectomy"[All Fields] AND "restorative"[All Fields]) OR "restorative proctocolectomy"[All Fields] OR ("restorative"[All Fields] AND "proctocolectomy"[All Fields])) OR (("colonic pouches"[MeSH Terms] OR ("colonic"[All Fields] AND "pouches"[All Fields]) OR "colonic pouches"[All Fields] OR ("ileal"[All Fields] AND "pouch"[All Fields]) OR "ileal pouch"[All Fields]) AND anal[All Fields] AND anastomosis[All Fields]) OR IPAA[All Fields]	1688	
16	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND “ileoanal” [Title] AND “pouch” [Title]) OR "restorative proctocolectomy"[Title] OR "ileal pouch"[Title] AND “anal” [Title] AND “anastomosis” [Title] OR “IPAA” [Title]	319	155
17	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND "stoma"[Title] OR "ostomy"[Title] OR "colostomy"[Title] OR "ileostomy"[Title]	790	6
18	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND perianal [Title] AND "fistula"[Title] OR ("rectal fistula"[Title] OR ("anal"[Title] AND "fistula"[Title]) OR ("rectal"[Title] AND "fistula"[Title]) OR "fistula in ano"[Title])	336	4
19	("Inflammatory Bowel Diseases/surgery"[Mesh] OR "Colitis, Ulcerative/surgery"[Mesh] OR "Crohn Disease/surgery"[Mesh]) AND (("intestines"[MeSH Terms] OR "intestines"[All Fields] OR "bowel"[All Fields]) AND resection[All Fields])	374	4

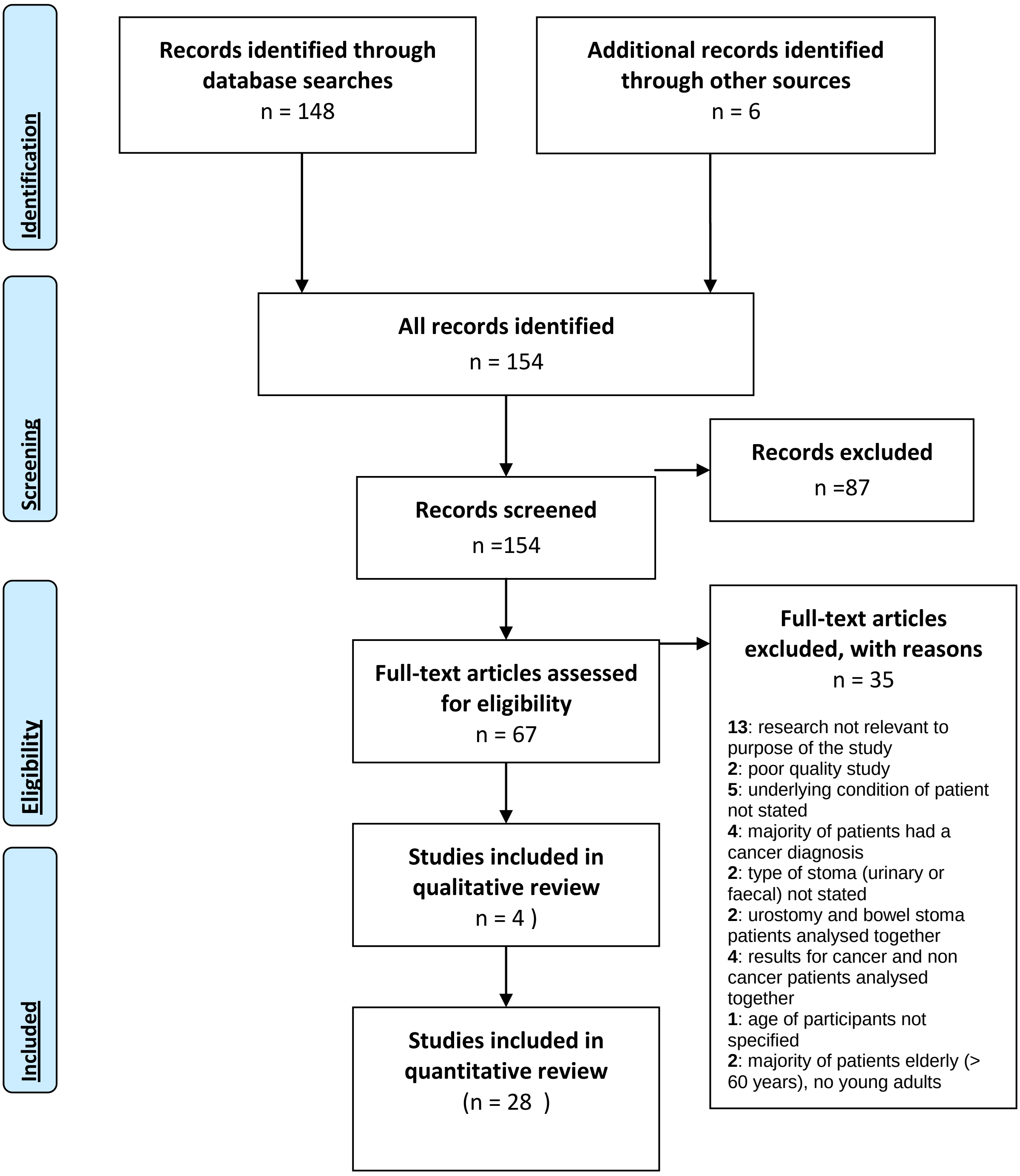
PROQUEST PSYCHOLOGY JOURNALS		Search 1: 4.4.2010	Search 2: 9.3.2014
Limiters - English Language; peer reviewed; Age Groups: All Adult. **Search modes** - Boolean/Phrase		Publication dates	Publication dates
SEARCHES		1.1.1999 – 3.4.2010	4.4.2010 – 8.5.2014
1	inflammatory bowel diseases or crohn disease or colitis	473	
2	Surgery	13645	
3	Perceptions of		
4	1 and 2 and 3	31	81
5	Adjustment		
6	1 and 2 and 5	55	84
7	Adaptation		
8	1 and 2 and 7	11	64
9	Outcome		
10	1 and 2 and 9	169	80
11	follow up		
12	1 and 2 and 11	173	46
13	Concerns		
14	1 and 2 and 13	83	38
15	Anxiety		
16	1 and 2 and 15	43	14
17	Satisfaction		
18	1 and 2 and 17	20	21
19	Recovery		
20	1 and 2 and 19	63	11
21	Function		
22	1 and 2 and 21	151	13

PROQUEST PSYCHOLOGY JOURNALS		Search 1: 4.4.2010	Search 2: 9.3.2014
Limiters -; English Language; peer reviewed; Age Groups: All Adult. **Search modes** - Boolean/Phrase		Publication dates	Publication dates
SEARCHES		1.1.1999 – 3.4.2010	4.4.2010 – 8.5.2014
23	quality of life		
24	1 and 2 and 23	86	20
25	body image		
26	1 and 2 and25	106	21
27	Coping		
28	1 and 2 and 27	15	14
29	Support		
30	1 and 2 and 29	151	13
31	Ileal pouch anal anastomosis OR restorative proctocolectomy OR ileoanal pouch	191	4
32	Inflammatory bowel disease AND ostomy OR Stoma OR colostomy OR ileostomy	135	68
40	inflammatory bowel disease AND surgery AND (perianal OR anal) OR (rectal AND fistula)	63	31
41	inflammatory bowel disease AND surgery AND bowel resection OR resection NOT cancer	81	45

CINAHL		Search 1: 5.4.2010	Search 2: 10.3.2014
Limiters - Research Article; Published Date: 19990101-20100404; English Language; Exclude MEDLINE records; Age Groups: All Adult. **Expanders** - Also search within the full text of the articles. **Search modes** - Boolean/Phrase		Publication dates	Publication dates
SEARCHES		1.1.1999 – 3.4.2010	4.4.2010 – 8.5.2014
1	inflammatory bowel diseases or crohn disease or colitis	92	80
2	Surgery	4041	3245
3	Perceptions of	4957	2961
4	1 and 2 and 3	1	0
5	Adjustment	26441	1352
6	1 and 2 and 5	0	0
7	Adaptation	33204	1355
8	1 and 2 and 7	0	0
9	Outcome	146007	4545
10	1 and 2 and 9	1	0
11	follow up	89045	1325
12	1 and 2 and 11	1	0
13	Concerns	30024	450
14	1 and 2 and 13	0	0
15	Anxiety	46729	1214
16	1 and 2 and 15	0	0
17	Satisfaction	77439	1886
18	1 and 2 and 17	0	0
19	Recovery	47117	671
20	1 and 2 and 19	0	0
21	Function	108265	1440
22	1 and 2 and 21	0	0

CINAHL		Search 1: 5.4.2010	Search 2: 10.3.2014
Limiters - Research Article; Published Date: 19990101-20100404; English Language; Exclude MEDLINE records; Age Groups: All Adult. **Expanders** - Also search within the full text of the articles. **Search modes** - Boolean/Phrase		Publication dates	Publication dates
SEARCHES		1.1.1999 – 3.4.2010	4.4.2010 – 8.5.2014
23	quality of life	6281	3076
24	1 and 2 and 23	0	3
25	body image	627	301
26	1 and 2 and25	0	0
27	Coping	4352	2062
28	1 and 2 and 27	0	0
29	Support	15280	7391
30	1 and 2 and 29	2	2
31	Ileal pouch anal anastomosis OR restorative proctocolectomy OR ileoanal pouch	5	4
32	Ostomy	476	153
33	1 and 2 and 32	1	0
34	Stoma	166	113
35	1 and 2 and 34	0	1
36	Ileostomy	46	29
37	1 and 2 and 36	1	3
38	Colostomy	128	45
39	1 and 2 and 38	17	0
40	Perianal fistula	0	0
41	Anal fistula	1	0
42	Rectal fistula	0	1
43	Perianal	5	12
44	Bowel resection	0	12
45	Resection	221	177
46	1 and 45	2	0

APPENDIX 3. FIGURE 2.1: FLOW CHART OF THE STUDY SELECTION PROCESS



13: research not relevant to purpose of the study
2: poor quality study
5: underlying condition of patient not stated
4: majority of patients had a cancer diagnosis
2: type of stoma (urinary or faecal) not stated
2: urostomy and bowel stoma patients analysed together
4: results for cancer and non cancer patients analysed together
1: age of participants not specified
2: majority of patients elderly (> 60 years), no young adults

APPENDIX 4. Table 2.2: CHARACTERISTICS OF THE 28 QUANTITATIVE STUDIES INCLUDED IN THIS REVIEW

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
Andersson et al, 2011 Norway	To evaluate long term health related quality of life and functional outcome in patients with IAP for UC and FAP	Cross-sectional questionnaire survey, prospective clinical data (post-surgery), retrospective review of patient's medical charts	N=110 patients (105 UC), (71% RR) 60M, 50F Mean age at surgery: 35 yrs (range: 11-59 yrs) Mean age at interview: 47 yrs (range: 19-66 yrs) Mean time after surgery: 12 yr (range: 2-22 yr) Comparison group from general Norwegian population	IAP surgery. Patients underwent IAP during the period 1984–2003 and still had an intact pouch	Quality of life SF-36 Bowel Function Wexner Continence Grading Scale.	Patients scored significantly lower than general population in 4 of 6 health domains: social functioning (p<0 .01), mental health (p<0 .001), vitality (p<0 .001), general health perception (0.001). Overall couldn't be measured-different versions of SF-36 Women scored significantly lower than men in all six domains, females had lower scores than female population in all domains, male patients had lower scores than general population in general health, vitality and mental health (data not shown) Defaecatory function: median frequency of bowel movements 7 (3-12) during the day and 2 (0-6) at night. 46 (42%) used anti-diarrhoeal medicine 31 (30%) never needed to. Majority of patients had some faecal leakage. Only 38 (36%) never had leakage during the day and 18 (17%) during the night 65 (60%) (75% men and 25% women) reported they were always or usually able to defer defaecation for a minimum of 15 minutes 56 (51%) patients who were unable to discriminate between stool and gas. These had more frequent episodes of FI (p= .002)	Valid (86%) Limitation: No suggestions provided for future research. No baseline measure of QoL. No follow-up.

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
						47% patients more content with bowel function than prior to IAP and 13% less content. Overall 81% of patients satisfied with the operation. Frequency of defaecation at night correlated strongly with HRQoL in 6 domains:PF p <0.01, SF p<0.01, MH p<0.03, vitality p<0.01, BP p<0.01, GH p<0.01 Incontinence related to HRQol in general healthp<0.01, vitality p< 0.02, social functioning p <0.04 Physical function was associated with night frequency, Wexner score p< 0.05 Social function associated with night frequency and urgency (p< 0.05), mental health associated with night frequency, Wexner and age (p<0 .05), vitality associated with night frequency and Wexner score (p<0.05), bodily pain with night function (p<0.05) and general health with night frequency and Wexner score (p<0.05)	
Berndtsson et al, 2011 Sweden	To describe long-term adjustment to life with an ileal pouch–anal anastomosis (IAP) after surgery for UC, to investigate the relationship of pouch function to adjustment, and to explore factors affecting QoL.	Cross-sectional mail questionnaire survey	N=252 patients (84% RR) 141 M 111 F median age, 51 (range, 26–77) years	Patients who underwent surgery with construction of an IAP for UC at single centre between 1982 and 1995.	Quality of life SF-36 IBDQ.	Quantitative Findings: Factors described as contributing to good QoL included: health, mentioned by 87 participants (58%); family, 50 (33%); restroom access, 33 (22%); friends, 33 (22%); employment, 32 (21%); and economy, 18 (12%). Qualitative Findings: Five categories emerged from the qualitative content analysis as important for QoL: feelings of living a “normal life,” food restrictions, physical limitations, influence of restroom access on social life, and being dependent on medical care.	Valid (77%) Limitations: Respondents were surveyed over a broad time period. Changes in operative techniques over time may have yielded improved IAP pouch function, thus improving average continence and reducing urge and frequency of defecation. No baseline measure of QoL. No follow-up.

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
Brandsborg et al, 2013 Denmark	To evaluate function and quality of life in all patients having ileoanal pouch (IAP) in Denmark for UC from 1980-2010	Cross sectional multi centre questionnaire survey;	1047 patients with UC (85% RR) 540 (52%) M 507 (48%) F Mean age 47 (range 14 – 84 years) Median follow up since surgery 11 years (1-30 yrs) Years since surgery 0 – 10, 514 patients 11 – 20, 368 patients 21 – 30, 165 patients	IAP surgery: all patients having restorative proctocolectomy in Denmark for UC from 1980 to 2010.	Quality of life IBDQ SF-36 Bowel Function self devised questionnaire	Total IBDQ score higher in M than F (p<0.001) Male patients scored higher in 5 of 8 SF36 domains (RP, BP, GH, VT, MH) (p<0.001) Bowel function: more F than M had urgency (56% vs 44%) (p=0.0021) Median number of bowel movements in 24 hr F 7 (1-23), M 6 (1-20) (p<0.001) Pad usage was more frequent in women (62% vs 38%) (p<0.001) Patients operated on 21 – 30 years previously had more major incontinence (p=0.009) and used more pads (p=0.01) than those who had their surgery 0 – 10 and 11 – 20 years previously. The proportion of patients with urgency was significantly higher for patients operated on 0 – 10 years previously than for those whose surgery was 11 – 20 years ago (p=0.009).	Valid (77%) Limitations: Exclusion of pouch failures is an inherent bias in selection of study population as researchers looked at patients with better-functioning pouches or patients who are able to tolerate worse-functioning pouches.
Bullen et al, 2012 Australia	To determine if pre-existing body image disturbance influenced psychological (emotional) adjustment during the recovery phase (up to 3 months) following surgery	Pre-post questionnaire battery pre-admission and three months after surgery. Patient info such as diagnosis, pathology and previous treatment, and outcome of surgery (stoma vs. non-stoma) obtained from hospital records post-surgery.	65 adult consecutive colorectal surgery patients recruited from July 2008 until February 2010 N=56 at follow-up (86% retention rate). 37=Colorectal cancer 30=benign tumours, diverticulitis, polyps, UC or CD Comparison of stoma (n=22) and non-stoma (n=42) patients Mean age: non	Bowel surgery with or without a stoma	Anxiety and depression HADS Quality of life SF-36 Body image BIQ ASIR BIS	At baseline: planned stoma patients were more depressed than non-stoma patients (p=0.043). At follow-up, stoma patients had higher depression (p=0.006), anxiety (p=.014), body image disturbance (p=.006), and lower physical health QoL (p=.006) than non-stoma patients. At baseline, planned stoma patients had significantly higher depression than non-stoma patients (p<.05), butgroups did not differ in QoL, anxiety or body image. At 3 months follow-up: Stoma patients had significantly higher body image disturbance (BIS) than non-stoma patients (p=0.006). Body image disturbance worsened	Not Valid (64%) Limitations: Study setting not disclosed (e.g., was it a single vs. multi-centre hospital/out-patient unit?) Some body image scales (BIQ and ASIR) not validated in an illness population, small sample size, and attrition Stoma vs non stoma groups may not have been well matched (differed on baseline on the level of depressive symptoms)

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
			cancer, 60.62, cancer 59.32 Non cancer: M, 12 (41%), F 17 (59%) Cancer: M 19 (50%), F 19 (50%)			over time (p=0.022). Negative body image before surgery was related to depression (p=0.000) and emotional quality of life (p=0.000). Stoma patients had significantly higher depression than non-stoma patients (p=0.006). Stoma patients had significantly higher anxiety than non-stoma patients (p=0.014). Stoma patients had significantly lower physical health QoL than non-stoma patients (p=0.006). No group difference in mental health QoL between stoma patients and non-stoma patients (p=0.167).	Strengths: Baseline assessments of QoL, body image and levels of psychopathology prior to surgery. The researchers recommended screening patients prior to body-altering surgery for body image related concerns, and refer to psychological support services.
Byrne et al, 2007 Australia	To compare patients' preferences for surgical intervention in patients with CD with the preferences of surgeons and gastroenterologists	Single centre cross sectional survey Patient interview Mailed questionnaires	41 patients with CD (33%RR) 92 colorectal surgeons (72%RR) 74 gastroenterologists (27%RR) Mean patient age 38.5 17M 24F 30 (74%) had had a consultation with a surgeon 24 (59%) previous abdominal surgery for CD 5 (12%) previous stoma	Surgery for CD	Prospective measure of preference WTG and WTT	To avoid ileocaecal resection Preferences of patients aligned with colorectal surgeons, but differed between patients and gastroenterologists (WTG p<0.001, WTT p<0.001) and between surgeons and gastroenterologist (WTG p<0.001, WTT p<0.001) To avoid laparoscopic ileocolic resection Preferences of patients aligned with colorectal surgeons but differed between patients and gastroenterologists (WTG p<0.001, WTT p=0.03) and between surgeons and gastroenterologists (WTG p< 0.001, WTT (p<0.001) To avoid subtotal colectomy Preferences of patients aligned with colorectal surgeons and with gastroenterologists in WTT but differed with gastroenterologists in WTG (p=0.04) and between colorectal surgeons and gastroenterologists (WTG p<0.001,	Valid (78%) Limitations: Only a few patients actually had a stoma Prospective-measured close to surgery Small population

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
						WTT $p<0.01$) To avoid proctocolectomy with stoma Patients with CD agreed with colorectal surgeons in WTG but disagreed in WTT ($p=0.001$). Patients' preferences to avoid aligned with gastroenterologists. Gastroenterologists and surgeons disagreed in WTG ($p< .001$, WTT $p= 0.001$) To avoid proctocolectomy with pouch No differences between groups Medically and surgically treated patients Those who had had surgery (59%) Large differences WTG, WTT to avoid laparoscopic (WTG .47/.29) or open (.47, .33) ileocolic resection No real difference in preferences for surgical treatment of colonic CD	
Carlsson et al, 2003 Sweden	To describe worries and concerns in subjects with IBD and an ileostomy, and aspects of quality of life and coping strategies	Cross-sectional questionnaire survey. Details of diagnosis, types of operation, length of resected small intestine and previous medical history collected from medical records Random matched control group from general population drawn from health care research records	21 patients with ileostomy Mean age 51 yr (range 36–65) M9, F12 CD n = 14, UC n = 6 indeterminate colitis (IDC) n = 1 Time elapsed since the ileostomy operation was mean 21 (±10) years (range 2–39 years).	Ileostomy for IBD	IBD patient concerns RFIPC Quality of life SF-36 Visual analogue scale. Own definition of QoL Coping strategies JCS	Greatest concerns (max score 100) related to intimacy: med 51 (range 11- 73) access to quality medical care: med 41 (11 – 43), energy level :med 39 (9 – 61), loss of sexual drive: med 27 (8 – 68), producing unpleasant odours: med 25 (5 – 68), being a burden: med25 (5 – 63), ability to perform sexually: med 22 (14 – 83), attractiveness: med 18 (7 – 76) and feelings about the body: med 18 (1 – 52). QoL scores (SF-36) after ileostomy were significantly lower than controls for vitality ($p=0.05$). Patients' definition of good quality of life mainly concerned social dimensions of life and health. Low perceived quality of life correlated with greater worries and concerns	Not Valid (64%) Limitations: RFIPC scale is validated, but not in patients with IBD and an ileostomy. Small sample size. Study not representative of all users/not bias-free.

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
						(p=0.002). Most used coping strategy was to try to maintain control over the situation (confrontational), used ‘often’, or ‘almost always’ by 17/21 pts (81%).	
Cornish et al, 2012 UK	To investigate quality of life, sexual, faecal, and urinary function in females undergoing restorative proctocolectomy (IAP).	Prospective case–control study performed in two tertiary centres. Controls were females with UC, without a stoma or IAP.	N=109F (43% RR) 55 (50.5%) IBD; 54 (49.5%) IAP for IBD IAP patients: Mean age of RPC patients 41.8 yrs (± 12.7 SD) vs. 43.8 yrs (± 15.8) Mean follow up time from operation IAP 10 (+/-7.5) years Controls 5.75 (+/- 6.5) years	Restorative proctocolectomy (IAP).	Quality of life SF-36, Sexual function FSFI Urinary function King’s questionnaire, Bowel function Wexner scale	QoL for physical health and bodily pain were worse following IAP (p<0.04). No significant difference in sexual function. IAP patients had bladder dysfunction (urgency, frequency or incontinence) at a mean age of 37.6 years, 10 years before the controls (p=0.044). The severity of bladder symptoms was also worse for IAP patients (p=0.004). Urgency in faecal function was experienced by more IBD patients (IBD 75.0% vs. IAP 47.9%; p =0.006).IAP patients had increased day (p<0.001) and night bowel frequency (p<0.001) and night seepage (p<0.001). IAP females who had a vaginal delivery were more likely to have day seepage (p=0.046) and require pads (p=0.026) than IAP females who had not.	Valid (77%) Limitations: Small sample size means study is underpowered to detect more clinically significant differences. Low RR (44%), which authors consider acceptable (comparable to previous studies) Main limitation of using FSFI: questions restricted to last 4 weeks; if patient had no sexual intercourse during that period, the overall scores cannot be used, reducing RR Possible source of bias: females who agreed to participate may represent a higher proportion of patients from either end of the clinical spectrum, e.g.those patients who experience more post-IAP complications may have been more motivated to participate. IAP patients had surgery a longer time ago than controls (p=0.041)

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
							IBD patients had significantly higher education level than IAPs (introduces recruitment bias, IAP=higher disease burden in uni years). No suggestions for further research areas.
da Silva et al, 2008 USA	To evaluate women's sexual function, self-esteem, body image and health related quality of life after colorectal surgery	Multi centre longitudinal prospective cohort survey baseline and follow up at 6 and 12 months	93 F Mean age 43 (+/- 11.6) 57 (61.7%) pelvic surgery 36 (38.7%) abdominal surgery	Abdominal or pelvic surgery for benign disease with or without a stoma	Sexual function FSFI Self esteem Self Esteem scale Body image Short body image scale Quality of life SF-36	Significant deterioration in sexual function at 6 months post op with partial recovery at 12 months (p=0.02) At 12 months sexual function had not returned to preop levels. Patients with a stoma had less sexual desire (p=0.05) and lower scores for orgasmic function (p=0.04) Patients with better self esteem (p=0.043) and body image (score<18) had better sexual function. Patients with a stoma had less sexual desire (p=0.05) and decreased orgasmic function (p=0.04) Self-esteem did not change significantly However, older patients demonstrated higher self-esteem, better mental health and better body image than younger patients. Married patients/in a relationship had a significantly better image of themselves than singles after surgery. Patients with a stoma had a poorer body image but not significantly (p= 0.06) Body image improved with slight	Not Valid (68%) Main limitation of using FSFI: questions restricted to last 4 wks; if patient had no sexual intercourse during that period, the overall scores cannot be used, reducing RR. Small sample size. Confounding variables not accounted for, and no suggestions for future research.

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
						changes at 6 months and significant improvement at 12 months (p= 0.05). This was more pronounced in the pelvic group (p=0.037) which had worse body image scores before surgery (p=0.004) Positive correlation among body image, self-esteem, sexual function, and QoL. At 6 months physical recovery was greater for the group with abdominal than pelvic surgery (p=.0031) but overall there was no difference between the 2 groups Mental health improved with significant changes at 12 months (p=0.007) 81.4% thought it somewhat or extremely important to discuss sexual issues with the patient.	
Davies et al, 2008 Canada	To assess the effect of ileal pouch-anal anastomosis (IAP) on sexual function and quality of life in men and women.	Prospective evaluation. Preoperative scores were compared with scores at 6 and 12 months postoperatively.	N=59 (53.6% RR)	Patients undergoing IAP from February 2005 to June 2006	<u>Sexual function</u> IIEF in men FSFI in women. <u>Quality of life</u> SIBDQ	Male sexual function and erectile function scores remained high 12 months after surgery: mean Erectile Function score 51.7 preoperative vs. 58.3 at 12 months (score of 42.9 or below = sexual dysfunction) postoperatively. Abnormal sexual function decreased from 33.3% before surgery to 22.7 % 12 months after surgery. Female sexual function improved 12 months after surgery (mean score 19.2 preoperative vs. 27 at 12 months postoperative (score of 26 or below =sexual dysfunction) (p=0.031). Abnormal sexual function decreased from 73.1% before surgery to 25% 12 months after surgery (p=0.001). Quality of life had significantly improved after IAP in both sexes 12 months after surgery (M p=0.02, F	Not Valid (64%) Limitations: Only 54% of patients agreed to participate, and of those 38% completed the questionnaires 12 months after surgery. In addition, patients completed the questionnaires while unsupervised and at home both before and after surgery to minimize the possibility of influencing the responses. It may be possible that the cohort is not generalizable to all patients who have surgery for IAP Main limitation of using

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
						p<0.001)	FSFI: questions restricted to last 4 wks; if patient had no sexual intercourse during that period, the overall scores cannot be used
Delaney et al, 2003 USA	The effect of surgery on quality of life in patients with CD	Prospective study Preoperative measurement and 30-days after surgery	82 (58% RR) 41 M, 41 F Mean age 40.1 years (+/= 12.5) 63 (77%) Abdominal 19 (23%) Perineal 17 with stoma	Patients who had had surgery for CD	<u>Quality of life</u> CGQL	Significant improvement in QoL 30 days after surgery (0.6 ± 0.2 preoperative to 0.7 ± 0.2 postoperative; mean ± SD; p<0.001). Mean preoperative CGQL was 0.56 ± 0.24 and mean improvement was 0.11 ± 0.20 toward a better QoL. Female patients (p<0.05) and those who did not develop complications within 30 days of surgery (p<.05) had a significantly greater improvement in CGQL after surgery than other groups. Patients who had abdominal surgery had greater improvement in current quality of health (CQH) than those with perineal procedures (p=0.012) CGQL was not affected by other patient characteristics, nature of disease, indication, or procedure performed. Most patients 65 (80%) who had surgery for CD felt that surgery had helped them and would undergo surgery again when contacted 30 days after surgery	Valid (82%) No clear inclusion and exclusion criteria reported. Confounding variables not accounted for in analysis. No suggestions provided for future research areas.
Dunker et al, 2001 Netherlands	To assess the functional outcome, quality of life, cosmesis (degree of satisfaction of patients with respect to the physical appearance of the scar), and body image of laparoscopic-		32 patients Two groups: laparoscopic-assisted IAP (n=15; mean age 30.6 ± 7.1 years) conventional IAP (n=17; mean age 39.2 ± 8.4 years) 4M,11F lap assisted 9M, 8W conventional	Laparoscopic-assisted IAP or conventional IAP	Length of hospital stay (LOS) <u>Functional outcome</u> Self devised questionnaire <u>Sexual activity and satisfaction</u> Self devised questionnaire <u>Quality of life</u>	Significantly shorter LOS in laparoscopic-assisted group compared with conventional group (mean 9.9 ± 2.4 vs. 12.5 ± 2.7 days; p<0.01). No significant differences in functional outcome between groups No difference in sexual activity or pleasure in sex pre and post operation in both groups. QoL (SF-36 and GQLI) similar	Not Valid (68%) Limitations: Conventional group were significantly older (p<0.01). Given the small number of patients, they were not able to analyze any effect of the size of the scar and the cosmetic score.

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
	assisted ileal pouch-anal anastomosis (IAP) compared with conventional ileal pouch-anal anastomosis.		Average time since surgery 14.4 months (+/- 6.7) lap assisted 16.7 months (+/- 6.3) conventional		SF-36 GIQLI Body image BIQ and cosmesis	between groups. Significantly higher cosmesis in laparoscopic-assisted group than conventional group (mean 19.8 ± 4.6 vs. mean 16 ± 4.6; p =0.03). Body image score was higher in the laparoscopic-assisted group than conventional group, and approached significance (mean 19 ± 1.3 vs. mean 17.9; p = 0.09). No male/female difference in body image (mean 18.7 ± 1.5, vs. mean 18.2 ± 2.0; p=0.37) and cosmesis (mean 16.2 + 4.6 vs. mean 18.8 ±5.1; p=0.14). No age differences in body image, cosmesis, QoL, and functional outcome of bowel and sexual function between the patients ≤36.5 and patients of 36.5+ years.	No suggestions were provided for further research areas. Article did not state if informed consent or ethics approval were obtained. Non validated instruments Confounding variables were not accounted for in the analysis.
Garcia-Aguilar et al, 2000 UK	To identify factors that may contribute to patient satisfaction after surgical treatment of fistula in ano	Retrospective mail questionnaire	375 out of 600 patients surgically treated for fistula-in-ano at one centre during a five-yr period Final sample n=300 (patients who had been followed up for a year) (50% RR) 220 M, 80F 265 aged <65 years 35 aged >65 years Fistulotomy 238 Seton 62	Surgery for fistula in ano	Patient satisfaction Self devised questionnaire	Patient satisfaction was not significantly associated with age, gender, history of previous fistula surgery, type of fistula, surgical procedure, time since surgery, or operating surgeon. Patient satisfaction was strongly associated with fistula recurrence, difficulty holding gas, soiling of undergarment, and accidental bowel movements. Full sample: 88% satisfaction. Fistula recurrence (p<0.001), yes (39% satisfied); no (92% satisfied). Patients with fistula recurrence reported a higher dissatisfaction rate (61%, 100-39%) than did patients with anal incontinence (24 %), Difficulty holding gas (p<0.001), yes: 74% satisfied, no: 93% satisfied Soiling of underwear (p<0.001), yes: 71% satisfied, no: 96% satisfied	Valid (82%) Limitations: Over-reporting of postoperative complications, particularly reports of anal incontinence. 50% RR; potential selection bias which can affect generalisability or validity of results. Suboptimal postoperative result may be less distressing than the preop condition which may explain high satisfaction even with poor clinical outcomes

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
						Accidental bowel movements (p<0.001), yes: 55% satisfied , no: 93% satisfied Anal incontinence had a significant impact on QoL including physical activities (63%, p=0.041), social activities (54%, p<0.001), and sexual activities (62%, p=0.03).	
Kasparek et al, 2007 Germany	To compare long term quality of life in people with symptomatic perianal fistulas who were treated with or without faecal diversion	Single centre survey Mailed questionnaires	77 CD (66% RR) 22M 55F Age Range: 24-76 yrs (mean age: 41) 34 faecal diversion (7M, 27F) 43 no faecal diversion (5M, 28F) Time since faecal diversion 5 yr (range 0-5)	Surgery for perianal fistula with or without faecal diversion (stoma)	<u>Quality of life</u> SF-36 GIQLI CGQL SIBDQ Newly developed questionnaire for diverted (stoma) patients	85% faecal diverted patients (stoma) reported better QoL in general Diverted patients: 29% no restrictions in everyday life, 56% minor in comparison with having perianal fistula before div, 15% reported restrictions that led them to avoid activities eg sports, swimming, sex 97% indicated they would opt for diversion again. Less likely to complain of CD symptoms when diverted compared to undiverted 34 of 43 (44%:79%) (p<0.05) No diff between groups in SF-36 (data not shown) No diff CGQL GIQLI revealed better QoL in diverted for overall score and GI symptoms (p<0.001) No overall diff SIBDQ, but diverted scored better on bowel function (p<0.0001) Results not dependent on length of time since diversion	Valid (77%) Data analysed appropriately by stoma/non stoma Subgroups further analysed for time since surgery and proctectomy Statistical tests explicit and appropriate Diff only shown in disease specific instruments But dis spec not designed for stoma so required adapting for the study Also div patients had CD longer than non div (p<0.05). Improving health may have made the difference not the actual stoma Div patients less likely to report CD related symptoms. Less active disease may be associated with better outcomes
Knowles et al 2013b Australia	To explore associations among elective versus	Multi centre cross sectional survey using a retrospective	31 patients (39% RR) with CD and a stoma	Stoma for CD	<u>Illness perceptions</u> Brief Illness Perceptions	No differences in anxiety, depression and stoma related QoL based on gender, planned v emergency	Non valid (50%) Small sample size and low

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
	emergency surgery, type of ostomy (temporary versus permanent), illness perceptions and coping style, anxiety, depression and health related quality of life in persons with CD	database	17 M 14 W Mean age 45 years Average age at time of surgery 32 years 24% more than 1 stoma procedure 22 (71%) elective 17 (55%) permanent stoma		Questionnaire Anxiety HADS Depression HADS Quality of life SQL	surgery, type of stoma, number of operations, or current use of psychological services Patients with a temporary stoma had significantly higher illness beliefs compared to those with a permanent stoma ($p>0.05$) Lower stoma QoL was associated with more negative illness beliefs ($p<0.05$), higher anxiety ($p<0.05$), and depression ($p<0.05$)	RR. Most participants described ongoing problems with the stoma and strong memories of problems from the outset, so sample may not be representative of wider stoma population Identified differences in temporary and permanent stoma patients and then analysed results together No preoperative measures so impossible to identify if results are attributable to the surgery
Kuruvilla et al, 2012 USA	To determine whether long-term quality of life among patients with a pelvic pouch (IAP) is better than those who chose a permanent stoma.	Cross-sectional observational study : interview or mailed questionnaire	59 participants 35 patients with an IAP and 24 with ileostomy 23 IAP and 11 stoma enrolled through interview at follow up appointment 12 IAP (65% RR) and 13 (50% RR) stoma enrolled through mailed survey 23 M, 12F IAP 16 M, 8W stoma Mean age IAP 50.7 years (+/- 14.5) Mean age stoma 54.8 years (+/- 15.6)	Consecutive patients who had undergone IAP or a permanent ileostomy for UC by a single surgeon, presenting for their annual follow-up visit from July through September 2011	Quality of life EQ-5D-3L SIBDQ CGQL FIQL SQL	No group difference in EQ-5D-3L, SIBDQ or FIQL CGQL: IAP group had significantly higher CGQL Fazio score (Mean 0.9 IAP vs. 0.8 ileostomy). IAP group had significantly higher current quality of health ($p<0.01$). IAP group had significantly higher energy level ($p<0.05$). SQL: IAP group had significantly higher sexuality/body image ($p<0.001$). IAP group had significantly higher work/social function ($p<0.01$). IAP group had significantly higher skin irritation ($p<0.01$).	Not Valid (73%) Multiple limitations: Some patients were enrolled through mailed surveys instead of on-site interview (50% RR). Small sample size, hence additional differences in QOL may have been observed with greater statistical power. Follow-up time since surgery was longer in IAP group than stoma group, and there were no baseline disease severity or QOL measurements before surgery.

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
			Mean follow up IAP 13.1 (+/- 4.7) years Mean follow up stoma 7 (+/- 5.2) years				All patients were operated upon by a single surgeon, limiting generalizability. All patients with IAP had scheduled annual follow-up visits, whereas ostomates were seen at their discretion; this could have biased the results against patients with an ileostomy because patients doing well may be less likely to seek follow-up. Adaptations made to stoma and continence QOL instruments were not validated.
Larson et al, 2008 USA	To compare self-report sexual function, body image and quality of life outcomes among UC patients undergoing laparoscopic or open IAP one year after surgery	Cross sectional single centre study	125 patients (43% RR) 51M 74F 46 laparoscopic (17M, 29W) 79 open (34M, 45W) Mean age 34	Open or laparoscopic IAP surgery	<u>Quality of life</u> SF-8 <u>Sexual function</u> FSFI IIEF <u>Body image</u> Non validated body image questionnaire	Quality of life: SF-8 scores equal in lap and open patients and similar in women and men. Men: orgasmic function in men poorer in lap group (p=0.04). In all sexual function domains, men with IAP had better IIEF scores than the general population (95% confidence interval) except overall satisfaction Women: no difference in FSFI scores between groups Sexual function lower than for general population in all but one domain (satisfaction) (95% confidence interval) No significant difference in body image and cosmetic scores between lap and open surgery patients (high in both)	Not valid (64%) Did not assess baseline QoL body image or sexual function preoperatively, hence no direct influence of the operation on each patient can be evaluated Non validated body image measure Low RR (43%)

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
Mahadev et al, 2011 Australia	To determine which factors are considered by patients with perianal CD to be the most important and most unfavourable to their quality of life To gauge the relative impact of perianal and non-perianal symptoms	Single centre cross sectional survey Mailed questionnaire Medical records audit	Patients with perianal CD who had been seen in previous 10 yrs 69 of 130 eligible patients participated (53% RR) M 26(38%) F 43 (62%) Recruited over 16 yr olds (mean age 42.7) Anal fistula 80%, skin tags 67%, anal fissure/ulcer 38%, anorectal stricture 12% 16 (23%) had a current stoma, 10% previous stoma and 28 (41%) past or current drain (seton)	Perianal CD 80% had had surgery	<u>Quality of life</u> Scale developed to rate importance of 16 aspects of QoL: physical, functional, emotional, cosmetic. Plus up to 3 additional QoL aspects not previously listed Proportion willing to accept (WTA) a stoma for each aspect calculated for each item <u>Prospective measure of preference</u> Impact of perianal dis on QoL calculated : Willingness to trade (WTT) part of life expectancy for permanent cure and time trade off (TTO), percentage of life expectancy participants were willing to trade	Patients ranked importance of symptoms: anal pain 40%, anal discharge 39%, physical activity restriction 39%, sleep interference 39%, feeling unclean39%, anal incontinence 38%, emotional distress 38% Patients ranked symptom aversion: anal incontinence 85%, anal pain 81%, anal discharge 78%, physical activity restriction 77%, loss of independence 77%, sleep interference 75%, social activity restriction 75% and sexual activity restriction 75% 85% were inclined to accept a stoma for relief of anal incontinence Women gave high importance to physical and emotional aspects of QoL. 53% women reported anal pain as highly important compared with 19% men (p=0005) Presence of a drain related to 13 of 16 domains. Drain (seton) was most predictive of ratings for incontinence (p=0.002), feeling unclean (p=0.001), sleep interference (0.001), self image (0.01) and confidence to go out (p=0.001) Past or current stoma was predictive of psychosocial aspects including sleep interference ((p=0.001), emotional distress (p=0.01), cosmetic appearance (p=0.03) and confidence to go out (p=0.003) Female sex was an independent predictor of pain (p=0.01) and self image (p=0.03) Trading life expectancy: almost half willing to trade some life exp for a cure. Younger patients more willing	Valid (77%) Limitations: small sample drawn from a single tertiary teaching hospital, where patients may be atypical. Utilities are traditionally elicited in the face-to-face interview setting, researcher adapted technique to self-completion questionnaires Low RR (53%) Clinical data were abstracted from the paper medical records, which may have involved a degree of underreporting and omission. Non validated instrument May be that drains are associated with ongoing symptoms, reflecting higher disease severity or contributing to symptom severity

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
						than older patients to trade to avoid non perianal symptoms (p=0.02) and to trade more life expectancy (p=0.04)	
Moskovitz et al, 2000a Canada	To examine the association between coping behaviour at the time of surgery and IBD related quality of life after surgery and the relationship between perceived social support, coping style and post surgical quality of life	Cross sectional mailed survey	86 patients (60% RR) 38M 48F Mean age 38 (range 17-71) 41 (48%) UC 42 (49%) CD 3 (3%) DNK 29 (34%) IAP 57 (66%) bowel resection/other	Surgery for IBD within the previous year	Quality of life IBDQ Coping Ways of Coping (WOC) Social support Medical Outcomes Study Social Support Questionnaire	Mean IBDQ did not differ by gender, diagnosis, type of surgery, age or time since surgery Adaptive coping used more frequently by both groups. Adaptive coping did not differ between high IBDQ and low IBDQ groups. Lower QoL group used maladaptive coping more frequently(p=0.006) Perceived social support differed between the high IBDQ group and the low IBDQ group (p=0.001) Current IBD symptoms differed between the low IBDQ group and the high IBDQ group (p<0.001) Current IBD symptoms (p<0.0001), current perceived social support (p<0.0001) and maladaptive coping behaviour at the time of surgery (p=0.002) each made a highly significant contribution to post surgical QoL	Not valid (73%) Limitations: Limited generalizability of findings due to narrow demographic profile of sample (white, well-educated adults), and by tertiary care setting. Retrospective design limits confidence in validity of information gathered about coping at time of surgery. Coping style may be affected by surgery, through changes in symptom severity or other coping challenges. RR (60%) limits confidence in representativeness of sample
Moskovitz et al, 2000b Canada	To survey awareness of community agency resources among patients who have surgery for IBD and to analyse the association between using these resources and	Cross sectional mailed survey	92 patients (68% RR) 43M 49F Mean age 38 (range 17-71) 46 (50%) UC	Individualised professional/ lay community agencies or social/educational agencies used preoperatively by IBD patients	Quality of life IBDQ Awareness of local community resources Self-report list of agencies compiled by researcher	Mean IBDQ did not differ by gender, diagnosis, type of surgery or time since surgery Awareness of community resources was high (98%) Almost all aware of at least 1 community resource: 22 (24%) at least 1 soc/ed, 20 (22%) at least 1 prof, 26 (28%) nothing, 24 (26%)	Not Valid (68%) Limitations: Limited generalizability of findings due to narrow demographic profile of sample (white, well-educated adults), and by tertiary care setting.

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
	qualitative surgical outcomes		43 (47%) CD 3 (3%) DNK 31 (34%) IAP 61 (66%) bowel resection/other Surgery in previous year			both resources Half had participated in educational/social resources use at least once. Just under half (47%) had participated in professional resource use at least once. Use of professional/individual resources had a positive effect on post surgical QoL (p=0 .015), systemic problems (p=0.007) and emotional problems (p=0.012).	Retrospective design limits confidence in validity of information gathered about use of resources before surgery. RR (68%) limits confidence in representativeness of sample
Persson et al, 2003 Sweden	To assess the quality of care in ostomy patients seen from a patient perspective.	Questionnaire-cross-sectional postal survey design	42 ileostomy and 49 colostomy patients completed the questionnaire, (72% RR) Mean age ileostomy patients 48 years (+/-18) 17M, 25W Time since surgery: 2: < 6 months 11: between 6 months and 1 year 29: more than a year	Patients who had a stoma for UC	Quality of care QPP	Most rated many aspects of QoL as unsatisfactory. Info Provision (importance/satisfaction, %): Surgical procedure (97% imp; 29% sat) Medical exam/results (98% imp, 52% sat) Surgery results (97% imp, 32% sat) Responsible doctors (97% imp, 41% sat) Responsible ET nurse (95% imp, 10% sat) Special diet (95% imp, 36% sat) Decision-making Participation (%) Medical care (92% imp, 53% sat) Personal care (93% imp, 58% sat) Perception of Psychosocial Issues (%) Health/life situation (89% imp, 39% sat) Sexual matters (83% imp, 53% sat). 52% of ileostomy patients dissatisfied with info received about results of medical exams and lab tests (p=0.03). Significantly more Ileo patients without complications (58%) (p=0.01) were dissatisfied with the opportunity to communicate with ET nurse about their health and life	Not Valid (68%) Results for groups appropriately analyzed separately Limitations: Criticised previous studies for small sample sizes, and then recruited a small sample size of 42 ileostomy and 49 colostomy patients, thereby continuing this trend. No information on non-respondents

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
						situation than those with complications (48%). Significantly more Ileo patients with complications (73%) were dissatisfied with ET nurses’ understanding of their situation vs. those (31%) without complications (p=0.03). Significantly more ileo than colostomy patients thought talking to the ET (stoma) nurse about sexual issues was important (p=0.01)	
Rini et al, 2011 USA	To investigate the influence of close others on the surgical decisions of inflammatory bowel disease patients referred for surgery to remove their colon	Cross sectional mailed survey	N = 91 40 M (44%) 51F (56%) 68 (75%) UC 23 (25%) CD 67 (74%) had had a colectomy 24 (26%) decided against an operation	Referred for colectomy for IBD within the previous 3 years	Surgical decision Self devised questions Decisional conflict Adapted DCS Close other person influence Self devised18 item scale Physician Trust 8 item subscale of Primary care assessment survey Perceived risk for CRC Single adapted question (from breast cancer measure)	Perceived greater risk of CRC more likely to have decided to have surgery (p=0.01) Perceived influence of referring doctor on surgical decision was greater than that of close others (p< 0.001) Most common form of influence by close others was: Helping with understanding (76%), then persuasion (83%), indirect influence (80%), and negative influence (23%) Greater decisional conflict was associated with a close female other (p=0.04) , more hospital related admissions prior to surgical referral (p =0.02) and lower physician trust (p<0.001) Less decisional conflict if close other helped with understanding the decision (p= 0.03) Negative influence (nagging, trying to take control, acting angry or disapproving) was associated with higher decisional conflict (p=0.02) and lower likelihood of choosing surgery (p<0.05)	Not Valid (73%) Limitations: Retrospective design. Sample limited to patients who perceived they could recall their decision making within the past 3 years. Non-random sample Self-selected. majority of sample were White, educated, and financially well-off Non completers were less likely to have had a colectomy (refused surgery) (p=0.03) Study relied on patient reports rather than observation or assessment of close others’ behaviors Authors justified study limitations as they were also common in previous research

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
							Followed up non-completers Tested for current negative mood as a confounder
Riss et al, 2013 Austria	To assess sexual function and quality of life in patients after surgery for perianal Crohn's disease	Single centre self completed questionnaire survey	88 (60%RR) completed questionnaire. Current stoma excluded N=69 included in final analysis (45%RR) M22 (32%), F 47 (68%) Aged 18-64 Mean 46.5 100% had had perianal operation 58 (84%) complex fistula 11 (16%) simple fistula 35 (51%) fistulotomy, 53 (77%) loose seton drainage 14 (20%) advancement flap 6 (9%) temp stoma: excluded from analysis 47 (68%) had 1 or more surgical resections Median follow up time since surgery104 months (3-186)	Surgery for perianal CD	Quality of Life IBDQ SF-12 Sexual Function FSFI IIEF	SF-12: Physical health score less than healthy matched controls (p=0.03). No diff in mental health IBDQ: CD patients had lower median total score of IBDQ than healthy controls (p<0.0001) Factors related to a worse disease specific QoL: fistulotomy better than loose seton drainage (p=0.03), simple better than complex fistula (p=0.004), active CD (p=0.0001) and current perianal probs (p<0.0001) significantly impacted QoL Logistical regression Active CD (p<0.0001) and type of operation (p=0.028) remained significant In men, loose seton (p=0 .013) and an abscess (p=0.003) were related to erectile dysfunction In men, additional pelvic floor operations (p= 0.013) and current pelvic complaints (p=0.003) impacted negatively on orgasmic function Sexual desire in men was negatively influenced by: abscess at operation (p=0.046), loose seton (p=0.046), current pelvic complaints (p=0.026) and complex fistula (p=0.024) In women, sexual desire (p=0.06) was lower than that of controls Overall satisfaction was reduced in patients with additional pelvic floor operations (p=0 .0001) QoL sig decreased in M and F with faecal incontinence (p=0.0006)	Not Valid (68%) Did not assess baseline QoL preoperatively, hence no direct influence of the operation on each patient can be evaluated Main limitation of using FSFI: questions restricted to last 4 wks; if patient had no sexual intercourse during that period, the overall scores cannot be used, reducing RR Low RR. This may be due to due to the very long follow-up period, and “‘taboo,’’ issue of sexuality

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
			Healthy control group matched by age (+/- 6 years) and gender				
Thaler et al, 2005 USA	To assess quality of life in patients after laparoscopic and open ileocaecal resection for CD	Single centre retrospective questionnaire.	37 patients Mean age 48.8 ± 18.4 years 14 M and 23 F 21 (57%) underwent laparoscopic resection 16 (43%) underwent open surgery Mean follow-up of 42.6 ±25.8 months (min 8 months)	Elective laparoscopic or open ileocaecal resection with primary anastomosis between 1992 and 2000	Quality of life SF-36 GIQLI	When compared to healthy US pop, mean GIQLI scores (-13.8, p=0.002) and mean PCS scores (-4.7, p= 0.001) were significantly lower. Individual SF-36 domains were lower in CD patients when compared to the general population in physical function (p<0.05), physical role limitations (p<0.05), bodily pain (p<0.05), general health perception (p<0.05), vitality (p<0.05) and social functioning (p<0.05) Only disease recurrence within follow-up period predicted reduced PCS (-35.1, p= 0.026) and GIQLI (-36.1, p=0.018).	Not Valid (68%) Small sample size. Non randomised No baseline measures pre-op. No reference to ethics approval or informed consent. Strength: Both groups well matched for age, gender, ASA class and BMI.
Thirlby et al, 2001 USA	To investigate quality of life following surgery for IBD	Pre-post cohort outcomes study with consecutive series of patients Assessed preoperatively and at 3. 6 and 12 months after surgery and each subsequent follow up visit	139 patients CD=56, UC=83 25 did not undergo operation so final sample was 104 patients 59M, 24F CD Mean age: 41 (range: 21-77 years) UC Mean age: 44 (range: 15-75 years) Underwent surgery for IBD between June 1994 and January 2000 Mean follow up: CD 16 months (range	56 CD patients underwent resections with or without stricturoplasties 78 UC patients underwent IAP	Quality of life HSQ	Low pre-op HSQ, scores improved significantly in both CD and UC groups (p<0.05) ≥ general population, and increased in CD patients despite disease recurrence and re-operations. QoL equivalent to general pop at last follow-up in both groups. In UC patients, there was improvement in postoperative scores in health perception (p<0.05), physical functioning (p<0.05), role physical (p<0.05), role emotional (p<0.05), social functioning (p<0.05), mental health (p<0.05), bodily pain (p<0.05), energy/vitality (p<0.05). At an average follow up of 5 months (range 3 – 70), scores equalled or excelled those in the general	Valid (77%) Limitations: Confounding variables not accounted for in analysis 25% of patients self referred, 75% physician referred by a single surgeon Marked difference in mean follow up between CD and UC Select group of patients with more severe IBD No suggestions provided for further areas to research

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
			3 – 76) UC 5 months (range 3 – 70)			population in all but role limitations due to physical health. For those (n=12) who had had surgery over a year ago (mean 32 months, range 12 – 70), results were similar to the early results but were lower than for the general population. Improvements in ability to function at home and work, social functioning, bodily pain and energy, were significant (*p*<0.001). Short and long term Gain scores were compared with preoperative scores. They were highest in long term patients (mean 29 months, range 12 – 76) and these changes were significant in all scales for UC In CD patients, HSQ scores increased across all quality of life domains at 5 months but did not reach significance. Neither did they reach the level of the general population except in mental health (p<0.05) and bodily pain (p<0.05) (average follow up 16 months (range 3 – 76). For those patients who had surgery for CD over a year ago (mean 26 months) n=22, mean scores were higher than those in whole group (CD and UC) (p<0.05).	
Tillinger et al, 1999 Austria	To investigate the short and long term effect of surgical resection for CD on quality of life	Single centre prospective pre-post cohort outcomes questionnaire survey investigated one week before surgery and 3, 6, and 24 months postoperatively.	16 patients 10M 6F Median age 31.5 yrs (range25-41). 2 patients had 1 previous resection 3 patients had 2 previous bowel	Bowel resection and anastomosis for CD	Quality of life TTO DQO RFIPC General well being Likert scale Disease activity CDAI Depression Beck Depression Inventory	3 months after the operation disease activity in all patients (remission and non -remission) (CDAI) was significantly reduced (p=0.0001) and remained that way at 6 months (p=0.0007). At 24 months still better than before surgery (p=.0166) Significant improvement of TTO and DQO scores between months 0-24 (p=0.05) Disease specific QoL showed	Not Valid (57%) Limitations: Very small sample. Unclear if study population is representative of all users, actual and eligible, who might be included in the study Data collection varied

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
			resections			significant improvement 3 (p=0.05) and 6 months (p=0.05) postoperatively. At 24 months, for patients in remission still an improvement compared with preop (p=0.005) Significant improvement in depression scores 3 (p=0.038) and 6 months (p=0.0013) postoperatively and for those in remission at 24 months (p=0.0122)	(some mail, telephone, home visits), hence data collection was not standardised, increasing risk of confounding factors Informed consent and ethics approval not stated in paper. Strength: Baseline measures collected (as own-control measure)
Wang et al, 2011 Canada	To examine sexual function and quality of life in men and women with IBD before and after proctectomy.	Prospective cohort study, pre and 6 months post-surgery	61 participants 41 M 25 F 48 IAP 31 M 17 F 18 permanent stoma 10 M 8 F	IAP surgery or a permanent stoma.	Sexual function IIEF FSFI SFQ Quality of life IBDQ SF-36 Urinary Function AUASI UIQ Completed before and 6 months after surgery. Compared pre-post outcomes within each gender, and then compared across genders.	Both men and women reported improvements in general and IBD-specific quality of life after surgery, but only men demonstrated several areas of improved sexual function. Women reported improved sexual desire (p=0.03) but no other sexual function improvement. Sexual function improved for men in: erectile dysfunction (p=0.05), sexual desire (p=0.02) and satisfaction with intercourse (p=0.01) 6 months postoperatively. Modified SFQ scores also improved overall (p=0.001) and in all subscales, desire (p=0.001), arousal/sensation (p=0.009), arousal/lubrication (p=0.01), orgasm (p=0.03), pain (p=0.006) and enjoyment (p=0.003). When IIEF scores of men with a permanent ileostomy were compared to men with IAP, those with an ileostomy only showed improvement in orgasmic function (p=0.03) and IIEF total score (p=0.02) whereas in those with IAP the IIEF	Valid (77%) Small sample size and sexually inactivity in 50% of cohort may have had an impact on our findings. Unbalanced sample sizes between men vs women and patients with IAP and end ileostomies Only 6 months follow up Main limitation of using FSFI: questions restricted to last 4 weeks; if patient had no sexual intercourse during that period, the overall scores cannot be used, reducing RR

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
						total score increased after surgery (p=0.05) with significant improvements in sexual desire (p=0.007). In the SFQ all domains except orgasm significantly improved (p=0.003). Women only reported improved sexual function (desire) (p<0.03) Male quality of life improved: IBD QoL p<0.001, Mental Functioning, p<0.003; Physical Functioning, p<0.001. Female quality of life improved: IBD QoL p<0.04, (Mental Functioning, p<0.02 and Physical Functioning, p<0.02). No significant changes in urinary function for either men or women following surgery	
Weinryb et al, 2003, Sweden	To study the relationship between quality of life in ileoanal pouch patients at three points in time: with a temporary ileostomy and at 18 months and 7 years after ileostomy closure.	Longitudinal study, cohorts of patients used as their own controls and prospectively assessed, follow-up at 18 months and 7 years post-operatively	40 UC patients 25M 15F Median duration of UC prior to colectomy was 6 years (mean 9, range 0 to 28). Median age at the second follow-up was 46 years (mean 44, range 23 to 67 years)	Pelvic pouch surgery. Underwent two stage IAP	Quality of life Psychosocial Adjustment to Illness Scale (PAIS) Well-Being Profile (WBP)	Good QOL at all three time points and high degree of stability in the patients' evaluation of QOL over time as indicated by low PAIS and WBP scores. Health care orientation (patients preoccupation with health care concerns and trust in the health care system) improved at short term but deteriorated at long term follow up, although it remained better than pre-operatively (p=0.001). For domestic environment (relationships at home) and PAIS total there was a deterioration between short term follow up (p=0.038) and long term follow up (p=0.029. Men had more problems than women at long term follow up with extended family relationships outside the nuclear family (p<0.006). Wellbeing profile scores were good at all stages of surgery with a mean	Not Valid (73%) Limitations: Small sample size No inclusion /exclusion criteria stated Informed consent not stated in paper Confounding variables not accounted for in analysis Positive: patients used as own controls

Authors	Aim of Study	Study Design	Study Sample	Surgical Intervention/ Experience	Outcome Measures	Findings	Study Quality & Limitations
						of 15.63 preoperatively, 15.9 at 3 months and 17 at 7 years (best possible score 11, worst 44).	
Wuthrich et al, (2009) Switzerland	To evaluate the functional results of ileal pouch-anal anastomosis (IAP) and to assess its impact upon patient quality of life.	Single centre cross sectional questionnaire survey	107 patients 66 completed SF-36 (61% RR) 40M, 26F Median age 38 (range 17–69) years Indications for IAP were UC (n=49) and FAP (n=17). Median duration of follow-up to assess functioning after surgery was 83 (range 4–230) months	Underwent IAP between 1981 and 2002	<u>Quality of life</u> SF-36 <u>Bowel, urinary and sexual function</u> Self devised questionnaire	SF-36: physical component summary was 54.6. Mental component summary was 45.8 (both are 50 in the general population). No clinical or surgical parameters (UC or other) and surgical variables e.g pouch size, surgical technique were significantly associated with better QoL (p>0.05). Function: Two thirds (n=46, 66%) opened their bowels 5 – 10 times during the day, 20 (28%) less than five times a day, and only four (6%) more than 10 times a day. Most patients (n=48, 69%) opened their bowels 1 – 4 times a night. A further 27% (n=19) never had nocturnal bowel movements. Daytime continence was good to excellent for 77%, 23% had some soiling and none were incontinent. Similar results pertained to night time continence. Two thirds of patients never used a pad, 7% sometimes and 28% often used one. The majority of patients either never experienced pouchitis (53%) or had had only one or two episodes (19%), 11% had less than five and 17% had more than five. Thirty percent of patients stated they were preoccupied with their intestinal function which had a significant impact on their daily activities but 42% were never bothered by their intestinal function.	Not Valid (64%) Limitations: Small sample size High non-response (35% of patients did not return the questionnaire) – QoL might be worse in non-responders. High percentage (30%) of FAP patients refused to participate, making the conclusions of this study difficult to generalise to this specific population. No baseline measure of QoL. Informed consent and ethics approval not stated in paper. No confounding variables accounted for in the analysis. No suggestions provided for further areas to research.

Note. AUASI= American Urological Association Symptom Index. AUASI= Appearance Schemas Inventory-Revised. BP= Bodily pain. BIQ= Body Image Questionnaire. BIS=Body Image Scale. CDAI= Crohn's Disease Activity Index. CGQL= Cleveland Global Quality of Life Questionnaire. CQH= current quality of health. CRC= Colorectal cancer. CD=Crohn's disease. DCS=Decisional Conflict Scale.

DNK= did not know. DQO= Direct Questioning of Objectives. ET= Enterostomal Therapy. EQ-SD-3L=EuroQol Questionnaire. FAP= Familial Adenomatous Polyposis. FI= Faecal incontinence. F= female. FIQL= Faecal Incontinence Quality of Life Scale. FSFI= Female Sexual Function Index. GH= general health. GIQLI=Gastrointestinal Quality of Life Index. HADS= Hospital Anxiety and Depression Scale. HRQOL= Health related quality of life. HSQ=Health Status Questionnaire. IBD=Inflammatory Bowel Disease. IBDQ= inflammatory bowel disease questionnaire. IAP= ileoanal pouch procedure/restorative proctocolectomy/ileal pouch-anal anastomosis. IIEF= International Index of Erectile Dysfunction. JCS= Jalowiecz Coping Scale. M= male. md= median. MH= Mental health. QPP= Quality of Care from the Patient's Perspective Questionnaire. PAIS= Psychosocial Adjustment to Illness Scale. PH= Physical functioning. QoL=quality of life. RFIPC= Rating form of IBD Patients Concerns. RR=Response Rate. RP= Role physical. SF= Social functioning. SF-36=Short Form (36) Health Survey. SF-12= SF-12=Short Form (12) Health Survey. SF-8= SF-8=Short Form (8) Health Survey. SIBDQ= Short Inflammatory Bowel Disease Questionnaire. SFQ= Stoma Function Questionnaire. SQL= Stoma Quality of Life Questionnaire. TTO= Time Trade Off technique. UC= Ulcerative Colitis. UIQ= Urinary Incontinence Questionnaire. VT= Vitality. WTG=Willing to gamble. WTT= Willing to trade.

APPENDIX 5. Table 2.3: EBL Quality Appraisal (Glynn, 2006) Results for the 28 Quantitative Studies Included in the Systematic Review

Study Authors	Overall Study Quality Rating (%)	Overall Validity of Study	Section A: Population (%)	Section B: Data Collection (%)	Section C: Study Design (%)	Section D: Results (%)
Andersson et al, 2011	86	Valid	100	67	83	67
Berndtsson et al, 2011	73	Invalid	50	83	83	50
Brandsborg et al, 2013	77	Valid	67	83	83	50
Bullen et al, 2012	64	Invalid	33	67	67	67
Byrne et al, 2007	73	Invalid	50	83	67	67
Carlsson et al, 2003	64	Invalid	33	83	83	33
Cornish et al, 2012	77	Valid	67	83	83	50
DaSilva et al, 2008	64	Invalid	50	67	67	50
Davies et al, 2008	64	Invalid	50	83	67	33
Delaney et al, 2003	82	Valid	83	83	83	50
Dunker et al, 2001	68	Invalid	50	83	67	50
Garcia-Aguilar et al, 2000	82	Valid	83	83	67	67
Kasparek et al, 2007	77	Valid	67	83	83	50
Knowles et al, 2013	50	Invalid	33	50	67	50
Kuruvilla et al, 2012	73	Invalid	50	83	83	50
Larson et al, 2008	64	Invalid	50	83	67	33
Mahadev et al, 2011	77	Valid	67	83	83	50
Moskovitz et al, 2000a	73	Invalid	50	83	67	67
Moskovitz et al, 2000b	68	Invalid	50	83	67	50
Persson et al, 2005	68	Invalid	67	67	67	50
Rini et al., 2011	73	Invalid	33	83	83	67

Study Authors	Overall Study Quality Rating (%)	Overall Validity of Study	Section A: Population (%)	Section B: Data Collection (%)	Section C: Study Design (%)	Section D: Results (%)
Riss et al, 2007	68	Invalid	33	83	83	50
Thaler et al, 2005	68	Invalid	50	67	50	83
Thirlby et al, 2001	77	Valid	83	83	67	50
Tillinger et al, 1999	59	Invalid	17	83	67	50
Wang et al, 2011	77	Valid	67	83	83	50
Weinryb et al, 2003	73	Invalid	33	83	83	67
Wuthrich et al, 2009	64	Invalid	50	83	67	33

APPENDIX 6.

Table 2.7: CHARACTERISTICS OF THE 4 QUALITATIVE STUDIES INCLUDED IN THIS REVIEW

CASP CRITERIA	BEITZ (1999) USA	NOTTER AND BERNARD(2006) UK	SAVARD AND WOODGATE (2009) Canada	SINCLAIR (2009) Canada
Aims of the research	To understand the lived experience of persons who have had construction of an IAP	To explore and describe the perceptions and experiences of women undergoing restorative proctocolectomy (IAP)	To arrive at an understanding of the lived experiences of young persons with inflammatory bowel disease and an ostomy	To understand the experiences of young adults living with a permanent ileostomy
Methodology	Qualitative	Qualitative	Qualitative	Qualitative
Design	Phenomenology	Phenomenology	Phenomenology	Narrative knowing
Recruitment	10 adults 4 M 6F UC All had had IAP surgery Average age at time of surgery was 37.7 years (range 26 – 51). Mean time elapsed since surgery was 2.6 years (range 6 months – 5 years). All were white, 8 had been university educated and all were employed. Researcher attended an IAP support group meeting to recruit volunteers Purposive sampling	50 women who had undergone IAP surgery, most of whom had UC Time since ileostomy ranged from 6 weeks to several years later and an unspecified number of women were included who had not had a stoma at all 'Purposive maximum variety sampling to select a heterogenous group'	six young American adults 1M, 5 W UC Had experienced a stoma. Five had had a reversal and IAP and 1 still had a temporary stoma. No participants were married, 1 engaged, 1 in a relationship for 6 months Caucasian Had to be able to speak, read and write English Recruited through intermediaries	7 young adults aged between 24 and 40 years 3M, 4W Permanent stoma for less than four years. (10 weeks to 3.5 years) Four had had a temporary stoma from 1- 10 years before having the permanent ileostomy. All were Caucasian. Three were married and four were single. Most had undergone higher education or vocational training. Had to be fluent in English and with medical, surgical and emotional stability. Recruited through intermediaries
Data collection	Interview Private setting in a health care facility, school or the participant's home Interviews were conducted by one researcher Field notes	Interview recorded and transcribed No information about the conduct or process of the interviews	Two audiotaped interviews: time and place convenient for each participant Interviews were conducted by one researcher Interview guide based on literature specific to young people living with IBD and a stoma. Broad data generating questions were asked, with questions subsequently asked only to help the narration of the experience 'Collected data until redundancy occurred' Field notes	Unstructured interview Interviews were conducted by one researcher Field notes

CASP CRITERIA	BEITZ (1999) USA	NOTTER AND BERNARD(2006) UK	SAVARD AND WOODGATE (2009) Canada	SINCLAIR (2009) Canada
Researcher relationship	Described the need for bracketing assumptions and attempted to identify how professional and life experiences influenced the researcher's thoughts	Stated that bracketing was an essential first stage, but provided no further information	No information	Acknowledged the researcher's role and relationship with participants in shaping the narrative and patient stories
Ethical issues	Research approved by an ethical committee Verbal information provided about the study and written consent to participate. Informed that consent could be withdrawn and were assured of confidentiality and anonymity as their information would not be linked to their identities	No information	Research approved by an ethical committee, as was process informed consent	Research approved by an ethical committee Provided written information concerning the study, voluntary nature of participation, right to withdraw at any stage, confidentiality and offered counselling if the interview triggered emotional distress
Data analysis	Analysed the data according to procedures proposed by Van Manen (1990). Synthesised data into theme clusters and categories	Analysed the data following procedures described by Giorgi to identify themes and categories.	Analysed the data according to procedures proposed by Van Manen (1990). Identified the essence of the experience, themes and associated subthemes.	Used Clandinin and Connolly's (2000) framework describing four directions (looking backward, looking forward, looking inward and looking outward) guiding research into human experience to analyse the participants' stories. Common and divergent themes from the stories were identified within the biophysical, psychological and social components.
Findings	Ten thematic categories emerged from the data, with 39 subsumed theme clusters. Thematic categories were: restricted life world, living with uncertainty and fear, seeking control, vicious cycles- crisis and normalizing, seeking and giving support, alienation from the body, living with bodily changes, gift of time, role and relationship changes, the end of the tunnel- relative results.The thematic clusters were then grouped into Van Manen's four existential concepts: lived body, lived space, lived time and lived other (relationships)	Four key issues emerged: pain and shock, body image and sexuality, the loop ileostomy, and the roles of the general and specialist nurses	The essence of the lived experience was concealing and revealing the self, with themes of uneasy feelings, 'It's hard' and renewed sense of self, and 10 subthemes: embarrassment, feeling different, frustration, worry, why me?, restrictions, unpredictability/loss of control, pain, freedom and new lease on life	Organised the findings within the four directions of Clandinin and Connolly's (2000) narrative knowing framework, and identified twelve major themes: personal struggles with the disease process, postoperative pain management, nursing care, stoma concerns, impact on body iamge, need for information and education, focus on living, struggles with surgical decision, emotions centring on the stoma, encountering and connecting with people, social roles, work roles

CASP CRITERIA	BEITZ (1999) USA	NOTTER AND BERNARD(2006) UK	SAVARD AND WOODGATE (2009) Canada	SINCLAIR (2009) Canada
Credibility of findings	Followed guidelines developed by Lincoln and Guba (1985) and Sandelowski (1986) in terms of auditability by providing sample data to another researcher for review, credibility by making results available to nurse scholars and wound and ostomy specialists and applicability by careful selection of participants. Confirmability was considered to have been achieved when the previous three criteria had been met.	Assessed the rigour of the study through the criteria of trustworthiness and authenticity and an audit trail for study rigour. In data analysis they avoided forcing or transforming the data to the extent that meanings were ascribed by the researcher	Two interviews were carried out, the second to allow participants to expand on their thoughts and ideas and to clarify information previously provided. Two researchers analysed the data.	Used member checking, returning scripts to five of the seven participants who could be contacted to verify their accuracy.
Value	Rich description with the discussion supported by quotes from the data and by reference to the published literature Discusses limitations: narrow demographic sample, retrospective. Discusses implications for practice and suggests further research	Rich description with the discussion supported by quotes from the data and by reference to the published literature Discusses implications for practice	Rich description with the discussion supported by quotes from the data and by reference to the published literature Discusses limitations: retrospective, conducted at one point in time, narrow demographic sample and suggests further work to address them.	Rich description with the discussion supported by quotes from the data and by reference to the published literature Discusses study limitations: single interview, retrospective, narrow demographic sample Discusses implications for practice

APPENDIX 7. FINDINGS FROM THE 4 QUALITATIVE STUDIES ANALYSED USING SCHLOSSBERG'S 4S FRAMEWORK (GOODMAN ET AL, 2006)

SITUATION

Preoperatively
Loss of control of illness. Perceived IAP as returning them to normal
Struggle with decision to have stoma surgery: some took years, others no control over this- emergency
Postoperatively
Renewed perspective: back on track, Can live again.
Surgery cured disease
Time great factor in adjustment

Severe pain and inadequate pain control

None wished they had the temporary stoma
Temporary stoma viewed as a trial that made adjustment to a permanent stoma easier

Terrified of discharge and coping with the stoma alone

SUPPORT

Postoperatively
Most relationships unaffected by stoma

Partner/family members
Partners supportive
Family was the best support system, gave practical help with stoma
Single patients **avoided dating** and the risk of forming a new relationship
Friends: if they **reacted negatively** to stoma, patient questioned whether they wanted them in their lives
Ward nurses: excellent, compassionate, caring vs lacking in quality, respect, non-caring, insensitive and some showed negative attitudes towards stoma
Stoma Nurse: very supportive
Employers: understanding

SELF

Preoperatively
With UC, **lost energy and desire to engage socially** with family and friends
With UC **felt different**, life of staying home, hospital appointments, medication

Postoperatively
Resumed former activities, education, careers despite concerns about participating in social activities and returning to work
Fear : of effect of complications on QoL, of pouch leakage which led to humiliation and embarrassment
Body image consequent to a stoma: shock and emotional distress related to seeing stoma for the first time, changed body appearance: 'damaged goods', feeling a freak, all objectified the stoma

STRATEGIES

Preoperatively
Talking to someone who had had surgery/ member of stoma association highly valued and helped adjustment
Postoperatively
Problem solved difficulties with the stoma themselves
Lack of information before and after surgery

Figure 2.2: 4S system applied to Sinclair's (2009) study of young adults with a permanent ileostomy

SITUATION	SUPPORT
Preoperatively **Primary motivation for surgery:** escape steroid therapy and side effects **Control**: desire for control of body functions and freedom from pain and urgency was the overriding impetus for surgery Decision making, preparing and self education were seen as efforts to control the situation **Assessment:** Sphincter sparing surgery patients chose it particularly as they wanted to avoid a stoma for the rest of their lives Postoperatively **IAP was perceived as a major positive change** in their lives, releasing them from vicious cycles of UC **Physical recovery**: overwhelming fatigue after major surgeries, needed time to recover. Initial pouch functioning: smell, frequency, incontinence, skin irritation, altered pelvic sensation **Relative nature of outcome**: pleased with improved bowel function, but it was not perfect. Those with bad UC symptoms very pleased. Those with mild UC symptoms less satisfied: IAP resulted in increased frequency, prolonged recovery perceived as worse than existing illness and a lack of closure because of awareness of worsening symptoms **Burden of managing an ileostomy**: perceived it as decreasing attractiveness, increased stress of recuperation, felt 'dirty', appliance leakage, unprepared for reality by surgeons or specialist nurses	**Spouse/significant others** ive but not fully understanding Preoperatively Feelings of inadequacy regarding parenting, spousal relationships and intimacy Strained relationships due to disease restriction Child/parent roles reversed Postoperatively IAP improved wellness and significant relationships Stoma interfered with intimate relations After IAP libido returned intimate relations returned to normal **Health professionals** Good and bad experiences **Specialist nurse**: lifeline, helped with adaptation to stoma **Ward nurse**: lacked knowledge **Support Group:** Only ones who truly understood **Giving support to others** Wanted to advocate and advise others in a similar situation. Some became IAP Visitors – 'got more than they gave'
SELF	STRATEGIES
Preoperatively **Role of sick person**: restricted life world, enforced proximity to bathroom, concealment of 'dirty' parts of the body, wished for freedom from UC, Strain related to a disease of relapse and remission, **Fear/ anxiety throughout experience**: of dying from UC, dying from major surgery, of cancer due to degeneration of IAP small intestine, not designed to store faeces. **Uncertainty throughout experience:** outcome of surgery, no guarantees that IAP would not deteriorate in years to come. Worried about need later for permanent stoma. Postoperatively **Alienation from the body with UC and with a stoma:** feelings of being different– a freak, decreased self respect and self confidence psychological splitting: talking about body parts in the third person. Wearing a stoma bag offensive and a great strain. **IAP:** positive effect on body image, didn't feel like a patient any more, felt and acted like a normal person. **Men:** fear of impotence threat to body image	Preoperatively **Information seeking:** All sought information about surgery but it was hard to find Postoperatively **Practical**: dietary modification **Self education**: Internet, support group **Prayer and relationship with God** **Humour**

Figure 2.3: 4S system applied to Beitz's (1999) study of the experience of IAP surgery

SITUATION	SUPPORT
Preoperatively Dreams of a full recovery from disease gone Postoperatively **Appalled at the impact of the surgery on the body:** Disappointment and distress at prolonged recovery Stoma surgery traumatic and debilitating (prolonged weakness tiredness) Dreaded the pouch failing Determined to keep **IAP at all costs**	Preoperatively **Spouse/significant others** red support by health professionals Postoperatively **Spouse/significant others** red Some supportive and reassuring. Others were not **Specialist nurse**: open access, very supportive, key to ongoing high quality care **Ward nurses**: unsure what to do and lacked confidence
SELF	**STRATEGIES**
Postoperatively **Postoperative pain:** severe, prolonged, uncontrolled- insufficient analgesia **Lack of bowel control:** couldn't get 'clean', felt disgust **Body image consequent to a stoma:** feelings of being different, referred to the stoma in the third person. Never fully recovered from the first sight of the stoma, felt disfigured, less feminine. Wearing a stoma bag **Distress and anxiety:** at family's negative reactions early after surgery **Need for privacy:** but not given it, humiliating to deal with stoma 'in public' ward '**Wanted to return to a normal life'**	Preoperatively **Information seeking:** wanted written information to refer to Postoperatively **Acceptance:** early postoperative period was a phase that they had to get through **Practical**: made up packs to manage a stoma appliance change when out **Avoidance:** limited social life, stayed at home Tried **'mind over matter'** with pain but not effective

Figure 2.4: 4S system applied to Notter and Bernard's (2006) study of the experience of a temporary stoma in first stage IAP surgery

SITUATION

Preoperatively

Loss of control of illness. Perceived IAP as returning them to normal

Unpredictability of illness: stayed home, had people come to them

Postoperatively

Frustration at hospitalisation- felt they were missing out

Not ready to assume stoma care

Stoma changed life for the better: felt healthy, renewed sense of self, no pain, no frequency, less restriction

Still some regret at having a stoma

SUPPORT

Postoperatively

Spouse/significant others: embarrassment with intimacy when had not come to terms with the stoma

Friends: illness not disclosed

SELF

Preoperatively

With UC **felt different**, life of staying home, hospital appointments, medication

Body changes from steroids- embarrassment

Postoperatively

With stoma, **feeling different**, different clothes to hide stoma, different activities from peers

Perception of stigma with a stoma

Better Self: felt had become a better person from the experience, had matured as a human being from the experience

Felt more like themselves after the stoma had been closed

Freedom after the operation: felt healthy (freedom from illness), more freedom to do things

STRATEGIES

Preoperatively

Self blame: felt illness may be their fault

Postoperatively

Avoidance: hiding stoma, non disclosure

Figure 2.5: 4S system applied to Savard and Woodgate's (2009) study of young people's experiences with UC and a temporary stoma in first stage IAP surgery

APPENDIX 8. PATIENT INFORMATION SHEET PHASE 1

Centre number:

Research study number:

Name of researcher:

PATIENT INFORMATION SHEET

We would like to invite you to take part in our research study, which is asking young adults with inflammatory bowel disease (IBD), who have had or may have surgery, their thoughts, feelings and concerns about its effect on their lives

Before you decide whether you want to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. One of our team will go through the information sheet and answer any questions you may have. Feel free to ask if there is anything that is not clear or if you would like further information.

Why do we need to do the research?

Inflammatory bowel disease (IBD) often develops in adolescents and is more extensive and more often requires surgical treatment than when it develops later in life. We know from a recent NACC (National Association for Crohn's and Colitis) survey that young adults with IBD have concerns and anxieties about relationships, sex and pregnancy. However, nobody has investigated how surgery, which may include a stoma, affects the lives of young adults with IBD. Because this research is lacking, health professionals know very little about what issues and concerns affect them, and do not understand them or address them as well as we could.

Why are you suitable to be in the study?

You have been chosen because you have experience of IBD and have either had, or may have to undergo surgery, so you should be able to tell the researcher how you think your life is, or could be, affected.

Do you have to take part?

It is up to you to decide if you want to join the study. If you do agree to take part, we will then ask you to complete a consent form. You are free to withdraw at any time without giving a reason. This would not affect the standard of care or treatment that you receive.

What will you have to do?

If you agree to take part, you will have a confidential taped interview with the Consultant Nurse, Marion Allison, who works at XXXXXXXXXX either at the hospital or in a neutral place, which takes about an hour. She will ask you what it is like to experience the surgery, or live with the prospect that you may need an operation, and about your thoughts, feelings and concerns related to this event. You will be free to tell her as much or as little as you like. She will tape record your conversation so that she can listen to what you have to say and then have a record of it. After the interview she will write down what is on the tape and then send it to you so that you can verify that this accurately reflects what you think and feel. There will also be the opportunity for you to write down more comments or anything which you felt unable to say during the interview on a secure ‘blog’ – you will be given an e mail address that you can post comments to. These comments will be private and confidential and can only read by the researcher. If you would like to take part but wish to talk to a male researcher, Dr James Kelly, who is also involved in the study, will be available for interviews. You may be asked if you are willing to be interviewed again, for instance, a few months after surgery, as your views and feelings may change over time. The researcher will also send you a copy of the results and ask you to comment on them to ensure they reflect accurately what you think and feel. We would expect your total involvement in this part of the research to be between 1 and 5 hours.

In the next phase of the study, we will carry out a national survey to check that the information we have obtained is similar to what other young adults with IBD across the country think and feel about this area of their lives. Questionnaires will be sent to doctors who run IBD clinics across the country and they will ask suitable patients if they will complete the questionnaire anonymously. You may be asked if you would like to do this when you attend clinic. This part of the study will take 20 minutes to half an hour.

We will use the information we are given to develop an educational resource - which will probably be web based - that answers questions, provides practical sources of support and addresses concerns that are expressed about the experience of surgery by young adults with IBD. If you would like to be part of this phase of the study, we will ask you to review the educational package, and give us your opinions about its format, content and presentation so that we can ensure that it is helpful, relevant and appropriate. This would probably require about 2 hours of your time.

Will you benefit directly from being in the study?

There is no direct benefit for you, but your involvement may help us to understand the condition better and also to improve care in the future for young adults with IBD who face surgery.

Are there any potential problems for you if you take part in this study?

We do not think that there will be any harm or injury that could directly affect you if you participate in the study. However, there may be issues that you are unhappy about. You can decide to withdraw from the study at any time, without giving a reason, and this will not affect any of your care, now or in the future. If you feel that you want to complain, please contact Marion Allison (XXXXXXXXXXXXX) first. If the problem cannot be easily resolved, then you can complain through the NHS Complaints Procedure. The hospital can give you details.

Will your involvement in this study be confidential?

The data we will collect from you will be used for research purposes only and will be strictly confidential. Only the researcher, her research supervisor and a professional colleague will have access to the information you give her. Nobody will be able to identify you and your name will not appear on any documents or published articles. Any information about you which leaves the hospital will have your name and address removed so you cannot be recognised. As a courtesy we will let your GP know that you have agreed to take part in the study.

What will happen if you don't want to carry on with the study?

If you withdraw from the study, you will be able to choose whether we can still use the information you have already given us

What will happen to the results of the study?

A written report of the study findings will be sent to the National Association for Crohns and Colitis, who have funded the research study. The results of the study will also be published in a medical journal and may be presented at medical and nursing conferences. We can send you a written summary of the results, if you would like one. You will not be identified in any report, publication or presentation unless you consent to this.

Who is funding the research?

The National Association for Crohns and Colitis, a registered charity, is funding this research study

Who has reviewed the study?

All research in the NHS is reviewed by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by East London and the City Research Ethics Committee.

What happens if you need further information, are worried or there is an emergency?

You will always be able to contact the principal researcher to talk over any concerns that you have. If you have any questions, please contact:

Marion Allison
Consultant Nurse in Colorectal Surgery
XXXXXXXXXXXXXXXXXXX
XXXXXXXXXXXXXXXXXXXX
XXXXXXXXXXXXXX
XXXXXXXXXXXX

Tel: XXXXXXXXXXXXX

IBD Version 9/X/XXXX

APPENDIX 9: INTERVIEW SCHEDULE

INTRODUCTION

Introducing self and role in research

Why research is being done

Why this participant was chosen

BEFORE THE OPERATION

When you first heard that you might have to have surgery how did you feel about that?

What were the main concerns you had?

How did you think your life might be affected by the surgery?

How did you come to the decision that you would go ahead with the surgery?

AFTER THE OPERATION

What changes were there is your life after you had the surgery?

What do you think has been the impact of this surgery on your everyday life?

How do you feel about your body after the surgery?

How do you feel about yourself after the surgery?

Sometimes after an operation relationships with other people can change. Has this been your experience?

What things in your life helped you to cope after your surgery?

Sometimes there are events or experiences related to surgery that are turning points in people's lives. Can you remember any of these happening to you?

What would you say to somebody else facing similar surgery for their IBD?

PROMPTS AND PROBES

Can you give me an example of …

What happened next...

Can you tell me a little more about…

What were you thinking when…

What were you feeling when…

How did….affect you?

How did you see yourself when…

CLOSURE

Is there anything else you would like to tell me?

Thanks for participating

APPENDIX 10. EXAMPLE OF AN INTERVIEW TRANSCRIPT.

RUHANA 11.8.2010

(Researcher) I'm really interested first of all in how you came to have surgery can you tell me a little bit about how that happened

(Ruhana) um the first time I had surgery it was actually a A and E case so I just had a pain in my bottom and I didn't think nothing of it until it just the pain got worse and worse and I kept going back and forth to my GP and then the GP couldn't do anything else cause he didn't know what it was and I didn't it was a case of I couldn't handle the pain and then I got myself admitted to A and E and as soon as they look at it it's called a abscess and they said it needs to be treated straight away so that's when surgery took place the next day and I had a seton put in and at that time no one classed it as Crohn's disease they just said we're not sure what it is but then they started finding out that previously I had another abscess when I was fifteen so it all started quite long ago but I never actually followed it up cause it wasn't giving me that much problems and then after it

was kind of coming to the hospital having tests they carried out various tests until finally it got to the point where it was like I need to have another drainage this was in March this year so I had a second seton put in so that's the third surgery that I've had done so far and another one on the way I think

so how did you feel when they told you you were going to have to have an operation for these things

um I felt very scared it was really scary and I was also scared that after I had the operation am I gonna have problems going to the toilet even if it's a minor operation I started thinking about is it gonna affect me having babies (laughs) because I knew that it could affect me anywhere on my stomach I thought is this gonna affect me in the future whether I'm gonna have babies cause I had to like cause some people have to have operations several times before the drainage stops and then now I've got two setons put in and the drainage still hasn't stopped and it's been like two years now and I'm thinking like is this going to go in time is this gonna affect me having babies cause the affected area's the whole stomach and my wombs near there so I did think about it that far yea and that's it really

mmm you said you had setons in for two years did you expect it was going to be

no the first one no never I thought maximum six months and it'll be gone and then I was told that like they could stay in there for really long

how did you feel when they told you that

not nice not that anyone will know because it's private but it's just that feeling that you've got plastic bits in your bottom it's not very nice *does it interfere with things on a day to day basis*

it doesn't interfere with things but as a young person I think if you're gonna have sex with your partner it's just you feel a bit weird but oh there's a bit of plastic down there (laughs) you know

have you been in that situation

I have been in that situation

and how did you handle it

um I think I forg I wasn't nervous but only because I was so close to that person I was confident it didn't bother me it is kind of like I forgot about it until afterwards I was like did you notice that plastic thing he was like no OK (laughs)

it wasn't as bad as you thought it might be

I think it all depends on support like you know if you get the right support then it doesn't feel as bad

you know some young people find it difficult to tell other people that they've had that surgery done but the feeling I'm getting is that

no not very hard all my friends know I've had an operation in my bottom

and with your boyfriend if you've been in that situation it's not so bad if he didn't notice is it

yea he didn't

when you think about your body because you're a very attractive young woman

thank you (laughs)

obviously your appearance is important to you and looking nice I can tell that by the way that you're dressed in terms of how you feel about your body having that kind of surgery were there any issues that came up for you

it does really bother me the fact that wearing them sanitary towels every day it really does make you even though it's not noticeable it really makes you feel unattractive like every day it's just the feeling like OK say I wanted to take it off one day and just wear my pants normally it wouldn't happen for me because the drainage it's just constant it won't stop sometimes it won't be there for a few hours but it's like I can't guarantee just walk out of my house like feeling normal cause I know it's there and wearing pads every day makes me realise that that makes me feel unsexy with my boyfriend it's like oh you know wearing pads oh (laughs)

do you feel that that aspect affects the way that you are with him

um I don't know because it's funny (laughs) but sometimes when I used to go and see him I never did used to because it made me feel really unattractive but sometimes it never used to come out like for hours nothing there and I'd be like oh hallelujah has it got anything to do with my hormones I wonder (laughs)

(laughs) do you think it does

I don't know I'm not sure that's something that I've never asked anyone

I think probably it doesn't if you're in a particular position you're lying down

yea

maybe it doesn't happen

mmm

it all sounds a bit unpredictable to me though does that have any effect on you

yea it seems like a little bit but when you're wearing pads every day it does get to you like it just feels weird like you can't wear pants without wearing pads like and it just I dunno it just feels unattractive I've stretched out all my pants I know it sounds like nothing but it's not nice you can't wear pants and walk out you know it's like you have to wear sanitary towels every day and it's like this thing that's there it becomes a part of you it is off putting sometimes you get used to it but at times you don't want it there (laughs)

is there anything that it kind of stops you doing in your every day life or that you have to do differently

um no not really it's just personal confidence not really sex cause I don't really have that a lot but it's more of when you're with someone and you're with them you just kind of feel like confident and it's that thing and you're oh it's like a bit off putting and then your confidence is down and your esteem goes down and kind of brings you down and that's all really

so has it affected you as a person would you say

not that other things to do with Crohn's disease but not that

what things to do with Crohn's disease have affected you

as a person dunno like it sometimes like before when people don't understand the disease they just put it down like I'm lazy and they didn't used to take me seriously and that used to really upset me because the thing with Crohn's is something that you can't see so someone's got to believe you to actually know what you're going through because you can't physically show them how much pain you're in whatever you can't physically show them anything that I've got an illness because anyone with Crohn's disease will know that if anyone else looks at them they'll think I'm a normal person they'll know that no one will ever tell that you've got Crohn's disease or not only you know and the effects are hidden underneath you know that's it

until they meet somebody with Crohn's disease lots of people don't know what it's like and your family never understood that

yea they just think they used to think cause I used to get tired a lot and I'm also anaemic so it kind of was like everything put together so I used to get tired and I'd feel unwell at times it would be an unwell where I just feel like sitting down cause my body feels so worn out and then they used to think oh she's lazy they might see there's nothing wrong with my body and a lot of people who aren't aware of things like Crohn's they wouldn't like look into it like my family it's the first they've heard of anything like this

when they found out that actually you couldn't help it it was part of the disease that you had did you find that things were a bit different then or not

um right OK considering my background it wasn't a massive difference but they didn't say it's cause she's lazy they'd just be like oh it's cause she doesn't eat they'd just try and give a reason for it they'd like oh it's cause you didn't eat properly that's why that's causing all this they think you don't eat properly all the illnesses come to you (laughs)

(laughs)

so it's to do with eating if you eat properly all this is gonna go away

so is that what they believe now

no now they just think they don't know what it is but they just think see how it is cause I'm attending hospital see how it goes

so once you started attending hospital that made it kind of all OK

it wasn't really OK it was more to do with they don't feel there's nothing they can do to help me obviously if I feel unwell they'll be there for me it's more like that because it's a part of me

when you talked to me a little while ago you said that you knew that Crohn's disease is a thing that can come back and that people can have one operation after the other and in a few weeks time you're going to see Mr – again and I think you're pretty sure that's going to end up with some more surgery

yea I've been told that it never goes away all it ever does is gets calmed down put like at ease but it never actually goes away that's what I've been told

how does that make you feel

like very very upset it's just like it makes you feel you have a defect inside you like dunno I'm not saying I'd be perfect but it's just the feeling of there's nothing wrong with you it's nice but um I do feel like there is something wrong with me and like um ever since I was young I've always wanted to have loads of kids I always wanted to be a young mother but now I feel like I have this bad inkling that is it going to affect my pregnancy and that's like the only thing that I don't want it to do affect my pregnancies

you ask the question but have you ever talked to anyone

I have talked to them about it and they said that um cause right in those early stages and I haven't even been put on any treatment that I think nearer the time we'll be able to know what's going on cause the body can change at any time so we'll never know what the treatment could do you know so I just have to wait *so no one's given you any concrete information*

they've given me information they've said that because of what's going on inside my stomach my stomach's weak as it is like if I do plan to have kids in the future it may be best to have a caesarean but I'm really unhappy to hear that cause I hear that you can't have the caesarean too many times and I don't to be going through that time and again as well

how many times did you want a caesarean (laughs)

(laughs) I heard you could have it up to three times is it you have a baby by caesarean and I want a natural birth as well I'm not too keen on that caesarean

so what does a caesarean mean to you

isn't that when they cut your baby out of you and that and it's not natural and you have to live with the pain (laughs)

so it's very important to you that you do everything naturally is it

yea if it's like a one off like the baby's in danger that's one thing but you know if I'm gonna have it because of this it puts you down it's not a case where it has to be done because of this and that it's a case of my stomach's weak you know

I see

and um coming from my background as well it's another worry that I want to get married and people from my background tend to get married at a young age but I'm looking to get married when I'm around twenty two but it really worries me because they hold a lot of expectations from you where we come from when you get married you kind of go over and take over the responsibilities of the mother in the house as a daughter in law so the way I feel I don't feel as active as a normal person so I'm thinking well I won't be as active and if I'm falling ill all the time I'll be kind of disappointed I don't want my husband to be disappointed in me cause not everyone understands like as I say it's not something you can see which is the biggest put down cause when people can't see it they can't tell it's there but I don't constantly want to be feeling worn out and tired and you know not feeling active not always being you know

you might feel a bit different when you're on medication

yea I might do

have you met the person you want to marry yet

um (laughs) maybe (laughs)

does that mean you think he might be the person you want to marry

yea yea

have you been able to talk about any of this with him

yea he just um he's just like oh don't worry it's gonna be OK (laughs) I'm sure you'll be fine (laughs) *does that mean he's supportive of you*

yea he's supportive and he's like to me oh don't worry my mother had four Caesareans (laughs)

(laughs) he thought that would make you feel better did he

but it's true the thing is it's actually true and he just makes me laugh thinking he just turns everything into a joke but he just makes everything seem not so serious like I don't want it to be that serious in my face

yes so that's the way he helps you to cope

yea yea

did he know you had Crohn's disease when you met him

no but he knew I had um he knew I had there was a problem but at the time it was an ongoing process of finding out what the problem is

so nobody knew you had Crohn's

yea so when this I always knew it was a possibility because I was told it's probably that and then when I did find out then I did tell him oh it's definitely that

and what did he say then

oh he's like oh you need to get better as soon as possible so he was always nagging me like make sure you don't miss hospital like make sure you go yea

so he's been supportive of you in a way other people haven't

yea but I don't blame them because sometimes the closeness you find in a friend you can't always get with your family because you have different relationships with different people don't you so yea

do they kind of rely on you in your family to do things

not rely on me but um like um I'm kind of the only one that kind of speaks English my brother does but he doesn't deal with house problems so I'm the one that deals with it but mostly I think I've got this um and because I'm the only one born in this country I have this pressure to make something out of myself but because of this disease it's been stopping me so it has put my life down in some ways like I had a period where after my operation I was off I was doing training but it was a work placement I was off for weeks and that made me feel really down like after all those weeks down it's hard to get back up by then my training finished so now I'm looking for a job and I'm like well

what were you doing your training in

I've finished now I've got an apprenticeship in business and administration

so that must have been hard because your placement is helping you towards a productive future isn't it uh huh and they're so understanding but I know I won't get that everywhere because it's not everywhere you'll go into work and you'll just make friends with everyone and those relationships but yea all my managers were really understanding and they're always telling me you know if you ever feel like you've got any sort of pain anything just let us know immediately you know we'll let you go off somewhere else and sit down so understanding

that must have been very helpful

yes very helpful and all my colleagues they're like really friendly I loved working there

it's a shame they couldn't have you back full time

yea it's because of all this recession going on they're even cutting jobs off of people that have been there for years and they don't have space to employ me I had like several managers and they were all really nice I had a lot of time off with my illness and they were really understanding

that makes a difference doesn't it so if you were to talk to me about the kind of future you see for yourself you've told me quite a bit about it already but obviously you have different considerations from people who don't have something like Crohn's so when you think about yourself say five years in the future what do you see

I see um five years like I'll be twenty four um I see myself married probably with my first kid but I see before then I will have accomplished a good career and save some money you know bought a house I would say and that's it but um but um the only reason like I'm pushing my career is that firstly I wanna become something so it's kind of like a pride thing in my family like where I want to show everyone that I can become something and being a female obviously it's more of a reason to become something and I've always had the ambition that I'd like to work for a big organisation and become a secretary you know in a good company you can say then I've become this a good accomplished one and then that's it really I wanna make my mum proud cause everyone else is married I'm just her last daughter like her baby daughter so I wanna make my mum proud and thenI plan to stop working when I get married but I because of the way things are going I always want to have the back up where if I need to go back into work I don't want to struggle I wanna be like yea I've got the experience I've got myqualifications and go straight into a job

what I'm hearing is although you've got this chronic illness you're not going to let it interfere with any of your plans is that the message you're telling me

yea but I'm going to have to wait and find out how it is because I haven't actually got another job yet I don't know how they're gonna react I think it's all about how supportive they are because I might be having a lot of time off I don't know how it's gonna go with things like that I haven't gone there yet (laughs)

you did say to me in the clinic it's not having the operation that bothers you yea

it's after the operation

yea

do you want to tell me a bit about

yea my biggest fear even today right now about getting another job is once I have another operation I'm going to have to go back off work because um I don't know how everyone else's body is but my personal body is very weak after my last operation like I couldn't move for days and I was crying in pain every time cause after the first few days the first day don't notice because you don't need to go toilet but after when you need to go toilet that pain it just hurts so much it's down there like boy I was just in tears when I was trying to go toilet that pain put you off eating (laughs) like you can't go and it's all sore and you've just had operation and you can't move and you have problems like when you're walking you can't even walk properly when I used to go toilet it used to burn it's not even

pain it burns after that like every time I go toilet for like an hour and a half I would sit there and cry in pain until that soreness goes away because it kind of leaves the place really sore and then it just hurts so badly it's like you are taking painkillers and it's still not enough for that pain and that lasts for quite a while

did anyone talk to you about how things would be after

no no they didn't it was more to do with what's going to happen at operation no one actually cause they those kind of effects are something to do with you personally not really that you are affected in any way but it's like things that are major to you they still call it a minor operation but it's major to you that's why I say cause if you think about it if you tell someone I was in the hospital had a quick operation came back out they'll be thinking I'm running the next day you're not that operation yea recovering it's best to do it in your house yea (laughs) it's really painful I think going to the toilet is the worst thing cause even

a normal day you have diarrhoea you know how it feels but imagine that every time it's burning it's like burning pain that doesn't go hurts like so much you can't even walk properly for ages (laughs) with your bottom (laughs)

(laughs) how did you feel knowing what it was going to be like as you'd had it done before when they told you you were going to have the same thing done again

oh trust me I didn't want to I was just I was so upset for days when I found out they were going to do it again but what everyone kept telling me it's gonna benefit you after and they were like my friends were really supportive they come with me to the hospital all the time that's what A (specialist nurse) says I have my army with me (laughs) yea they all come it's always someone different someone's always here for me and then today I thought I'd just come cause it's just like a little talk today but when I found out that is the worst thing you know when you don't know what you're in for it doesn't scare you that much but when you know what's gonna happen it's scary knowing you are gonna put yourself in that situation where you're gonna go through that but you can't help it cause it's onlyfor the better

so that's the way you kind of came to terms with it really was it

I didn't really come to terms with it I was just like OK do I want to avoid this and not feel nothing now but then it's going to affect me in the future yea that's the way you have to put it do I want to have a good future yes I do OK

as a young person when you compare yourself to your friends you're having to go through things and deal with things that they don't have to do you have any feelings about that

not really because I feel they're really supportive I don't feel like oh you know I'm missing out or anything personally but the only biggest disappointment is that it's slowed down my life so much cause I think if I was better I'd have progressed so much more now I would be so much more active there's days where you want to do something but you're so tired that it's just like no if I'd have been normal I'd have been more able to get up to speed with things try and think about how I'm gonna build my life and like every time I try to go forward something stops me like cause it's coming to a point with the pain surgery you know this and that it's always holding you back that's the biggest thing really

so you have all these plans but the illness or its treatment can interfere there are some other people in your situation and they feel not jealousy but they feel looking at their friends

I'm gonna be honest that I don't know how other people are but the one thing that does sometimes get me down a lot is in a relationship you know like all this pain all this slowing down it can make you feel depressed sometimes like cause you're like you personally feel like you're being put down and it's something that you can't physically do nothing about and it does affect you it starts sometimes you get like self pity like oh I'm ill I'm lazy I can't do

tell me a bit more about

Yea sometimes you got into this sometimes you go into a phase where you feel there's something wrong with you it's like I wouldn't call it jealousy but you think there's people out there and there's nothing wrong with them and then you kind of sit there thinking that there is something wrong with me I'm not as this person or you know I can't do this effectively and it does make you feel down

so you don't get jealous but you kind of compare yourself with other people

not compare myself but I think that it's just that feeling of something wrong with you and it's not it's not nice cause you can it can like affect you cause you can have those feelings where you're going through a lot of pain and you start doing you start taking it out on other people like I do that if I ever start feeling that there's something wrong with me why is there something wrong with me you have days and then *so it's why did it have to happen to me and I think the worst thing about that is that nobody can answer that question for you can they*

yea yea

when you think about the operations and you're quite experienced at those now

yea

if there was anybody else and they were going to have that type of surgery is there anything that you feel they should know or you would have liked to have known before you had the operation

no but erm I think the thing is the things that happen to you after are things that have to happen there's nothing that can ease it it's just that be ready for the pain and having to know be ready because after the operation you're not gonna feel nothing you're gonna feel like you'll be normal after a few hours but it's being like going to the toilet you know that's gonna affect you the worst

and the worst thing about that is that there's nothing anybody can do to make it better

yea that's it that's the one because you have to go to the toilet you know even when you're not eating you have to you still have to go and it just really affects you

when you think about other people who are going to have surgery is there anything that you want to tell them about your experiences

OK I think what I've found is the biggest thing that can make you feel better is support because when you're going through that stage after the operation the only thing that can take your mind off it is when you distract yourself because you know sometimes you feel like some people think like oh you know leave her to rest no that's not the best action because you are just in pain pain pain that's all you're gonna think about what you need is people distracting you people in front of your face people talking to you about other things going on I think the biggest thing to have is people around you because medication's not gonna work you need people talking to you distracting you telling you this that you know orthey need to be cause you're distracting your self cause once you're alone the
pain's just gonna be there and that's all you're gonna feel (laughs)

so that was your friends and your boyfriend as well was it

yea and my family as well being around you's the best possible thing someone can do just talking to you I think when you're alone it kind of gets to you more like look at me I'm alone and in pain and just laying here like oh (laughs)

so that for you is the key thing to helping you

I think yea because your medication can only do it to a certain extent the rest of the time you have to learn yea I thing that is the biggest thing

and I think you're fortunate because you do seem to have that strong network yea that's the thing cause they're not there all the time I know how it feels like when there's no one there and you're just laying in bed like I had those moments where I couldn't go downstairs because I was in pain and I'd be like but I've no one to sit next to me and it just felt you just feel really worse I think mentally you feel worse you're really not that bad but when you're alone you just you are mentally telling yourself oh you know I've just no one around me I'm in pain and that kind of makes it worse I think when you're happy you just kind of avoid those feelings

is there anything else you want say about your experience of surgery

No not really I think that's it

thank you for talking to me today about your experiences what you have told me has been very interesting and I appreciate you taking the time to do it

<u>APPENDIX 11. EXAMPLE OF A STORYMAP: RUHANA</u>

	Self	**Disease**	**The surgery**	**Health professionals**
Past experiences	I felt very scared it was really scary not that anyone will know because it's private but it's just that feeling that you've got plastic bits in your bottom it's not very nice	and at that time no one classed it as Crohn's disease they just said we're not sure what it is but then they started finding out that previously I had another abscess when I was fifteen so it all started quite long ago but I never actually followed it up cause it wasn't giving me that much problems and then after it was kind of coming to the hospital having tests they carried out various tests I've been told that it never goes away all it ever does is gets calmed down put like at ease but it never actually goes away that's what I've been told (I feel) like very very upset it's just like it makes you feel you have a defect inside you I'm not saying I'd be perfect but it's just the feeling of there's nothing wrong with you it's nice but um I do feel like there is something wrong with me	the first time I had surgery it was actually a A and E case so I just had a pain in my bottom and I didn't think nothing of it until it just the pain got worse and worse and I kept going back and forth to my GP and then the GP couldn't do anything else cause he didn't know what it was and I didn't it was a case of I couldn't handle the pain and then I got myself admitted to A and E and as soon as they look at it it's called a abscess and they said it needs to be treated straight away so that's when surgery took place the next day and I had a seton put in until finally it got to the point where it was like I need to have another drainage this was in March this year so I had a second seton put in so that's the third surgery that I've had done so far and another one on the way I think I was also scared that after I had the operation am I gonna have problems going to the toilet even if it's a minor operation some people have to have operations several times before the drainage stops and then now I've got two setons put in and the drainage still hasn't stopped and it's been like two years now and I'm thinking like is this going to go in time the first one no never I thought maximum six months and it'll be gone and then I was told that like they could stay in there for really long I don't know how everyone else's body is but my personal body is very weak after my last operation like I couldn't	(was she told about after effects of surgery) no no they didn't it was more to do with what's going to happen at operation no one actually cause they those kind of effects are something to do with you personally not really that you are affected in any way but it's like things that are major to you they still call it a minor operation but it's major to you

			move for days and I was crying in pain every time cause after the first few days the first day don’t notice because you don’t need to go toilet but after when you need to go toilet that pain it just hurts so much it’s down there like boy I was just in tears when I was trying to go toilet that pain put you off eating (laughs) like you can’t go and it’s all sore and you’ve just had operation and you can’t move and you have problems like when you’re walking you can’t even walk properly when I used to go toilet it used to burn it’s not even pain it burns after that like every time I go toilet for like an hour and a half I would sit there and cry in pain until that soreness goes away because it kind of leaves the place really sore and then it just hurts so badly it’s like you are taking painkillers and it’s still not enough for that pain and that lasts for quite a while if you think about it if you tell someone I was in the hospital had a quick operation came back out they’ll be thinking I’m running the next day you’re not that operation yea recovering it’s best to do it in your house yea(laughs) it’s really painful I think going to the toilet is the worst thing cause even a normal day you have diarrhoea you know how it feels but imagine that every time it’s burning it’s like burning pain that doesn’t go hurts like so much you can’t even walk properly for ages (laughs) with your bottom (laughs) (the second operation) oh trust me I didn’t want to I was just I was so upset for days when I found out they were going to do it again**... when I found out that is the worst thing you know when you don’t know what you’re in for	

			it doesn't scare you that much but when you know what's gonna happen it's scary knowing you are gonna put yourself in that situation where you're gonna go through that but you can't help it cause it's only for the better... I didn't really come to terms with it I was just like OK do I want to avoid this and not feel nothing now but then it's going to affect me in the future yea that's the way you have to put it do I want to have a good future yes I do OK the thing is the things that happen to you after are things that have to happen there's nothing that can ease it it's just that be ready for the pain and having to know be ready because after the operation you're not gonna feel nothing you're gonna feel like you'll be normal after a few hours but it's being like going to the toilet you know that's gonna affect you the worst	
Present experiences	it's just personal confidence not really sex cause I don't really have that a lot but it's more of when you're with someone and you're with them you just kind of feel like confident and it's that thing and you're oh it's like a bit off putting and then your confidence is down and your esteem goes down and kind of brings you down I'm gonna be honest that I don't know how other people are but the one thing that does sometimes get me down a lot is in a relationship you know like all this pain all this slowing down it can make you feel depressed sometimes like cause you're like you personally feel like you're being put down and it's something that you can't physically do nothing about and it does affect you it starts sometimes you get like self pity like oh I'm ill I'm lazy I can't do... sometimes you go into a phase where			

	you feel there’s something wrong with you it’s like I wouldn’t call it jealousy but you think there’s people out there and there’s nothing wrong with them and then you kind of sit there thinking that there is something wrong with me I’m not as this person or you know I can’t do this effectively and it does make you feel down... it’s just that feeling of something wrong with you and it’s not it’s not nice cause you can it can like affect you cause you can have those feelings where you’re going through a lot of pain and you start doing you start taking it out on other people like I do that if I ever start feeling that there’s something wrong with me why is there something wrong with me you have days and then			
Future intentions	five years like I’ll be twenty four um I see myself married probably with my first kid but I see before then I will have accomplished a good career and save some money you know bought a house I would say and that’s it			

	Family	Friends/other people	Intimate relationships
Past experiences	they used to think cause I used to get tired a lot and I'm also anaemic so it kind of was like everything put together so I used to get tired and I'd feel unwell at times it would be an unwell where I just feel like sitting down cause my body feels so worn out and then they used to think oh she's lazy they might see there's nothing wrong with my body and a lot of people who aren't aware of things like Crohn's they wouldn't like look into it like my family it's the first they've heard of anything like this (family response to diagnosis) considering my background it wasn't a massive difference but they didn't say it's cause she's lazy they'd just be like oh it's cause she doesn't eat they'd just try and give a reason for it they'd like oh it's cause you didn't eat properly that's why that's causing all this they think you don't eat properly all the illnesses come to you (laughs) so it's to do with eating if you eat properly all this is gonna go away	I think it all depends on support like you know if you get the right support then it doesn't feel as bad all my friends know I've had an operation in my bottom a person dunno like it sometimes like before when people don't understand the disease they just put it down like I'm lazy and they didn't used to take me seriously and that used to really upset me because the thing with Crohn's is something that you can't see so someone's got to believe you to actually know what you're going through because you can't physically show them how much pain you're in whatever you can't physically show them anything that I've got an illness because anyone with Crohn's disease will know that if anyone else looks at them they'll think I'm a normal person they'll know that no one will ever tell that you've got Crohn's disease or not only you know and the effects are hidden underneath you know ** what everyone kept telling me it's gonna benefit you after and they were like my friends were really supportive they come with me to the hospital all the time that's what A- says I have my army with me with me to the hospital all the time that's what A- says I have my army with me(laughs) yea they all come it's always someone different someone's always here I feel they're really supportive I don't feel like oh you know I'm missing out or anything personally	I started thinking about is it gonna affect me having babies (laughs) because I knew that it could affect me anywhere on my stomach I thought is this gonna affect me in the future whether I'm gonna have babies is this gonna affect me having babies cause the affected area's the whole stomach and my wombs near there so I did think about it that far sometimes when I used to go and see him I never did used to because it made me feel really unattractive but sometimes it never used to come out like for hours nothing there and I'd be like oh hallelujah has it got anything to do with my hormones I wonder (laughs)... I don't know I'm not sure that's something that I've never asked anyone (when she met him) he knew I had there was a problem but at the time it was an ongoing process of finding out what the problem is so when this I always knew it was a possibility because I was told it's probably that and then when I did find out then I did tell him oh it's definitely that he's like oh you need to get better as soon as possible so he was always nagging me like make sure you don't miss hospital like make sure you go yea
Present experiences	now they just think they don't know what it is but they just think see how it is cause I'm attending hospital see how it goes... they don't feel there's nothing they can do to help me obviously if I feel unwell they'll be there for me it's more like that because it's a part of me I'm kind of the only one that kind of speaks English my brother does but he	(getting support) I don't blame them because sometimes the closeness you find in a friend you can't always get with your family because you have different relationships with different people don't you I think what I've found is the biggest thing that can make you feel better is support because when you're going through that stage after the operation the only thing that can take your mind off it is	but as a young person I think if you're gonna have sex with your partner it's just you feel a bit weird but oh there's a bit of plastic down there (laughs) you know...I have been in that situation I wasn't nervous but only because I was so close to that person I was confident it didn't bother me it is kind of like I forgot about it until afterwards I was like did you notice that

	doesn’t deal with house problems so I’m the one that deals with it but mostly I think I’ve got this um and because I’m the only one born in this country I have this pressure to make something out of myself but because of this disease it’s been stopping me	when you distract yourself because you know sometimes you feel like some people think like oh you know leave her to rest no that’s not the best action because you are just in pain pain pain that’s all you’re gonna think about what you need is people distracting you people in front of your face people talking to you about other things going on I think the biggest thing to have is people around you because medication’s not gonna work you need people talking to you distracting you telling you this that you know or they need to be cause you’re distracting your self cause once you’re alone the pain’s just gonna be there and that’s all you’re gonna feel (laughs) (friends and boyfriend) and my family as well being around you’s the best possible thing someone can do just talking to you I think when you’re alone it kind of gets to you more like look at me I’m alone and in pain and just laying here like oh (laughs) because your medication can only do it to a certain extent the rest of the time you have to learn yea I thing that is the biggest thing yea that’s the thing cause they’re not there all the time I know how it feels like when there’s no one there and you’re just laying in bed like I had those moments where I couldn’t go downstairs because I was in pain and I’d be like but I’ve no one to sit next to me and it just felt you just feel really worse I think mentally you feel worse you’re really not that bad but when you’re alone you just you are mentally telling yourself oh you know I’ve just no one around me I’m in pain and that kind of makes it worse I think when you’re happy you just kind of avoid those feelings	plastic thing he was like no OK (laughs) ever since I was young I’ve always wanted to have loads of kids I always wanted to be a young mother but now I feel like I have this bad inkling that is it going to affect my pregnancy and that’s like the only thing that I don’t want it to do affect my pregnancies... I have talked to them about it and they said that um cause right in those early stages and I haven’t even been put on any treatment that I think nearer the time we’ll be able to know what’s going on cause the body can change at any time so we’ll never know what the treatment could do you know so I just have to wait like if I do plan to have kids in the future it may be best to have a caesarean but I’m really unhappy to hear that going through that time and again as well I heard you could have it up to three times is it you have a baby by caesarean and I want a natural birth as well I’m not too keen on that caesarean... isn’t that when they cut your baby out of you and that and it’s not natural and you have to live with the pain (laughs)... if it’s like a one off like the baby’s in danger that’s one thing but you know if I’m gonna have it because of this it puts you down it’s not a case where it has to be done because of this and that it’s a case of my stomach’s weak you know (thinks she has met the person she wants to marry) he just um he’s just like oh don’t worry it’s gonna be OK (laughs) I’m sure you’ll be fine (laughs) he’s supportive and he’s like to me oh don’t worry my mother had four caesareans it’s true the thing is it’s actually true and he just makes me laugh thinking he just turns everything into a joke but he just makes everything seem not so serious like I don’t want it to be that serious in my face

Future intentions	coming from my background as well it's another worry that I want to get married and people from my background tend to get married at a young age but I'm looking to get married when I'm around twenty two but it really worries me because they hold a lot of expectations from you where we come from when you get married you kind of go over and take over the responsibilities of the mother in the house as a daughter in law so the way I feel I don't feel as active as a normal person so I'm thinking well I won't be as active and if I'm falling ill all the time I'll be kind of disappointed I don't want my husband to be disappointed in me cause not everyone understands like as I say it's not something you can see which is the biggest put down cause when people can't see it they can't tell it's there but I don't constantly want to be feeling worn out and tired and you know not feeling active the only reason like I'm pushing my career is that firstly I wanna become something so it's kind of like a pride thing in my family like where I want to show everyone that I can become something and being a female obviously it's more of a reason to become something and I've always had the ambition that I'd like to work for a big organisation and become a secretary you know in a good company you can say then I've become this a good accomplished one and then that's it really I wanna make my mum proud cause everyone else is married I'm just her last daughter like her baby daughter so I wanna make my mum proud		

	Appearance	College/work	Activities
Past experiences		because of this disease it's been stopping me so it has put my life down in some ways like I had a period where after my operation I was off I was doing training but it was a work placement I was off for weeks and that made me feel really down like after all those weeks down it's hard to get back up by then my training finished so now I'm looking for a job...	
Present experiences	it does really bother me the fact that wearing them sanitary towels every day it really does make you even though it's not noticeable it really makes you feel unattractive like every day it's just the feeling like OK say I wanted to take it off one day and just wear my pants normally it wouldn't happen for me because the drainage it's just constant it won't stop sometimes it won't be there for a few hours but it's like I can't guarantee just walk out of my house like feeling normal cause I know it's there and wearing pads every day makes me realise that that makes me feel unsexy with my boyfriend it's like oh you know wearing pads oh when you're wearing pads every day it does get to you like it just feels weird like you can't wear pants without wearing pads like and it just I dunno it just feels unattractive I've stretched out all my pants I know it sounds like nothing but it's not nice you can't wear pants and walk out you know it's like you have to wear sanitary towels every day and it's like this thing that's there it becomes a part of you it is off putting sometimes you get used to it but at times you don't want it there (laughs)	I've got an apprenticeship in business and administration and they're so understanding but I know I won't get that everywhere because it's not everywhere you'll go into work and you'll just make friends with everyone and those relationships but yea all my managers were really understanding and they're always telling me you know if you ever feel like you've got any sort of pain anything just let us know immediately you know we'll let you go off somewhere else and sit down so understanding very helpful and all my colleagues they're like really friendly I loved working there... because of all this recession going on they're even cutting jobs off of people that have been there for years and they don't have space to employ me I had like several managers and they were all really nice I had a lot of time off with my illness and they were really understanding I haven't actually got another job yet I don't know how they're gonna react I think it's all about how supportive they are because I might be having a lot of time off I don't know how it's gonna go with things like that I haven't gone there yet (laughs) yea my biggest fear even today right now about getting another job is once I have another operation I'm going to have to go back off work	the only biggest disappointment is that it's slowed down my life so much cause I think if I was better I'd have progressed so much more now I would be so much more active there's days where you want to do something but you're so tired that it's just like no if I'd have been normal I'd have been more able to get up to speed with things try and think about how I'm gonna build my life and like every time I try to go forward something stops me like cause it's coming to a point with the pain surgery you know this and that it's always holding you back that's the biggest thing really
Future intentions		I plan to stop working when I get married but I because of the way things are going I always want to have the back up where if I need to go back into work I don't want to struggle I wanna be like yea I've got the experience I've got my qualifications and go straight into a job	

APPENDIX 12: RUHANA'S STORY

Aged 19, Ruhana has perianal Crohn's disease and has required several operations for her condition: *'the first time I had surgery, it was actually a A and E case so I just had a pain in my bottom and I didn't think nothing of it until...the pain got worse and worse and I kept going back and forth to my GP and then the GP couldn't do anything else cause he didn't know what it was and I didn't. It was a case of I couldn't handle the pain and then I got myself admitted to A and E and as soon as they look at it, it's called a abscess and they said it needs to be treated straight away. So that's when surgery took place the next day and I had a seton put in'. 'Finally it got to the point where it was like I need to have another drainage. This was in March this year so I had a second seton put in. So that's the third surgery that I've had done so far and another one on the way I think'. 'At that time no one classed it as Crohn's disease. They just said we're not sure what it is but then they started finding out that previously I had another abscess when I was fifteen. So it all started quite long ago but I never actually followed it up cause it wasn't giving me that much problems and then after it was kind of coming to the hospital having...various tests'.*

She thought the first operation would resolve the problem and the seton would soon be removed: *'I thought maximum six months and it'll be gone and then I was told that like they could stay in there for really long'*. Now she knows more about her condition– *'some people have to have operations several times before the drainage stops and then now I've got two setons put in and the drainage still hasn't stopped and it's been like two years now and I'm thinking like is this going to go in time. I've been told that it never goes away. All it ever does is gets calmed down, put like at ease but it never actually goes away. That's what I've been told. (I feel) like very very upset. It's just like it makes you feel you have a defect inside you. I'm not saying I'd be perfect but it's just the feeling of there's nothing wrong with you, it's nice, but um I do feel like there is something wrong with me'*.

Faced with further surgery and its after effects, she feels that health professionals have different perceptions about these things. In telling her what to expect, *'it was more to do with what's going to happen at operation...those kind of effects are something to do with you personally...It's like things that are major to you they still call it a minor operation but it's major to you'*. Based on her previous experiences and told she needed another operation *'I felt very scared. It was really scary'. 'I was also scared that, after I had the operation, am I gonna have problems going to the toilet even if it's a minor operation'. 'Oh trust me, I didn't want to. I was just...so upset for days when I found out they were going to do it again'. 'When*

I found out that is the worst thing. You know, when you don't know what you're in for, it doesn't scare you that much but when you know what's gonna happen, it's scary knowing you are gonna put yourself in that situation where you're gonna go through that, but you can't help it cause it's only for the better... I didn't really come to terms with it. I was just like OK, do I want to avoid this and not feel nothing now but then it's going to affect me in the future. Yea, that's the way you have to put it- do I want to have a good future. Yes I do, OK'.

She recounts how she was affected after her previous operations: *'I don't know how everyone else's body is, but my personal body is very weak. After my last operation like I couldn't move for days and I was crying in pain every time cause...the first day don't notice because you don't need to go toilet but after when you need to go toilet, that pain. It just hurts so much. It's down there like, boy, I was just in tears when I was trying to go toilet. That pain put you off eating. Like you can't go and it's all sore and you've just had operation and you can't move and you have problems like when you're walking. You can't even walk properly. When I used to go toilet it used to burn. It's not even pain, it burns after that. Like every time I go toilet, for like an hour and a half I would sit there and cry in pain until that soreness goes away because it kind of leaves the place really sore and then it just hurts so badly. It's like you are taking painkillers and it's still not enough for that pain and that lasts for quite a while. If you think about it, if you tell someone I was in the hospital, had a quick operation, came back out, they'll be thinking I'm running the next day. You're not. That operation, yea, recovering- it's best to do it in your house...It's really painful. I think going to the toilet is the worst thing, cause even a normal day you have diarrhoea, you know how it feels but imagine that every time it's burning. It's like burning pain that doesn't go, hurts like so much, you can't even walk properly for ages with your bottom'. She feels that these problems are inevitable after surgery: 'the thing is, the things that happen to you after are things that have to happen. There's nothing that can ease it. It's just that- be ready for the pain and having to know be ready, because after the operation you're not gonna feel nothing, you're gonna feel like you'll be normal after a few hours but it's being like going to the toilet, you know, that's gonna affect you the worst'.*

She feels that the most important thing that helps her to cope with the surgery and its consequences and that makes her feel better is *'support, because when you're going through that stage after the operation the only thing that can take your mind off it is when you distract yourself. Because, you know, sometimes you feel like some people think like oh, you know, leave her to rest. No, that's not the best action because you are just in pain, pain, pain. That's all you're gonna think about. What you need is people distracting you, people in front* *of your face, people talking to you about other things going on. I think the biggest thing to have is people around you, because medication's not gonna work. You need people talking to you, distracting you, telling you this, that, you know...cause once you're alone, the pain's just gonna be there and that's all you're gonna feel'*. She feels that having her friends, boyfriend and her family around her is *' the best possible thing... when you're alone it kind of gets to you more like, look at me, I'm alone and in pain and just laying here like, oh, because your medication can only do it to a certain extent... cause they're not there all the time. I know how it feels like when there's no one there and you're just laying in bed like. I had those moments where I couldn't go downstairs because I was in pain and I'd be like, but I've no one to sit next to me and...you just feel really worse. I think mentally you feel worse. You're really not that bad but when you're alone...you are mentally telling yourself oh, you know, I've just no one around me. I'm in pain and that kind of makes it worse. I think when you're happy you just kind of avoid those feelings'.*

She derives a lot of support from her friends: *'All my friends know I've had an operation in my bottom... if you get the right support then it doesn't feel as bad.'* When confronted with the need for further surgery, *'what everyone kept telling me, it's gonna benefit you after and they were...really supportive. They come with me to the hospital all the time. That's what A (her specialist nurse) says, I have my army with me...Yea, they all come. It's always someone different, someone's always here...I feel they're really supportive. I don't feel like oh, you know, I'm missing out or anything personally... sometimes the closeness you find in a friend, you can't always get with your family because you have different relationships with different people.'*

She doesn't like the setons, put there to drain the perianal area and prevent further infection. *'Not that anyone will know, because it's private, but it's just that feeling that you've got plastic bits in your bottom. It's not very nice'.* Because of the setons, she always has to wear a pad. *'It does really bother me, the fact that wearing them sanitary towels every day...Even though it's not noticeable, it really makes you feel unattractive. Like every day it's just the feeling like OK, say I wanted to take it off one day and just wear my pants normally, it wouldn't happen for me because the drainage, it's just constant. It won't stop. Sometimes it won't be there for a few hours, but it's like I can't guarantee just walk out of my house like feeling normal , cause I know it's there and wearing pads every day makes me realise that that makes me feel unsexy with my boyfriend...When you're wearing pads every day it does get to you. Like, it just feels weird. Like, you can't wear pants without wearing pads like and it just...feels unattractive. I've stretched out all my pants. I know it sounds like nothing but* *it’s not nice. You can’t wear pants and walk out, you know. It’s like you have to wear sanitary towels every day and it’s like this thing that’s there. It becomes a part of you. It is off putting. Sometimes you get used to it but at times you don’t want it there’.*

The disease and the surgery impact on her relationship with her family, her life plans and cultural expectations of her. *‘I’m... the only one that kind of speaks English. My brother does but he doesn’t deal with house problems, so I’m the one that deals with it but mostly I think I’ve got this...and because I’m the only one born in this country, I have this pressure to make something out of myself but because of this disease it’s been stopping me’. ‘I used to get tired a lot and I’m also anaemic ...and I’d feel unwell at times. It would be an unwell where I just feel like sitting down cause my body feels so worn out and then they used to think, oh she’s lazy. They might see there’s nothing wrong with my body and a lot of people who aren’t aware of things like Crohn’s, they wouldn’t like look into it. Like my family, it’s the first they’ve heard of anything like this. Considering my background, it wasn’t a massive difference but they didn’t say it’s cause she’s lazy. They’d just be like oh, it’s cause she doesn’t eat. They’d just try and give a reason for it...that’s why that’s causing all this. They think you don’t eat properly, all the illnesses come to you so it’s to do with eating. If you eat properly, all this is gonna go away... Sometimes like before, when people don’t understand the disease, they just put it down like I’m lazy and they didn’t used to take me seriously and that used to really upset me. Because...Crohn’s is something that you can’t see, so someone’s got to believe you to actually know what you’re going through, because you can’t physically show them how much pain you’re in, whatever. You can’t physically show them anything that I’ve got an illness, because anyone with Crohn’s disease will know that if anyone else looks at them, they’ll think I’m a normal person. They’ll know that no one will ever tell that you’ve got Crohn’s disease...and the effects are hidden underneath...Since her diagnosis, ‘now they just think- they don’t know what it is- but they just think, see how it is. Cause I’m attending hospital, see how it goes... they don’t feel there’s nothing they can do to help me. Obviously if I feel unwell, they’ll be there for me. It’s more like that because it’s a part of me’.*

‘The only biggest disappointment is that it’s slowed down my life so much. Cause I think if I was better, I’d have progressed so much more now. I would be so much more active. There’s days where you want to do something but you’re so tired that it’s just like, no. If I’d have been normal, I’d have been more able to get up to speed with things, try and think about how I’m gonna build my life and like every time I try to go forward something stops me like. Cause it’s coming to a point with the pain, surgery, you know this and that. It’s always holding you back. That’s the biggest thing, really... Coming from my background as well, it’s

another worry that I want to get married...People from my background tend to get married at a young age, but I'm looking to get married when I'm around twenty two, but it really worries me because they hold a lot of expectations from you where we come from. When you get married, you kind of go over and take over the responsibilities of the mother in the house as a daughter in law. So the way I feel, I don't feel as active as a normal person so I'm thinking well I won't be as active and if I'm falling ill all the time I'll be kind of disappointed. I don't want my husband to be disappointed in me, cause not everyone understands like. As I say, it's not something you can see which is the biggest put down, cause when people can't see it, they can't tell it's there, but I don't constantly want to be feeling worn out and tired'.

She met the person she thinks she wants to marry before her diagnosis. *'He knew...there was a problem but at the time it was an ongoing process of finding out what the problem is. So...I always knew it was a possibility, because I was told it's probably that and then when I did find out then I did tell him, oh it's definitely that. He's like, oh you need to get better as soon as possible. So he was always nagging me like, make sure you don't miss hospital like, make sure you go'.* Having the draining setons does affect her in this relationship: *'It's just personal confidence, not really sex, cause I don't really have that a lot but it's more of when you're with someone. And you're with them, you just kind of feel like confident and it's that thing and you're oh, it's like a bit off putting and then your confidence is down and your esteem goes down and kind of brings you down... sometimes when I used to go and see him, I never did used to because it made me feel really unattractive, but sometimes it never used to come out. Like for hours, nothing there and I'd be like oh hallelujah...As a young person, I think if you're gonna have sex with your partner, it's just you feel a bit weird but oh there's a bit of plastic down there...I have been in that situation. I wasn't nervous, but only because I was so close to that person I was confident. It didn't bother me...Like, I forgot about it until afterwards. I was like, did you notice that plastic thing. He was like no, OK'.*

She is very concerned that the disease and her surgery will affect her ability to conceive and bear children. When she was diagnosed, *'I started thinking about is this gonna affect me having babies, cause the affected area's the whole stomach and my womb's near there, so I did think about it that far...Ever since I was young, I've always wanted to have loads of kids. I always wanted to be a young mother but now I...have this bad inkling...is it going to affect my pregnancy and that's like the only thing that I don't want it to do, affect my pregnancies'* She has asked her doctors about this. *'They said that... in those early stages, and I haven't even been put on any treatment,...nearer the time we'll be able to know what's going on, cause the body can change at any time, so we'll never know what the treatment could do you* *know, so I just have to wait... If I do plan to have kids in the future, it may be best to have a caesarean but I’m really unhappy to hear that. Going through that time and again as well. I heard you could have it up to three times...a baby by caesarean and I want a natural birth as well. I’m not too keen on that caesarean... isn’t that when they cut your baby out of you and that and it’s not natural and you have to live with the pain... If it’s like a one off, like the baby’s in danger, that’s one thing but you know if I’m gonna have it because of this, it puts you down. It’s not a case where it has to be done because of this and that, it’s a case of my stomach’s weak you know.’*

She has confided these thoughts to her boyfriend. *‘He’s just like, oh don’t worry, it’s gonna be OK. I’m sure you’ll be fine. He’s supportive and he’s like to me, oh don’t worry. My mother had four caesareans- it’s true, the thing is it’s actually true, and he just makes me laugh thinking. He just turns everything into a joke, but he just makes everything seem not so serious like. I don’t want it to be that serious, in my face.’*

She does sometimes have times where she feels bad: *‘I’m gonna be honest that I don’t know how other people are, but the one thing that does sometimes get me down a lot is in a relationship, you know like all this pain, all this slowing down. It can make you feel depressed sometimes like, cause... you personally feel like you’re being put down and it’s something that you can’t physically do nothing about and it does affect you....Sometimes you get like self pity, like oh I’m ill, I’m lazy, I can’t... sometimes you go into a phase where you feel there’s something wrong with you...You think there’s people out there and there’s nothing wrong with them, and then you kind of sit there thinking that there is something wrong with me. I’m not as this person or you know I can’t do this effectively and it does make you feel down... it’s just that feeling of something wrong with you and it’s... not nice, cause...it can like affect you. Cause you can have those feelings where you’re going through a lot of pain and you start...taking it out on other people, like I do that...start feeling that there’s something wrong with me. Why is there something wrong with me.’*

Despite the uncertainty of her disease and the surgery, her plans for the future are quite definite: In *‘five years like, I’ll be twenty four... I see myself married, probably with my first kid, but I see before then I will have accomplished a good career and save some money, you know, bought a house... I plan to stop working when I get married but...because of the way things are going, I always want to have the back up where if I need to go back into work, I don’t want to struggle. I wanna be like yea, I’ve got the experience, I’ve got my qualifications and go straight into a job’.* Nevertheless, these plans have also been affected. *‘I’ve got an* *apprenticeship in business and administration and they’re so understanding, but I know I won’t get that everywhere, because it’s not everywhere you’ll go into work and you’ll just make friends with everyone and those relationships. But yea, all my managers were really understanding and they’re always telling me you know if you ever feel like you’ve got any sort of pain, anything, just let us know immediately. You know, we’ll let you go off somewhere else and sit down. So understanding, very helpful and all my colleagues, they’re like really friendly. I loved working there... because of all this recession going on, they’re even cutting jobs off of people that have been there for years and they don’t have space to employ me. I had like several managers and they were all really nice. I had a lot of time off with my illness and they were really understanding. I haven’t actually got another job yet. I don’t know how they’re gonna react. I think it’s all about how supportive they are, because I might be having a lot of time off. I don’t know how it’s gonna go with things like that. I haven’t gone there yet. Yea my biggest fear, even today, right now about getting another job is once I have another operation, I’m going to have to go back off work’.*

She sums up, *‘The only reason like I’m pushing my career is that firstly I wanna become something, so it’s kind of like a pride thing in my family like, where I want to show everyone that I can become something and being a female, obviously it’s more of a reason to become something...I’ve always had the ambition that I’d like to work for a big organisation and become a secretary, you know, in a good company. You can say then I’ve become this, a good accomplished one... That’s it, really. I wanna make my mum proud, cause everyone else is married. I’m just her last daughter, like her baby daughter, so I wanna make my mum proud.’*

APPENDIX 13. Table 4.2: PHASE 1 DATA ANALYSIS EXAMPLE SHOWING THE DEVELOPMENT OF THEMES, SUBTHEMES AND FACTORS THAT HELPED OR HINDERED TRANSITION FROM PARTICIPANTS' STORIES

DIMENSION	THEME	SUBTHEME	FACTOR	PARTICIPANT	QUOTATION
SELF	Feelings after surgery	Personal Strength	**Personal Strength** Always been strong Surgery made him stronger	James	*'I'm really strong inside...I don't show a lot of emotion. Sometimes I put up a barrier like, get on with it. I've always been really strong minded about things so if I say...I'm gonna do it, I'll do it...Going through all this has made me strong'*
			Coping with pain Unrelieved pain	Rob	*'It hurt a bit when I woke up cause there weren't a battery in the pain thing, so I was like shouting...it's not working. Took about an hour to listen, they thought I was just gone on drugs. They went, oh you should have been like crying and everything. I went why'd I wanna cry...It hurts. That's what I been telling you'*
			Personal Strength Born with it Brave and determined	Humza	*'I think being brave and being determined that...I can do something, that's what kind of helped me a lot. Just my mindset...I was just born with it, to be honest, brave and committed, determined so...from the start that helped me a lot.'*
			Coping with pain Mental attitude	Olu	*'(I) don't want to make a fuss about anything...unless it's something really really bad...I don't really make a big deal of it'(pain)* *'It's more mental than anything, to be honest...If you want to live a normal life, you live a normal life'*
			Stoicism Pain Also Coping – 'Getting on with it'	Paul	*'I get a fair bit of joint pain and my back's been in knots for years...Pretty much the last six months I've been on a liquid diet and...kind of trying to...tide my body over to having the operation... I never really took painkillers if ever I was in pain. I just kind of grunted and got on with it'*
			Inner Strength Uncontrolled disease, not giving in	Fazeel	*'Ever since I've been a teenager...I've had a really active life...so I've been able to live a life where I've been able to leave the Crohn's to one side...I don't want Crohn's to get in the way. I'm not gonna let it beat me*
			Coping with pain	Dave	*'They put the epidural in the wrong place so I woke up and no pain relief whatsoever...Once I had that sorted I was fine'*
			Developed Strength Decided to be strong	Sam	*'I try to be strong...From a young age I did used to cry a lot and I think I just said to myself, you know there's no point crying any more. Might just as well be strong and get through things yourself...So ever since then I've just started to develop into a person who you know thinks and calculates everything he can...It does keeps me intact and I think it makes me think more clearly a lot of the time'*
			Stoicism (NB unhealed wounds, pain)	Lesley	*'I've had to deal with it for a long time I suppose...It is...my life so I just go on with it every day...I can't...change it at the minute so...I just deal with it'.*
			Inner Strength Not giving in to uncontrolled disease	Daisy	*'I never just feel like I can't do anything and if I feel like that then I just work a way round it...'I don't wanna be trapped by this illness so I'm not gonna let it trap me'*
			Determination	Victoria	*'I was always quite a determined child'*

APPENDIX 14. QUESTIONNAIRE FRONT SHEET

Centre no. /Participant no.

Male ☐ **Female** ☐

Crohn's disease ☐ **Ulcerative colitis** ☐

Age now (please circle) 18

19

20

21

22

23

24

25

Previous IBD surgery

Operation	Year
Small bowel resection and anastomosis	
Proctocolectomy and permanent stoma	
Colectomy and ileorectal anastomosis	
Ileoanal pouch formation and temporary stoma	
Ileoanal pouch formation without stoma	
Temporary stoma	
Permanent stoma	
Stoma reversal	
Perianal surgery with seton insertion	
Other perianal surgery	
Other (please write operation below)	

APPENDIX 15. PRETESTING QUESTIONNAIRE

1. How long did it take you to complete the questionnaire

2. Were you clear what the survey was about

3. Were you clear that your anonymity and confidentiality would be maintained

4. Was the way it was set out clear to follow

5. Did you feel the questionnaire had a logical flow

6. Were the instructions for completing the questionnaire clear and easy to follow

7. Was the questionnaire easy to read.

8. Were there any phrases or jargon you did not understand

9. Did you have to think very hard or for a long time about any of the questions before you could answer it (what to do or what to put)

10. Did you feel any of the questions were expecting you to give a particular answer

11. Did the choices you were given cover everything you wanted to say

12. Did you feel comfortable answering all the questions (irritated, confused, embarrassed)

13. Was the questionnaire too cluttered

14. Was it too long

15. Was it too boring

16. Do you have any suggestions for how it could be improved

APPENDIX 16. SURVEY QUESTIONNAIRE

Centre no. /Participant no.

Surgery and Me

The experiences of young people who have had surgery for their IBD

Thank you for completing this questionnaire, which will take 15 – 20 minutes. You have been chosen to take part in this national survey supported by Crohn’s and Colitis UK (NACC) because you have had one or more operations for your Crohn’s Disease or ulcerative colitis. What you tell us will be in confidence, and you do not have to give your name. Your answers will help us to understand what it is like for young people with IBD to undergo surgery and how they cope.

Please follow the instructions for each question and do your best to answer all of them. Most questions ask you to put a tick in boxes.

If you have had more than one operation, please use the experience of your most recent surgery when you respond to the questions

Thank you

A. BEFORE THE OPERATION

1. How long before your operation took place did you know that it might be necessary. Please tick the response that applies to you

Less than a week ☐

1 – 2 weeks ☐

More than 2 weeks but less than a month ☐

A month or more ☐

2. We would like to know how you reacted when you were first told that you needed to have an operation for your IBD. Please complete ALL the statements below that apply to you.

I welcomed it because….

I thought it was the right thing for me because….

I tried not to think about it because….

I didn’t want to have it because….

I refused to have it because….

I felt I didn’t have a choice because….

If none of the above statements apply to you, please write your reaction here

3. Below is a list of things that other young people told us concerned them about their operation before they had it. We would like to know the things that concerned you before surgery. Please tick the appropriate boxes in the table below:

	This concerned me a great deal	**This concerned me fairly often**	**Can't remember**	**This concerned me once in a while**	**This never really concerned me**
Being cut					
Having a part of me removed					
Having an anaesthetic					
Being in pain					
Having a scar					
Having a bag (stoma)					
Having complications afterwards					
Not knowing how I would cope emotionally with the operation					
Being in hospital					
Being away from my family					
Being away from my partner					
Being away from my friends					
Not knowing how long it would take to physically recover					
Missing college/school/work					
Missing out on socialising with friends					
Being less physically attractive after surgery					
Being rejected by an existing or potential partner after surgery					
Surgery might affect my ability to have children					
If you had any additional concerns please write them here and tick the appropriate box					

Please go to the next page

4. We would like to know what you did to prepare yourself for the operation. Please read the list in the table below, then tick the appropriate boxes

	I did this a great deal	**I did this fairly often**	**Can't remember**	**I did this once in a while**	**I didn't do this at all**
Read written information about it					
Looked the operation up on the Internet/You Tube					
Read about other people's experiences of surgery on the Internet					
Spoke to the doctor about it					
Spoke to the specialist IBD and/or stoma care nurse about it					
Spoke to the nurses on the ward about it					
Spoke to my family about it					
Spoke to my friends about it					
Spoke to other people who had had surgery about it					
Arranged for it to fit in with my school/college/work commitments					
Prayed about it					
If you prepared yourself in other ways please write them here					

5. How helpful were the things that you did to prepare yourself for the operation? Please tick the appropriate boxes in the table below

	This helped a great deal	**This helped a fair bit**	**Can't remember**	**This didn't help very much**	**This didn't help at all**
Reading written information about it					
Looking the operation up on the Internet/You Tube					
Reading about other people's experiences of surgery on the Internet					
Speaking to the doctor about it					
Speaking to the specialist IBD and/or stoma care nurse about it					
Speaking to the nurses on the ward about it					
Speaking to my family about it					
Speaking to my friends about it					
Speaking to other people who had had surgery about it					
Arranging for it to fit in with my school/college/work commitments					
Praying about it					
If you wrote something here in question 4, tick the appropriate box to show how helpful it was					

B. WHEN YOU CAME OUT OF HOSPITAL AFTER THE OPERATION

6. We would like to know the things you did to help you to cope after the operation. Please tick the appropriate boxes to tell us what you did.

	I did this a great deal	**I did this fairly often**	**Can't remember**	**I did this once in a while**	**I didn't do this at all**
I turned to work or other activities to take my mind off things					
I concentrated my efforts on doing something about the situation I'm was in					
I said to myself "this isn't real"					
I used alcohol or other drugs to make myself feel better					
I got emotional support from others					
I gave up trying to deal with it					
I took action to try to make the situation better					
I refused to believe that it had happened.					
I said things to let my unpleasant feelings escape					
I got help and advice from other people					
I used alcohol or other drugs to help me get through it					
I tried to see it in a different light, to make it seem more positive					
I criticized myself					
I tried to come up with a strategy about what to do					
I got comfort and understanding from someone close to me					
I gave up the attempt to cope					
I looked for something good in what was happening					
I made jokes about it					
I did something to think about it less, such as going out, watching TV, reading, daydreaming, sleeping, or shopping					
I accepted the reality of the fact that it had happened					
I expressed my negative feelings					
I tried to find comfort in my religion or spiritual beliefs					
I tried to get advice or help from other people about what to do					
I learned to live with it					
I thought hard about what steps to take					
I blamed myself for things that happened					
I prayed or meditated					
I made fun of the situation					
If there were any other things you did that aren't listed, please write them below and tick the appropriate boxes					

7. We would like to know about the things people close to you – your parents, partner and friends- did to try to help you after the operation. Please tick the appropriate boxes in the tables below

7a. MY PARENTS...	**They did this and it was helpful**	**They did this and it wasn't helpful**	**Can't remember**	**I wanted this from them and I didn't get it**	**I didn't want this from them and I didn't get it**
Said reassuring things to encourage me					
Listened to me when I was down					
Let me talk about my feelings					
Gave me advice when I was recovering					
Visited me often when I was recovering in hospital					
Helped me with practical tasks after the operation					
Gave me a hug or a cuddle when I needed it					
Stopped doing things if I couldn't do them as well					
Shared some of the things I went through with me					
Encouraged me to be more independent					
Encouraged me to live life to the full					
Stopped me feeling sorry for myself					
Distracted me when I was feeling down					
Helped me not to dwell on my operation					
Used humour to help me feel better					
Gave me straight talking when I needed it					
Seemed to forget at times I had had an operation					
Treated me as if I was normal					
Got less protective as I got better					
Tried to stop me doing things if they thought they would affect my recovery					
Treated me the same as others my age					
If there were any other things they did please write them below and tick the appropriate boxes					

<u>If you do not have a partner, please leave this table blank and go to 7c on the next page.</u>

7b. MY PARTNER...	**They did this and it was helpful**	**They did this and it wasn't helpful**	**Can't remember**	**I wanted this from them and I didn't get it**	**I didn't want this from them and I didn't get it**
Said reassuring things to encourage me					
Listened to me when I was down					
Let me talk about my feelings					
Gave me advice when I was recovering					
Visited me often when I was recovering in hospital					
Helped me with practical tasks after the operation					
Gave me a hug or a cuddle when I needed it					
Stopped doing things if I couldn't do them as well					
Shared some of the things I went through with me					
Encouraged me to be more independent					
Encouraged me to live life to the full					
Stopped me feeling sorry for myself					
Distracted me when I was feeling down					
Helped me not to dwell on my operation					
Used humour to help me feel better					
Gave me straight talking when I needed it					
Seemed to forget at times I had had an operation					
Treated me as if I was normal					
Got less protective as I got better					
Tried to stop me doing things if they thought they would affect my recovery					
Treated me the same as others my age					
If there were any other things they did please write them below and tick the appropriate boxes					

Please go to the next page

7c. MY FRIENDS	**They did this and it was helpful**	**They did this and it wasn't helpful**	**Can't remember**	**I wanted this from them and I didn't get it**	**I didn't want this from them and I didn't get it**
Said reassuring things to encourage me					
Listened to me when I was down					
Let me talk about my feelings					
Gave me advice when I was recovering					
Visited me often when I was recovering in hospital					
Helped me with practical tasks after the operation					
Gave me a hug or a cuddle when I needed it					
Stopped doing things if I couldn't do them as well					
Shared some of the things I went through with me					
Encouraged me to be more independent					
Encouraged me to live life to the full					
Stopped me feeling sorry for myself					
Distracted me when I was feeling down					
Helped me not to dwell on my operation					
Used humour to help me feel better					
Gave me straight talking when I needed it					
Seemed to forget at times I had had an operation					
Treated me as if I was normal					
Got less protective as I got better					
Tried to stop me doing things if they thought they would affect my recovery					
Treated me the same as others my age					
If there were any other things they did please write them below and tick the appropriate boxes					

8. We would like to know how you feel NOW after your operation. Please tick the appropriate boxes

	All the time	**Quite a lot**	**Not sure**	**Only slightly**	**Not at all**
After my operation my day to day life has improved					
After my operation I can physically do anything I want to					
After my operation I feel self confident					
Now I have had the operation I feel better					
I wish I had had my operation earlier					
I have adjusted well after my operation					
After my operation I'm healthier					
After my operation I feel happier					
After my operation I feel like a normal person					
After my operation I have adapted to changes in the way my body looks					
After my operation I feel physically attractive					
My scars bother me					
After my operation my body looks OK					
Going through the surgery has made me a lot stronger as a person					
After my operation I have adapted to changes in the way my bowel works					
The after effects of the operation get me down					
I would be more outgoing if I hadn't had the operation					
I regret having my operation					
After my operation I feel positive about the future					
After my operation I can make plans for the future					

Please go to the last question on the next page

9. Finally we would like to know the three worst things and the three best things about your surgery. Please put them below:

The three WORST things about my surgery were:	**1.**
	2.
	3.
The three BEST things about my surgery were:	**1.**
	2.
	3.

Thank you for completing this questionnaire

Draft9/5.10.2011

APPENDIX 17. Table 5.1: PARTICIPANTS IN PHASE 1

MALE

ID	AGE	ETHNICITY	DIAGNOSIS	AGE AT OPERATION	OPERATION	PLANNED/ EMERGENCY
Rayhanul	23	Asian	Ileocolonic CD	Waiting	Terminal ileal resection and anastomosis	Planned
James	18	White	Panenteric UC	15 17 18	Subtotal colectomy and ileorectal anastomosis Proctocolectomy, J pouch and ileostomy Reversal of ileostomy	Planned
Rob	18	White	Colonic CD	17 18	Subtotal colectomy and ileostomy Ileosigmoid anastomosis and reversal of ileostomy	Planned
Jack	22	White	Ileocolonic CD	15 21	Right hemicolectomy Laparoscopic subtotal colectomy and sigmoid anastomosis	Planned
Humza	20	Asian	Colonic and perianal CD	7 9	Subtotal colectomy and ileoanal pouch formation Excision of ileoanal pouch and ileostomy formation	Planned
Olu	22	BlackBritish	Panenteric UC			Refused
Paul	22	White	Ileocolonic CD	22	Laparoscopic right hemicolectomy and sigmoid resection	Planned
Fazeel	23	Asian	Ileocolonic CD	22	Right hemicolectomy	Planned
Krish	20	Asian	Colonic and Perianal CD	19	Incision and drainage of posterior horseshoe abscess	Emergency
Dave	20	White	Panenteric UC	15 20	Total colectomy and ileostomy Completion proctectomy and formation of ileoanal pouch	Planned
Sam	21	Chinese	Panenteric UC	21 21	Laparoscopic subtotal colectomy and ileostomy Laparoscopic division of adhesions	Emergency Planned

FEMALE

ID	AGE	ETHNICITY	DIAGNOSIS	AGE AT OPERATION	OPERATION	PLANNED/ EMERGENCY
Ruhana	19	Asian	Perianal and ileocaecal CD	15, 17	Drainage of perianal abscess, laying open of perianal fistula and insertion of seton x2	Emergency
Ruby	18	BlackBritish	Terminal ileal CD	17	Terminal ileal resection and anastomosis	Planned
Lesley	23	White	Ileocolonic and perianal CD	7 10 12 13 - 23	Temporary stoma Stoma reversal Proctectomy and formation of permanent ileostomy Multiple perianal debridements and biopsies	Planned
Victoria	25	White	Colonic and perianal CD	11 Waiting	Pan proctocolectomy and permanent ileostomy Parastomal hernia repair =/- stoma resiting	Planned Planned
Sadie	22	BlackBritish	Ileocaecal and perianal CD	16 21	Right hemicolectomy Perianal fistulotomy and seton insertion	Planned
Daisy	21	White	Panenteric CD	14 16 15, 20	Formation of temporary colostomy Revision of stoma Drainage of perianal and rectovaginal fistulae and seton insertion x 2	Planned
Helen	23	White	Ileocolonic and perianal CD	13 19	Total colectomy and sigmoid colostomy Defunctioning colostomy and proctectomy Refashioning of stoma	Planned Emergency
Bernice	20	BlackBr	Perianal duodenal and ileocolonic CD	18 18 19	Ileocaecal resection end ileostomy and mucous fistula Drainage of low anastomotic leak and abscess Closure of ileostomy	Planned Emergency Planned
Mariam	21	BlackBritish	Panenteric CD	19	Ileocaecal resection and formation of ileostomy	Planned
Rania	24	Asian	Perianal CD	23	Drainage of perianal fistula and seton insertion	Emergency
Mia	22	White	Perianal CD	18, 19, 21	Drainage of perianal abscess and seton insertion x 3	Emergency
Yasmin	20	Asian	Panenteric UC	19 20	Colectomy and ileostomy Refashioning of stoma	Planned Planned
Anne	20	White	Panenteric UC	17 18	Subtotal colectomy, temporary ileostomy and ileoanal pouch formation Closure of ileostomy	Planned

APPENDIX 18. Table 7.1: PATIENT CHARACTERISTICS OF SURVEY RESPONDENTS, N=120

Patient characteristics of respondents	**Variables**	**Number**	**Per Cent**
Gender	Male	50	42%
	Female	70	58%
Age (in years)	18	14	12%
	19	17	14%
	20	13	11%
	21	12	10%
	22	16	13%
	23	12	10%
	24	17	14%
	25	19	16%
Age range	18 - 21 years	47	56%
	22 - 25 years	64	53%
Partner status	With Partner	42	35%
	No Partner	78	65%
Disease type	Crohn’s Disease	99	83%
	Ulcerative Colitis	21	17%
Had a stoma bag fitted	Bowel resection without stoma	33	39%
	Bowel resection with stoma	52	61%
How long before your operation took place did you know that it might be necessary?	<1 week (Emergency)	36	30%
	1-4 weeks (Urgent)	30	25%
	> 4 weeks (Planned)	52	44%

APPENDIX 19. Table 7.2: BOWEL SURGERY HISTORY

Number and Timing of Bowel Surgery Operations for IBD among Survey Respondents, *N*=120

Type of operation	**Number of operations**		**Timing of operation**			**Gender**	
	UC	CD	≤ 6 months	7 – 24 months	Over 2 years	M	F
Small bowel resection and anastomosis	0	34	2	3	29	7	27
Colonic resection and anastomosis	1	24	0	1	24	12	13
Bowel resection with stoma formation	13	17	0	10	20	16	14
Temporary stoma	0	15	1	3	11	4	11
Permanent stoma	2	4	0	0	6	0	6
Ileoanal pouch and temporary stoma	9	3	2	2	8	9	3
Ileoanal pouch without stoma	3	0	0	1	2	2	1
Stoma reversal	7	11	2	5	11	9	9
Other abdominal surgery	2	8	0	3	7	3	7
Perianal surgery with seton	0	29	5	6	18	6	23
Other perianal surgery	0	14	0	5	9	10	4
Total	23	173	12	41	143	78	118

APPENDIX 20. Table 7.4: INITIAL REACTIONS TO SURGERY, CATEGORIES, CATEGORY DEFINITIONS FOR CODES AND EXAMPLE QUOTATIONS, *N*=120

Categories and Frequency of Mention (%)	**Category definitions for codes to place under each the category**	**Example Quotations**
Getting well / Improve my quality of life (41%)	References to wellness, return of health and improved quality of life	‘I would be able to live a relatively normal life’ ‘I could start to enjoy things I was too tired to do or too ill to eat’ ‘I knew it would improve my quality of life’
No choice (32%)	References to survival, death, emergency operations and failure of medical treatment	‘I would have died without the surgery due to the extent of my illness’ ‘I had exhausted all medications available to me’ ‘It was an emergency and I only had half an hour to agree and understand what it meant’ ‘They said I wouldn’t survive without it’
Provide pain relief (23%)	References to improving or stopping pain	‘I was in a lot of pain and on a lot of drugs and they said it would make the pain stop’ ‘I was in a lot of pain at that moment and was willing to try anything’ ‘I was in such pain it was unbearable’
Positive appraisal of surgery itself (17%)	References to surgery as a positive treatment option	‘I felt so awful and unwell that it was good to find a solution to getting better’ ‘I knew it would help my symptoms more than the medication had been doing’ ‘This promised an end to the medical drama that had been going on for more than a year’

Categories	**Category definitions for codes to place under each the category**	**Example Quotations**
Preoperative anxiety (19%)	References to feelings of unhappiness, fear, confusion or uncertainty	‘I wasn’t sure what it is exactly and I was really scared’ ‘The potential complications were frightening’ ‘They asked me for a decision but to be honest I didn’t really understand what I was agreeing to’
Body image concerns (10%)	References to surgical outcomes such as stoma formation or scarring that are associated with body image concerns	‘I was only twenty one and I thought the stoma wouldn’t be well hidden’ ‘I wasn’t ready to have such a big change in my personal appearance’
Followed medical advice to have the surgery (6%)	References to receiving information and advice from medical staff about the necessity of surgery	‘The doctors thought it was the right thing’ ‘My surgeon explained what was wrong and how it would help me’ ‘I was so ill the doctors said I had to have it immediately’
College/career disruption (5%)	References to concerns about the operation interfering with college and work activities	‘I didn’t want to have the time off college’ ‘I was worried about the impact it would have on my university studies as I had essays and exams coming up’ ‘I was worried about time off work’
Denial/Disbelief (4%)	References to concealing the illness, disbelief that young people could have the stoma, disgust, and lack of understanding	‘I didn’t want to admit I had IBD’ ‘I thought only old people had this operation and I thought it was disgusting’ ‘I didn’t really understand what they were telling me. I thought they were joking. Stomas are for old people (I thought) so I thought it would be something different’

APPENDIX 21. Table 7.5: MEAN PREOPERATIVE CONCERNS FOR FULL SAMPLE, SUBGROUPS, AND INDEPENDENT *T*-TEST *P*-VALUES

	Mean	Scale Range	*t*-test *p*-value
Preoperative Concerns	*Full Sample (n=120)*		
Post-Surgery Body Image	**9.31**	3-15	n/a
Physical After Effects	9.04	3-15	n/a
Preoperative Anxiety	8.36	3-15	n/a
Fear of Surgery	6.34	3-15	n/a
Isolation in Hospital	8.22	6-30	n/a
Gender	*Males (n=49)*	*Females (n=67)*	
Post-Surgery Body Image	8.29	**10.04**	.004**
Physical After Effects	8.16	**9.69**	.015*
Preoperative Anxiety	7.39	**9.07**	.009**
Fear of Surgery	6.16	**6.48**	.616 ns
Isolation in Hospital	7.49	**8.75**	.030*
Stoma Groups	*Without Stoma (n=33)*	*With Stoma (n=49)*	
Post-Surgery Body Image	8.91	**10.44**	.034*
Physical After Effects	8.73	**9.29**	.469 ns
Preoperative Anxiety	7.73	**9.04**	.102 ns
Fear of Surgery	6.33	**6.55**	.776 ns
Isolation in Hospital	**8.65**	8.25	.579 ns
Disease Type	*Crohn's Disease (n=96)*	*Ulcerative Colitis (n=20)*	
Post-Surgery Body Image	9.06	**10.55**	.064 ns
Physical After Effects	8.97	**9.38**	.616 ns
Preoperative Anxiety	8.32	**8.55**	.792 ns
Fear of Surgery	6.33	**6.40**	.935 ns
Isolation in Hospital	**8.27**	7.95	.718 ns
Timing of Surgery	*Emergency (n=34)*	*Non-Emergency (n=50)*	
Post-Surgery Body Image	**10.43**	9.12	.062 ns
Physical After Effects	**10.29**	8.69	.032*
Preoperative Anxiety	**9.68**	7.84	.017*
Fear of Surgery	**7.56**	5.94	.035*
Isolation in Hospital	**9.13**	7.47	.016*

Note. Emergency = < 1 week, Non-Emergency = > 4 weeks.
* $p < .05$, ** $p < .01$, ns = no significant difference between groups.

APPENDIX 22. Table 7.9: MEAN PREPARATION ACTIVITIES BETWEEN HIGH (*N*=68) AND LOW (*N*=47) PREOPERATIVE ANXIETY GROUPS

What Patients Did to Prepare	Group	Mean	SD	*t*-value	*p*-value
Researched operation	High	8.62	3.82	1.44	.154
	Low	7.57	3.84		
Spoke to health professionals about it	High	**9.64**	3.55	3.04**	.003
	Low	7.64	3.36		
Spoke to family and friends	High	6.29	2.21	1.76	.081
	Low	5.49	2.54		
Read written information about it	High	2.88	1.45	.898	.371
	Low	2.64	1.41		
Looked the operation up on the Internet/You Tube	High	1.94	1.39	1.59	.115
	Low	1.55	1.21		
Read about other people's experiences of surgery on Internet	High	2.07	1.36	.872	.385
	Low	1.85	1.32		
Spoke to the doctor about it	High	**3.75**	1.26	3.59***	.001
	Low	2.87	1.35		
Spoke to the specialist IBD and/or stoma care nurse about it	High	3.19	1.53	1.50	.135
	Low	2.77	1.43		
Spoke to nurses on ward about it	High	**2.78**	1.53	2.83**	.005
	Low	2.04	1.23		
Spoke to my family about it	High	**3.91**	1.28	2.92**	.004
	Low	3.15	1.44		
Spoke to my friends about it	High	2.38	1.43	.157	.876
	Low	2.34	1.39		
Spoke to other people who had had surgery about it	High	1.72	1.23	.865	.389
	Low	1.53	1.02		
Arranged for it to fit in with my school/college/work commitments	High	2.21	1.58	-.297	.767
	Low	2.30	1.56		
Prayed about it	High	**2.63**	1.77	4.74***	.001
	Low	1.40	.99		
Prepared yourself in other ways	High	3.56	1.67	1.16	.272
	Low	2.33	1.15		

Note. High fear of surgery (median >= 5.00), low fear of surgery (median < 5.00). * $p < .05$, ** $p < .01$, *** $p < .001$.

Appendix 23. Table 7.10: MEAN PREPARATION ACTIVITIES BETWEEN HIGH (*N*=68) AND LOW (*N*=47) FEAR OF SURGERY GROUPS

What Patients Did to Prepare	Group	Mean	SD	*t*-value	*p*-value
Researched operation	High	8.62	3.82	1.44	.154
	Low	7.57	3.84		
Spoke to health professionals about it	High	**9.64**	3.55	3.04**	.003
	Low	7.64	3.36		
Spoke to family and friends	High	6.29	2.21	1.76	.081
	Low	5.49	2.54		
Read written information about it	High	2.88	1.45	.898	.371
	Low	2.64	1.41		
Looked the operation up on the Internet/You Tube	High	1.94	1.39	1.59	.115
	Low	1.55	1.21		
Read about other people's experiences of surgery on Internet	High	2.07	1.36	.872	.385
	Low	1.85	1.32		
Spoke to the doctor about it	High	**3.75**	1.26	3.59***	.001
	Low	2.87	1.35		
Spoke to the specialist IBD and/or stoma care nurse about it	High	3.19	1.53	1.50	.135
	Low	2.77	1.43		
Spoke to nurses on ward about it	High	**2.78**	1.53	2.83**	.005
	Low	2.04	1.23		
Spoke to my family about it	High	**3.91**	1.28	2.92**	.004
	Low	3.15	1.44		
Spoke to my friends about it	High	2.38	1.43	.157	.876
	Low	2.34	1.39		
Spoke to other people who had had surgery about it	High	1.72	1.23	.865	.389
	Low	1.53	1.02		
Arranged for it to fit in with my school/college/work commitments	High	2.21	1.58	-.297	.767
	Low	2.30	1.56		
Prayed about it	High	**2.63**	1.77	4.74***	.001
	Low	1.40	.99		
Prepared yourself in other ways	High	3.56	1.67	1.16	.272
	Low	2.33	1.15		

Note. High fear of surgery (median >= 5.00), low fear of surgery (median < 5.00). * $p < .05$, ** $p < .01$, *** $p < .001$.

Appendix 24. Table 7.12: FREQUENCY PERCENTAGE OF PERCEIVED SOCIAL SUPPORT FROM PARENTS, PARTNER AND FRIENDS (%), *N*=120

Perceived Social Support	Parents Support		Partner Support		Friends Support	
	Pos.	**Neg.**	**Pos.**	**Neg.**	**Pos.**	**Neg.**
AVERAGE PERCEIVED SUPPORT	84%	16%	91%	9%	91%	10%
Emotional (Encouraging)						
Said reassuring things to encourage me	85%	15%	97%	3%	86%	14%
Encouraged me to live life to the full	87%	13%	94%	6%	93%	7%
Encouraged me to be more independent	84%	16%	94%	7%	91%	9%
Emotional (Listening)						
Listened to me when I was down	90%	10%	90%	10%	87%	13%
Let me talk about my feelings	88%	12%	95%	5%	88%	12%
Emotional (Distraction)						
Distracted me when I was feeling down	86%	14%	95%	5%	89%	11%
Helped me not to dwell on my operation	89%	11%	97%	3%	90%	10%
Used humour to make me feel better	91%	9%	95%	5%	93%	7%
Emotional (Comfort)						
Gave me a hug or a cuddle when I needed it	84%	10%	32%	3%	79%	8%
Informational (Advice)						
Gave me advice when I was recovering	82%	18%	79%	21%	89%	11%
Gave me straight talking when I needed it	86%	14%	89%	11%	92%	8%
Tried to stop me doing things if they felt it would affect my recovery	68%	32%	86%	14%	89%	11%
Tangible (Practical)						
Visited me often when I was recovering in	93%	7%	95%	5%	86%	14%
Helped me with practical tasks after the	91%	9%	90%	10%	90%	10%
Stopped doing things if I couldn't do them as	87%	13%	85%	15%	92%	8%
Shared some of the things I went through with	86%	14%	89%	11%	89%	11%
Appraisal (Normalising)						
Seemed to forget at times I had had an	73%	27%	81%	19%	83%	17%
Treated me as if I was normal	81%	19%	90%	10%	90%	10%
Got less protective as I got better	76%	24%	88%	12%	92%	8%
Treated me the same as others my age	77%	23%	92%	8%	94%	6%
Appraisal (Comparison)						
Stopped me feeling sorry for myself	80%	20%	91%	9%	93%	7%

APPENDIX 25. Table 7.14: COMPARISON OF COPING STRATEGIES BASED ON LEVELS OF PARENTAL SUPPORT (HIGH (N=62) AND LOW PARENT SUPPORT (N=56) GROUPS)

Coping Strategies	Parental Support	Mean	SD	*t*-value	*p*-value
Positive reframing	High	**7.13**	2.71	**2.47***	.015
	Low	5.93	2.56		
Planning	High	5.44	2.30	-.568	.571
	Low	5.71	2.73		
Acceptance	High	8.47	1.76	.034	.973
	Low	8.44	6.94		
Active coping	High	6.39	2.43	1.77	.080
	Low	5.58	2.44		
Use of emotional support	High	**7.37**	2.03	**3.99*****	.000
	Low	5.64	2.60		
Use of instrumental support	High	**5.71**	2.47	**2.88****	.005
	Low	4.44	2.24		
Humour	High	**7.10**	2.71	**3.26*****	.001
	Low	5.38	2.88		
Self-distraction	High	6.68	2.01	.387	.700
	Low	6.52	2.41		
Religion	High	3.92	2.87	-.150	.881
	Low	4.00	2.95		
Self-blame	High	4.08	2.61	.389	.698
	Low	3.91	2.14		
Denial	High	2.81	1.74	-.968	.335
	Low	3.13	1.87		
Substance use	High	2.62	1.64	-.038	.970
	Low	2.63	1.65		
Behavioural disengagement	High	4.13	1.90	**-1.99***	.049
	Low	4.88	2.13		
Venting	High	**5.18**	2.53	**2.36***	.020
	Low	4.12	2.16		

Note. High parental support (median >= 34.00), low parental support (median < 34.00).
* *p* < .05, ** *p* < .01, *** *p* < .001.

APPENDIX 26. Table 8.2: PROFILE OF TWO IBD PATIENT CLUSTERS WHO HAVE POSITIVE VERSUS NEGATIVE PERCEPTIONS OF SURGERY

Variables	Cluster 1 (*n* = 78) Positive Perceptions	Cluster 2 (*n* = 40) Negative Perceptions	*p-values*
Overall Post-Op Perception of Surgery			
Negative	9%	**100**%	<.001
Positive	**91**%	0%	
Patient Characteristics			
Male	42%	38%	NS
Female	58%	**63**%	
Age group 18-19 years	44%	46%	NS
Age group 24-25 years	56%	54%	
Stoma Groups			
Bowel resection without stoma	44%	28%	NS
Bowel resection with stoma	56%	**72**%	
Disease Type			
Crohn's Disease	85%	80%	NS
Ulcerative Colitis	15%	20%	
Surgery Timing			
Emergency (<1 week)	42%	41%	NS
Planned (>4 weeks)	58%	59%	
1 operation	60%	53%	NS
2 operations	27%	33%	
3 operations	10%	8%	
4 operations	1%	5%	
5 operations	1%	0%	
7 operations	0%	3%	
Pre-Op Concerns about Surgery	Mean	Mean	
Pre-operative anxiety	7.70	**9.67**	<.01
Fear of surgery	6.26	6.56	NS
Post-surgery physical after effects	8.84	9.54	NS
Post-surgery body image	9.09	9.75	NS
Isolation	8.05	8.55	NS
What Patients Did to Prepare			
Researched operation	8.26	8.26	NS
Read written information about it	2.73	2.97	NS
Looked op up on internet/you tube	1.79	1.84	NS
Read other people’s experiences Of surgery on the internet	1.97	2.08	NS
Spoke to health professionals	9.18	7.90	NS
Spoke to the doctor about it	3.44	3.26	NS
Spoke to the specialist IBD and/or Stoma care nurse about it	**3.21**	2.62	<.05
Spoke to the nurses on ward about it	2.57	2.29	NS
Spoke to family and friends	6.18	5.51	NS
Spoke to my family about it	3.72	3.33	NS
Spoke to my friends about it	2.46	2.24	NS
Spoke to other people who had had Surgery about it	1.76	1.50	NS
Arranged for it to fit in with my School/college/work commitments	2.34	2.13	NS
Prayed about it	2.10	2.26	NS
Prepared yourself in other ways	2.50	4.20	NS

Note. NS = not significant.

Variables	Cluster 1 (*n* = 78) Positive Perceptions	Cluster 2 (*n* = 40) Negative Perceptions	*p-values*
	Mean	Mean	
What Patients Did to Prepare That Helped			
Researched operation	**10.55**	8.34	<.01
Read written information about it	**3.33**	2.80	<.05
Looked operation up on internet/you tube	**2.31**	1.70	<.05
Read about other people's experiences of surgery on the internet	2.55	2.24	NS
Spoke to health professionals about it	**11.24**	8.57	<.001
Spoke to the doctor about it	**4.13**	3.39	<.01
Spoke to the specialist IBD and/or Stoma care nurse about it	**3.85**	3.11	<.05
Spoke to the nurses on ward about it	**3.40**	2.53	<.01
Spoke to family and friends	**6.91**	5.25	<.001
Spoke to my family about it	**3.97**	3.17	<.001
Spoke to my friends about it	**2.97**	2.27	<.05
Spoke to other people who had had Surgery about it	**2.59**	1.94	<.05
Arranged for it to fit in with my School/college/work commitments	2.70	2.56	NS
Prayed about it	2.39	2.30	NS
Prepared yourself in other ways	3.71	4.33	NS
Coping Strategies Post-Surgery			
Acceptance	**9.14**	7.21	<.05
Active coping	**6.38**	5.33	<.05
Humour	6.63	5.76	NS
Self-distraction	6.84	6.18	NS
Use of emotional support	6.86	6.03	NS
Use of instrumental support	5.39	4.64	NS
Positive reframing	6.95	6.05	NS
Planning	5.61	5.47	NS
Self-blame	3.35	**5.31**	<.001
Denial	2.64	**3.61**	<.05
Substance use	2.27	**3.32**	<.01
Religion	3.79	4.32	NS
Behavioural disengagement	4.35	4.70	NS
Venting	4.49	4.97	NS
Social Support Post-Surgery			
Total parent support	32.10	30.98	NS
Total partner support	33.24	32.41	NS
Total friend support	32.74	33.71	NS
Post-Op Perceptions of Surgery			
Overall post-op perceptions	**67.27**	41.28	<.001
Positive perception of surgery	**25.40**	15.43	<.001
Recovery of physical health	**17.21**	11.58	<.001
Psychological recovery	**24.67**	14.28	<.001
Body image perception	**14.58**	8.80	<.001

Note. NS = not significant.

APPENDIX 27. Table 8.3: PEARSON CORRELATIONS BETWEEN THE EXPLANATORY VARIABLES AND OUTCOME MEASURES, *N*=120

Explanatory Variables	Outcome Measures				
	Overall Perceptions of Surgery	Positive Perception of Surgery	Recovery Physical Health	Psychological Recovery	Body Image Perception
Pre-operative concerns about surgery					
Pre-operative anxiety	**-.251****	**-.232***	**-.195***	**-.244****	**-.358****
Fear of Surgery	-.170	-.132	**-.224***	-.136	**-.191***
Post-Surgery Physical After Effects	-.068	-.092	-.059	-.084	**-.237***
Post-Surgery Body Image	-.103	-.071	-.056	-.139	**-.342****
Isolation in hospital	-.105	-.137	-.096	-.083	**-.190***
What patients did to prepare					
Researched operation	.017	.057	-.015	-.005	-.030
Spoke to health professionals	**.192***	**.204***	.077	.205*	-.038
Spoke to family and friends	.104	.119	.030	.095	.004
Prayed about it	-.123	-.068	-.146	-.134	**-.250****
Prepared yourself in other ways	-.437	-.308	-.333	-.455	-.431
What patients did that helped					
Researched operation	**.309****	**.316****	**.247****	**.276****	.103
Spoke to health professionals	**.426****	**.417****	**.278****	**.430****	**.202***
Spoke to family and friends	**.384****	**.390****	**.261****	**.364****	.178
Prayed about it	.022	.035	.019	.006	-.104
Prepared yourself in other ways	-.329	.088	-.384	-.450	-.083
Coping strategies					
Humour	**.268****	**.247****	**.276****	**.224***	**.196***
Self-distraction	**.244****	**.185***	**.266****	**.211***	.150
Active coping	**.297****	**.250****	**.288****	**.283****	**.295****
Denial	**-.259****	**-.253****	-.146	**-.279****	**-.299****
Substance use	**-.193***	**-.193***	-.125	**-.194***	**-.187***
Use of emotional support	**.222***	**.249****	.173	.172	.029
Use of instrumental support	**.199***	**.202***	.147	.180	.159
Behavioural disengagement	-.037	-.063	.068	-.068	.016
Venting	-.046	-.066	.065	-.085	-.142
Positive reframing	**.345****	**.325****	**.244****	**.321****	**.204***
Planning	.157	.170	.145	.114	.070
Acceptance	.173	**.189***	.105	.167	**.188***
Religion	-.111	-.094	-.085	-.119	-.123
Self-blame	**-.304****	**-.273****	-.153	**-.362****	**-.383****
Social Support					
Parent Support	**.282****	**.214***	**.221***	**.258****	.156
Partner Support	**.328***	.282	.260	**.334***	.169
Friend Support	.183	.165	.102	.154	.123

**. Correlation is significant at the 0.01 level (2-tailed).

APPENDIX 28. Table 8.4: PEARSON CORRELATION COEFFICIENTS AMONG PRE-OPERATIVE CONCERNS AND POST-SURGERY PERCEPTIONS MEASURES, BY DISEASE GROUPS

		Pre-Op Concerns about Surgery				
Disease Groups	*Post-operative Perceptions of Surgery*	Fear of Surgery	Post-Surgery Physical After Effects	Post-Surgery Body Image	Pre-operative Anxiety	Isolation in Hospital
Crohn's Disease[1]	Positive Perception of Surgery	-.050	-.048	.011	**-.242***	-.107
	Recovery of Physical Health	-.147	-.068	.014	**-.208***	-.122
	Psychological Recovery	-.084	-.069	-.072	**-.224***	-.081
	Body Image Perception	**-.224***	**-.251***	**-.330****	**-.347****	-.151
Ulcerative Colitis[2]	Positive Perception of Surgery	-.396	-.196	-.296	-.197	-.238
	Recovery of Physical Health	**-.539***	-.029	-.430	-.140	-.016
	Psychological Recovery	-.341	-.120	**-.458***	-.331	-.099
	Body Image Perception	-.030	-.172	-.417	-.424	-.393

[1] Might have permanent, temporary or repeated stoma [2] Will usually only have a temporary stoma.

*p<.05, **p<.01, ***p<.001 (2-tailed).

APPENDIX 29. Table 8.5: PEARSON CORRELATION COEFFICIENTS AMONG PRE-OPERATIVE CONCERNS AND POST-SURGERY PERCEPTIONS MEASURES, BY STOMA GROUPS

		Pre-Operative Concerns about Surgery				
Stoma groups	*Post-operative Perceptions of Surgery*	Fear of Surgery	Post-Surgery Physical After Effects	Post-Surgery Body Image	Pre-operative anxiety	Isolation
With Stoma[1]	Positive Perception of Surgery	-.202	-.148	-.132	-.123	-.194
	Recovery of Physical Health	**-.293***	-.067	-.146	-.058	-.053
	Psychological Recovery	-.195	-.082	-.250	-.175	-.080
	Body Image Perception	-.246	-.205	**-.393****	**-.343***	-.260
Without Stoma[2]	Positive Perception of Surgery	.123	.139	.033	-.221	-.025
	Recovery of Physical Health	-.216	.020	-.072	-.267	-.084
	Psychological Recovery	-.115	.074	.013	-.193	-.116
	Body Image Perception	-.221	-.156	-.323	-.284	-.133

Note: [1]Bowel resection with stoma, [2]Bowel resection without stoma.
**p*<.05, ***p*<.01, ****p*<.001 (2-tailed).

APPENDIX 30. Table 8.6: PEARSON CORRELATION COEFFICIENTS BETWEEN PRE-OPERATIVE CONCERNS ABOUT SURGERY AND POST-OPERATIVE PERCEPTIONS OF SURGERY, BY GENDER

		Pre-Operative Concerns about Surgery				
Gender	*Post-operative Perceptions of Surgery*	Fear of Surgery	Post-Surgery Physical After Effects	Post-Surgery Body Image	Pre-operative Anxiety	Isolation in Hospital
Male	Positive Perception of Surgery	**-.353***	.042	-.077	-.123	-.120
	Recovery of Physical Health	**-.443****	.007	-.178	-.263	-.221
	Psychological Recovery	**-.304***	.049	-.269	-.272	-.154
	Body Image Perception	-.160	-.092	**-.391****	-.278	-.163
Female	Positive Perception of Surgery	.004	-.185	-.067	**-.307***	-.150
	Recovery of Physical Health	-.092	-.128	.012	-.174	-.031
	Psychological Recovery	-.039	-.183	-.052	-.228	-.037
	Body Image Perception	-.203	**-.290***	**-.284***	**-.372****	-.175

**p*<.05, ***p*<.01, ****p*<.001 (2-tailed).

APPENDIX 31. Table 8.7: PEARSON CORRELATION COEFFICIENTS FOR WHAT PATIENTS DID TO PREPARE FOR SURGERY AND POST-OPERATIVE PERCEPTIONS OF SURGERY, BY DISEASE TYPE

Disease Type	*What Patients Did to Prepare for Surgery*	Positive Perception of Surgery	Recovery of Physical Health	Psychological Recovery	Body Image Perception
Crohn's Disease[1]	Read written information about it	-.183	**-.237***	-.197	-.185
	Looked the operation up on the Internet/You Tube	-.168	-.106	-.082	-.055
	Read about other people’s experiences of surgery on Internet	-.087	-.063	-.139	-.198
	Spoke to the doctor about it	.062	-.010	.087	-.187
	Spoke to the specialist IBD and/or stoma care nurse about it	**.302****	**.228***	**.223***	-.015
	Spoke to the nurses on the ward about it	**.251***	.115	**.271****	-.058
	Spoke to my family about it	.128	-.003	.104	-.049
	Spoke to my friends about it	**.246***	.134	.194	.122
	Spoke to other people who had had surgery about it	**.232***	.051	.105	.137
	Arranged for it to fit in with my school/college/work commitments	.146	.028	.145	.153
	Prayed about it	-.091	-.129	-.128	**-.234***
Ulcerative Colitis[2]	Read written information about it	.415	.373	.334	.425
	Looked the operation up on the Internet/You Tube	.415	.359	.253	.287
	Read about other people’s experiences of surgery on Internet	**.476***	.372	**.452***	**.489***
	Spoke to the doctor about it	-.090	-.123	-.020	-.065
	Spoke to the specialist IBD and/or stoma care nurse about it	.102	.138	.211	.303
	Spoke to the nurses on the ward about it	-.218	-.367	-.164	.249
	Spoke to my family about it	.056	-.014	-.086	-.049
	Spoke to my friends about it	**-.490***	**-.472***	**-.583****	-.294
	Spoke to other people who had had surgery about it	.219	.124	.091	-.008
	Arranged for it to fit in with my school/college/work commitments	.217	.199	.043	.142
	Prayed about it	.011	-.224	-.165	-.350

[1] Might have permanent, temporary or repeated stoma , [2] Will usually have a temporary stoma. $*p<.05$, $**p<.01$, $***p<.001$ (2-tailed).

APPENDIX 32. Table 8.8: PEARSON CORRELATION COEFFICIENTS FOR WHAT PATIENTS DID TO PREPARE FOR SURGERY AND POST-OPERATIVE PERCEPTIONS OF SURGERY, BY STOMA GROUPS

Stoma Groups	*What Patients Did to Prepare for Surgery*	Positive Perception of Surgery	Recovery of Physical Health	Psychological Recovery	Body Image Perception
With Stoma[1]	Read written information about it	.022	-.129	-.085	-.054
	Looked the operation up on the Internet/You Tube	.110	.071	.078	.045
	Read about other people's experiences of surgery on the Internet	.151	.110	.142	.060
	Spoke to the doctor about it	.003	-.092	.075	-.211
	Spoke to the specialist IBD and/or stoma care nurse about it	**.308***	**.300***	**.403****	.159
	Spoke to the nurses on the ward about it	.120	.002	.195	-.014
	Spoke to my family about it	.072	-.065	-.024	-.101
	Spoke to my friends about it	-.167	-.130	-.173	-.034
	Spoke to other people who had had surgery about it	.211	.090	.163	.071
	Arranged for it to fit in with my school/college/work commitments	.142	.059	.162	.209
	Prayed about it	-.008	-.250	-.222	**-.332***
Without Stoma[2]	Read written information about it	-.164	-.304	-.170	-.231
	Looked the operation up on the Internet/You Tube	-.292	-.115	-.142	-.090
	Read about other people's experiences of surgery on the Internet	.035	.062	.068	-.026
	Spoke to the doctor about it	.313	.056	.189	-.165
	Spoke to the specialist IBD and/or stoma care nurse about it	**.469****	.106	.300	.024
	Spoke to the nurses on the ward about it	.306	-.029	.170	-.071
	Spoke to my family about it	-.005	-.221	-.158	**-.465****
	Spoke to my friends about it	.195	-.101	.042	-.087
	Spoke to other people who had had surgery about it	.279	-.080	-.013	.146
	Arranged for it to fit in with my school/college/work commitments	.267	.134	.195	.166
	Prayed about it	.104	-.179	-.054	.000

Note: [1]Bowel resection with stoma, [2]Bowel resection without stoma.
**p*<.05, ***p*<.01, ****p*<.001 (2-tailed).

APPENDIX 33. Table 8.9.PEARSON CORRELATION COEFFICIENTS AMONG WHAT PATIENTS DID TO PREPARE FOR SURGERY AND POST-OPERATIVE PERCEPTIONS OF SURGERY, BY GENDER

Gender	*What Patients Did to Prepare for Surgery*	Positive Perception of Surgery	Recovery of Physical Health	Psychological Recovery	Body Image Perception
Male	Read written information about it	.055	-.062	.063	-.084
	Looked the operation up on the Internet/You Tube	.235	.221	**.309***	.126
	Read about other people's experiences of surgery on the Internet	.135	.180	.111	-.054
	Spoke to the doctor about it	-.150	-.186	-.134	**-.460****
	Spoke to the specialist IBD and/or stoma care nurse about it	.214	.155	.221	-.142
	Spoke to the nurses on the ward about it	-.032	-.122	-.049	-.168
	Spoke to my family about it	.112	-.216	-.141	-.169
	Spoke to my friends about it	.015	-.163	-.178	-.127
	Spoke to other people who had had surgery about it	.209	-.022	-.035	-.107
	Arranged for it to fit in with my school/college/work commitments	.179	.105	.167	.069
	Prayed about it	-.129	-.100	-.164	**-.332***
	Prepared yourself in other ways	.399	-.376	-.598	-.738
Female	Read written information about it	-.128	-.163	-.184	-.102
	Looked the operation up on the Internet/You Tube	-.148	-.102	-.147	-.027
	Read about other people's experiences of surgery on the Internet	-.025	-.061	-.089	-.102
	Spoke to the doctor about it	.127	.083	.189	-.025
	Spoke to the specialist IBD and/or stoma care nurse about it	**.260***	**.249***	.221	.121
	Spoke to the nurses on the ward about it	.229	.124	**.328****	.073
	Spoke to my family about it	.114	.139	.213	.051
	Spoke to my friends about it	.120	.104	.166	.191
	Spoke to other people who had had surgery about it	.228	.120	.182	.227
	Arranged for it to fit in with my school/college/work commitments	.145	.033	.101	.191
	Prayed about it	-.025	-.172	-.121	-.229
	Prepared yourself in other ways	-.463	-.145	-.245	-.438

*$p<.05$, **$p<.01$, ***$p<.001$ (2-tailed).