



Surgery in young adults with Inflammatory Bowel Disease: A narrative account



Marion Allison^{a,*}, James Lindsay^b, Dinah Gould^c, Daniel Kelly^d

^a Barts Health NHS Trust, Clinic 3 Ground Floor, South Tower, Royal London Hospital, Whitechapel, London, E1 1BB, UK

^b Barts Health NHS Trust, Endoscopy Unit, Royal London Hospital, Whitechapel, London, E1 1BB, UK

^c Nursing and Director of Research, School of Nursing and Midwifery Studies, Cardiff University, Cardiff, CF24 0AB, UK

^d Royal College of Nursing Chair of Nursing Research, School of Nursing & Midwifery Studies, Cardiff University, Cardiff, CF24 0AB, UK

ARTICLE INFO

Article history:

Received 27 August 2012

Received in revised form 31 March 2013

Accepted 2 April 2013

Keywords:

Inflammatory Bowel Disease

Narrative study

Surgery

Young people

ABSTRACT

Background: Inflammatory Bowel Disease comprises two major intestinal disorders, Crohn's Disease and Ulcerative Colitis. When medical management cannot control the disease, surgery is necessary. Having an operation is a major concern for young people with Inflammatory Bowel Disease. Some may try to avoid or defer it. Despite this, afterwards they may have a significant improvement in quality of life.

Objectives: The aim of the study was to explore the experiences of young people with Inflammatory Bowel Disease who have had, or are about to have, surgery for their condition.

Design and method: Narrative study using semi structured interviews.

Participants: Twenty-four young adults aged between 18 and 25 (11 male and 13 female) with Inflammatory Bowel Disease who had undergone or were awaiting surgery from one tertiary referral centre in the United Kingdom.

Findings: Key factors that affected young people as they approached and adjusted to an operation were elicited which provided an understanding of this change in their lives from their own perspective. The prospect of having an operation, particularly the fear of a stoma, generated anxiety and concern for many of these young people. As young adults, participants tended to want to be involved in deciding when their surgery should occur and to have their opinions considered. The data revealed the different types of support that were given to these participants, what they found helpful and the function that they served. Gender differences were identified in the nature of support required from partners and in body image concerns. Issues and concerns were identified which can be addressed in clinical nursing practice to prepare young adults for this life changing event. These helped to explain how young people viewed the prospect, impact and experience of surgery.

Conclusion: The findings of this study revealed new information relating to the experience of surgery in young adults with Inflammatory Bowel Disease including their perceptions of the event itself, their decision making, their greatest concerns, the support they require and their ways of coping. Since there is little published work regarding how surgery affects this particular patient group, the study should be of interest to specialist nurses who are closely involved in the care of young adults with Inflammatory Bowel Disease.

© 2013 Elsevier Ltd. All rights reserved.

* Corresponding author. Tel.: +44 02035941781.

E-mail address: marion.allison@bartshealthnhs.uk (M. Allison).

What is already known about the topic?

- A significant number of young people with Inflammatory Bowel Disease will require at least one operation for their condition.
- Undergoing surgery is a major concern for young people with Inflammatory Bowel Disease, some of whom will try to avoid or delay having an operation.
- Surgery for Inflammatory Bowel Disease is not always curative and some patients will undergo multiple operations to manage the disease.
- Many patients who have surgery for Inflammatory Bowel Disease benefit from improved health and a better quality of life.

What this paper adds

- The experience of surgery can have a major impact on the lives of young people with Inflammatory Bowel Disease.
- Multiple factors and experiences affect young people with Inflammatory Bowel Disease as they try to cope with and adjust to their operations.
- Young adults desire some control, negotiation and participation in the process of decision making relating to surgery for their Inflammatory Bowel Disease.
- Parents, partners and friends provide different types of support serving different functions for young adults with Inflammatory Bowel Disease undergoing surgery.
- The most common strategies used by young adults with Inflammatory Bowel Disease to prevent, or cope with, the stress of facing an operation and in living with the consequences are direct action, advice and information seeking.

1. Introduction

Inflammatory Bowel Disease is a chronic intestinal condition that affects about 240,000 people in the UK (British Society of Gastroenterology, 2003; Rubin and Rubin, 2005). Inflammatory Bowel Disease has been described as the most significant chronic disease of childhood and adolescence (Moses et al., 1998) because of the high number of new cases that are diagnosed in this age group. Between 15 and 20% of all new cases of Ulcerative Colitis develop before the age of 20 and 20–25% of patients first develop Crohn's disease in childhood or adolescence (Rayhorn, 2001). Therefore many young people will learn of their disease and require treatment as they reach adolescence and young adulthood.

Whilst advances in medical therapy may control the disease, failure of medical management continues to be the most common indication for surgical intervention (Hwang and Varma, 2008). Childhood onset Inflammatory Bowel Disease appears to be more extensive and progressive than adult disease with higher rates of panenteric involvement, more extensive inflammation and complications (Van Limbergen et al., 2008; Vernier-Massouille et al., 2008; Goodhand et al., 2010). Therefore the need for an operation can arise at a young age and in patients with disease of short or long duration; estimates of the need for surgery in those diagnosed with Crohn's Disease before adulthood vary

between 28 and 56% and of those with moderate to severe Ulcerative Colitis at diagnosis, 25% require colectomy within 5 years (Freeman, 2004; Gupta et al., 2006; Hymans et al., 1996).

2. Literature review

Young people will often need more than one operation to treat the problems that arise in Crohn's Disease (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, structuring 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; Rigueiro and Mardini, 2003).

Adolescents and adults alike greatly fear the prospect of surgery for Inflammatory Bowel Disease 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 and quality of life (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).

There is a growing body of literature that explores the changes which occur in people's lives as a result of surgery for Inflammatory Bowel Disease. Long term improvements in health related quality of life for the majority of patients after ileoanal pouch (IAPP) surgery have been documented (Fazio et al., 1999; Thirlby et al., 2001). Patients have described their transition from having the temporary ileostomy as a journey from illness to health and a return to normality (Berndtsson et al., 2004). However, poor pouch function, food restrictions and physical limitations following the operation adversely affect quality of life (Fazio et al., 1999; Häuser et al., 2004; Coffey et al., 2002). One paper described the experiences of young adults four years after permanent stoma formation who recalled struggles related to their decision to undergo stoma surgery and distressing emotions centering on the stoma but also perceived that they now focused on living with a new perspective (Sinclair, 2009). However, the transition patients undergo after surgery as they adjust to changes in their body and its function has never been specifically

Download English Version:

<https://daneshyari.com/en/article/7516225>

Download Persian Version:

<https://daneshyari.com/article/7516225>

[Daneshyari.com](https://daneshyari.com)