



MICHAEL P. KELLY

# COLITIS



THE EXPERIENCE OF ILLNESS SERIES

Series Editors: Ray Fitzpatrick and Stanton Newman

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# Colitis

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Ulcerative colitis, a chronic condition with many long-term complications, also poses certain short-term problems for the sufferer. In *Colitis*, the latest title in The Experience of Illness series, Michael Kelly considers the reality of living and coping with a condition that is constantly unpredictable, generally debilitating and presents the threat of a long-term major decline in health.

He outlines and assesses the curative surgery that is sometimes performed, namely total colectomy and ileostomy, and discusses the various strategies which sufferers develop and adopt in order to keep their condition under control.

Of immense value to all health professionals who care for and counsel people with colitis, the book will also provide help and encouragement to sufferers, their families and friends.

**Michael Kelly** is Senior Lecturer in the Department of Public Health at Glasgow University.

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# The Experience of Illness

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Michael P.Kelly



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# Preface

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This is a book about the experiences of men and women who have had ulcerative colitis and have had that disease cured surgically. The main subject matter is the words of people describing their experiences. The book tries to provide an authentic representation of what it is like to be ill with colitis, to undergo major surgery, and to live with an ileostomy. The idea which is implicit or explicit in most patients' and ex-patients' descriptions of their experiences is 'coping'. They talk about how they coped with their symptoms, their pain, their distress and their recovery. The central sociological and psychological organizing concept in the text is therefore coping.

The main audience for this text will probably be professionals with an interest, such as doctors, nurses or stoma therapists, in colitis and its sequelae. A sub-theme in the book is to show what the disciplines of sociology and psychology can contribute to an understanding of the patient's experience and can contribute to the care of such patients. The book may also be of interest to medical sociologists and medical psychologists as an example of the application of aspects of their disciplines to a specific disease. I hope too that the book will be of interest to lay readers. Patients and relatives may find some comfort in the text. This is not because the book contains a message of hope (there are no miracle cures or strange psychological theories here) but rather because the realization that someone with colitis is not suffering alone may be helpful. One of the very surprising things about doing the research for this book was the discovery that many people with colitis had never spoken to anyone, other than their doctor



and close relatives, about their illness and that they had little conception of a group of other people in a similar predicament until after they had surgery. To the lay reader who has the disease or to the relative of a sufferer, there may be some consolation in the sharing of experience.

My qualifications for writing this book are twofold. First, I am a sociologist with a smattering of psychology, and on that basis I researched the experiences of people with colitis in the Department of Psychiatry at the University of Dundee. Second, I contracted ulcerative colitis long before I became a sociologist. I had the disease for nineteen years and it was eventually cured when I was 30 by the surgical removal of my colon, anus and rectum. I now have an ileostomy. The experience of colitis and colectomy is therefore something with which I, and my family, are very familiar. Inevitably this book reflects my personal experiences, but overlaid, I hope, by my scientific training.

Michael P.Kelly, 1992

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# Acknowledgements

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In preparing this book very many people have helped, advised or supported me. My wife Tessa has endured the inconvenience of a husband who periodically needed to write, or be engaged in research, when time could, or should have been spent together. Likewise our children, Paul, Rachel and Helen, have had to put up with mounds of paper and books in various rooms in the house as the project drew to a close. My family, including my parents, Hilda and Pat, also experienced the illness and the surgery with me and in many ways would be as able to write a book as I am. For all their encouragement I am very grateful.

I am a professional academic and a number of colleagues have been particularly helpful over the years. David May of Dundee University was instrumental in getting me to formulate the personal experience of illness in scientific terms, Ray Fitzpatrick of Oxford University helped translate a research project into a book. In David and Ray respectively as mentor and editor I have been very fortunate. Several other colleagues have made encouraging noises along the way, notably Gareth Williams of Manchester University, Ruth Pinder of Brunel University, Hilary Thomas of Cambridge University, Priscilla Alderson in London, Neil McKeganey, John Anderson, Patrick West, Rex Taylor, Andrew Boddy, Robin Knill-Jones and Andrew Tannahill in home base in Glasgow, and Sarah Cunningham-Burley in Edinburgh.

The research on which this book is based was not funded through public sources. It is perhaps a sign of the times that I had to find

private funds from industry to undertake the work. I am very grateful therefore to Hollister Ltd, Salt & Son, Simcare, Convatec, and Clinimed Ltd. In particular Ms Jean Marceau, Mr Peter Salt, Mr John Cottrell and Mr Hugh Brady were prepared to support scientific work when it was far from clear that any definite outcome would follow.

Several other individuals have advised or helped and I would like to record my thanks to Barbara Wade then of the RCN, Professor Brian Brooke, Margaret McBride, Eleanor Russell, Caron Butler, Andy Malone, Cameron McDonald, Jim Attree, Charles Abraham, Jan Ireland, Norma Ballany, Archie Pagan, Maureen Munns, Carol Gordon, Kathy Staddle, Chris Penney, George Fenton, Jim McEwen, Jean Leiper and Jean Money.

Finally, there would be no research without subjects. My warmest appreciation goes to the unacknowledged and anonymous fifty men and women who had had ulcerative colitis or who had it and were about to undergo surgery to cure it. They shared with me in the most intimate and revealing ways, their struggles, their disasters, their shame and their embarrassments. They also shared their triumphs and their successes. I have tried to report their experiences as accurately as possible in this book. Their stories represent the real experience of coping with ulcerative colitis and colectomy as described here.

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## Editors' preface

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Ulcerative colitis is a disease that assaults the individual in particularly distressing and disturbing ways. Initial symptoms are unpleasant, disruptive, embarrassing and difficult to explain. When eventually individuals seek medical care, the examinations and investigations that lead to diagnosis are also distressing. Eventually symptoms may become so overwhelming that patient and doctor have to consider surgical rather than drug therapy. The need to accept the idea of surgery imposes new demands on the individual, as the severity of symptoms are weighed against the threat of ileostomy and its consequences. Once surgery is over the individual has to adjust to the quite different body produced by ileostomy. A number of new and vital competencies have to be acquired, particularly learning how to wear, use and change a stoma appliance. The individual has to gain technical mastery over bodily functions others take for granted. In addition he or she also wants to continue normal life with a stoma, coping with potential embarrassments and disruptions in everyday interactions as well as potential threats to more intimate relationships.

Michael Kelly has written a volume which demonstrates beyond doubt the value of sociological and psychological concepts in drawing out the general truths to be gained from patients' accounts of such intimate and personal sources of suffering. To examine how individuals cope with a disease involving the most taboo of problems such as frequent and unpredictable diarrhoea pre-surgically or acceptance and management of a stoma post-surgically, he draws out the relevance of classic concepts of self, identity and coping from the

social sciences. To do this, Michael Kelly pays close attention to the meanings of illness experience for individuals. For many individuals the experience of colitis is a source of anger and resentment, and surgery with all of its consequences a traumatic challenge. Nevertheless, post-surgical life was, for the vast majority of individuals interviewed by Kelly, viewed positively and with hope and contrasted very favourably with their pre-surgical state. The complex ways in which the individual comes through the enormously varied challenges to live a full and independent life with ileostomy is analytically and sharply delineated in this account. Michael Kelly has drawn on a broad and rich understanding of the social sciences as well as his own personal experience of colitis to achieve this invaluable contribution to our series concerned with the experience of illness.

Ray Fitzpatrick and  
Stanton Newman, 1992

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## Chapter one

# The background

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The basic medical facts about ulcerative colitis may be described very simply: it is a non-specific inflammatory condition of the mucous membrane of the large bowel and rectum (Bouchier, 1977:136), which tends to appear in early adulthood (Goligher *et al.*, 1980:689). Its causes are unclear, but its pathology is well defined (Morson and Dawson, 1979:331). The core symptoms are diarrhoea with passage of blood and mucus, abdominal pain, loss of energy and weight, and raised temperature (Goligher *et al.*, 1980:701). There are a variety of complications which may include perforation of the bowel, and cancer.

For the people who have this illness there are social and psychological dimensions to the disease far beyond the pathology of the specific lesion. The ability to function socially can be severely undermined. Episodes of unpredictable diarrhoea punctuate all life's activities: from eating, through sleeping, to sex. Life may, at times, literally revolve around going to the toilet, or at least being near a toilet in case the need to evacuate arises. The unpredictability of the diarrhoea may render even an otherwise innocuous situation terrifying. A simple stroll in the country, a journey on a bus, a weekend away at friends can all be ruined, not only by the diarrhoea but also by the fear that it might overtake the person at any moment and cause mess and embarrassment.

However, there is more than just embarrassment associated with this disease. Young adults are not supposed to soil themselves: in infancy and in old age it might be accepted, but in the prime of life it is quite unacceptable. One of the most basic human functions is

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control of the bowel and control is undermined by this disease. The grown man and woman who suffers from this condition is in a situation which may at times resemble that of a child, and whose strategies for containing the diarrhoea may involve using nappies, pads or other aids, all of which may serve to reinforce loss of adult social status.

There is no medical cure for ulcerative colitis at present. There are, however, surgical cures, the most common of which involves the complete removal of the colon, anus and rectum and the diversion of the ileum through the skin to produce a new artificial anus called an ileostomy. This new opening has no muscular control, so the patient becomes permanently incontinent of faeces. After the operation the patient will have to wear, for the rest of his or her life, a plastic or rubber bag to collect digestive waste matter.

For many patients the operation may seem like jumping out of the frying pan into the fire. The operation leaves them free of disease so long as there have not been any malignant complications. However, the cure all but destroys the wholeness and the symmetry of the body. They have to wear an appliance (a bag) which may be bulky and appear to be visible under their clothing. They may have difficulties with the wearing of this appliance. Sometimes bags come off; not infrequently they leak. The person with the ileostomy may feel that his or her whole body has been violated and damaged.

However, most patients come through the experience reasonably well. Most get back to something like a normal existence, and most lead quite ordinary lives post-operatively. Nevertheless, the experience of the illness and surgery can be quite devastating and this book highlights these things as well as the problems of long-term adjustment.

Before proceeding to consider the main elements in the experience of illness and surgery, this chapter describes the basic medical details of colitis.

### **Epidemiology and aetiology**

Ulcerative colitis was first described by Wilks in 1859 (Wilks and Moxon, 1875). In some ways the name ulcerative colitis is misleading because the term ulcerative does not mean the existence of discrete ulcers in all patients, and the rectum as well as the colon is involved in most cases (Goligher *et al.*, 1980:689). It is predominantly a