Kent Academic Repository

Rutter, Claire (2001) *Illness representation, coping and outcome in irritable bowel syndrome.* Doctor of Philosophy (PhD) thesis, University of Kent.

Downloaded from

https://kar.kent.ac.uk/85993/ The University of Kent's Academic Repository KAR

The version of record is available from

https://doi.org/10.22024/UniKent/01.02.85993

This document version

UNSPECIFIED

DOI for this version

Licence for this version

CC BY-NC-ND (Attribution-NonCommercial-NoDerivatives)

Additional information

This thesis has been digitised by EThOS, the British Library digitisation service, for purposes of preservation and dissemination. It was uploaded to KAR on 09 February 2021 in order to hold its content and record within University of Kent systems. It is available Open Access using a Creative Commons Attribution, Non-commercial, No Derivatives (https://creativecommons.org/licenses/by-nc-nd/4.0/) licence so that the thesis and its author, can benefit from opportunities for increased readership and citation. This was done in line with University of Kent policies (https://www.kent.ac.uk/is/strategy/docs/Kent%20Open%20Access%20policy.pdf). If y...

Versions of research works

Versions of Record

If this version is the version of record, it is the same as the published version available on the publisher's web site. Cite as the published version.

Author Accepted Manuscripts

If this document is identified as the Author Accepted Manuscript it is the version after peer review but before type setting, copy editing or publisher branding. Cite as Surname, Initial. (Year) 'Title of article'. To be published in *Title of Journal* , Volume and issue numbers [peer-reviewed accepted version]. Available at: DOI or URL (Accessed: date).

Enquiries

If you have questions about this document contact ResearchSupport@kent.ac.uk. Please include the URL of the record in KAR. If you believe that your, or a third party's rights have been compromised through this document please see our Take Down policy (available from https://www.kent.ac.uk/guides/kar-the-kent-academic-repository#policies).

Illness Representation, Coping and Outcome in Irritable Bowel Syndrome

Claire Rutter

Centre for Research in Health Behaviour
Department of Psychology
University of Kent at Canterbury

Thesis submitted in accordance with the requirements for the degree of
Doctor of Philosophy in the Faculty of Social Sciences
at the University of Kent at Canterbury

December 2001

Dedicated to Margaret Rutter
(1930 – 1996)

Abstract

The majority of research using the commonsense model of illness representation has focused upon observable, organic illness; little research has been directed at invisible, functional illness, even though a clear understanding of the cognitive mechanisms in functional illness is warranted. The main purpose of this thesis is to explore the illness cognitions (or illness representation) of different populations of irritable bowel syndrome (IBS) sufferers over time, to examine whether these cognitions can predict simultaneous and subsequent outcome, and to determine if coping mediates the link between illness representation and outcome as the commonsense model suggests.

The first two chapters introduce the commonsense model, and discuss why IBS is a worthwhile illness to study in this way. Chapters 3, 4, 5 and 6 describe each of the four studies conducted in order to examine the commonsense model with IBS sufferers/patients.

Sufferers/patients were recruited from three different populations: self-help groups, primary and secondary care. Three of the four studies were longitudinal so that the predictive nature of the representation components could be assessed over time. In addition, three of the four studies compared the responses of IBS sufferers to sufferers of other illnesses: inflammatory bowel disease (IBD) (an organic illness) and chronic fatigue syndrome (CFS) patients (a functional non-GI illness).

All four studies confirmed that the illness representation of IBS sufferers can predict outcome, and have shown that the representation can predict anxiety significantly 12 months later. All four studies demonstrated the importance of the serious consequence component of the illness representation; reporting that IBS has serious consequences was related significantly to poor outcome. Avoidant coping was found to partially mediate the link between illness representation and outcome, but was found to not contribute much to the illness representation. The predictive strength of the illness representation is stronger in IBS sufferers compared to IBD sufferers. While we can hypothesise that the strength of the representation is attributable to the illness' functional status we cannot make any further assessment regarding the role of symptom presentation due to the small number of CFS patients recruited.

The final chapter outlines the main findings of the thesis, and discusses the salient points. The theoretical and empirical implications of this research are discussed.

Memorandum

The research for this dissertation was conducted whilst the author was a part-time (October 1997 – September 1999) and full-time (October 1999 – May 2001) postgraduate student at the University of Kent at Canterbury.

The theoretical and empirical work herein is the independent work of the author. While the execution of the studies contained here did not require the physical assistance of any person other than the author, outside help was required for the recruitment of participants. Intellectual and practical debts are acknowledged.

The author has not been awarded a degree by this or any other university for work included in this thesis.

Acknowledgements

Primarily, I would like to thank the 686 individuals who participated in this research; without their help, this thesis would not have been possible. These people not only gave up their time to complete questionnaires, but also often wrote so many words of encouragement. Their words of support, and frankness in describing deeply personal (and often traumatic) life events and circumstances have been incredibly humbling, and have ensured that whatever the future brings, that I hope always be involved in researching these intriguing illnesses.

Thanks go to the IBS Network Trustees and Peter Cartwright of NACC for allowing me to advertise my research in their respective newsletters. Thanks to Penny and Hazel at the IBS Network office, Sheffield, for manually inserting my information sheet into new member packs. Thank you to Dr Barton (consultant gastroenterologist at the Kent and Canterbury Hospital) for being interested in the research, helping me to recruit patients and for providing a private room in the clinic so that I could meet and talk to patients in private. Thanks to Sue (secretary to Dr Barton) for enduring the countless phone calls from me as I tried to find out the dates of consultations and investigations of patients. Thanks go to the large number of GPs who distributed my information envelopes to the many patients in their care.

A big thank you to Derek Rutter, for allowing me to develop my own ideas, helping me to write "proper" and for the constructive guidance in the design and write up of the studies. Thanks also to Elizabeth, Trudy, Tamsin and Lynne for their help with administration over the last four years.

I would also like to thank my friends and family who have had to endure me throughout the highs and lows of this thesis. To Giles, for "putting up with me" this past year and a half – we both know how important to me and difficult for you this has been! To Nic, who luckily for me, found herself at a similar stage of writing up - I wouldn't want to go through this with anyone else. To my fellow "Olive Cottagers" both old and new, for providing such a supportive environment, especially to Kate Hamilton-West for helping me sort the individual coping behaviours. To Adam, Al, Andy, Chantelle, Claire, James, Jenny, Julie, Phil and Rachel for visiting, making the move from London to Canterbury a lot easier than it could have been, and for being such good friends. To Chris, Lindsay, Sam, Sarah and Tonia for also being excellent mates, and providing some excellent memories of my time in Canterbury - ensuring that I'll return. Most importantly, I would like to thank my family, for being at the end of the telephone and forever telling me that it would be ok when times have been incredibly difficult - your reassuring words have been invaluable.

I would like to say a special thank you to Dr Christine Dancey who not only co-founded the IBS Network, also gave me my first "real" job interviewing IBS sufferers. This experience stirred my interest in this fascinating and often misunderstood condition. Also, to Dr Helen Fidler and Professor John Weinman for their interest in developing the commonsense model further with IBS patients in the future.

Contents

List of Tables

Chapter 2

Chapter 3

Chapter 4

Chapter 5

Chapter 6

List of Figures

Chapter 3

Chapter 4

Chapter 5

Chapter 6

"You must do the thing you think you cannot do."
-- Eleanor Roosevelt

Introduction

Research using the commonsense model of illness representation (Leventhal, Nerenz and Steele, 1984) has shown that the way patients think about their illness affects outcome. The potential of this model to help explain and understand individual adaptation to illness is huge. However, while the general principles of the model have been tested in a variety of different illnesses, it is difficult to assimilate all the findings together into a coherent whole; the majority of researchers who choose to use the commonsense model to investigate adaptation to illness have designed cross-sectional studies using heterogeneous measurements. In addition, the role of coping in the commonsense model has received little attention from these researchers. Therefore, one of the main aims of this thesis was to examine illness representation longitudinally and to use measures readily available in the literature.

The illness chosen for examination in this thesis is irritable bowel syndrome. This illness was chosen for a number of reasons. Firstly, IBS is a functional illness (i.e. it has no clinical, observable markers), and functional illnesses (with the exception of chronic fatigue syndrome (e.g. Moss-Morris, Petrie and Weinman, 1996), and chronic pain (e.g. Williams, Robinson and Geisser, 1994)) have been overlooked in favour of organic illnesses, possibly because of the hard outcome measures that can be obtained. Secondly, there are many medical and psychological researchers examining different aspects of IBS, however these findings exist in virtual isolation, more integration of these findings are needed. Finally, medical researchers are increasingly citing the connection between the brain and the gut (also known as the "Brain-Gut Link") as playing a central role in the experience of symptoms. Researchers often describe IBS within a cognitive-behavioural framework, such that cognitions affect symptoms and symptoms affect cognitions. Therefore, IBS was selected as the illness to be examined using the commonsense framework.

This thesis is organised into seven chapters. The first two chapters help to provide background information regarding the commonsense model and the illness under investigation. The first chapter introduces the commonsense model of illness representation. It discusses the stages of the model and introduces the representation components. It presents research that has used the commonsense model, and finally it critically evaluates the model both conceptually and empirically.

Chapter 2 introduces IBS as the illness under investigation. This chapter presents previous research regarding the prevalence, diagnosis, prognosis and treatment of IBS. Medical theories regarding the onset of IBS are presented, together with patient perceptions regarding the cause of their illness. This chapter concludes with a reminder of the main objectives of this research.

Chapters 3, 4, 5 and 6 present the four studies that comprise the work of this thesis. All studies are questionnaire based, and use the same measures. However, the participants in these studies have been recruited from different populations as most of the work carried out on IBS has used easily accessible populations of self-help group members, or those referred for investigations. Active researchers in the area (Grant Thompson, 1999; Drossman, 1999) call for more work to be carried out with different populations of IBS sufferers. However, since researchers have mostly recruited IBS patients from tertiary care centres and self-help group members it is unknown how, or even if, these different populations of sufferers differ. Therefore, this work draws participants from self-help groups, primary and secondary care.

Chapter 3 presents the first study in this body of work. The first study presents a cross-sectional examination of illness representation, coping behaviour and outcome of IBS and IBD (an organic illness) sufferers. Two hundred and nine IBS sufferers, and two hundred and seventy-four IBD sufferers were recruited from national self-help organisations.

Chapter 4 presents the first longitudinal examination of the illness representation of IBS sufferers. This second study examined 74 IBS sufferers who completed measures of illness representation, coping and outcome measures at the time of joining an IBS self-help organisation, and again eight months later.

Chapter 5 is a prospective study in which the illness representation of 35 IBS and 12 IBD patients recruited from secondary care are examined. The illness representation is measured at the time of diagnosis and again two months later. At Time 2, coping and outcome measures are taken to examine whether the initial illness representation can predict outcome.

Chapter 6 examines the illness representations, coping behaviours and outcomes of 37 IBS, 24 IBD and 21 CFS patients recruited from primary care. All variables are measured at three time points, over a 12 month period (6 month intervals).

The four studies can be classified thus:

STUDY	CHAPTER	DESIGN	LENGTH OF STUDY PERIOD	POPULATION STUDIED	PATIENT GROUP
1	3	Cross sectional	N/A	Self-Help Group Members	IBS / IBD
2	4	Longitudinal: 2 Time Points	8 Months	New Self-Help Group Members	IBS
3	5	Prospective: 2 Time Points	2 Months	Secondary Care Patients	IBS / IBD
4	6	Longitudinal: 3 Time Points	12 Months	Primary Care Patients	IBS / IBD /CFS

The thesis concludes with Chapter 7, in which the main findings of the research are presented and the implications of this work are discussed.

Chapter 1
An Introduction to the Commonsense Model of Illness Representation

"Theory is essential for the development of science.
Theory is a key analytic tool for intelligent practice."
Leventhal, Meyer and Nerenz (1980, p.8)

Theory Driven Research

Research within health psychology has been criticised for lacking adequate theoretical direction (e.g. Abraham and Sheeran, 1997; Cameron, 1997). More specifically, the research literature has been largely empirically driven by the practical needs associated with specific health conditions. As a result, data tend not to generalise across different health-defined populations: research findings exist in virtual isolation. Using a theoretical framework allows research findings to be assimilated through coherent theoretical integration. Also, Nicasso and Smith (1995) suggest that by examining different illnesses using similar methodologies, assists health psychologists to develop general principles that can be developed into versatile and flexible treatment approaches across patient groups. Thus, theory driven research is a necessary pre-requisite for the identification and examination of processes underlying health behaviour.

Several theoretical interpretations have been offered as potential explanatory frameworks in which health behaviours can be examined. The association between health beliefs and performance (actual and intention to perform) of health behaviours have been extensively examined using social cognition models like the Health Belief Model (e.g. Rosenstock, 1974) and the Theory of Planned Behaviour (e.g. Ajzen, 1985)[1]. While these models include predictors relating to the individual perception of illness (the Health Belief Model gives weight to the patient's perception of vulnerability and severity of illness as a predictor of behaviour; the Theory of Planned Behaviour includes

---

[1] Extensive reviews evaluating the relative merits and disadvantages of each are available (e.g. Janz and Becker, 1984; Norman and Conner, 1996; Horne, 1998; Leventhal, Zimmerman and Gutmann, 1984).

perceived control as an important predictor of behaviour) these models lend themselves more readily to investigations of compliance, and less to idiosyncratic adaptation to illness.

Originally, psychologists interested in individual adaptation and response to illness conducted research atheoretically, by focussing on a variety of demographic (e.g., socio-economic status, age, sex) and personality variables (e.g. locus of control, neuroticism), however, such studies provided ambiguous results. Then in 1980, Howard Leventhal et al published a paper that emphasised the role of the patient's personal model of illness, which directs coping behaviour. This personal model of illness is based on previous illness experience and generalised information about illness (Leventhal, Meyer and Nerenz, 1980). After conducting many interviews with patients, the authors stated that patients view their illness along 4 dimensions: illness identity, timeline, cause, consequence. The *identity* component is concerned with the patients' ideas about the label and nature of their condition, the *timeline* component reflects the perceptions of the likely duration of their health problems, the *cause* component is concerned with the patients' ideas about the likely cause of their illness, the *consequence* component comprises the individual's beliefs about illness severity and the likely impact upon psychological, social, physical and economic functioning. Cure / control was later added to these dimensions[2] and indicates the extent to which the patient believes their condition is possible to cure or at least control.

Leventhal developed the mental representation perspective further, incorporating the five representation components into the commonsense model (also known as the self–regulation model) of illness representation (Leventhal, Nerenz and Steele, 1984). Leventhal et al. (1980) argued that

---

[2] Lau and Hartman (1983) proposed the fifth dimension, *cure or controllability.* While Leventhal and Nerenz (1985) stated that it was debatable whether cure/control should be defined as a further attribute of the illness representation, or whether it could be used as a summary of expectations with respect to coping effectiveness, researchers have acknowledged and incorporated cure/control as constituting a further dimension of the illness representation.

these components create the patient's own unique and commonsense model of their illness. Leventhal et al. described the components as a loosely organised set that defines the objective problem/danger. They define the goals or targets for coping, and coping is evaluated against these targets. The simplicity of this "commonsense model" has attracted many health psychologists over the last two decades, and much of this research will be examined in this chapter.

Before more detailed discussion of the commonsense model is presented, it is important to understand the impact that Leventhal's ideas about the personal cognitive models have had upon the work of other health researchers. While most researchers examine the five representation components directly, other researchers have built upon Leventhal's work, and have tried to find a generic illness representation (i.e. representation dimensions that are common across illnesses; Turk, Rudy and Salovey, 1986), or argue that instead of actual illness memories (or illness schemas) directing the five representation components, that illness prototypes are triggered (Bishop, 1991).

Turk, Rudy and Salovey, (1986) constructed their Implicit Models of Illness Questionnaire (IMIQ) based around the five representation components and items related to personal responsibility and disruptiveness. After carrying out exploratory and confirmatory factor analysis they identified a four dimensional structure of illness: seriousness, personal responsibility, controllability and changeability, which they argued was applicable to a wide variety of illnesses. The authors argue that patients are more concerned with the impact of the illness on themselves, and its likelihood for it continuing to have personally relevant consequences on them, than they are regarding the length of time they expect the illness to last (referring to Leventhal's representation component of timeline). While this seems to oppose the five component structure of the commonsense model, it is likely that are examining complementary aspects of the same phenomena, with the difference resulting from the different assumptions and methods used by the researchers.

Leventhal posits that experiencing symptoms triggers previous illness memories in order to identify and adapt to the illness (Leventhal, Meyer and Nerenz, 1980). Bishop (1991) agrees that memories are triggered, but argues that prototypes rather than actual illness memories are involved. Prototypes are similar to schemas, but are referred to as "idealized standards retrieved from memory to which people compare physical symptoms" (Croyle and Barger, 1993, p.33). For example a highly prototypical symptom set for IBS could be diarrhoea, abdominal pain and wind, whereas a symptom set low in prototypicality could be nausea, vomiting and constipation. Bishop believes that the selection of a prototype is not contingent upon a perfect fit between prototype and symptoms; rather a resemblance is enough to make a plausible interpretation. Leventhal disagreed and stated that matching to a prototype rather than a specific illness memory would result in outcomes that are more ambiguous, and that the uncertainty would motivate additional search to identify the illness (Leventhal and Diefenbach, 1991). Therefore Leventhal believes that previous, and specific illness episodes will be recalled rather than general prototypes. Croyle and Barger (1993) suggest that both researchers are correct, saying that it is likely that prototypes could be invoked in frequent illnesses such as colds and the flu, and severe or unusual episodes may need direct and specific comparisons.

In the context of the present research, The Commonsense Model (Leventhal, Nerenz and Steele, 1984) appears the most appropriate model to explain the heterogeneous adjustment to illness experienced by sufferers of irritable bowel syndrome: firstly, the representation components are unique in that they were derived from interview studies of patients, and they are empirically based (Hampson, Glasgow and Strycker, 2000), and secondly, data pertaining to the commonsense model is readily available in the literature. This wealth of research not only indicates the likely importance of illness representation components in explaining variance in outcome, but also enables comparison between different empirical investigations. Such comparisons represent a necessary first step in evaluating the causal stability of specific underlying processes.

The theory and its components have been examined in relation to a diverse range of health conditions, including among others, lymphoma (Nerenz, Leventhal, Love and Ringler, 1984), hypertension (Meyer, Leventhal and Gutman, 1985), multiple sclerosis and rheumatoid arthritis (Schiaffino, Shawaryn and Blum, 1998), chronic fatigue syndrome (Moss-Morris, Petrie and Weinman, 1996) and diabetes (Hampson, 1997). All data support components of the commonsense model to a greater or lesser extent. Given the lack of theory driven research more generally, the availability of illness representation data and the diversity of populations on which it has been tested, suggests that the theory provides a useful point of departure for understanding adjustment to irritable bowel syndrome.

The Commonsense Model of Illness Representation

Throughout this review, Leventhal's model will be referred to as the "Commonsense Model" but it should be noted that this model has been called many different names since its introduction in 1980. Researchers have described it as the "Self-Regulation Theory", a "Parallel Model", and an "Information-Processing Model". All the terms convey a common theme: they view the patient as actively construing a definition or representation of his/her illness episode and regulating his/her behaviour on the basis of the representation. The term "Commonsense Model" derives from the description of the model by Leventhal and his colleagues (Leventhal et al. 1980) who defined illness cognition as a patient's implicit and unique commonsense beliefs about their illness. I chose to use the term "commonsense" instead of the equally popular "self-regulation" because the research presented here focuses on the stages of processing: interpretation, coping and outcome, but does not examine the parallel processing of cognition and emotion, and hierarchical processing that Leventhal, Nerenz and Steele, (1984) described in the self-regulation context (these processes will be discussed later). The decision to omit the measurement of emotional representation in this research was taken due to the lack of published work examining this process. While it is expected that emotional representation components such as worry, fear, shame or despair will be impacting upon coping and outcome, no research to date has examined these components (along with the cognitive representation) as important predictors of outcome within the commonsense framework. It is believed that the theorised emotional representation will be as important as the cognitive representation in predicting outcome, so future researchers should take time to identify the relevant emotional representation components and to develop appropriate measures. However, by examining the cognitive representation alone allows the present research to be compared to existing research, as well as allowing more focussed analysis of illness cognition in this thesis.

The commonsense model of illness representation is based upon problem solving models and suggests that individuals deal with illness/symptoms in the same way as other problems. It assumes that people are motivated to avoid and treat illness, "Individuals are motivated to regulate or minimise their health-related risks and to act to reduce these health threats in ways consistent with their perception of them" (Leventhal, Nerenz and Steele, 1984, p.219). In essence, when a threat to one's health becomes salient, the individual will attempt to understand and regulate the illness threat. The model is constructed with 3 stages: interpretation (making sense of the problem), coping (dealing -or not- with the problem) and appraisal (assessing how successful the coping has been). These three stages of the model interrelate in order to re-establish the state of normality (i.e. they will continue until satisfactory appraisal has been attained).

The commonsense model will be examined in this chapter. Firstly, the three stages: interpretation, coping and appraisal will be addressed in detail, before briefly introducing the additional features of the model: parallel processing of cognition and emotion, and hierarchical processing. Secondly, empirical work using the commonsense framework will be presented. Finally, the conceptual and empirical limitations of the model will be discussed.

1. Interpretation, Coping and Appraisal

Interpretation

On experiencing symptoms or sensations individuals actively attend or psychologically blunt the significance of them. Those who attend to these symptoms observe and interpret them by comparing the present symptoms to previous illness episodes/experiences. These illness schemas help individuals construct a representation of their illness along five dimensions: identity, timeline, cause, consequences, and cure/control. This unique representation gives personal meaning to the symptoms, and acts as a framework for guiding coping efforts (which may or may not involve seeking consultation with a GP). Therefore the same presenting symptoms can generate quite different representations of the illness threat. This can be explained more easily by the use of an example. Suppose a person experiences abdominal pain and diarrhoea; most likely he/she will remember back when they have experienced similar symptoms before. The patient may hypothesize that the symptoms are the result of mild food poisoning (as was diagnosed in a previous illness episode when similar symptoms were experienced). Here the representation of the illness will be defined as acute, caused by external factors, having no serious consequences and the belief that the symptoms will disappear in a day or so. However another individual with different personal experience may interpret the same symptoms completely differently. If a close friend or family member recently died from cancer, the individual may automatically think that their symptoms are caused by cancer, and the resulting representation reflects this idea, with timeline being chronic, extremely severe consequences and little possibility for cure. While the formation of the illness representation can be automatic, there is real potential for delay in the formation of the illness representation and its influence on behaviour. Nerenz and Leventhal (1983) describe "appraisal delay", "illness delay" and "utilization delay". (Although initially developed for acute conditions, it is believed that these stages can be applied to chronic conditions also).

Appraisal Delay This stage relates to the development of the representation, and so obvious coping behaviour is not visible. It is the appraisal reactions here that allow the individual to assess the potential meaning of the symptoms by examining how different the new symptoms are from normal. The individual will compare the observed symptomatic state to implicit templates of illness they have developed from past experience of illness and of illnesses from those around them. In developing the representation the individual may engage in behaviours such as talking to others, observing the situation closely, or reading a medical book. These behaviours may or may not be automatic. There may be huge individual differences concerning the length of this stage but it is expected that this stage would be rather short if the presenting symptoms are intense or severe pain or bleeding are experienced. This is easily illustrated in a recent study, which examined patient delay in reaching hospital during acute myocardial infarction. Of the 88 patients studied, who were admitted to hospital with their first MI, 58% reported a mismatch between expected symptoms and symptoms experienced. This mismatch was associated with delay, and these patients were more likely to have a third party decide to call for help (Horne, James, Petrie, Weinman and Vincent, 2000).

Illness Delay Once the individual has perceived that they are probably suffering from an illness for which they need medical assistance, this stage relates to the time elapsed from the recognition of illness to the realisation that they should seek help from a health professional. Once again there may be differences regarding the length of this stage. Factors that may shorten it include support and encouragement from friends and family to seek help, while fear of investigations and/or treatment may lengthen it.

Utilization Delay This stage relates to the time the individual has reached the decision to seek help until the time of seeing a medical professional. It can be very short if the individual has the time and opportunity to get assistance straight away; however GP waiting times and work and social schedules may lengthen this stage.

Once an individual is diagnosed with an illness, the representation of the illness is refined. Additional information received from health care professionals and information regarding the illness in the public domain is incorporated.

The Representation Components The *identity* component is concerned with patients' ideas about the label and nature of their condition, and the link with associated symptoms. The *timeline* component reflects the perceptions of the likely duration of their health problems and has been classified as acute, cyclical or chronic. The *cause* component is concerned with the patients' ideas about the likely cause of their illness (e.g. stress, virus, genetic inheritance). The *consequence* component comprises the individual's beliefs about illness severity and the likely impact upon psychological, social, physical and economic functioning. The *cure / control* component indicates the extent to which the patient believes their condition is possible to cure or at least control.

Illness Identity The illness identity component is an extremely interesting dimension of the illness representation. Having a dimension relate to the illness in terms of concrete symptom experience helps order and explain the self-regulatory process. The symptoms provide a cognitive short cut that give instant and continuous feedback about the progress of the illness. The symptoms can be used to (1) identify factors that may influence the progression of the disease (e.g. noticing that symptoms are often worse after consuming certain foods), and (2) to evaluate coping behaviours (e.g. planning meals). However, using symptoms as objective measures can be problematic. If for example, an IBS sufferer notices that his/her IBS symptoms have lessened; he/she may become less vigilant about his/her diet, which may result in a reoccurrence of the symptoms. Most IBS patients can often identify certain foods that contribute to symptom exacerbation. IBS like most chronic illnesses is characterised by periods of exacerbation and remission; therefore, it is usually in the patient's best interests to be aware of their condition even in periods of remission.

Using symptoms as indictors of disease can be problematic and produce more distress; Nerenz, Leventhal, Love and Ringler (1984) observed lymphoma patients undergoing chemotherapy. The palpable tumours were easily visible and were monitored by patients to observe the effectiveness of the treatment. Nerenz et al. observed that some patients' tumours reduced rapidly at the beginning of treatment, while other patients' tumours reduced slowly and steadily. Contrary to the expected outcome, those whose tumours disappeared quickly exhibited more distress than those who experienced slow but consistent tumour regression. This was attributed to two factors: those whose tumours disappeared quickly were firstly, thought to have lost their yardstick to measure effective treatment, and secondly, not understand why they must still endure the distressing treatment if their tumour has disappeared and they are effectively "cured". Buick (1997) states that this provides evidence that individuals have an implicit model of illness where symptoms define the presence or absence of disease, which ultimately influences the patient's illness representation.

The illness identity dimension is not limited to the concrete experience of symptoms, it also relates to the tendency of the individual to define the illness at an abstract level too (i.e. the diagnostic label). The label of the illness also impacts upon the resulting representation: some diagnostic labels are more distinct because of fear of the condition (e.g. cancer), some because of the embarrassing nature of the condition (e.g. irritable bowel syndrome), and some conditions are more familiar than others (e.g. diabetes compared to Addison's disease). While the concrete aspects of the identity component have received the most attention from researchers, Leventhal Nerenz and Straus, (1980) propose that the relationship between the concrete and abstract level of the identity dimension is reciprocal. When presented with an illness label people will seek to attribute symptoms to it (Baumann, Cameron, Zimmerman and Leventhal, 1989), and when experiencing symptoms they will seek to attach a label to it (Croyle and Jemmott, 1991; Leventhal, Meyer and Nerenz, 1980; Leventhal, Nerenz and Steele, 1984; see also Pennebaker and Skelton, 1978). This process of labelling and symptom finding involves deliberate search and automatic referencing from memory. Deliberate search is seen in talking to others, comparing symptoms and seeking out more information. Automatic activation of memory is witnessed with the emotional reaction to the symptoms and/or the illness label (Leventhal, 1970, 1980; Leventhal, Nerenz and Straus, 1982; Pennebaker, 1982; Pennebaker and Skelton, 1981). This is supported by Meyer's work with hypertensives.

Hypertensive patients were asked if they could tell when their blood pressure is high[3]. Eighty per cent of the sample correctly said that people cannot tell when their blood pressure is up. However when followed up with the question "can you tell?" 90% said they could tell that their blood pressure was elevated by monitoring symptoms of face flushing and the occurrence of headaches (Meyer, Leventhal and Gutmann, 1985) supporting the hypothesised reciprocal relationship between the concrete and abstract processing of information.

Timeline Leventhal and Nerenz (1985) argue that "a timeframe is implicit in every attribute of the representation, every action plan and every action" (p.521), however, the timeline component has been described as the weakest component of the model. Lau and Hartman (1983) asked subjects to report a previous illness episode; only 26% of the participants mentioned anything regarding the temporal parameters of the illness. However, Leventhal and Nerenz stated that the timeline component is implicit in the representation, asking people in general about their illness is unlikely to generate explicit comments about the timeframe of their illness. In addition, while people may not explicitly hold the length of the illness as the most important element of the illness experience, believing a chronic illness to have a short timeline is likely to contribute to poor outcome. An example of this can be drawn from Meyer, Leventhal and Gutmann's (1985) work with hypertensives. Meyer showed that those patients (in treatment) who viewed hypertension as an acute rather than the chronic condition were more likely to terminate treatment within six months. However, research demonstrating the predictive power of the timeline component is scant with symptomatic illness. Further problems with this component are the difficulty in its measurement. Leventhal hypothesised that this item could be acute, cyclical or chronic, all of which are quite distinct from one another (Leventhal, Nerenz and Straus, 1980); however, this has not been matched by effective measurement procedures.

---

[3] Hypertension is asymptomatic, and therefore there are no symptom indictors.

Cause A common reaction to illness is to attempt to find a causal explanation for it, and a large number of studies have generally found that causal attributions are associated with both psychological and physical outcomes. Wilson et al. (1994) reported that the more firmly chronic fatigue syndrome (CFS) sufferers attributed their symptoms to a disease process (i.e. an external attribution such as a virus), the more likely they were to remain functionally impaired three years on. Sharpe et al. (1992), Vercoulen et al. (1996) and Chalder et al. (1996) have also reported similar findings. Moss-Morris and Petrie (1996) explain that the external attributional style protects CFS patients' self esteem, but helps promote helplessness and a lack of responsibility for health. Believing that the illness was caused by internal factors no doubt increases anxiety about the condition, but possibly promotes attempts to deal with it. Fortune et al. (2000) reported that psoriasis patients who believed that their condition was caused by emotional factors (stress, other people's behaviour, own behaviour and state of mind) scored higher on a worry scale. While cure/control beliefs were not related to worry, the belief that psoriasis was caused by emotional factors was related to strong feelings of control.

Consequence The consequence component can also have a powerful impact upon coping and outcome. The belief that the illness has serious consequences may guide coping procedures to tackle the worst of the consequences (e.g. devising ways to combat the limitations the condition makes to his/her social life). The resulting appraisal may then focus on the evaluation of the coping procedure in reducing the serious consequences. Furthermore, if the illness severity is perceived to be small and the consequences negligible, the individual may choose not to engage in coping at all. Focusing on the serious consequences of a condition is likely to be related to a negative and depressive frame of mind, and consequently, likely to be related to a poorer adaptation than those who express less serious consequences. Therefore it is likely that this component may be directly related to outcome and not always mediated by coping as Leventhal's model suggests. This is an interesting area that will be addressed in this research.

Cure / Control Feelings of control over an illness are often related to positive outcomes (e.g. lower depression scores). However, as mentioned previously, control over an illness (i.e. internal causal attribution) often relates to feelings of responsibility. Conversely, if the patient has little control over the illness when they believe they have control, could be associated with a negative outcome. Both rheumatoid arthritis (RA) and multiple sclerosis (MS) patients, who believed that they had some control over their condition, believed they had responsibility for their illness (Schiaffino et al. 1998). In addition, the RA patients who believed RA to be curable, and believed it was their fault, reported higher levels of depression. Schiaffino et al. explained "perceptions of control in the face of the continuing presence of the disease (no matter what the symptom severity may be) can be expected to contribute to feelings of discouragement as the permanence of the illness becomes apparent, and may lead to self blame when one's best efforts have not produced meaningful change" (p.267).

While the five representation components are distinct, there have been some direct links reported between them. The number of symptoms reported by osteoarthritis patients was highly correlated with the perceived seriousness of the illness (Hampson et al. 1994). Schiaffino and Revenson (1992) found that perceptions of controllability of the illness interact with the causal attributions in rheumatoid arthritis patients. Also the identity or controllability of the condition is always implicitly if not explicitly linked to timeline (Leventhal and Nerenz, 1985), as people make the implicit decision about whether the illness is acute, cyclical or chronic when they first attribute the identity label.

Several studies involving different methodologies across a range of clinical conditions have confirmed the validity of the five representations (Baumann et al. 1989; Bishop, 1987; Lau et al. 1989; Meyer et al. 1985; Skelton and Croyle, 1991). They have been shown to be related to the decision to seek health care (Leventhal Diefenbach and Leventhal, 1992), compliance with medical advice (Leventhal, Zimmerman and Gutmann, 1980), as a predictor for returning to work (Lacroix et al. 1991; Petrie et al. 1996) and as a predictor of successful outcome in coping with chronic illness (Hampson et al. 1990; Moss-Morris et al. 1996; Schiaffino et al. 1998).

Once the illness representation has been formed it is neither stable nor independent. Representations can change via a number of processes: if present experience is incongruent with the representation of the illness, if the condition worsens, after the appraisal of coping, with the experience of new symptoms, or after some interaction with the emotional representation of the illness threat. All of these components interact with one another to create the unique nature of the illness model. Representations change over time and they are influenced by outside factors such as the medical profession, friends, family, the media and continuing experience. If the person who believes that they have a mild bout of food poisoning still experiences symptoms after 2 or 3 days, the timeline dimension of the representation could be considered to be incorrect which could trigger a revision to the original representation. Information or emotional support may be sought from friends and family, or informational support can be gained from other sources such as the internet or medical books. Usually the more information the individual gains about their condition, the more the representation will reflect this information. The resulting representation may then guide the individual to seek help from a health professional.

This first stage of the commonsense model, interpretation, has been widely researched, with the number of studies increasing significantly as acceptable measurement tools became available to researchers.

Measuring the Illness Representation Two different scales have been constructed to measure the illness representation components formulated by Leventhal et al. (1980; 1984). Firstly, Turk, Rudy and Salovey (1986) developed the 24-item Implicit Model of Illness Questionnaire (IMIQ), which was based upon the 5 representation components, as well as items related to personal responsibility and disruptiveness. As reported earlier this scale gives four domain scores: seriousness, personal responsibility, controllability and changeability. However, this scale has been criticised because only one third of the sample on which it was formulated were patients (55 diabetic patients, 55 nurses and diabetic educators, and 55 university students).

The Illness Perception Questionnaire (IPQ) developed by Weinman, Petrie, Moss-Morris and Horne, (1996) was constructed solely around the five representation components and was based on 848 patients from 7 illness groups: myocardial infarction (MI), asthma, chronic fatigue syndrome, diabetes, pain, renal and rheumatoid arthritis. Researchers seem to favour this questionnaire because of its simplicity and ability to measure all 5 representation components.

Coping

Once an individual constructs a representation of their illness, it is assumed to direct coping behaviours. In the early stages, the representation may (or may not) direct the individual to seek professional help, or informational and emotional support from family and friends. Waiting and monitoring symptoms, (i.e. passively acquiring information) is often reported at the onset of slowly developing episodes of illness (Prohaska et al. 1987). Active procedures such as talking to others or reading about it (Carver, Scheier and Weintraub, 1989), and seeking professional help (Cameron, Leventhal and Leventhal, 1993) replace passive ones if a symptom passes the individual's threshold of severity or duration. Also active social comparison for interpreting symptoms is extremely common among older adults (Cameron, Leventhal and Leventhal, 1993).

The representation that the sickness and diarrhoea are a result of food poisoning may lead the individual to rest for a few days; alternatively, the individual who believes that their symptoms may be caused by cancer may be more inclined to ignore the symptoms or visit a GP (this distinction is likely to arise from differences in self efficacy and self-esteem). When the individual receives a confirmatory or contradictory diagnosis from a medical practitioner more refinement of the illness representation is likely, which will impact on the coping behaviours selected. For example the patient who thought that their symptoms were due to cancer may end up visiting their GP because of pressure from friends and/or family. Reassurance from the physician that the symptoms are more indicative of IBS than cancer may or may not be readily accepted by the patient (possibly depending on how much time and effort the cancer representation has received). However it is likely that the representation of the illness will be altered to some degree.

Some individuals receive a diagnosis of IBS without any investigation, while others (usually older patients, or patients who have mentioned more serious symptoms like rectal bleeding) are referred to consultant gastroenterologists for tests: these often include colonoscopy, endoscopy and barium enemas. For those patients who are referred to a gastroenterologist, the amount of information they are given regarding the possible nature of their symptoms will vary. Some gastroenterologists may prefer to say what they want to rule out, while others may refer to the possibility that the symptoms are indicative of IBS. Whatever the gastroenterologist says, it will undoubtedly help develop the resulting representation. However it is probable that the representation will be constructed to be more serious if the procedures are perceived to be 'scary' and/or painful as the individual weighs up the benefits of the tests. This may lead the patient to adopt more avoidant coping behaviours.

For those individuals who receive a diagnosis of IBS at the initial consultation (without any invasive procedures), it is probable that they would see IBS as not having as many serious consequences as a cancer diagnosis. If the individual accepts the GP's diagnosis, the original representation of the illness would have to change. It would be re-evaluated primarily from the information given by the GP, either voluntarily or in response to specific questions regarding the prognosis (i.e. timeline and cure/control components) and also from previous experience and/or knowledge of IBS. The GP may offer suggestions as to the cause of the condition (e.g. stress or food intolerance) but cannot say with certainty what the cause is. The GP is likely to describe IBS as a chronic illness, which is characterised by periods of exacerbation and periods of remission. However once an IBS diagnosis has been given, the patient is left to develop their own coping behaviours to deal with the symptoms. Previous indirect experiences of IBS, or advice from the GP may lead to specific coping behaviours like watching diet, or engaging in relaxation, which may or may not benefit the individual. However coping with chronic illness is not focussed exclusively upon the removal of symptoms. The predominant feature of adjustment to chronic illness is the striving to deal with the symptoms as they impose limitations on everyday activities.

The choice of specific coping behaviours will be directed in part by the representation of the illness, but it is also acknowledged that this may be influenced by at least three other factors (Leventhal, Nerenz and Steele, 1984). Firstly, the individual's self-efficacy or self-esteem, their belief that they can cope with the illness, will ultimately influence if and what coping behaviours are chosen. Secondly, the individual's strategies for relating themselves to problem situations and for testing the effectiveness of response alternatives will influence specific coping behaviours. Thirdly, the selection of coping behaviours will depend upon the repertoire of coping behaviour they have at their disposal and their belief in the effectiveness of each one.

People differ in the way they cope with chronic illness. Some may adapt lifestyle to accommodate illness restrictions; others may adapt to their illness and restrict lifestyle. Nerenz and Leventhal (1983) describe at least two ways that coping with illness can be differentiated: (1) total involvement with the disease, and (2) encapsulation. Those individuals who adapt to their illness become totally involved with their illness; every person-situation interaction becomes a disease-situation interaction. A parallel can be drawn here with the reported "sick role" or "illness behaviour" syndrome witnessed in a sample of chronic pain patients (Wooley et al. 1978). Wooley et al. describe people who cope by doing nothing other than attending to, and attempting to control, their pain. Social relationships are evaluated by the amount of attention others give to their illness and life activities are limited because of illness demands. As a result of this focussed attention, Wooley et al. describe these people as grossly over medicated, depressed and distressed. Encapsulation refers to those individuals who acknowledge that a component of the self is diseased but also recognise that large areas of the self are disease free. Those individuals who recognise that large areas of the self are disease free are more likely to succeed in isolating the impact of the illness.

Total involvement with disease and encapsulation both refer to a dispositional style of coping, while Leventhal's commonsense model views the representations as the primary force directing the choice of specific situational coping behaviours. Leventhal measured coping by simply asking patients a list of specific questions in order to identify the coping behaviours that are engaged in. However the interview technique is extremely time consuming, and therefore researchers are left to decide on one of the many coping scales available. Due to the large number of scales available, and the lack of standardised measurement of coping within the commonsense framework, this stage of the model has the least theoretical integration.

Measuring Coping Recent researchers have used a number of methods to analyse the coping strategies that patients' use to cope with illness. Some researchers have developed their own coping scale, which investigates the specific illness experience (e.g. Hampson, Glasgow and Strycker, 2000, for diabetes), however these are often so specific to one illness, they cannot be adapted to other illnesses. Other researchers analyse the unique coping experience of patients by using a semi-structured interview (e.g. Earll, Johnston and Mitchell, 1993 for motor neurone disease), but once again comparison across illness groups is extremely difficult because of the unique nature of the coping behaviours elicited. Some researchers have simply ignored the coping process and instead focus exclusively upon the relationship between the representation of illness and the outcome (e.g. Petrie, Weinman, Sharpe and Buckley, 1996; Fortune, Richards, Main and Griffiths, 2000; Schiaffino, Shawaryn and Blum, 1998). It can be argued that ignoring the coping process removes important predictive power from the commonsense model and therefore should not be undertaken without sound theoretical basis.

Some researchers use more general coping strategy scales that can be adapted for coping with illness (e.g. Moss-Morris, Petrie and Weinman, 1996; Heijmans, de Ridder and Bensing, 1999). It is suggested that a more general measure of specific coping strategies/behaviours may be a more appropriate measure of coping within the commonsense model. However, most coping instruments are empirically rather than theoretically driven, which often results in post hoc interpretations which are poorly related to theory (Carver et al. 1989). Also many of the current measures suffer from both methodological and psychometric weaknesses (e.g. different response formats, unstable factor structures, problems of validity and reliability). Coping scales that make the simplistic distinction between emotion and problem focused coping often imply that one particular type of coping is better than another in controllable and uncontrollable situations. However, there is accumulating evidence that an assortment of coping behaviours may be associated with favourable health outcomes. Measures such as the COPE (Caver, Scheier and Weintraub, 1989) allow researchers to examine how the representation may affect a range of coping behaviours that can be grouped together as problem-focused, emotion-focused and avoidant behaviour, and can also be examined as theoretically independent from one another.

The commonsense model was initially constructed with the cognitive representation directing problem-focused coping, and the emotional representation directing emotion-focused coping. Problem-focused coping refers to the attempt to do something to reduce or eliminate the source of the stress (e.g. the symptoms) or the consequences of the illness threat (e.g. constant monitoring of the body). Emotion-focused coping refers to the attempt to manage or reduce the psychological distress caused by the stressor. However, this distinction between problem and emotion focused coping has not received much support, and avoidant behaviours such as behavioural disengagement have been found to be more predictive (e.g. Moss-Morris et al. 1996). Most stressors can elicit both types of coping, in situations that are long lasting and have to be endured (such as in chronic illness) people seem to favour emotion-focused coping, whereas problem-focused coping is more likely to arise in situations where people feel that there is something constructive to be done (Folkman and Lazarus, 1980; Carver et al. 1989).

Effective coping strategies will contribute to the enhancement of a patients' quality of life, and possibly help with the psychological adjustment to chronic illness. Using an established scale such as the COPE to investigate a previously unstudied illness like IBS runs the risk of specific and powerful coping behaviours being left unstudied, and thus the understanding of coping in IBS will be distorted. However, for researchers who do not have the resources for interviewing patients, the COPE at least provides a diverse number of sound coping behaviours.

Appraisal

The third stage of the commonsense model is appraisal. This involves individuals assessing their coping behaviour in response to the health threat and deciding whether to continue with a particular strategy or to opt for a new one. The measurement of appraisal is often rejected in favour of the more convenient measure of outcome. In this situation if outcomes are appraised as successful it provides evidence that: the coping behaviour was effective, the initial representation was correct, and the individual is capable of bringing about an effective response. If goals are not reached and outcome is poor Leventhal, Nerenz and Straus (1980), hypothesise that re-evaluation will first focus upon the coping procedure, then the representations, and then at the last resort, the self. Leventhal explains that this is because change will usually occur in the least differentiated and least well anchored of components.

Measuring Outcome A number of different outcome variables have been used in the literature, from objective reports of severity (e.g. Earll et al. 1993), pure physiologic measures (e.g. Hampson et al. 2000) and return to work (e.g. Petrie et al. 1996), to subjective reports of quality of life and/or functioning with illness (e.g. Hampson et al. 2000; Moss-Morris, Petrie and Weinman, 1996) and psychological adjustment (e.g. Schiaffino et al. 1998). Since there are no objective tests for IBS and there is the lack of effective therapy, greater emphasis on quality of life and psychological adaptation to the disorder seem more appropriate. It is expected that quality of life and psychological adjustment will be negatively related to one another.

Quality of Life There are many problems with the conceptualisation and measurement of the construct, quality of life, which Skevington (1999) argues "has resulted in a tendency to lose sight of the entirety of the concept" (p.451). It has been argued that the measurement of quality of life should take both subjective and objective factors into account (Künsebeck, Körber and Fereyberger, 1990). However Skevington (1999) argues that quality of life cannot be measured with objective indicators because it is a subjective experience. Subjective definitions range from patient reports of physical functioning and psychological well being, to social and occupational functioning. Most published scales have included measures of functional status for physical illness (which covers mobility and daily activities) and negative mood for psychological disorders.

Criticisms of previous scales encouraged researchers in the field to re-think the measurement of quality of life. A new measure, designed by the international WHOQOL group, now enables cross-cultural comparisons of quality of life. The construction of this scale revolved around the "facets" and "domains" of life that were believed to be important by an international panel of health professionals and patient-led focus groups. "A facet was defined as a specific aspect of life for which coherent definition could be agreed. Domains were defined as broad groupings (e.g. physical, psychological, social and environmental) of related facets". (Power, Bullinger, Harper, and The WHOQOL Group, 1999, p.496). A shortened version of the WHOQOL-100 has also been developed alongside the larger version: the WHOQOL-BREF contains facets of the larger scale, and has a total of 26 questions. The conceptual structure of the WHOQOL has been confirmed in the UK, with British respondents giving priority to psychological aspects of illness. Both versions of the scale include two, one-item measures of, quality of life ("How would you rate your quality of life?") and satisfaction with health ("How satisfied are you with your health?") that have been described as useful measures in their own right.

Psychological Adjustment Psychological adjustment to illness has also received attention in the illness representation literature (e.g. Fortune, Richards, Main and Griffiths, 2000; Moss-Morris, Petrie and Weinman, 1996; Schiaffino, Shawaryn and Blum, 1998). Studies have shown, CFS patients with a strong illness identity, who believed their illness was out of their control and who reported very serious consequences, were the most psychologically impaired (Moss-Morris, Petrie and Weinman, 1996). Symptom variability in multiple sclerosis patients contributes to later depression, and rheumatoid arthritis patients who believe their illness to be curable and caused by emotional factors, reported higher levels of depression (Schiaffino, Shawaryn and Blum, 1998). Serious consequences beliefs and attributing illness to emotional causes was associated with pathological worry in psoriasis patients (Fortune et al. 2000). Motor neurone disease patients who view their condition as serious reported significantly more anxiety and depression (Earll, Johnston and Mitchell, 1993).

A number of different measures have been used to measure the psychological adjustment of patients; a particularly favoured one is the Hospital Anxiety and Depression Scale (Zigmond and Snaith, 1983). It is useful because it gives a separate measure of anxiety and depression, and with only 14 items, each answered on a 4-point scale, it is quick to use and acceptable for patients who are quite unwell (Johnston, Pollard and Hennessey, 2000).

Interpretation, Coping and Appraisal

Although each stage of Leventhal's model has been examined separately it should be remembered that the commonsense model of illness representation is a feedback (iterative) model in which all three stages interrelate and affect one another. Once again this can be best described by use of example. A woman experiencing abdominal pain, diarrhoea and wind, who believes her symptoms are caused in part by diet, may chose to monitor her diet and avoid foods which she suspects contribute to her condition. If she notices that this behaviour is having no effect on the presentation of symptoms she may choose to buy over the counter medicines to treat the most problematic of symptoms (e.g. anti-diarrhoeals). If these coping behaviours are also unsuccessful, she may then reappraise the representation of the illness she has, believing the illness to be very serious with few control beliefs. This new representation may direct new coping behaviours, which may include avoidant coping (e.g. cognitive and/or behavioural disengagement), or she may choose to go back to her GP for more help and advice. If there is still no improvement, this situation may start to have a detrimental effect upon her psychological health; IBS sufferers are often reported to have higher levels of psychiatric comorbidity than organic gastrointestinal patients (the debate regarding the sequence of presentation of somatic and psychiatric symptoms will be addressed in Chapter 2). At this point she may be referred to a therapist who may be able to introduce her to new coping behaviours, and encourage her to talk about her representation of the illness. If a patient believes their symptoms are caused by stress, integral to this belief is the implication that stress-reducing procedures (e.g. relaxing, ignoring and /or reinterpreting life stressors) are appropriate treatments. If relaxation reduces symptoms it will reinforce this causal belief, however if these behaviours do not help, further changes to the representation may be necessary.

The interactions among representations and coping behaviours will generate changes in both representation and coping behaviour during the course of an illness episode. The changes reflect the reciprocal relationship among these active components and the social context in which these transactions take place. Thus, while it would be expected to identify commonalities in illness models across persons, the process should also generate a substantial degree of specificity by disease, culture and the individual (Leventhal and Benyamini, 1997).

In summary, the characteristics of processing change over time, in that processing becomes more complex both within and across illness episodes. Interpretations are added and modified in response to the specific situation. If the appraisals show that the output does not meet expectations there is an increase in arousal and deployment of more conscious attention and effort to behaviours. Most importantly, the basic goal of self-regulation is to get back to the pre-illness state - but people with chronic illness cannot achieve this pre-illness state and so try to limit the effect of the illness on their life. It could therefore be hypothesised that people who exhibit a poorer outcome have become stuck because their representations suggest that there is little they can do to control the illness, and their emotion focused coping strategies are more maladaptive than adaptive.

Additional Features of the Commonsense Model

As stated earlier in the Chapter, the commonsense model was constructed as an iterative and recursive stage model in which information is hierarchically processed (at concrete and abstract levels, which may be automatically or deliberately processed), via two interdependent (parallel) pathways (objective and subjective information). While the hierarchical and parallel processing features are not being examined in this thesis (due especially to the lack of effective measurement tools), this section will briefly introduce these concepts to allow full understanding of the commonsense framework.

The experience of illness is not solely confined to cognition. The cognitive representation of illness can have multiple and complex effects on emotion (e.g. the cancer representation). In return, the emotional reaction to the perceived symptoms may be so powerful that it directly alters the illness representation. As described earlier, the interaction of the observed stimuli and features of the individual's unique experience generate the illness representation. Therefore the person experiencing diarrhoea and pain may automatically invoke a perceptual schema that includes intense emotional reaction regarding the cause of the symptoms as cancer. Deliberate reflection may suppress the intense emotion by focussing on other possible causes such as food poisoning, however, the strength of the automatic schema vs. the strength of the deliberate schema will drive the resultant coping behaviour. If the automatic (cancer) schema is stronger, the illness representation may become elaborated and catastrophic due to the anxiety and/or fear of the potential consequences (e.g. pain and/or death). In such circumstances, therapy targeted at reducing the emotional arousal may be beneficial.

"Immediate, concrete goals facilitate coping and outcome appraisal: abstract, remote goals generate uncertainty and distress" (Leventhal, Meyer and

Nerenz, 1980, p.20). Johnson and Leventhal (1974) have shown that fear can interfere with coping, and the reduction of fear can facilitate the individual's ability to cope. Patients about to undergo endoscopic examinations (i.e. the endoscope is passed though the mouth and into oesophagus, stomach and duodenum) were given detailed preparatory information regarding what to do and what to expect. The cognitive control strategies for distress reduction based on blocking out irrelevant information (e.g. distraction) and strategies to take in information (sensory preparation, e.g. gagging and numbness of the throat) helped the patients to form a clear schema of the concrete properties of the noxious event. By objectifying the experience, the sensations were converted to cues of coping and as a result, those patients coped better (by displaying a lower heart rate and fewer gagging sensations).

While concrete processing involves the use of schematic memory structures that combine with new information to give rise to concrete experiences of the ongoing illness event, the abstract system is a highly flexible medium for rearranging information and anticipating future actions. Although both concrete and abstract processing may be automatic, concrete processing is nearly always so, whereas abstract processing maybe either automatic or deliberate (Nerenz and Leventhal, 1983). While each level can be thought of as unique, Leventhal has argued that they probably operate jointly, with abstract representation dimensions built on more concrete ones (Leventhal, Nerenz and Straus, 1980).

2. The Illness Representation and Empirical Evidence

As mentioned previously, Leventhal developed the commonsense model after his research into fear communication. Much of the early work used interview data to investigate the representation of illness, especially when researchers started to examine chronic illness using the commonsense framework. Scharloo and Kaptein (1997) conducted a systematic review spanning 10 years (from 1985 to 1995) of studies examining illness perceptions in chronic illness. Of the five representation dimensions, they report that cure/control was the most frequently studied, and chronic pain patients were the most frequently investigated group during this period. They confirm that the most widely used methods of obtaining data were by using semi-structured or open-ended interview approaches. However because interview data is time consuming, most studies restricted their assessment to just one or two dimensions, and little effort was directed at finding relationships between dimensions. Although drawing a detailed comparison proved difficult, it was concluded that illness perceptions (especially perceived consequences[4] and perceived control) are important factors influencing medical, psychological and behavioural outcome.

Research examining the illness representations of patients using an interview format has proved quite successful. Earll, Johnston and Mitchell (1993) revealed that motor neurone disease patients who expressed a strong illness identity were more likely to have tried an alternative remedy, and those believing the illness to be serious were more likely to seek out information about it. The belief that the illness has serious consequences was also associated with higher anxiety and depression and lower well-being scores. Hampson (1994) interviewed osteoarthritis patients and reported that those who reported a higher perceived seriousness reported higher levels of self-management, and more use of medical services, and experienced poorer quality of life. Also, Hampson (1990) interviewed diabetic patients and showed that the diabetic patients' models were generally consistent with medical views. The perceived importance of treatment and the perceived seriousness of the condition enhanced the prediction of diet level and exercise. More recently Heijmans and de Ridder (1998) used the interview format to assess the structure of the 5 illness representation components in patients with chronic fatigue syndrome (CFS) and Addison's disease (AD). They showed that the representation components merged together differently and produced different factor solutions for the two patient groups: with CFS patients a four factor solution was identified of manageability, seriousness,

---

[4] Researchers examined perceptions of the seriousness of the illness, which is strongly related to Leventhal's consequence component.

personal responsibility and external cause; for AD patients another four factor structure emerged, but with factors of seriousness, cause, chronicity and controllability. Heijmans and de Ridder called for future research to develop from a disease-specific perspective; however doing this would be taking a step away from theoretical integration.

Due to the issues regarding reliability and assessment of interview data, and their time consuming nature, specific questionnaires have been developed. These make testing large numbers of people possible, they allow replication, and allow us to compare across illness populations. The Illness Perception Questionnaire (IPQ: Weinman et al. 1996) and the Implicit Models of Illness Questionnaire (IMIQ: Turk, Rudy and Salovey, 1986) were developed to make the investigation of the representation components easier.

Petrie, Weinman, Sharpe and Buckley (1996) examined the illness representations of 143 myocardial infarction patients via the IPQ, to examine whether the representation components had any relationship with subsequent attendance at a cardiac rehabilitation clinic, return to work, disability and sexual function. They report that the attendance at the rehabilitation course was significantly related to the belief that the illness could be controlled. Participants' causal beliefs were attributed to: (1) stress, (2) lifestyle and (3) heredity; a belief that lifestyle caused the MI was associated with positive changes in personal behaviours. Return to work within six weeks was significantly predicted by the perception that the illness would last a short time and have less serious consequences for the patient. Patients' belief that their heart disease would have serious consequences was significantly related to greater sexual dysfunction at both three and six months.

Edwards et al. (2001) assessed the representations of 173 patients attending a multidisciplinary clinic for CFS to assess the prediction of disability and psychological adjustment. While only consequences and illness identity were significant predictors of fatigue, anxiety and depression were predicted by serious consequence beliefs, illness identity, the emotional causal beliefs and weak control, accounting for 28% and 30% of the variance in depression and anxiety respectively.

Similar findings were produced earlier by Moss-Morris, Petrie and Weinman (1996) who assessed the illness representations of 233 CFS sufferers via the IPQ. They showed that identity demonstrated the most significant associations with dysfunction, vitality and psychological adjustment. The cure/control component was related to vitality, and serious consequences were associated with dysfunction. These researchers also measured the coping behaviours of CFS sufferers and showed that control beliefs were associated positively with positive coping responses such as active coping, planning and reinterpreting the situation, while negative representation components: chronic timeline, strong illness identity and serious consequences, were associated with the more maladaptive coping behaviours such as venting of emotion and disengagement. However, overall, Moss-Morris et al. argue that the coping strategies/behaviours may not be as important as the representation components in predicting overall adjustment.

Moss-Morris et al. (1996) also contributed to the highly contentious debate of attributional cause in CFS. The researchers reported that emotional attributions (e.g. causes such as stress, other people and own behaviour) were negatively related to psychological adjustment but positively associated with vitality. The former association appears rational, in that those who believe that they possibly had something to do with the onset of symptoms may experience more psychological problems. However this belief is also positively associated with vitality (a finding rather rare in CFS research), which is a positive outcome for CFS sufferers. One explanation could be that the psychological causal attribution may contribute to feelings of control over the illness, which are in turn related to vitality. Other research has shown that the more firmly CFS sufferers attribute their symptoms to a disease process (e.g. a virus), the more likely they were to remain functionally impaired (Wilson et al. 1994; Sharpe et al. 1992; Vercoulen et al. 1996; Chalder et al. 1996).

In an effort to understand the role of attributional cause in CFS Moss-Morris and Petrie (1996) asked depressed patients and CFS patients about their illness. Drawing from attributional theories of depression (Abramson, Seligman and Teasdale, 1978) patients were asked to rate the major cause of their illness on four dimensions: locality (how much the cause relates to something about themselves); globality (how much the cause influences other areas of their lives), stability (how likely the cause is to be ongoing) and control (how controllable the cause is). Depressed patients typically make internal, stable, global and uncontrollable attributions for negative events. These attributions have been related to feelings of personal failure and helplessness. The CFS patients reported similarly on all dimensions except locus. Not only were these causal components distinct, they were also stable over time; a 6 month test-retest of illness identity, consequences and cure/control provided reliabilities all greater than 0.7. Moss-Morris and Petrie explain that the external attributional style protects CFS patients' self esteem, but helps promote helplessness and a lack of responsibility for health. While it can be argued that this external attributional style may help to maintain the illness experience Deale, Chalder and Wessely (1998) have shown that these causal attributions do not interfere with improvement in CFS. In their study CFS patients were assigned to cognitive-behavioural therapy (CBT). Although external causal attributions were not challenged, fatigue and disability improved. However, no control group was included in the design. It may be that any psychotherapy would help as it allows sufferers to talk about their pain and problems in a supportive atmosphere. This would need to be repeated with another group in which causal attributions are challenged.

Heijmans (1998) ignored causal attributions and showed that CFS patients who considered their illness to be a serious condition, who believed they had no control over their illness and who saw little possibility for cure, tended to cope with their illness in a passive way. This was related to high levels of impairment in physical and social functioning. CFS patients who reported a stronger illness identity, more pessimistic time-line and limited cure beliefs were more likely to use avoidant coping strategies, and less likely to vent emotions, seek social support and engage in problem focused coping. It may be that the causal attribution is less important than researchers have been led to believe.

Murphy, Dickens, Creed and Bernstein (1999) examined illness perception, and coping in 62 RA patients. Depressed RA patients showed more functional impairment, reported more serious consequences, weak feelings of control and used more negative coping strategies than less depressed patients. When functional impairment is controlled for, there is still a relationship between depression and serious consequences and weak control beliefs, however the relationship with coping becomes non significant showing that the representation components of consequences and control are more powerful predictors than coping. The coping scale used in this study was the Coping with Rheumatoid Arthritis Questionnaire, which may make comparison across illness groups difficult.

Scharloo et al. (1998) examined illness representation and coping in 84 RA patients, 80 psoriasis patients and 80 patients with chronic obstructive pulmonary disease (COPD). They reported that strong illness identity, passive coping, long timeline, and serious consequences were related to poor functioning. Seeking social support and strong control beliefs were related to better functioning. The majority of these patients were followed up one year later, and illness representation components still strongly predicted outcome (Scharloo et al. 2000a; Scharloo et al. 2000b; Scharloo et al. 1999).

Schiaffino, Shawaryn and Blum (1998) conducted one of the first studies to examine the dynamic nature of representations and illness adaptation. Focusing on multiple sclerosis (MS) and rheumatoid arthritis (RA) patients they hypothesised that "an individual's adjustment to chronic illness would be a function of both the symptoms they are experiencing and the representations they hold about the illness. Further, these illness representations should influence one's illness; if one believes RA to be a relatively minor illness without serious consequences but is still in serious pain several months later, the earlier beliefs combined with current health status should result in more negative mood than if the illness course was more consistent with one's beliefs. Therefore it was further hypothesised that "initial illness representations would interact with later illness status to influence later psychological adjustment" (p.263). Cognitive dissonance (Festinger, 1964) has shown that it is reasonable to assume that illness representations will develop and change over the course of the illness, and that this match or mismatch at any point in time between personal experience and personal beliefs could contribute to emotional distress. Schiaffino et al. reported that MS patients' beliefs in symptom variability were associated with higher depressed mood four months later, over and above initial levels of depression. RA patients who saw RA as curable or who saw themselves as responsible for the illness (using the IMIQ) reported significant increases in depression over time. Belief in the serious consequences of RA interacted with later illness severity to predict change in depression. When belief in the serious consequences of RA was high, less severe illness status was associated with less depression and more severe illness status was associated with more depression. When RA was initially viewed as only moderately serious, less severe illness was associated with somewhat higher levels of depression. This study attempted to assess the predictability of illness representations over time and to take account of mediating factors such as mood and symptom progression. However Schiaffino et al. (1998) report that both patient groups had been diagnosed for about three years, which may mean that initial representations have been altered several times over the course of their illness. It would be more informative if newly diagnosed patients were measured over time. Also the authors do not explain why they chose to have a time interval of only four months. It is possible that the representations reported in the time one and two measurements may not be entirely reliable. The only way to clarify these points is to assess these representations over several points in time.

3. Critical Evaluation of the Commonsense Model

As with most models in the health psychology literature, there are limitations, which must be addressed. This section will focus first upon the conceptual limitations before examining the empirical limitations of the commonsense model.

Conceptual Issues

The first conceptual issue to be addressed concerns the theorised role of coping in the commonsense model. Leventhal proposed that the illness representation components are directly related to coping and via coping to outcome (Leventhal, Nerenz and Straus, 1980). However, recent researchers (e.g. Edwards et al. 2001; Moss-Morris, Petrie and Weinman, 1996; Petrie, Weinman, Sharpe and Buckley, 1996; Scharloo et al. 1998; Weinman, Petrie, Moss-Morris and Horne, 1996) have conducted studies where illness perceptions have been assessed independently of coping. More research needs to be conducted to investigate the theorised mediating role of coping.

Secondly, it can be argued that the five representation components proposed -identity, timeline, cause, consequence, cure/control - do not account for all possible representation dimensions. Other undefined illness cognitions may be playing a significant role in making sense of an illness for a particular individual without being accounted for in the commonsense model of illness representation: such as the *distinctiveness* of the illness. The illness may be distinctive to the sufferer for a number of reasons, such as fear of the diagnosis, unfamiliarity of the diagnostic label, embarrassment of symptoms, or the rarity of the diagnosis. The distinctiveness of a particular illness may impact upon the other representations and coping strategies (like seeking out instrumental and emotional support, or feelings of isolation may encourage depression and avoidance coping, such as, denial, the use of alcohol, and disengagement strategies). In relation to the distinctiveness of the illness to the individual, Wills (1981; 1987 cited in Croyle, 1992) proposed that when individuals perceive a threat to their well-being, they are motivated to compare themselves to people who are worse off in order to enhance their own well-being. Taylor (1983) adds that downward comparison seems to be a robust method of self-protection against threat. Thus if the individual is motivated to compare him/herself to others with more serious forms of the illness, this may add new problems for people with a rare, or less well communicated illness.

Thirdly, the representation dimensions have been criticised for conceptual overlap. There are patterns of association between the representation components (e.g. high illness identity and the belief in serious consequences) which may contribute to a loss of predictive power in empirical tests of the model. Heijmans (1998) suggests that the intercorrelations between the representation dimensions can be avoided if they are combined and conceptualised as groups of beliefs or schemata instead of single cognitions. Heijmans examined the illness representations of CFS and AD patients using a semi-structured interview and then subjected the data to factor analysis. Both patient groups produced four-factor solutions, but with different structures. This made comparison between the illness groups extremely difficult, and so Heijmans calls for research to be disease specific. It can be argued that to change the way we collect and analyse these representation components would be taking a backwards step in the investigation of individual adaptation to illness, by making data collection more difficult and time consuming, and making the data less interpretable and generalisable. Also, it could be argued that there is no real problem with this conceptual overlap because there will probably always be patterns of association in people's personal illness models; if not they would probably be contradictory. In addition, Tabachnick and Fidell (1996) recommend that there may be a problem with multicollinearity if associations are .70 and above (p. 86), and most published work reports associations of much lower magnitude.

The final conceptual limitation to be discussed concerns the cure/control component of the illness representation; it is conceptualised and measured as a single component, yet there is a huge difference between being able to control an illness and being able to cure an illness. A person suffering from an acute treatable illness may place less importance upon this component than someone suffering from a chronic, untreatable illness. It is likely that a patient suffering from chronic illness will experience more distress regarding this component than the person with acute illness, who expects to be cured. The health service was constructed to treat acute illness, therefore more advice and help may be given to the acute patient; most individuals with chronic illness are encouraged to devise their own methods to help control their symptoms. Researchers must be aware of this distinction when comparing between patient groups. Also, the cure/control component could be addressing feelings of personal control or treatment efficacy, the IPQ is in the process of revision currently and this is one of the new scales it addresses.

Empirical Issues

Although most researchers would agree that the model makes intuitive sense, there has been a lack of empirical assessment of its theorised features: its iterative nature, the theorised role of coping, its hierarchical structure and the parallel processing of cognition and emotion. Most research studies simply collect cross-sectional illness representation data from different patient populations to find associations between the representation components and outcome measures. Future studies must develop new ways of measuring data pertaining to the commonsense framework if we are to benefit from the commonsense nature of this framework.

The lack of empirical assessment regarding this model could be a result of the lack of direction received from Leventhal regarding how to test the model. Indeed it has been criticised for being more heuristic than algorithmic (Weinman, 1997). If research is to be assimilated into a coherent whole, more guidance regarding the construction and design of studies should be available. When researchers plan to design prospective studies to attempt to investigate the illness representation components over time, they are left to decide upon their own temporal parameters. There has been no research to suggest when the best time is to collect more data from the same individuals. If researchers decide on different time periods between data collection points it will not be possible to simply compare across patient groups. In addition, planning longitudinal studies can create problems regarding the length of time of study, as researchers are left to decide when to end the study. Leventhal et al. (1980; 1984) theorised that patients continue to work through the model until they get back to a state of problem free “normality”, or until some relief is encountered. However, there may be considerable individual differences regarding the length of time people take to achieve positive outcomes with illness; some may never achieve a satisfactory outcome. Much of these empirical problems arise because the model was constructed for acute, common, everyday illnesses such as a cold. Adapting the model to fit chronic illness needs to be reviewed. However, although there is no definite end point for chronic illness, Moss-Morris (1997) reports that the CFS patients in her study had relatively stable representation dimensions over time, which correlated with the continued experience of symptoms.

The lack of empirical assessment of the parallel processing of cognitive (objective) and emotional (subjective) representations is surprising. While at the theoretical level the subjective representation of the illness is as important as the objective representation, there has been an exclusive focus on the objective representation of illness. Researchers have so far ignored the role of the emotional representation of illness; it is not known how or if the subjective representation exerts an influence on the choice of coping procedure. In addition, it is also likely that person and situation variables interact and possibly moderate the effect of the subjective representation upon the choice of coping behaviour. Although most studies investigating the commonsense model include measures of affective state such as anxiety and depression, they often feature them as outcome measures of psychological adjustment to the illness. Research needs to be targeted at how and what emotional representations are involved in a wide variety of illnesses. It is likely that feelings such as fear, shame, worry and despair are evident in some illnesses more than others, and that these feelings arise from both the concrete and abstract levels of the identity component, however research needs to develop these components directly from patients themselves.

The final empirical limitation to be discussed regards the measurement of coping, which was addressed earlier in this chapter. The theoretical model was constructed so that problem focused coping mediates the relationship between objective representation and outcome: emotion focused coping mediates the link between the subjective representation and outcome. What may be theorised as emotionally based coping responses such as expressing distress, calling for assistance or manipulating the social environment, may be adopted in a problem focused style. Researchers, then, are left to decide how to measure coping. The lack of direction regarding measurement ensures that research studies will use heterogeneous measures, limiting comparisons between them.

Summary

It has been shown that illness representations and the commonsense model have a lot to offer in the understanding of patients' views of their illness. Representation components have been shown to predict coping and outcome in a variety of illnesses. However, if the commonsense model is to thrive in the future, then more uniform prospective analysis should be carried out within and between different illness populations and samples.

This thesis assesses the illness representations, coping behaviours and outcome (measures of quality of life and psychological adjustment) in IBS patients. IBS patients were selected for study because of the lack of attention they have received in the health psychology literature, despite the reported efficacy of psychological treatments such as cognitive-behavioural therapy (Toner, et al. 1998). Chapter 2 examines the issues surrounding IBS, introduces the questions to be examined by this research, and introduces the four research studies.

Chapter 2
An Examination of the Irritable Bowel Syndrome

As reported in Chapter 1, the population to be examined using the commonsense model in this research is irritable bowel syndrome (IBS). IBS was chosen to be the main focus of this research for three reasons: (1) the majority of the research conducted using the commonsense model has focused upon organic illness, and IBS is a functional illness; (2) the psychological research focused upon IBS lacks a sound theoretical basis; and (3) gastroenterologists increasingly cite the importance of the "Brain-Gut Link". If cognition is influencing, and being influenced by, symptom experience in GI illness, then examining the illness representation of IBS sufferers may foster more effective psychological treatments.

Functional Illness

There are many functional, or *psychosomatic* conditions, which are diagnosed today: IBS, Chronic Fatigue Syndrome (CFS), fibromyalgia, chronic headache, premenstrual syndrome and chronic pain are some of the most prevalent. The term "*functional*" will be used throughout this thesis, because it is neutral regarding the role of psychosocial factors. *"Functional simply means that the bowel is not diseased in any way and looks perfectly normal, but for some reason it functions abnormally"* (Howard, 1998). *Psychosomatic* is a pejorative term: it was coined to refer to symptoms or illnesses that are caused or aggravated by psychological factors, mainly emotional distress (Lipowski, 1986).

Functional illnesses have historically been referred to as "diagnoses of exclusion" as they were often only given once organic, observable illness was ruled out (usually after various medical investigations). Now, due to the high prevalence of functional illness, physicians are encouraged to diagnose patients on the presence of symptoms alone. The IBS diagnostic criteria will be discussed further later (p.47-9).

The lack of objective, physical markers in these illnesses has led some to believe that functional illness is of less importance than organic, observable illness. The medical model, which advanced science over the last 300 years, has not helped to counter this view. Its major premise is that any illness can be reduced to a single cause, and that identifying and modifying the causal agent will explain the cause and ultimately produce a cure. The medical model promotes the dualistic Cartesian view that the illness is either organic (i.e. there is objectively defined pathology) or it is functional (i.e. there is no specifically identifiable pathology). This dualism forces a distinction between medical and psychological illness. However the medical model fails: organic illness is affected by psychosocial factors and psychosocial factors have been shown to influence outcome in both organic and functional illness.

Due to shortcomings in the medical model, the biopsychosocial model was developed (Engel, 1977) which proposes that illness is experienced via the interplay of biological, psychological and social mechanisms. However while the model is accepted theoretically, there is still some way to go before the model will be accepted by all in the medical profession; the idea that illness cannot exist without an organic, biological basis is still observed. This view is unlikely to change quickly as medical students (in the west) are still reared in the biomedical tradition of the detection of disease and then treatment of the disease; the more psychosocial aspects of illness are often left as subsidiary modules for interested students.

This refusal to accept the biomedical model can create conflict between doctors and patients. After a battery of GI investigations have been employed, all revealing no evidence of disease, GP's and gastroenterologists may appear (or may be reported to be) abrupt and insensitive (Sarafino, 1994). Some may feel that functional patients are perfectly healthy, and simply wasting time and health service funds, removing care from people with serious GI disease. A survey was conducted with 148 members of an IBS self-help group and 25% reported that their physicians did not understand their problems. Furthermore, it was reported that GP's laughed, were patronising, or implied that the patients were neurotic (Dancey and

Backhouse, 1993). Another survey focussing on the GP perception also supports this view. Of a sample of GPs, 76% agreed that IBS patients fit a particular profile - professional women under the age of 35, described as neurotic, tense, anxious worriers who are likely to have money and/or relationship problems (Letson and Dancey, 1996) - yet there is no evidence to support this view. Other practitioners, who may be sympathetic to the functional patient, can offer little in the way of treatment. The patient on the other hand has the worry that serious organic disease was missed in the tests, since they are so aware of their symptoms.

These factors make functional illness distinct from organic illness and therefore worthy of further research. It is important to examine the illness representations of people with functional illness to examine whether their personal models are predictive of outcome as has been shown with patients of organic illnesses (e.g. diabetes, rheumatoid arthritis and multiple sclerosis, Hampson, 1997; Schiaffino et al. 1998). As reported in Chapter One, Weinman et al. (1996) examined the illness cognitions of CFS sufferers and found them to be predictive of outcome; however to date this is the only functional illness to be examined using the commonsense framework.

Previous IBS Research

Gastroenterologists have carried out the majority of the research into IBS. In the 1980's, many gastroenterologists conducted studies by administering personality inventories in an effort to identify "the IBS personality"(e.g. Whitehead et al. 1988). Research of this nature failed to find a specific "personality type", but did report high psychiatric comorbidity in IBS patients compared to organic GI patients and healthy controls (Camilleri and Choi, 1997). This led researchers to debate whether the high levels of anxiety and depression were a cause or a consequence of IBS. A satisfactory conclusion to this debate has yet to be reached, although psychological treatments that have focused on reducing anxiety and depression have helped reduce the number of symptoms experienced (e.g. Blanchard et al. 1992; Whorwell et al. 1987; Guthrie et al. 1993), providing further evidence of a link between GI symptoms and psychiatric symptoms, regardless of causality.

Only recently have psychologists (e.g. Stenner et al. 2000; van Dulmen et al. 1994; 1995; 1996a; 1996b; 1997; 1998; Dancey and Backhouse, 1997) started to examine IBS from a psychological perspective. The research into IBS has shown that IBS patients have very different ideas concerning the cause of their symptoms (Stenner et al. 2000); that IBS patients are more worried about their illness than organic GI patients (Gomborone et al. 1995); and also that if physicians address the concerns (e.g. cancer worry) of IBS patients in the diagnostic consultation, the patients were more satisfied with their diagnosis, and were less likely to return for further consultations (van Dulmen et al. 1996a; 1997; 1998). However, research of this nature is scant and disjointed, and while replication should be encouraged, theory driven research is probably of more use if we are to understand the cognition of IBS patients.

The "Brain-Gut Link"

The hypothesised "Brain-Gut Link" proposes that cognition and emotion are ultimately linked to gut function in a bidirectional manner. While the interaction between stress and GI function has peppered the literature for centuries (Wolf, 1981; Cannon, 1902) and is supported by clinical observations (Young et al. 1987; Anderson et al. 1989; Rao et al. 1998), it is only in the last couple of years that evidence of this link has started to be uncovered.

The digestive system is unique in that it is controlled by the brain and also by its own nervous system: the enteric nervous system (ENS). The ENS is located in the lining of the oesophagus, stomach, small intestine and colon. The GI tract and the brain develop from the same part of the embryo, and as a result they have many similar nerve endings and neurotransmitters. There is a complex circuit that enables the "two brains" to act independently, and interdependently to remember, learn, and produce gut feelings (Salt, 1997). Researchers have named the circuit the brain-gut link, or brain-gut axis.

Unfortunately, technology has not yet advanced so far that we can directly study this brain-gut link. Researchers instead have focused on brain and gut stimulation and imaging techniques in an attempt to understand the mechanisms better. Research of this nature has increased understanding about the bilateral organisation of gut function: while one cerebral hemisphere is usually more dominant than the other, the non dominant hemisphere can recover and be taught to relearn gut function if the dominant hemisphere is damaged (as in stroke), (Aziz et al. 1996; Hamdy et al. 1994; Turnbull et al. 1994). While reflexes from the autonomic nervous system primarily control gut motor activity, cortical activity can also play a significant role (Ringel and Drossman, 1999).

Functional brain imaging such as positron emission tomography (PET) and functional magnetic brain imaging (fMRI) are able to measure (quite accurately) regional changes in cerebral blood flow. Experimental brain imaging using PET or fMRI has demonstrated specific changes in brain activity in response to various visceral stimuli (Ringel and Drossman, 1999). Recent studies have shown that PET and/or fMRI can differentiate IBS patients from healthy subjects. When compared with normals, IBS patients respond to painful rectal distension (usually measured by balloon inflation in the rectum) with greater activation of the thalamus (Mertz et al. 1998) and the left prefrontal cortex (Silverman et al. 1997). Also perhaps most interestingly of all, IBS patients fail to activate an area of the central nervous system (CNS) called the anterior cingulated cortex (ACC) that is activated by balloon distension in normals (Silverman et al. 1997). Dysfunction of the ACC has been found in depressive disorders in hospitalised patients (Mayberg et al. 1997; George et al. 1993). Using pre-treatment PET imaging, Mayberg et al. showed a significant increase in ACC activity in patients who later responded to antidepressant treatment compared to those who did not respond to treatment. They further suggested that ACC hyperactivity may represent an important adaptive response to depression, and failure to achieve this response may predict poor outcome in antidepressant therapy. The ACC is activated in response to moderate or intense pain stimuli, and is involved in determining the affective perception of gut sensation. For whatever reason, this lack of activation of the ACC represents accumulating evidence of the role of the brain in the perception of symptoms (Ringel and Drossman, 1999). "It also supports the importance of psychological factors, which, by their effects on affective and cognitive centres in the brain, can also influence gut (sensory and motor) physiology as well as patients' symptom perception and illness behaviour" (Ringel and Drossman, 1999, p.208). It seems increasingly likely that claims of a link between symptoms, cognition and emotion will become stronger with new evidence.

Having now established IBS as an illness worthy of investigation using the commonsense framework, I intend to spend the remaining part of the chapter describing and discussing specific issues unique to the IBS experience. Firstly I will discuss the issues surrounding the prevalence, diagnosis, prognosis and treatment of IBS. Secondly, I will explore medical theories of hypersensitivity and abuse history (incorporating the "Brain-Gut Link") as possible explanations for the presentation of IBS. Thirdly, I will examine recent psychological research into IBS cognition, and explore the most investigated representation component: causal attribution. Here I will consider the role of stress in IBS as a causal and/or maintaining factor, and I will briefly examine the problems concerning the measurement of stress. This chapter will conclude by re-stating the main objectives of this research.

Irritable Bowel Syndrome:
Prevalence, Diagnosis, Prognosis and Treatment

Prevalence of IBS: Consulters and non consulters

Community surveys estimate that between 15 and 25% of the general population fulfil diagnostic criteria for IBS (Jones and Lydeard, 1992; Camilleri and Choi, 1997). This variation in prevalence estimates has been suggested to be a result of using different symptom criteria. IBS in the community (as well as in consulting patients) is more common in women: female to male ratio 2.2:1 (Kennedy and Jones, 1998). However, this dominance of female IBS patients is not mirrored in Eastern or African societies (Jeong et al. 1993; Kapoor et al. 1985; Segal and Walker; 1984; Danivat et al. 1988). Researchers have argued that this is unlikely to be an epidemiological finding, rather an artefact of consultation behaviour determined by society.

Reasons for seeking medical care include symptom severity, fear about serious illness, disability, or psychosocial factors. In the UK, approximately 30% of those people experiencing IB symptoms consult health professionals for help (Jones and Lydeard, 1992). Of those who enter primary care, an even smaller percentage is referred on to the gastroenterologist, yet functional GI illnesses (of which IBS is a leading diagnosis) account for approximately 50% of the gastroenterologist's time (Drossman et al. 1988).

Most of the research carried out into IBS has recruited patients from secondary care, however these patients have been shown to be unrepresentative of the majority of IBS patients, as differences have been shown in symptom severity and disability experienced, psychiatric comorbidity and fears about serious illness. There are several studies comparing consulters and nonconsulters (Heaton et al. 1992; Drossman et al. 1988; Kettell et al. 1992; Talley et al. 1991; van der Horst et al. 1997; Talley et al. 1997). They demonstrate that severity of pain and bloating is more severe in consulters (Kettell, Jones and Lydeard, 1992; Whitehead et al. 1988; Lydeard and Jones, 1989; Talley et al. 1997). Heaton et al. (1991; 1992) report a linear relationship between the number of IBS symptoms and the consulting rate. Consulters show higher anxiety (Heaton et al. 1992) and depression scores (Drossman et al. 1988; Talley et al. 1990). In contrast IBS nonpatients have a similar number of psychiatric diagnoses to the general population (Whitehead et al. 1988). In addition to experiencing more anxiety and depression than controls, consulting IBS patients have been reported as significantly more likely to have experienced recent adverse life events than non consulters (e.g. Creed et al. 1988). In addition, the degree of worry about the symptoms, such as believing that they may represent undetected cancer, is higher in consulters than non consulters (Drossman et al. 1988; Kettell et al. 1992; Van der Horst et al. 1997), as is hypochondriasis (Drossman et al. 1988).

Diagnosing IBS

There are many investigations and tests available to the gastroenterologist to rule out organic disease. However in the case of the IBS patient, the discomfort (and often embarrassment) associated with most GI investigations produces little reassurance, as the tests will show no sign of disease. Often the very process of the test increases anxiety about the possible cause of the symptoms, and receiving a negative diagnosis does little to help.

Gastroenterologists suggest that a positive diagnosis based on symptom criteria should be given. "Care should be taken to avoid unnecessary investigations that are costly and harmful" (Schmulson and Chang, 1999, p.21S). Dialogue between patient and practitioner, examination of the abdomen, and a positive diagnosis are encouraged in an effort to reassure the patient (Thompson, 1984). While the diagnosis of IBS based on symptoms alone may seem a little cursory, follow-up studies extending up to 9 years after an IBS diagnosis based on symptom criteria and limited diagnostic evaluations have found that fewer than 5% of patients had other explanations for their symptoms (Vanner, et al. 1997; Svendsen, et al. 1985).

Three symptom criteria have been developed to help clinicians to make a positive diagnosis of IBS. In 1978, a gastroenterologist named Manning created the "Manning Criteria" (Manning et al. 1978). Manning et al. stated that a diagnosis of IBS could be given if a patient presents with three or more of the criteria presented below.

Table 1 The Manning Criteria

THE MANNING CRITERIA
Pain relieved by defecation
Looser stools at the onset of pain
More frequent bowel movements at onset of pain
Abdominal distension (visible)
Mucus per rectum
Feeling of incomplete rectal emptying

Several studies have attempted to validate the Manning criteria (e.g. Rao et al. 1993; Talley et al. 1990; Thompson, 1984) and most have found that they can discriminate between IBS and organic upper GI tract disease, but less so with organic diseases of the large intestine. This should not be interpreted to mean that the symptoms making up the criteria for IBS are invalid, rather that they are not specific to IBS, since there is a limit to the repertoire of GI symptoms (Hammer and Talley, 1999). However, more serious symptoms such as passing blood or weight loss are indicative of organic GI disease (such as ulcerative colitis, Crohn's disease, or cancer) and are not included in any of the IBS criteria.

Since the Manning criteria were introduced, three working groups have been formed in an effort to update them. Since these working groups met in Rome, they have been named the Rome I and Rome II criteria for IBS (the third working group attempted to classify all functional GI disorders; for a detailed review of those criteria see Hammer and Talley, 1999). The criteria have become more stringent and conservative with each revision.

The Rome I criteria recommend the diagnosis of IBS in the presence of one of the main criteria and two or more of the supportive criteria. In contrast, Rome II recommends that the diagnosis be based on the presence of 2 of the 3 main diagnostic criteria alone; the supportive criteria may then be used to further classify IBS into diarrhoea or constipation predominant. The new conservative criteria have been criticised for insisting that abdominal pain is required for diagnosis; whether IBS can exist in the absence of abdominal pain is unresolved (Hammer and Talley, 1999).

Table 2 The Rome Criteria

THE ROME CRITERIA
Abdominal pain or discomfort plus altered defecation
Abdominal pain or discomfort relieved by defecation
Abdominal pain associated with a change in the frequency or consistency of stool
Altered stool frequency
Altered stool passage
Passage of mucus
Bloating and visible distension

NB. The main criteria are in bold; the supportive criteria are presented below in italics

The new criteria are deliberately conservative in an effort to reduce heterogeneity in pharmaceutical research studies. Heterogeneity of symptoms is an important confound in the randomised controlled trials of new drugs, but for the purposes of the research reported in this thesis, the Manning criteria were thought acceptable, for two reasons. First, most physicians and GP's are less stringent than the Rome II criteria when diagnosing patients in their surgeries, and second, since the majority of patients recruited for this research have been diagnosed with IBS for over five years, it is likely that GP's will have based their diagnosis on the Manning criteria alone.

Prognosis of IBS

Both the symptoms experienced and the severity of IBS symptoms are often reported to be quite changeable. Agreus et al. (1995) applied repeated measures to a stable population in Sweden, and observed that participants report different predominant functional GI symptoms over time and move between different functional diagnostic groups. Fowlie et al. (1992) followed up patients with IBS over 5 years. While a majority of the sample improved, it was concluded that outcome was not associated with age, symptom duration, or any of the bowel symptoms measured at initial assessment. Patients whose symptoms were unchanged or worse at follow-up had higher anxiety scores at baseline than the improved group. These scores remained high at follow-up. The authors suggested that persistent high anxiety is the key factor that identifies those who have IBS with symptoms that do not respond over time.

While many patients report recurrent functional abdominal symptoms dating back to childhood and teenage years, others report the first appearance of symptoms in later life. Lembo et al. (1996) argue that IBS patients with short symptom duration (less than 2 years from onset), and with fewer psychological symptoms have a better prognosis than patients with a long history of IBS (5+ years) and associated psychological distress. The short-term group had significantly lower scores for anxiety, hostility, illness phobia and paranoia than the long-term group, however the two groups showed similar degrees of rectal hypersensitivity. These results are in agreement with previous reports demonstrating that measures of neuroticism are not correlated with rectal hypersensitivity. However, there are several ways in which neuroticism and psychological symptom severity could influence self reports of symptom severity and duration. First, the distress from decades of abdominal symptoms could generate secondary neuroticism and amplify psychological symptoms, whereas shorter duration of symptoms should not have such an effect. Alternatively, the presence of significant psychological distress could influence the chronicity of IBS symptoms in predisposed individuals and motivate them to seek care. While the experience of IBS is unique to each sufferer, it seems likely that those people who have experienced both IBS symptoms and associated psychological distress for many years will have a poorer outcome than those who have not.

Treatment of IBS

Between 5 and 8% of people are unemployed due to IBS symptoms (Dancey and Backhouse, 1997; Rees et al. 1994) and it costs the UK NHS millions of pounds each year for physician visits, prescriptions, investigations, and patients' loss of productivity (Talley et al. 1995b). Due to the high prevalence of IBS and the significant costs to society and the NHS, pharmaceutical industries have attempted to define and "cure" IBS, but to no avail. The pharmacological treatment of IBS is limited to treating the specific GI symptoms (i.e. antidiarrhoeals for diarrhoea, antispasmodics for the treatment of abdominal pain, laxatives for constipation). Although some clinicians have prescribed antidepressants, which have shown some improvement in some IBS sufferers, the approach is controversial and is often discouraged by working parties examining IBS treatments.

Research examining psychological treatments of IBS, such as cognitive behavioural therapy (CBT) (Blanchard et al. 1992), psychotherapy (Guthrie et al. 1991; 1993) and/or hypnotherapy (Houghton, Heyman and Whorwell, 1996; Whorwell et al. 1987); have shown that they are superior to any specific drug treatments currently available. In a review of studies examining the CB treatment of IBS, Toner et al. (1998) reported 10 controlled studies over the past 12 years (Bennett and Wilkinson, 1985; Blanchard and Schwarz, Neff and Gerardi, 1981; Corney, Stanton, Newell, Clare and Fairclough, 1991; Greene and Blanchard, 1995; Lynch and Zamble, 1989; Neff and Blanchard, 1987; Payne and Blanchard, 1996; Rumsey, 1991; Shaw et al. 1991; van Dulmen, Fennis and Bleijenberg, 1996b). Most of the studies used a multicomponent behavioural or cognitive behavioural treatment package. The packages have used various combinations of cognitive therapy, relaxation techniques, educational components and stress management training. In general the results support the efficacy of CB techniques: three studies report improvement in GI symptoms and psychological distress (Bennett and Wilkinson, 1985; Lynch and Zamble, 1989; Neff and Blanchard, 1987). Furthermore, three studies reported a similar improvement (Bennett and Wilkinson, 1985), or even superior improvement (Corney et al. 1991; Shaw et al. 1991) to antispasmodics and / or bulking agents. Van Dulmen et al. (1996b) found improvement in abdominal symptoms, coping strategies and avoidance behaviour. Greene and Blanchard (1994) found a significant improvement in IBS symptoms, depression and anxiety when compared to cognitive therapy alone. Long term improvement was cited in two studies (Neff and Blanchard, 1987; van Dulmen et al. 1996b).

Guthrie et al. (1993; 1991) conducted psychotherapy with IBS patients. Those who improved had greater social support, fewer psychiatric symptoms, less illness worry (hypochondriacal beliefs), and a psychological (as opposed to somatic) attribution. Also, hypnotherapy aimed at reducing stress has been shown to be effective in some patients (e.g. Whorwell et al. 1987).

Although it is rare for IBS sufferers to be offered psychological treatment under the NHS in the UK (Dancey et al. 1998), the recent surge of interest in complementary and alternative medicines as cost-effective treatments may mean that psychological treatments may be incorporated as successful NHS treatment in the future. There are no immediate plans, however.

Hypersensitivity and hyperarousal in IBS

Fight / Flight Response

William James (1884) saw the psychological experience of emotion as our conscious perception of physiological changes (Evans, 2000): we are afraid because we run, rather than we run because we are afraid. Walter Cannon (1914; 1927) followed James' reasoning. Like James he believed physiological processes were at the heart of emotional phenomena, but he argued that feedback from the peripheral autonomic nervous system would be too slow and too general across the different emotional states. Cannon introduced the concept of the fight or flight response, which he described as an adaptive autonomic response to threat by preparing the organism to attack the threat or to flee. This idea was expanded by Hans Selye who proposed that the fight/flight response is only the first in a series of reactions the body makes when stress is long lasting (Seyle, 1956; 1976). He named the series the General Adaptation Syndrome (GAS). He proposed that when threat is encountered, the organism is initially thrown out of balance, lacking the energy and resources to meet the challenge (which he labelled shock). The body then mobilises rapidly to encounter the shock (hyperarousal) and resistance increases as the body tries to adapt to the stressor (e.g. by releasing stress hormones such as cortisol and norepinephrine, which act upon the body). Seyle reports that one outcome of this impairment is that the organism becomes increasingly vulnerable to health problems, including "diseases of adaptation" e.g. ulcers, high blood pressure, asthma. As time goes by, if the challenge or threat is still present, or is not successfully met, the organism passes into the stage of exhaustion, which could ultimately lead to death. Although the GAS may seem a little simplistic in its description, its basic structure is supported by research, it has been argued (Sarafino, 1994, p.81).

Hyperarousal and Sensitisation

As reported above, chronic hyperarousal is an abnormal state of activation that occurs in the wake of highly stressful or traumatic events. The normal stress response is adaptive, but becomes a problem when the stressor is extreme, flooding the system with stress hormones (Kendall-Tackett, 2000). It has been proposed that chronic hyperarousal may also alter such brain structures as the hippocampus and the anterior cingulated cortex (ACC), after exposure to abnormal levels of stress hormones (e.g. Bremner, 1999).

McCarty and Gold (1996) argue that hyperarousal can make victims of past traumatic events more vulnerable to current life stress through a process called sensitisation. Here the brain has become threat-sensitised (i.e. the body remembers the traumatic event and over-reacts when faced with a new stressor) (Schwarz and Perry, 1994). This is relevant here because hypersensitivity of visceral stimuli is frequently reported in IBS patients.

Hypersensitivity and GI Function

Research on gastric distension by inflating balloons at different sites in the GI tract has shown that participants with functional GI disorders are more sensitive to experimental stimulation than are healthy participants (Coffin et al. 1994; Mearin et al. 1991). They have also been shown to perceive greater discomfort at lower stimulation levels than their healthy counterparts (Cheng et al. 2000). This suggests that they may be in some way predisposed by a monitoring perceptual style[1], which may influence not only their appraisals of their health but also their anxiety levels (Cheng et al. 2000).

Cheng Hui and Lam (2000) asked IBS patients to respond to a number of controllable and uncontrollable threats. They concluded that IBS patients with the lowest anxiety and depression levels tended to engage more action-orientated strategies in controllable situations, but more emotion-focussed in uncontrollable situations. In contrast, those who experienced the highest anxiety and depression levels were those who consistently deployed action-oriented coping regardless of the controllability of the situation. Cheng, et al. (2000) conclude that functional GI patients have more of a monitoring perceptual style, and engage in less blunting, and also that they adopt a non-discriminatory action-oriented coping pattern, regardless of the controllability of the stressful event, more than do healthy controls and rheumatic patients. A possible interpretation is that the monitoring perceptual style and non-discriminatory action-oriented coping pattern may influence symptom severity. Also, a study on gastric motor functioning (Bennett et al. 1992) showed that participants with functional GI disorders who adopted a fighting spirit when encountering stressful events reported prolonged gastric motor dysfunctions. These results suggest two possible explanations: first their non-discriminatory usage of action-oriented coping to “fight” the stressors leads to a greater severity of functional GI symptoms and higher anxiety (Cheng et al. 2000); alternatively, that functional GI symptoms may influence one's perceptual style and coping behaviours. Individuals with these disorders often suffer severe symptoms, but are left untreated by medical professionals, receiving limited medical explanations and treatment. They may seek alternative ways to relieve their unpredictable and distressing somatic symptoms, such as by paying close attention to their body and adopting inappropriate action-oriented coping (when they have little control over the situation).

---

[1] Monitoring and blunting are "cognitive informational styles" (Miller, 1989), the former referring to the tendency to focus one's attention on threatening signals, the latter away from threat related cues.

Abuse History and Sensitisation

IBS patients are more likely to report a history of threatened sex, incest, forced intercourse and frequent physical abuse than patients with organic GI illness (Drossman et al. 1990). Also, female IBS patients with a history of abuse report more psychological distress, poorer daily function, more frequent physician visits and more surgery than those patients who were not abused (Drossman et al. 1996). Drossman et al. (1990; 1996) suggest that sexual abuse may be specifically associated with functional GI disorders via sensitisation.

The sensitisation hypothesis is supported by the fact that more severe sexual acts have been shown to be associated with more severe GI symptoms (Drossman et al. 1990; Leserman et al. 1996; Walker et al. 1993). Life threatening physical abuse and rape led to more severe symptoms than less severe physical or sexual abuse (Leserman et al. 1996). An additive effect was also apparent, in that those who experienced all three types of abuse (physical, sexual and emotional) had the highest odds ratios for IBS symptoms (Talley et al. 1995a).

According to Leserman et al. (1996) women with a history of sexual abuse had more pain, overall somatic complaints, bed disability days, surgeries, psychological distress, and functional disability than those who were not sexually abused. Physically abused women displayed the worst outcome, and patients whose abuse first occurred in adulthood displayed worse health outcomes than those whose first abuse took place in their childhood. Bremner et al. (1997) argue that this could be attributed to neural plasticity, where parts of the brain take over the functions normally performed by damaged sections. Symptoms may be more pronounced if the abuse takes place at a later age because the brain is not as able to have other sections take over for the damaged portion.

While the sensitisation hypothesis looks attractive, we must be careful in labelling IBS patients as victims of abuse: there will be many sufferers who have, and many sufferers who have not been abused. Also, we must refrain from the belief that all victims of abuse will experience IBS, since the human response to chronic stress is diverse and varied (Kendall-Tackett, 2000). However, it seems increasingly likely that hyperarousal and sensitivity will continue to be implicated in the experience of IBS. Since psychological therapy such as cognitive behavioural therapy (CBT) has shown some success in treating IBS patients, researchers have started to focus on patient cognition.

Empirical Examination of IBS Cognition

Previous research (e.g. Gomborne et al. 1995; Drossman et al. 1988) has revealed that individuals with functional GI disorders have more negative perceptions of themselves and their illness than healthy individuals and those with organic GI disorders. Drossman et al. (1997) showed that those IBS patients who scored higher on a catastrophising scale, and who reported a low ability to control symptoms, perceived a poor health outcome. Gomborone et al. (1995) examined the illness attitudes of IBS patients, and in an effort to control for depression and GI symptoms, investigated the illness attitudes of IBS, IBD (patients with ulcerative colitis and crohn's disease: organic GI disorders), depressed patients and healthy controls. On measures of depression the IBD group did not differ significantly from the healthy controls, but the IBS group scored significantly higher than these two groups. As expected, the depressed patients scored significantly higher than all groups for depression. On illness attitudes measures, both the IBS and depressed group scored significantly higher than the IBD and healthy group on subscales of the negative effects of symptoms, worry about the illness and death phobia. Also the IBS group scored higher than all groups on hypochondriacal beliefs, disease phobia and bodily preoccupation, (while no correlation was found between the scores on these three subscales and the degree of depression). This study shows that for hypochondriacal beliefs, disease phobia and bodily preoccupation, the attitudes of IBS patients are distinct from those of organic bowel disease patients and depressed patients. Thus, it is unlikely that these elevated scores are a consequence of having either GI symptoms or associated depression. Drossman et al. (1988) have also shown that IBS patients score higher than normal patients on hypochondriasis. However, it could be argued that as both the Gomborone and Drossman studies were carried out on secondary care patients, the beliefs of these patients are unrepresentative of IBS patients as a whole. As clinic attenders, it is likely that they have experienced a series of GI investigations. The experience of troublesome symptoms and lengthy investigations may contribute to the idea that serious illness may have been missed, thus leading to bodily preoccupation and the detection of further symptoms. Studies of this nature should be replicated with different populations of IBS sufferers.

Studies conducted in the Netherlands have shown that the disease focus displayed by IBS patients can be challenged in the GP surgery. Van Dulmen and colleagues have shown that if doctors actively challenge the IBS patient's unsupported illness beliefs that his/her illness has a physical cause and address possible cancer worries, anxiety, fear of cancer and catastrophising are significantly reduced in the next out-patient visit (Van Dulmen et al. 1994; 1995; 1996a; 1997; 1998). These changes have also been related to a reduction in future use of medical services (Van Dulmen et al. 1996a), thus indicating the importance of illness cognition in the utilisation of health services.

One of the most frequently investigated illness beliefs in functional illness is causal attribution. As reported earlier, little is known about the causal factors involved in functional illness, however sufferers will often try to make sense of their illness (i.e. constructing a representation of their illness) often with the causal attribution at the heart of the representation. Brown and Williams (1995) demonstrated that the "search for meaning" within the context of uncertainty regarding symptoms was of great importance to women with rheumatoid arthritis. Osborn and Smith (1998) conducted a qualitative analysis of interview transcripts of chronic low back pain patients, and identified four themes, the most important being "searching for an explanation". Also, in Chapter One, I reported how the causal attribution has been implicated in the levels of functioning of CFS patients. It has been shown that the more firmly CFS sufferers attributed their symptoms to an external cause, the more functionally impaired they were in the future (Wilson et al. 1994; Sharpe et al. 1992; Vercoulen et al. 1996; Chalder et al. 1996).

Stress and IBS

The idea of a relationship between stress and GI symptoms is widely believed by clinicians, patients and the general public. In a survey conducted with members of a self-help organisation, 72% of participants reported that stress made their IBS symptoms worse (Dancey and Backhouse, 1993), and a high proportion described themselves as worriers (Dancey and Backhouse, 1997, p. 85). Van der Horst et al. (1997) reported that those IBS patients who attribute their symptoms at least in part to stress have a better outcome than those who attribute it to a physical intestinal disorder. It could be argued that IBS patients who implicate stress (to some degree) in their experience of symptoms may be taking some responsibility, and thus may experience feelings of control over their illness, which may be contributing to a favourable outcome.

While the term "stress" is often used in the health psychology literature, it may not always be clear what the term means. Lazarus and Folkman (1984) developed the most common definition of stress used by researchers today. They suggest that stress occurs only when the imposed demands of a situation are perceived to exceed the individual's resources to cope with the demand. Therefore stress is seen as a result of a transaction between the individual and the environment. However for researchers studying this transaction, there is some confusion over whether stress should be thought of as a stimulus or response. While the former position has received much attention from researchers, such as life event research (e.g. Creed et al. 1988) and daily hassles research (e.g. Dancey et al. 1998), the latter view has been relatively ignored. Yet, some sufferers have described their IBS symptoms as the only stressful part of their lives (Dancey and Backhouse, 1993).

Even though some studies have failed to demonstrate an association (Drossman et al. 1988; Talley et al. 1997), stressful life events are often implicated in the onset of IBS symptoms. Research has found that IBS patients are likely to report that the onset of pain is a result of a stressful life experience (Creed et al. 1988; Whitehead et al. 1992). When asked directly, more than 50% of IBS patients reported the first onset or the exacerbation of chronic symptoms in association with stressful life events (Ford et al. 1987), and most researchers find that IBS patients score higher than controls on stressful life event scales, even after controlling for neuroticism (Mendeloff et al. 1964; Whitehead et al. 1992). However, researchers investigating the link between stress and symptoms have often used retrospective accounts by sufferers. Such studies are fraught with difficulties as people have a tendency to look back to identify a cause that can explain their illness (Brown, 1984), and if asked, most people can identify stressful episodes in retrospect. Whitehead (1996) explains that stress accounts for only 10% approximately, of the variance in bowel symptoms, which is less than would be expected given the frequency with which patients attribute their symptoms to stress. Whitehead states "this finding suggests that people exaggerate the importance of stress in an effort after meaning (i.e. a tendency to dismiss inexplicable events and to focus on those that seem to have a recognisable cause)"p.28. This is supported further by Jenkins, Hurst and Rose (1979) who showed that recall for stressful life events occurring more than three months previously was so inaccurate as to be useless. They explain that effects of poor recall were compounded by the tendency for subjects to search for explanations for their physical symptoms and to fall back on the popular belief that stress could be the cause.

Current researchers, who understand the difficulties of retrospective accounts and the low frequency of "life events", have started to examine the relationship between stress and symptoms quite differently. These researchers have tried to overcome the problems associated with retrospective reports by designing prospective studies using sophisticated time-series analyses. Dancey et al. (1995) found that the relationship between stress and symptomatology was strongest on the same day, but their study was criticised for using a between-participants approach which ignores individual differences. Suls, Wan and Blanchard, (1994) argue that because of the large individual differences in chronic levels of stress and symptoms individual differences should be removed before any estimation of the relationship.

Dancey et al. (1998) refined the previous study and conducted a 28-day within-participants study of stress and symptoms with IBS sufferers. They found that the best regression model was one in which symptoms were a function of hassles and symptoms on the previous 2 days, and hassles on the same day for 67% of sufferers. However, Suls et al. (1994) studied 44 IBS patients over 21 days using different time-series strategies and concluded that prior or concurrent daily stress had no consistent effects. The contradiction between these two studies has been attributed to the fact that Suls et al. recruited participants from a clinical population, while Dancey et al. recruited from a self help group who had previously expressed an interest in research. A criticism of the time series approach is that symptom reports and hassles are completed daily for approximately a month. The time commitment in this kind of study warrants questions regarding the motivation of participants and social desirability. Research of this nature needs further replication before any firm conclusions can be drawn.

Although it is thought likely that stress exacerbates symptoms, the opposite association (that an increase in the severity of the symptoms can influence the perception of stress) is seldom considered. Dancey et al. (1998) showed that for more than a third of their participants, an increase in the severity of symptoms, for whatever reason, led to an increase in the perception of severity of stress. Whether this was a result of "effort after meaning" (Whitehead, 1996), an accumulation of negative experiences creating a catastrophising position, or an as yet unidentified reason, will remain uncertain until more research on these questions is conducted. However it is the main finding of the Dancey et al. (1998) study that an increase in the perception of stress leads to an increase in the perception of symptoms. This has wider implications for treatment programmes such as stress management training and CBT.

Whilst no firm conclusions can be drawn as to the role of stress in the cause or maintenance of IBS, it seems reasonable to ask patients to assess the impact that stress and other psychological factors have in their illness. A recent study employed a qualitative approach to try to assess how IBS sufferers view the role of stress and other psychological factors in their illness (Stenner, Dancey and Watts, 2000). This interesting study shows that while the majority of sufferers may implicate stress as a causal or maintaining factor in their illness, some are quite resistant to the idea that stress plays any role in their illness. The qualitative analysis used in this study was Q methodology (for a detailed review of this methodology see Smith, Harre and van Langenhove, 1995).

The study produced 4 conflicting main factors with regard to the role of psychological factors and stress. The dominant "narratives" for each of the main factors are presented here. **Factor A:** "IBS is caused by worry and stress" with most agreement to statements in this factor that stress and worry are a significant cause of IBS symptoms and that the condition arises in part from coping with the stresses and strains of modern life". Factor A statements also agree that IBS sufferers have personalities that make them prone to IBS, and that they tend to be worriers and feel unable to express feelings of anger and aggression. **Factor B:** "A problem of body, not mind". These statements reflect that IBS is more than just a result of being stressed, suggesting that it is more of an effect than a cause, with statements strongly suggesting that IBS is a physical not a psychological problem. **Factor C:** "Depressed, stressed and despairing of doctors". Factor C exemplars present themselves as profoundly depressed, and this depression is presented as an effect, not as a cause. They also present themselves as frustrated by unsympathetic and ignorant doctors. **Factor D:** "A partly psychological problem with definite physical consequences". Here the depressing nature of IBS is emphasised, however stress is presented as both a cause and effect of IB symptoms. A link is sketched from both the social and psychological realms, with a picture painted of a "type of person" whose response to stressful life circumstances, which the individual feels unable to control, is to suffer from bowel problems.

While the authors make it clear that these accounts are not exhaustive and are open to subjective interpretation, the study shows the diversity in accounts of the role of stress that sufferers describe. Accounts that give a key role to stress in the causation of IBS involve accepting the psychological and social factors implicated in the illness, and such a position then raises the issue of responsibility to the patient for his/her illness. The factor D account emphasises the need to maintain control, where the factor A account has less explicit concentration on the theme of control and gives more emphasis to managing the symptoms. Factors B and C by contrast are deeply resistant to what the patients understand as "psychosomatic" and to implications of responsibility.

Since medical research so far has provided no significant or reliable medical indicators, psychological research into IBS is warranted. The research presented in this thesis attempts a new approach to the study of IBS - to examine IBS cognition from a theory based psychological perspective.

Examining the illness representation of IBS sufferers, allows the IBS experience to be compared to a number of organic and functional conditions, and should make replication relatively straightforward. A further purpose of this research is to examine different populations of IBS sufferers using the same methodology, so that some comparison of different populations of IBS can be made. This increased understanding about IBS illness beliefs should increase knowledge about IBS for therapists to improve psychological treatments.

The main purpose of this thesis is to explore the illness cognitions (or illness representation) of different populations of irritable bowel syndrome (IBS) sufferers over time, to examine whether these cognitions can predict simultaneous and subsequent outcome, and to determine if coping mediates the link between illness representation and outcome as the commonsense model suggests.

Chapter 3

Illness Representation, Coping and Outcome of Self Help Group Members: A Cross-Sectional Study of IBS and IBD Sufferers

Introduction

As reported earlier, while there has been no research examining the illness representations of IBS patients, there has been some research exploring the representations of other functional somatic syndromes, such as chronic pain and chronic fatigue syndrome (CFS). The majority of these studies, like much of the research in this area, have designed cross-sectional studies (e.g. Moss-Morris et al. 1996) as a way of obtaining their data pertaining to the commonsense model. Although most authors make the point that their findings should be replicated with prospective, longitudinal designs, this has not been followed up. Therefore, this study was designed to be cross-sectional so that it can be compared to published work, such as Moss-Morris et al's examination of the illness representations of CFS patients. It should also allow a comparison between designs, since the rest of the studies are longitudinal. In Chapter 7 comment will be made on the usefulness of cross-sectional data in predicting outcome using the commonsense model.

The majority of studies investigating the commonsense model have recruited from easily accessible samples such as self-help organisations (e.g. Moss-Morris et al., 1996). It is likely that individuals who belong to these organisations will develop equivalent representations of their illness to those endorsed by the organisation and its members. This is the first of two studies using self-help group members as participants.

The purpose of this first study is to replicate the Moss-Morris et al. (1996) procedure: examining the illness representations, coping strategies and outcomes of patients at one point in time. The procedure followed here is as close as possible to the Moss-Morris study in order for a comparison between the two functional illnesses (i.e. IBS and CFS) to be made. However, outcome measures in this study are different due to the differences in symptoms experienced. The Moss-Morris study examined levels of disability as the outcome measure (which was defined as daily functioning, vitality and psychological well-being). As IBS sufferers can physically perform most of their daily tasks, disability was not appropriate as an outcome measure. Research examining the impact that IBS has on sufferers' lives has shown that it affects their quality of life (Dancey and Backhouse, 1993). Research also suggests that IBS patients report significantly higher on measures of anxiety and depression than organic GI patients and healthy controls (Drossman et al. 1988). Therefore, quality of life and psychological adjustment were chosen as outcome measures.

IBD sufferers were also recruited so that a comparison between functional GI illness and organic GI illness can be made. The IBS Network and the National Association for Colitis and Crohn's Disease (NACC) were contacted. Both the IBS Network and NACC welcomed psychological research into their respective illnesses.

The IBS Network is a UK charitable support network providing information and support for approximately 3000 IBS sufferers. As a member of the Network, sufferers receive a quarterly newsletter (The Journal of the IBS Network), which contains articles and letters written by health professionals, psychologists and lay members with their own experiences.

The National Association of Colitis and Crohn's Disease (NACC) is a charitable support organisation for sufferers of IBD. NACC is considerably larger than the IBS Network, with approximately 15 000 members. NACC members also receive a quarterly newsletter (NACCNews) in which information from professionals and lay members is disseminated.

Objectives of the Study

Objectives are presented instead of hypotheses because this is an exploratory study. The study was designed with three objectives.

1. The first was to examine the representation components of the IBS and IBD sufferers
2. The second was to explore whether the illness representations of IBS and IBD sufferers predict outcome.

3. The third was to examine whether any links that might emerge between representation components and outcome are mediated by coping.

Design and Procedure

An advert was placed in the *Journal of the IBS Network* and *NACCNews* to gain access to IBS and IBD sufferers respectively (see adverts in appendix A1). It was explained that upon receipt of their letter, they would be sent more detailed information (see appendix A2), the questionnaire (see appendix A4), a consent form (appendix A3) and a prepaid envelope.

The IBS advert was placed in the Journal of the IBS Network in October 1999, issue 35. Two hundred and sixteen people wrote to say they would be interested in the research, and were sent questionnaires. Of the 211 questionnaires returned, 2 were removed from this study because these people reported that they had not received a medical diagnosis of IBS (i.e. self diagnosed), thus N = 209.

The IBD advert was placed in NACCNews in the Spring 2000 edition, number 21. Two hundred and eighty eight NACC members wrote to me volunteering for this research. A total of 274 (95% of the original 288) IBD sufferers (155 Crohn's disease (CD) and 119 ulcerative colitis (UC)) returned their questionnaires. Demographic details are given in Table 1.

Participants

In the IBS sample, ages ranged from 19 to 88 with a mean age of 53.5 (SD = 15.0). Sixty two percent of the sample was married and the majority of the sample was not working, with thirty percent retired and twenty six percent currently unemployed. The self reported mean length of the illness was 16.9 years (SD = 12.4) and the time from diagnosis was 9.9 years (SD = 8.8).

For the IBD sample, the mean age of the CD sufferers was 42.4 years (SD = 15.6), and for UC sufferers the mean age was 44.1 (SD = 16.2). Independent t tests of the CD and UC data for age and sex were found to be non significant and the groups were therefore combined; throughout they will collectively be referred to as IBD. For the IBD sample, age ranged from 14 to 80 years, with a mean of 43.2. Forty nine percent of the sample was married and the majority of the sample was not working, with twelve percent currently unemployed. The self reported mean length of the illness was 13.2 years (SD = 11.9) and 9.7 years (SD = 10.4) from diagnosis.

Table 1 Descriptive demographic information of the participants

	IBS		CD		UC	
	N	%	N	%	N	%
Sex						
Male	32	15.3	31	20.0	31	26.1
Female	175	83.7	123	79.4	86	72.4
Not Reported	2	1.0	1	0.6	2	1.7
Age						
0-20 years	2	1.0	4	2.6	9	7.6
21-30 years	14	6.7	37	23.9	16	13.5
31-40 years	27	12.9	39	25.2	21	17.6
41-50 years	38	18.2	30	19.4	30	25.1
51-60 years	57	27.3	21	13.5	22	18.5
61-70 years	37	17.7	13	8.4	11	9.2
70 + years	32	15.3	10	6.6	8	6.7
Not Reported	2	1.0	1	0.6	2	1.7
Marital Status						
Single	36	17.2	41	26.5	30	25.2
Married	129	61.7	75	48.4	59	49.6
Divorced	11	5.3	12	7.7	12	10.1
Separated	3	1.4	3	1.9	1	0.8
Widowed	17	8.1	6	3.9	7	5.9
Cohabiting	11	5.3	17	11.0	7	5.9
Divorced + Cohabiting	0	0.0	1	0.6	1	0.8
Not Reported	2	1.0	0	0.0	2	1.7
Occupation						
No Occupation	54	25.8	42	27.1	19	16.0
Retired	62	29.7	21	13.5	13	10.9
Manual	11	5.3	20	12.9	15	12.6
Administration	18	8.6	23	14.8	24	20.2
Professional	26	12.4	24	15.5	21	17.6
Student	0	0.0	8	5.2	8	6.7
Other	38	18.2	17	11.0	19	16.0

When the IBS and IBD groups are compared it can be observed that men are more represented in the IBD group (t (476)= -2.03, $p<0.05$), and the IBS group are significantly older than the IBD group. The mean age for the IBS group was 53.5 (SD = 15.0) and the mean age for the IBD group was 43.4

(SD = 15.5), (t (476)= 7.18, p<0.001). No differences were detected for marital status or occupation.

Those who stated that they had no occupation were asked whether this was connected to their illness (see section 1, appendix A4). Thirty-three (non-working) IBS sufferers claimed that their symptoms were the reason why they were unemployed; this is compared to fifty-two IBD sufferers giving their symptoms as the main reason for unemployment. The impact of gastrointestinal symptoms upon working lives can be illustrated more clearly when we examine reported days taken as sick leave (over the last 12 months) by the sufferers. For the IBS sample the number of days reported as being taken as sick ranged from 0-300. The mean is 18.3 (SD = 44.8) days and the median is 5 days. For the IBD sample the reported number of days taken as sick ranged from 0-365. The mean is 34.3 (SD = 61.2) days and the median 10 days. An independent t test shows that the IBD group report significantly more days off sick than the IBS group (t (224) = -2.0, p<.05). However the mode for both illness groups was zero showing that the majority of respondents report taking no days off sick due to their gastrointestinal symptoms, thus reflecting the diversity of both the IBS and IBD prognoses.

The participants were asked to estimate how often they had been to see their GP in the past year. The IBS group gave a mean of 13.9 (SD = 18.5) and the IBD group gave a mean of 17.1 (SD = 22.2). An independent t test was computed on this data and it showed that the 2 illness groups did not differ significantly (t (302)= -1.4, p>.05). However this measure could not be considered reliable: some people gave a range estimate (e.g. 10 - 15 times), others wrote comments like “too many to count”, “can’t remember” “many times”. Therefore, the usefulness of this measure is extremely limited and will not be examined further.

The participants were asked to indicate which investigations they received before a diagnosis (either IBS or IBD) was given. Participants were presented with a list of nine common investigations; they were asked to tick those experienced. The investigations presented were: barium meal, barium enema, colonoscopy, rectal examination, blood test, urine sample, stool sample, ultrasound scan and endoscopy. The responses were summed to give an investigations score ranging from 0 – 9, with high scores indicating more investigations. The IBS sufferers reported a mean of 3.72 (SD = 2.4) compared to the IBD group's mean of 4.84 (SD = 2.5) investigations. The IBD group reported significantly more investigations than the IBS sufferers (t(474) = -4.93, p<0.001). The three most frequent investigations for the IBS sufferers were a rectal examination (N = 131: 62.7%), blood test (N = 112: 53.6%), and a barium enema (N = 104: 49.8%). The three most frequent investigations for the IBD sufferers were a rectal examination (N= 213: 77.7%), blood test (N = 208: 75.9%) and a stool sample (N = 163: 59.5%).

All participants were recruited from the self-help organisations of the IBS Network or NACC. Both of these support organisations encourage members to meet and share personal experience by creating local groups. Only 22 IBS and 12 IBD sufferers in this sample reported that they regularly met fellow sufferers. Of those who did, meeting once a month was the most reported.

Measures

Illness Representations

The Illness Perception Questionnaire (IPQ) ***(Weinman, Petrie, Moss-Morris and Horne, 1996)*** This questionnaire was chosen to measure the cause, consequences, timeline and cure/control beliefs that IBS and IBD sufferers have about their illness. The items from the four scales are presented in a mixed order and are rated by the respondent on five-point scales from (1) *"Strongly Disagree"* to (5) *"Strongly Agree".* The total score is summed for each scale and divided by the number of items. The responses of the consequence scale have been reverse coded so that lower scores indicate fewer reported consequences of the illness and high scores represent serious consequences. Lower scores indicate weaker cure/control beliefs and a short timeline; high scores represent stronger cure/control beliefs and a longer timeline. The "cause" representation has to be measured differently because each of the ten causal items represents a specific causal belief (e.g. "my state of mind caused my IBS/IBD", or "pollution caused my IBS/IBD").

Weinman, Petrie, Moss-Morris and Horne (1996) constructed the items such that half relate to internal causal factors and half relate to external causal factors. Here, a higher score indicates a stronger belief in a specific cause (see section 7, appendix A4).

The identity measure provided by the authors was dropped from this study because it is a short (12 item) *general* measure of non-specific symptoms. A search of the literature for a suitable IBS symptom scale found scales either with poor reliability (e.g. Talley et al. 1995), or that were designed to measure severity rather than frequency (e.g. Francis et al. 1997). Therefore a short GI measure based on the identity scale from the IPQ was constructed. Gastrointestinal (GI) symptoms were taken from the Rome criteria for IBS and from symptoms reported in the NACC literature (for IBD). The ten selected symptoms were: abdominal pain, diarrhoea, bloating, wind, constipation, blood in stools, incomplete evacuation of the bowel, passage of mucus, incontinence, rumbling and grumbling. Participants rated their identification with each symptom from (0) “No experience of the symptom” to (4) “Experience the symptom more than once every week”. Higher scores indicate greater identification with the illness. Cronbach’s alpha for this scale yielded .61 for the IBS group and .74 for the IBD group. Since symptom reports are the only means available to clinicians regarding diagnosing IBS, it was believed that illness identity based on the perception of frequency of IBS symptoms would be a valuable measure of this component. While Moss-Morris et al. (1996) argue that an identity measure based solely on illness specific symptoms could be seen as a measure of symptom *severity* rather than symptom *perception,* the rating scale is worded so that it reflects symptom perception rather than severity. “I have never experienced the symptom”, “Experienced the symptom less than 3 or 4 times per year”, “Experienced the symptom every month or so”, “Experienced the symptom every week or so”, “Experience the symptom more than once every week” (see section 6, appendix A4).

Coping

COPE ***(Carver, Scheier and Weintraub, 1989)*** The situational version of the COPE was selected as the coping measure because it allows the analysis of individual coping items. Other coping scales make the simplistic distinction between emotion and problem focused coping, and imply that one particular type of coping may be better in more controllable than uncontrollable situations and vice versa. However, there is accumulating evidence that an assortment of coping behaviours may be associated with favourable health outcomes. Also, since no research so far has examined the coping strategies of IBS patients it is more prudent to examine each coping strategy independently of other coping strategies - which the COPE allows us to do. The situational version of the COPE asks participants to think about periods when symptoms have "been at their worst", and then to indicate the extent to which they have used a particular strategy. Sixty items are presented, which relate to 15 theoretically independent scales. The fifteen scales are: Active coping; Planning; Seeking instrumental social support; Seeking emotional social support; Suppression of competing activities; Turning to religion; Positive reinterpretation and growth; Restraint coping; Acceptance; Focus on and venting of emotions; Denial; Mental disengagement; Behavioural disengagement; Alcohol/Drug use; Humour. Total scores for each scale are computed by summing the scores from the four component items, from (1) *"Don't do this at all"* to (4) *"Do this a lot"*. The scores for each scale (4-16) indicate the extent to which this type of coping is typically employed when symptoms are at their most severe. The higher the score on each scale, the greater the extent to which the coping style is typically employed by IBS sufferers to cope with their symptoms (see section 12, appendix A4).

Outcome

WHOQOL-Bref ***(Division of Mental Health, WHO, Geneva, 1999)*** The WHOQOL-Bref (brief 26 item version) was selected as the quality of life outcome measure because the questionnaire gives two one-item measures of quality of life "How would you rate your quality of life" and satisfaction with health "How satisfied are you with your health". In addition, this measure also gives ratings of quality of life in four separate domains: the physical domain incorporates measures of pain and discomfort (e.g. How well are you able to get around?); the psychological domain includes self esteem and body image (e.g. How fed up do you feel?); the social domain includes measures of personal relationships and social support (e.g. How satisfied are you with your personal relationships?); and the environmental domain assesses financial resources, transport and opportunities for recreation and leisure (e.g. How satisfied are you with your access to health services?). Respondents are asked to think about their life in the last two weeks, and to rate the quality of life statements on five-point scales. Raw scores are transformed to produce normalised domain scores with a range of 4-20, however the one-item measures are scaled 1 - 5. Higher scores denote a higher quality of life in each domain (see section 13, appendix A4).

The Hospital Anxiety and Depression Scale (HADS) ***(Zigmond and Snaith, 1983)*** This 14-item scale was selected because it is a widely used measure of emotional distress in clinical populations. It is short and provides separate scores for anxiety and depression. Respondents are asked to respond to how they have been feeling over the last two weeks, on four-point scales, with higher scores indicating greater severity (see section 10, appendix A4). Using this scale allows the comparison of respondents' scores to that of clinically anxious and depressed patients. The authors suggest that 0 to 7 is “normal”, 8 to 10 is “mild”, 11 to 14 is “moderate”, and 15 to 21 is “severe” (Johnston, Wright and Weinman, 1995).

Additional measures Note that not all measures taken in the study are used in the thesis.

Results

The results will be presented according to the objectives outlined on page 64 and 65.

1. The first objective was concerned with the illness representations that IBS and IBD sufferers hold. Firstly, the individual representation components of the IBS and IBD sufferers will be presented. Secondly,

the representations of IBS and IBD sufferers will be compared statistically. Thirdly, relationships between representation components for both illness groups will be explored. After assessing the representation patterns of the IBS and IBD sufferers, some informal comparison to other illnesses reported in the literature will be made.

2. The second objective was to explore whether the representations of IBS and IBD sufferers predict outcome. Firstly, outcome measures will be examined and statistically compared between the two illness groups. Secondly, relationships between representation components and outcome measures will be explored. Analysis will then focus on whether representation components can predict outcome.
3. The third objective was to examine whether any links that might emerge between representations and outcome are mediated by coping. Firstly, the individual coping behaviours will be introduced and compared statistically. Secondly, relationships between representations and coping, and coping and outcome are introduced. Then the theorised role of coping will be examined by path analysis using multiple linear regression.

Finally, any further issues that arise from the data will be explored.

1. The Illness Representations

1.1 The Representation Components

Illness identity For the IBS group, the three most frequently perceived symptoms (by reporting the experience of the symptom more than once every week) were wind (68.9%), rumblings and grumblings (56.9%), and bloating of the abdomen (54.5%). For the IBD group, the three most frequently perceived symptoms were wind (64.6%), rumblings and grumblings (64.2%), and diarrhoea (50%). We could assume then that the IBS illness identity score would be lower than the IBD score, due to IBD's organic status, however while the IBS mean score is slightly lower, the difference is not significant (t (480) = -0.95 p>0.05). Table 2 presents descriptive data for all the representation components.

Causal attribution For the IBS group, the most commonly reported causal attributions (where participants agree or strongly agree with the statement) were stress (57.4%), state of mind (45%) and other people (35.9%). The most commonly reported causal attributions for the IBD group were stress (48.5%), chance (35.4%) and state of mind (25.6%). IBD sufferers were more likely to cite "chance" than the IBS group. It is possible that this results from information given by health professionals. While there is no accepted theory regarding the aetiology of either IBS or IBD, psychological factors are often highlighted for the functional patient. However, as the traditional medical model separates the mind from the body, it is likely that the same psychological emphasis will not be given to an organic GI patient. Therefore, in an organic illness with no known aetiology, "chance" may well be a reliable explanation for the health professional.

Interestingly sufferers were more likely to disagree with a causal attribution than agree with one (no causal attribution produced a mean of 4 or above). This is understandable since both of these illnesses have poorly-defined aetiologies. Only "stress" and "state of mind" produced a mean above 3 for the IBS group, while "stress" and "chance" found more agreement with the IBD group.

For further detailed analysis, the 10 causal items from the IPQ were analysed using principal components analysis. Three interpretable components were found for the IBS group: psychological cause (stress, state of mind, other people and own behaviour); external cause (pollution, germ/virus and poor medical care); and biological cause (diet and heredity). The psychological cause component accounted for 26.4% of the item variance, with 16.5% for external cause and 13.7% for biological cause. A similar analysis was run for the IBD group in which similar factor structures occurred. However, diet loaded more strongly in external cause, and in biological cause chance loaded with heredity. These causal sub scales were then subjected to a reliability analysis. The four items comprising the psychological causal attribution yielded an alpha of .82 and .81 for the IBS and IBD groups respectively. This structure is comparable to the emotional attribution scale used by Moss-Morris et al. (1996), and Fortune et al. (2000). External cause was selected to be pollution, germ/virus, and poor medical care (from the IBS component structure). The three items comprising the external causal attribution yielded an alpha of .50 and .59 for the IBS and IBD groups respectively. While these reliabilities are considered rather low, it was thought best to have an alternative to the psychological causal attribution. The psychological and external cause components were then summed and divided by the number of items so they could be directly compared with the other representation components. (Biological cause was ignored in further analyses as diet and hereditary produced low alpha reliabilities: .36 and .14 for the IBS and IBD groups).

Table 2 shows the means and standard deviations for each of the illness representation components. Note that the identity measure is higher than the other representations because it is summed, not averaged like the other components. The means show that psychological causal attributions are favoured more than the external attributions by both GI illness groups, and that both groups expect their illness to last for a long time, and report the serious consequences of living with their illness. The cure/control component cannot be interpreted.

Table 2 Means and standard deviations of the illness representation components of IBS and IBD sufferers

Representation	IBS			IBD				
Components	Mean	SD	α	Mean	SD	α	t values	df
GI Symptom Score	23.6	5.8	.61	24.2	7.0	.74	-0.1	480
Psychological Cause	3.1	1.0	.82	2.7	1.0	.81	5.4**	480
External cause	2.2	0.8	.50	2.2	0.8	.59	-0.7	479
Timeline	4.1	0.7	.73	4.3	0.7	.71	4.0**	479
Consequences	3.5	0.7	.73	3.7	0.7	.74	-2.8*	480
Cure / Control	3.0	0.7	.73	3.1	0.7	.60	-1.2	480

NB: Higher symptom scores indicate more perceived symptoms. A higher score on the causal representation component shows more agreement with the causal factor. Lower scores indicate a shorter timeline, fewer reported consequences and weaker cure/control beliefs.
*$p < 0.01$ **$p<0.001$

1.2 Statistical Comparison of the IBS and IBD Representation Components

A comparison of the means shows that psychological causes are cited more by the IBS group than the IBD group, and that the IBD sufferers cite a longer timeline than the IBS group. The IBD group report more serious consequences of the illness (however this was not significant at the lower alpha of $p<0.008$ –Bonferoni adjustment), no significant differences were detected regarding the GI symptoms perceived, the amount of control sufferers feel they have and in their external causal beliefs, which are low for both groups.

1.3 Relationships Among Representation Components

Firstly, univariate correlations were carried out on the illness representation components (Tables 3 and 4) to examine inter-relationships. The emergent patterns are consistent with that seen in other illnesses (e.g. Moss-Morris, Petrie & Weinman, 1996; Petrie, Weinman, Sharpe & Buckley, 1996).

Strong illness identity was positively associated with serious consequences ($r=.21$, $p<0.01$), negatively with perceived control ($r= -.19$, $p<0.01$), and positively with timeline (i.e. expecting the illness to last a long time) ($r=.19$, $p<0.01$). Psychological cause was related positively to serious consequences ($r=.24$, $p<0.001$), and control beliefs ($r=.29$, $p<0.001$). A long timeline was associated positively to serious consequences ($r=.21$, $p<0.01$) and negatively to control beliefs ($r= -.29$, $p<0.001$). Serious consequences were associated negatively to control ($r= -.19$, $p<0.01$).

Table 3 Univariate relationships between the illness representation components for the IBS sample: Pearson's r

		(1)	(2)	(3)	(4)	(5)	(6)
(1)	Identity	1.0					
(2)	Psychological Cause	-.12	1.0				
(3)	External Cause	.02	.00	1.0			
(4)	Timeline	.19**	-.04	-.08	1.0		
(5)	Consequences	.21**	.24***	.07	.21**	1.0	
(6)	Cure / Control	-.19**	.29***	.12	-.29***	-.19**	1.0

*p<.05, **p<.01, ***p<.001

Table 4 Univariate relationships between the illness representation components for the IBD sample: Pearson's r

		(1)	(2)	(3)	(4)	(5)	(6)
(1)	Identity	1.0					
(2)	Psychological Cause	.02	1.0				
(3)	External Cause	.08	.13*	1.0			
(4)	Timeline	.09	-.27***	-.08	1.0		
(5)	Consequences	.23***	.21***	.25***	.22**	1.0	
(6)	Cure / Control	-.12*	.21***	-.01	-.32***	-.16**	1.0

*p<.05, **p<.01, ***p<.001

A similar pattern is found with the IBD group (Table 4). Strong illness identity was associated positively to serious consequence beliefs (r=.23, p<0.001) and negatively to control beliefs (r= -.12, p<0.05). Psychological causal factors were related negatively to timeline (r= -.27, p<0.001), but positively to cure/control beliefs (r=.21, p<0.001), and serious consequence beliefs (r=.21, p<0.001). External causal beliefs were associated positively to serious consequences (r=.25, p<0.001). Timeline was associated positively to consequences (r=.22, p<0.01), and negatively to control (r= -.32, p<0.001). Serious consequences were associated negatively to control (r= -.16, p<0.01).

2. Predicting Outcome

Several outcome measures were chosen: two one-item measures, assessing quality of life and satisfaction with health; quality of life in four life domains: physical, psychological, social, and environmental; measures of psychological adjustment to illness: anxiety and depression.

2.1 Statistical Comparison of IBS and IBD Outcome Measures

An initial examination of the outcome measures (Table 5) shows that both IBS and IBD sufferers rate their perceived quality of life as higher than their perceived satisfaction with their health. Both IBS and IBD sufferers perceived their environmental quality of life as the best. IBS sufferers rated quality of life in the psychological domain the lowest, while the IBD sufferers rated quality of life in the physical domain the lowest. Both IBS and IBD sufferers reported more anxiety than depression.

Table 5 Means and standard deviations of the outcome measures of the IBS and IBD sufferers

Outcome Measure	IBS Mean	SD	IBD Mean	SD	t value	df
Quality of Life (general)	3.1	1.0	3.4	1.0	-3.1*	477
Satisfaction with Health	2.3	1.0	2.4	1.0	-1.2	477
Physical Quality of Life	12.9	3.1	12.1	3.4	2.3	477
Psychological Quality of Life	12.4	3.0	12.9	3.2	-1.8	477
Social Quality of Life	13.4	3.6	13.3	3.9	0.2	469
Environmental Quality of Life	14.3	2.6	14.3	2.7	0.3	476
Anxiety	10.9	4.6	9.5	4.3	3.6**	479
Depression	6.5	3.7	5.9	3.9	1.6	479

NB: Quality of Life (general) and Satisfaction with Health are single items, range 1-5. Quality of life domain scores have been transformed so that scores range 4-20, higher scores indicating a higher quality of life. Anxiety and depression scores range 0-20 with higher scores indicating more psychological disturbance.
*p<0.01 **p<0.001

The IBS and IBD groups did not differ greatly from each other (Table 5). However the IBS group reported lower quality of life in general, less satisfaction with health, lower quality of life psychologically, and more anxiety and depression. The IBD group reported lower physical quality of life. An examination of this data confirms that the IBS group were more clinically anxious than the IBD group (t (479)=3.6, p<0.001).

An analysis of the anxiety data shows that over half of the IBS group could be classified as having moderate to severe anxiety (24% "normal" anxiety, 22.1% "mild" anxiety, 31.7% "moderate" anxiety, and 22% "severe" anxiety), compared to approximately 40% of the IBD group (33.7% "normal" anxiety, 26.5% "mild" anxiety, 27.1% "moderate" anxiety, and 12.7% "severe" anxiety).

2.2 Relationships between Representation Components and Outcome Measures

Univariate correlations were computed between the illness representation components and the eight outcome measures to examine how patients' views of their illness related to their perception of their quality of life, satisfaction with health, quality of life in the four domains and with measures of anxiety and depression (Tables 6 and 7).

Table 6 Univariate relationships between illness representation components and outcome measures of the IBS sufferers: Pearson's r

	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)
Identity	-.14*	-.21**	-.21**	-.19**	-.08	-.18*	.12	.16*
Timeline	-.05	-.14*	-.10	-.08	-.12	-.04	.09	.08
Psychological Cause	-.08	-.14*	-.04	-.21**	-.14*	-.09	.44***	.21**
External Cause	-.04	-.11	-.10	.05	-.04	-.14*	-.11	.05
Consequences	-.48***	-.50***	-.39***	-.48***	-.31***	-.34***	.46***	.46***
Cure / Control	.28***	.26***	.23**	.25***	.17*	.18**	-.11	-.25***

(1) Quality of Life (General), (2) Satisfaction with Health, (3) Quality of Life in Physical Domain, (4) Quality of Life in Psychological Domain, (5) Quality of Life in Social Domain, (6) Quality of Life in Environmental Domain, (7) Anxiety; (8) Depression
*p<.05, **p<.01, ***p<.001

Strong illness identity (i.e. by scoring higher on the symptoms of IBS) was associated negatively with quality of life in general (r=-.14, p<0.05), satisfaction with health (r= -.21, p<0.01), quality of life in the physical (r= -.21, p<0.01), psychological (r= -.19, p<0.01) and environmental domains (r= -.18, p<0.01) and positively with depression (r=.16, p<0.05). Timeline was associated negatively with satisfaction with health (r= -.14, p<0.05). Psychological causal attributions were associated negatively with satisfaction with health (r= -.14, p<0.05), quality of life in the psychological (r= -.21, p<0.01) and social domains (r= -.14, p<0.05), and positively with anxiety (r=.44, p<0.001) and depression (r=.21, p<0.01). External causal attributions were associated negatively with quality of life in the environmental domain (r= -.14, p<0.05). Serious consequence beliefs were strongly associated with all outcome measures (all p<0.001). Serious consequences were associated negatively with quality of life and satisfaction measures, and positively with anxiety and depression measures. Control beliefs were related positively to quality of life in general (r=.28, p<0.001), satisfaction with health (r=.26, p<0.001), quality of life in the physical (r=.23, p<0.01), psychological (r=.25, p<0.001), social (r =.17, p<0.05) and environmental domains (r = .18, p<0.01) and negatively with depression (r= -.25, p<0.001).

Table 7 Univariate relationships between illness representation components and outcome measures of the IBD sufferers: Pearson's r

	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)
Identity	-.21***	-.12	-.27***	-.16**	-.14*	-.19**	.20**	.15*
Timeline	-.13*	-.11	-.17**	-.13*	-.11	-.06	.07	.08
Psychological Cause	-.10	-.12	-.12	-.25***	-.21**	-.23***	.23***	.25***
External Cause	-.21**	-.09	-.19**	-.17**	-.11	-.30***	.16**	.15*
Consequences	-.42***	-.36***	-.51***	-.40***	-.32***	-.41***	.38***	.42***
Cure / Control	.27***	.25***	.28***	.23***	.21***	.22***	-.15*	-.20**

(1) General Quality of Life, (2) Satisfaction with Health, (3) Quality of Life in Physical Domain, (4) Quality of Life in Psychological Domain, (5) Quality of Life in Social Domain, (6) Quality of Life in Environmental Domain, (7) Anxiety, (8) Depression
**p<.01, ***p<.001

Similar patterns were detected for the IBD population, although the magnitudes of the relationships were much greater. In summary, illness identity was associated negatively to quality of life in general as well as in the four domains, and positively to anxiety and depression. Timeline was associated negatively to quality of life in the physical and psychological domains. Psychological causal beliefs were associated negatively to quality of life in the psychological, social and environmental domain and positively to anxiety and depression. A belief that the illness was caused by external factors such as a germ or virus was associated negatively with perceived quality of life in general, quality of life in the physical, psychological and environmental domains, and positively to anxiety and depression. Perceiving IBD to have serious consequences was related negatively to quality of life in general, in the four domains, satisfaction with health, and positively to anxiety and depression. Control beliefs were also highly associated with outcome measures. Control was associated positively to quality of life in general and in all four domains, satisfaction with health and negatively to anxiety and depression.

2.3 Multiple Outcome Measures

One of the objectives of this study was to examine whether the illness representation could predict outcome. However, six quality of life measures were considered too many for the detailed analysis needed in this thesis, therefore some reduction of measures was considered necessary. Unfortunately, a total quality of life score derived by summing data from all items is not recommended. The WHOQOL group stated however, that the two one-item measures ("How would you rate your quality of life?" and "How satisfied are you with your health?") could be used for interpretation and research. Relationships between these two and the four remaining quality of life measures were therefore first examined to test whether the single items could be used safely.

As can be observed from Tables 8 and 9, all the quality of life measures were highly correlated with one another. The single item quality of life measure, quality of life in general, produced strong relationships with all quality of life domains, but with the physical and psychological domains especially. This is important because while studies have reported that IBS affects social relationships and travel (Dancey and Backhouse, 1993), it is not the symptoms that restrict these activities, but worry over the potential consequences. Sufferers often report that they do not go out for meals, or that they restrict travelling by public transport "just in case". Thus, without objective symptom markers, the individual interpretation of quality of life is very important. However, some people may regard their symptoms as troublesome, yet do not restrict their activities, thus satisfaction with health should be retained. The relationship of satisfaction with health to the quality of life measures showed a lower magnitude, which may reflect the differences between the two one-item measures.

Table 8 Univariate relationships between the quality of life measures for the IBS sufferers: Pearson's r

		(1)	(2)	(3)	(4)	(5)	(6)
(1)	Quality of Life (General)	1.0					
(2)	Satisfaction with Health	.59***	1.0				
(3)	Physical Quality of Life	.58***	.59***	1.0			
(4)	Psychological Quality of Life	.67***	.60***	.58***	1.0		
(5)	Social Quality of Life	.46***	.40***	.35***	.58***	1.0	
(6)	Environmental Quality of Life	.45***	.43***	.52***	.61***	.49***	1.0

***p<.001

Table 9 Univariate relationships between the quality of life measures for the IBD sufferers: Pearson's r

		(1)	(2)	(3)	(4)	(5)	(6)
(1)	Quality of Life (General)	1.0					
(2)	Satisfaction with Health	.58***	1.0				
(3)	Physical Quality of Life	.67***	.56***	1.0			
(4)	Psychological Quality of Life	.63***	.52***	.60***	1.0		
(5)	Social Quality of Life	.41***	.33***	.39***	.63***	1.0	
(6)	Environmental Quality of Life	.58***	.40***	.56***	.61***	.48***	1.0

***p<.001

To clarify these relationships further, two regression analyses were conducted with both one-item measures as the criterion variables and the four domains as the predictor variables for both the IBS and IBD illness groups (Tables 10 and 11).

Table 10 Predicting general quality of life from the four quality of life domains

	IBS		IBD	
	β	*sr*	β	*sr*
Physical Quality of Life	.31***	.24	.40***	.30
Psychological Quality of Life	.46***	.31	.32***	.20
Social Quality of Life	.11	.09	-.03	-.03
Environmental Quality of Life	-.05	-.03	.17**	.13
	$\Delta R^2 = .51$		$\Delta R^2 = .55$	
	F = 52.2***		F = 81.8***	
	d.f. = 4, 196		d.f. = 4, 261	

**p<0.01 ***p<0.001

Table 11 Predicting satisfaction with health from the four quality of life domains

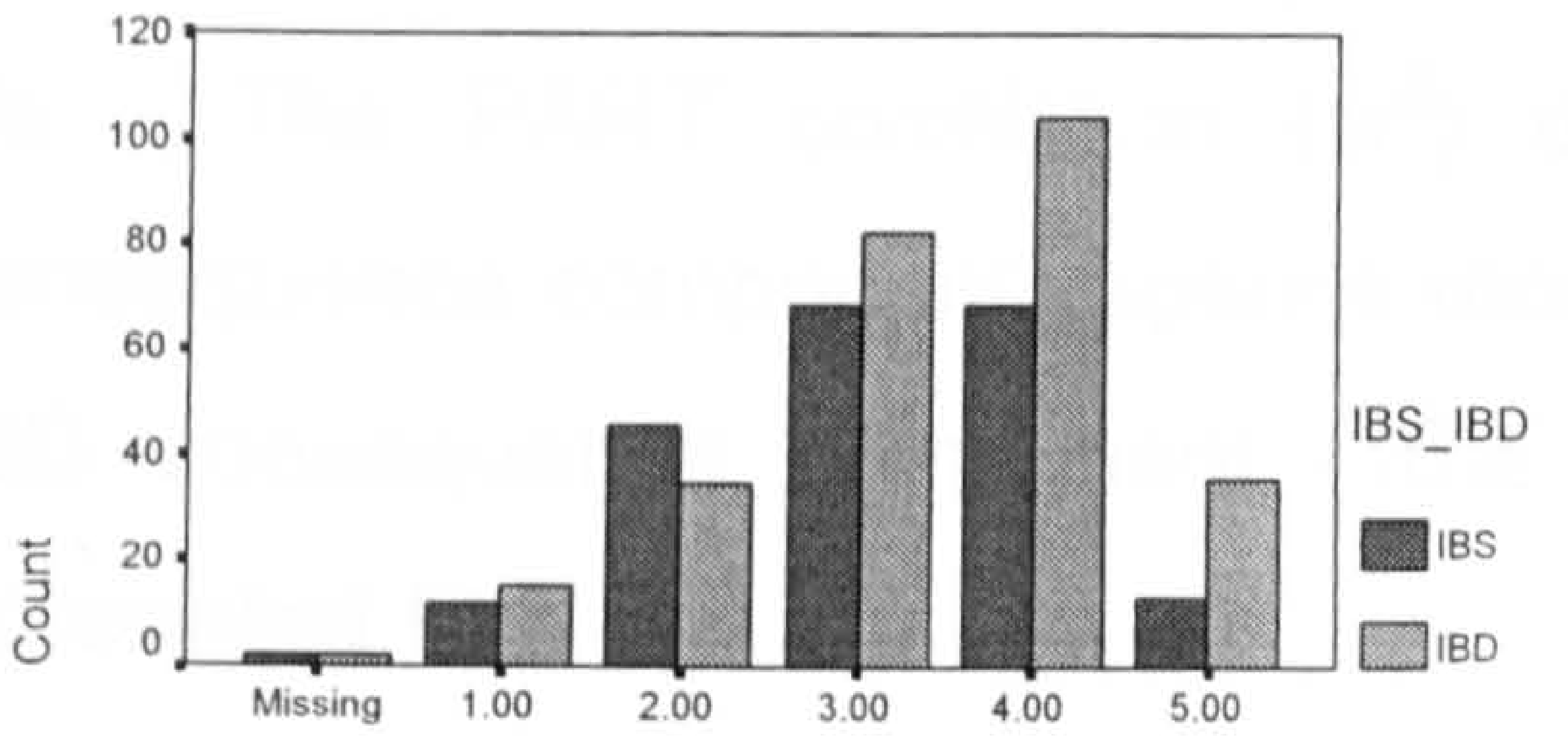
	IBS		IBD	
	β	*sr*	β	*sr*
Physical Quality of Life	.36***	.28	.38***	.29
Psychological Quality of Life	.36***	.24	.29***	.19
Social Quality of Life	.06	.05	-.00	-.00
Environmental Quality of Life	-.01	-.01	.01	.01
	$\Delta R^2 = .44$		$\Delta R^2 = .36$	
	F = 40.6***		F = 37.4***	
	d.f. = 4, 196		d.f. = 4, 261	

***p<0.001

The four quality of life domains successfully predicted both general quality of life and satisfaction with health, more variance was explained by the quality of life measure as expected. However, it should be noted that the social and environmental domains did not significantly contribute to the prediction, however since the physical and psychological domains significantly contributed, this was thought acceptable. The response distributions for the two items can be observed in bar charts (Figures 1 and 2) below.

Figure 1 General Quality of Life

Bar Chart showing the range of scores



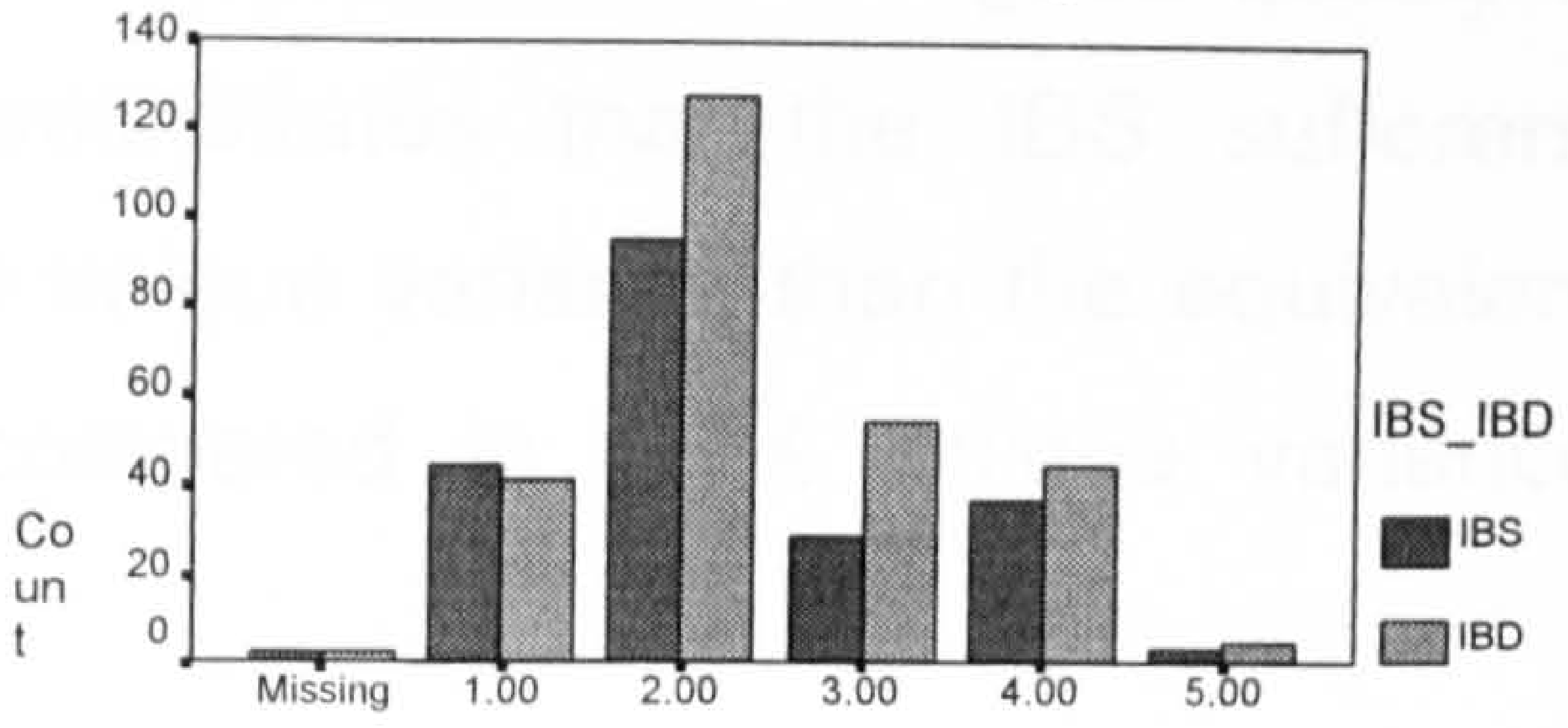
WHOQOL1

"How would you rate your Quality of Life?"

1 = Very Poor, 3 = Neither Poor nor Good, 5 = Very Good

Figure 2 Satisfaction with Health

Bar Chart showing the range of scores



WHOQOL2

"How satifsfied are you with your health?"

1 = Very Dissatisfied 3 = Neither, 5 = Very Satisfied

The bar charts show that while the *majority* of the IBS and IBD sufferers rate their quality of life as good, the *minority* report that they are satisfied with their health. Therefore, it seems prudent to keep both one-item measures for future analyses.

2.4 Representation Components Predicting Outcome

Now that a more conservative number of outcome measures have been selected, a series of four standard regression models were computed for both illness groups. Each analysis is presented in pairs for each outcome measure, so that the IBS and IBD representations can be directly compared. These analyses are presented in tables 12 - 15.

Table 12 Predicting quality of life from the illness representation of the IBS and IBD sufferers

	IBS		IBD	
	β	*sr*	β	*sr*
Illness Identity	-.03	-.03	-.10	-.10
Psychological Cause	-.05	-.04	-.06	-.06
External Cause	-.03	-.03	-.11	-.10
Timeline	.11	.10	-.00	-.00
Consequences	-.44***	-.40	-.32***	-.28
Cure / Control	.24***	.21	.22***	.20
		$\Delta R^2 = .26$ *F* = 13.11*** d.f. = 6, 200		$\Delta R^2 = .23$ *F* = 14.23*** d.f. = 6, 264

As can be observed in Table 12 above, the illness representation held by the IBS sufferers is slightly more predictive of quality of life than the IBD illness representation (26% compared to 23% of the variance accounted for). The same representation components of consequences and cure/control are significant predictors for both the IBS and IBD sufferers; few serious consequence beliefs and strong control beliefs are related to good quality of life. The PART correlation (sr^2) demonstrates that the IBS sufferers' consequence component explains more unique variance than the equivalent IBD consequence component (16% compared to 7.8% unique variance accounted for).

Table 13 Predicting satisfaction with health from the illness representation of the IBS and IBD sufferers

	IBS		IBD	
	β	*sr*	β	*sr*
Illness Identity	-.11	-.10	-.03	-.03
Psychological Cause	-.12	-.11	-.10	-.09
External Cause	-.11	-.10	.00	.00
Timeline	.01	.01	.00	-.00
Consequences	-.40***	-.36	-.29***	-.26
Cure / Control	.21**	.18	.22***	.21
		ΔR^2 = .28		ΔR^2 = .18
		F = 14.47***		*F* = 9.34***
		d.f. = 6, 200		d.f. = 6, 264

When predicting satisfaction with health (Table 13), once again, the IBS representation predicts outcome better than the IBD representation of illness (28% compared to 18% of the variance accounted for). In addition, consequences and cure/control are once again the significant predictors of outcome. Serious consequence beliefs and weak control beliefs were related positively to dissatisfaction with health. Serious consequence beliefs explain the majority of the variance in this outcome measure for both IBS and IBD sufferers (13% and 6.8% respectively unique variance explained – PART correlation). While the IBS components taken together account for more variance explained, the cure/control component explains slightly more unique variance in the IBD model (3.2% explained in the IBS model compared to 4.4% in the IBD model).

In predicting anxiety (Table 14 below), again the IBS representation is more predictive than the IBD representation (35% compared to 18% variance explained). While the belief in the serious consequences of the illness and weak control beliefs are again predictive of poor outcome, the belief that the illness was caused by psychological factors also contributed significantly to the experience of anxiety for both IBS and IBD sufferers (13.7% unique variance explained in the IBS model and 3.2% in the IBD model). While external causal beliefs were associated with less anxiety for the IBS sufferers, those IBD sufferers who reported more IBD symptoms reported more anxiety.

Table 14 Predicting anxiety from the illness representation of the IBS and IBD sufferers

	IBS		IBD	
	β	*sr*	β	*sr*
Illness Identity	.08	.08	.12*	.12
Psychological Cause	.41***	.37	.20**	.18
External Cause	-.12*	-.12	.06	.06
Timeline	-.04	-.03	.02	.02
Consequences	.34***	.30	.27***	.23
Cure / Control	-.15*	-.13	-.13*	-.12
		$\Delta R^2 = .35$		$\Delta R^2 = .18$
		F = 19.91***		*F* = 11.12***
		d.f. = 6, 201		d.f. = 6, 265

The IBS model was more predictive of depression than the IBD model (26% of the variance explained compared to 22% in the IBD model). Once again the same components were implicated; those sufferers who reported that their illness had serious consequences, reported few control beliefs, and who reported that their illness was caused by psychological factors reported more depression, and once again, the consequence component was the strongest predictor.

Table 15 Predicting depression from the illness representation of the IBS and IBD sufferers

	IBS		IBD	
	β	*sr*	β	*sr*
Illness Identity	.07	.06	.06	.05
Psychological Cause	.20**	.18	.22***	.20
External Cause	.05	.05	.04	.04
Timeline	-.07	-.06	.02	.02
Consequences	.36***	.32	.31***	.28
Cure / Control	-.25***	-.22	-.19**	-.17
		$\Delta R^2 = .26$		$\Delta R^2 = .22$
		F = 12.88***		*F* = 14.03***
		d.f. = 6, 201		d.f. = 6, 265

3. Theorised Mediating Role of Coping

The coping measure that was chosen was the COPE that incorporates 15 theoretically independent scales, which can be merged if necessary.

3.1 Statistical Comparison of IBS and IBD Coping Behaviour

Table 16 Means and standard deviations of the coping behaviours employed by the IBS and IBD group

Coping Behaviour	IBS Mean	SD	IBD Mean	SD	t value	df
Active Coping	11.5	3.0	11.6	2.9	-0.7	478
Planning	10.3	3.1	9.9	3.1	1.1	475
Suppression	9.0	2.8	9.3	2.5	-1.3	473
Restraint Coping	8.6	2.8	9.4	2.8	-2.9*	475
Instrumental Support	8.0	3.5	8.9	3.6	-2.7*	476
Emotional Support	8.5	3.5	9.2	3.6	-2.1	476
Positive Reinterpretation	7.6	3.0	9.8	3.3	-7.3**	476
Acceptance	11.2	3.1	12.6	2.9	-5.2**	479
Religion	7.1	4.4	6.8	4.0	0.7	477
Venting Emotion	9.1	3.4	9.1	3.4	-0.2	476
Mental Disengagement	8.5	2.4	9.2	2.7	-3.1*	479
Behavioural Disengagement	6.8	2.5	6.6	2.4	0.9	475
Denial	6.0	1.9	6.6	2.4	-3.0	476
Alcohol	5.5	2.9	5.1	2.5	1.7	476
Humour	5.7	2.5	7.8	3.5	-7.5**	476

*p<0.01 **p<0.001

Means and dispersion scores were calculated for the 15 coping strategies (Table 16 above). A statistical comparison of the means shows differences between the two groups in the strategies of positive reinterpretation and growth (t (476)= -7.3, p<0.001), acceptance (t (479)= -5.2, p<0.001) and humour (t (476)= -7.5, p<0.001). All three of these strategies could be interpreted as adaptive, and in each case the IBD sufferers report using these strategies more often than the IBS sufferers when coping with the worst of their symptoms. The IBD group also reported using the strategies of Restraint Coping, Seeking Instrumental Support and Mental Disengagement more than the IBS group, however these are not significant at the adjusted alpha of p<0.003 (Bonferoni adjustment).

3.2.1 Relationships between Representation Components and Coping Behaviour

Simple univariate correlations were carried out between the representation components and the COPE scales to investigate how patients' views of their illness related to the coping behaviour they report using to cope with their illness. These relationships are presented in Tables 17 and 18.

Table 17 Univariate relationships between the illness representation components and coping behaviours in the IBS sample: Pearson's r

	Identity	Timeline	Psycho Cause	External Cause	Conseq -uence	Cure/ Control
Active Coping	-.10	-.06	-.06	.12	-.05	.33***
Planning	-.03	-.05	.04	.02	.03	.32***
Instrumental Support	.09	-.16*	.05	.07	.03	.11
Emotional Support	.13	-.06	.04	-.11	-.01	-.02
Suppression	.01	.02	.03	.12	.13	.11
Religion	-.01	.01	.02	.03	.09	-.01
Positive Reinterpretation	.00	-.04	-.01	.18**	-.01	.28***
Restraint Coping	.10	.00	.09	.17*	.19**	.04
Acceptance	.01	.21**	-.13	-.13	-.19**	-.05
Venting Emotions	.05	.05	.25***	-.11	.26***	-.01
Denial	-.05	-.01	.04	-.03	.02	-.04
Mental Disengagement	.07	-.02	.04	.01	.18**	.11
Behavioural Disengagement	.07	.08	.18**	-.02	.31***	-.21**
Alcohol	-.03	-.01	.19**	-.05	.09	.03
Humour	.06	-.13	-.16*	-.01	-.13	.06

*p<.05, **p<.01, ***p<.001

Timeline was associated negatively with instrumental support (r= -.16, p<0.05) and positively to acceptance (r=.21, p<.01). Psychological causal beliefs were associated positively to venting of emotions (r=.25, p<0.001), behavioural disengagement (r=.18, p<0.01), using alcohol to cope (r=.19, p<0.01) and negatively to humour (r= -.16, p<0.05). External causal beliefs (such as a germ or virus) were associated positively to positive reinterpretation (r=.18, p<0.01) and restraint coping (r=.17, p<0.05). Serious consequence beliefs were associated positively with venting emotions (r=.26, p<0.001), behavioural disengagement (r=.31, p<0.001) mental disengagement (r=.18, p<0.01) and restraint coping (r=.19, p<0.01), and negatively to acceptance (r= -.19, p<0.01). Cure/control beliefs were related positively to active coping (r=.33, p<0.001), planning (r=.32, p<0.001) and positive reinterpretation (r=.28, p<0.001), and negatively to behavioural disengagement (r= -.21, p<0.01).

In the IBD sample the number of symptoms perceived (illness identity) were weakly associated with planning (r=.13, p<0.05), the suppression of competing activities (r=.13, p<0.05), and humour (r=.12, p<0.05). Timeline was associated negatively to planning (r=-.18, p<0.01), and positively to acceptance of the illness (r=.24, p<0.001). Psychological causal beliefs were associated positively to venting emotions (r=.17, p<0.01), denial (r=.15, p<0.05), using alcohol to cope (r=.14, p<0.05), and negatively to acceptance (r=-.20, p<0.01). External causal beliefs were associated positively to the use alcohol (r=.13, p<0.05) and humour (r=.14, p<0.05) to cope. Serious consequence beliefs were associated positively to the coping strategies of suppression of competing activities (r=.28, p<0.001), venting emotions (r=.27, p<0.001), restraint coping (r=.25, p<.001), mental disengagement (r=.15, p<0.05) and behavioural disengagement (r=.24, p<0.001). Believing that IBD symptoms were controllable were related to active coping (r=.23, p<0.001), planning (r=.24, p<0.001), seeking instrumental support (r=.16, p<0.01), positive reinterpretation (r=.25, p<0.001) and humour (r=.13, p<0.05) and negatively to behavioural disengagement (r= -.21, p<0.01).

Table 18 Univariate relationships between the illness representation components and coping behaviours in the IBD sample: Pearson's r

	Identity	Timeline	Psycho Cause	External Cause	Conseq -uence	Cure/ Control
Active Coping	.09	-.11	.01	-.05	-.02	.23***
Planning	.13*	-.18**	-.01	.01	.03	.24***
Instrumental Support	.03	-.03	-.03	.05	.10	.16**
Emotional Support	.02	-.02	-.01	.02	.07	.12
Suppression	.13*	.03	.10	.08	.28***	.12
Religion	-.01	-.04	.02	.11	.09	.02
Positive Reinterpretation	.11	-.08	.01	.04	.05	.25***
Restraint Coping	.06	.08	.06	.10	.25***	.05
Acceptance	.06	.24***	-.20**	-.01	-.10	-.08
Venting Emotions	.10	.07	.17**	.03	.27***	-.03
Denial	.01	-.08	.15*	.11	-.06	.06
Mental Disengagement	.10	.01	.07	.05	.15*	.05
Behavioural Disengagement	.08	.08	.11	.07	.24***	-.21**
Alcohol	.07	-.02	.14*	.13*	-.01	-.02
Humour	.12*	.09	-.07	.14*	.03	.13*

*p<0.05 **p<0.01 ***p<0.001

3.2.2 Relationships between Coping Behaviour and Outcome Measures

To examine how coping behaviour relates to the outcome measures, univariate correlations were computed between the coping strategies and the outcome measures (Tables 19 and 20).

Table 19 Univariate relationships between coping behaviour and outcome measures in the IBS group: Pearson's r

	General Quality of Life	Satisfaction with Health	Anxiety	Depression
Active Coping	.19**	.17*	-.08	-.25***
Planning	.08	.01	.03	-.13
Instrumental Support	.03	-.05	.14*	.00
Emotional Support	.05	-.03	.13	-.06
Suppression	-.08	-.12	.16*	.15*
Religion	-.03	-.03	.14*	-.01
Positive Reinterpretation	.14*	.13	-.13	-.17*
Restraint Coping	.01	-.09	.14*	.04
Acceptance	.31***	.25***	-.24***	-.27***
Venting Emotions	-.14*	-.21**	.45***	.13
Denial	-.07	.14*	.11	.02
Mental Disengagement	-.03	-.11	.23**	.08
Behavioural Disengagement	-.26***	-.27***	.31***	.35***
Alcohol	-.10	-.17*	.19**	.11
Humour	.17	.10	-.12	-.16*

**p<.01, ***p<.001

For the IBS group, the coping strategies that were associated with good outcome were acceptance and active coping. The coping strategies that were associated with poor outcome were behavioural disengagement and venting emotions. A similar analysis was carried out for the IBD group. Once again, active coping and acceptance, along with positive reinterpretation, were strongly associated with good outcome, and venting emotion and behavioural disengagement were associated with poor outcome.

Table 20 Univariate relationships between coping behaviour and outcome measures in the IBD group: Pearson's r

	General Quality of Life	Satisfaction with Health	Anxiety	Depression
Active Coping	.18**	.11	-.12*	-.20**
Planning	.11	.05	-.11	-.16**
Instrumental Support	-.03	.06	.07	-.04
Emotional Support	.11	.06	.12*	-.09
Suppression	-.08	-.06	.12*	.14*
Religion	.03	.06	-.05	.03
Positive Reinterpretation	.25***	.20**	-.10	-.21**
Restraint Coping	.12	-.12	.10	.20**
Acceptance	.21***	.16**	-.13*	-.26***
Venting Emotions	-.10	-.04	.38***	.23***
Denial	.10	.11	.19**	.06
Mental Disengagement	-.02	-.10	.12	.04
Behavioural Disengagement	-.24***	-.10	.39***	.38***
Alcohol	.01	-.01	.19**	.15*
Humour	.02	.10	.00	-.10

*p<.05, **p<.01, ***p<.001

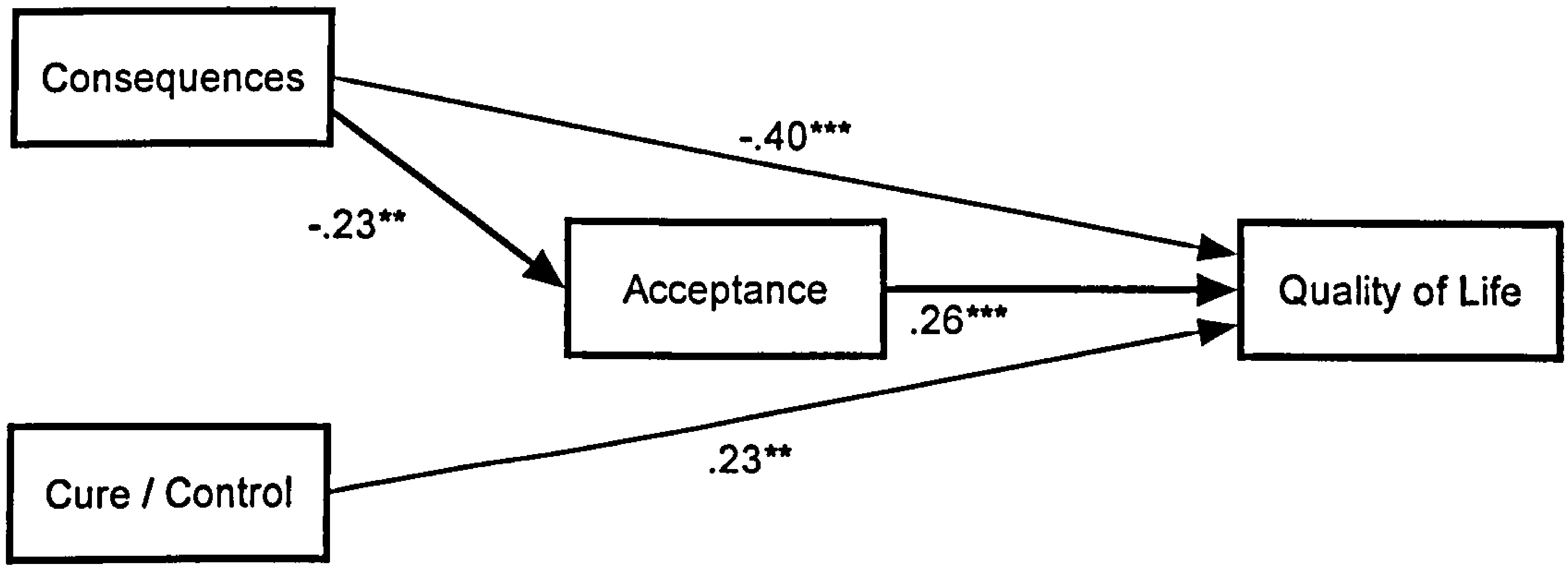
3.3 Illness Representation, Coping and Outcome

The remaining analyses tested the possibility that the links between illness representations and outcome are mediated by coping strategies. Each of the four outcomes (quality of life, satisfaction with health, anxiety and depression) were examined by path analysis, using multiple linear regression. The IBS and IBD analyses are presented in pairs (Figures 3 to 6).

The first analysis examined overall perceived quality of life (Figure 3a and b). The IBS model accounted for 32% of the variance in outcome, compared to 25% in the IBD model.

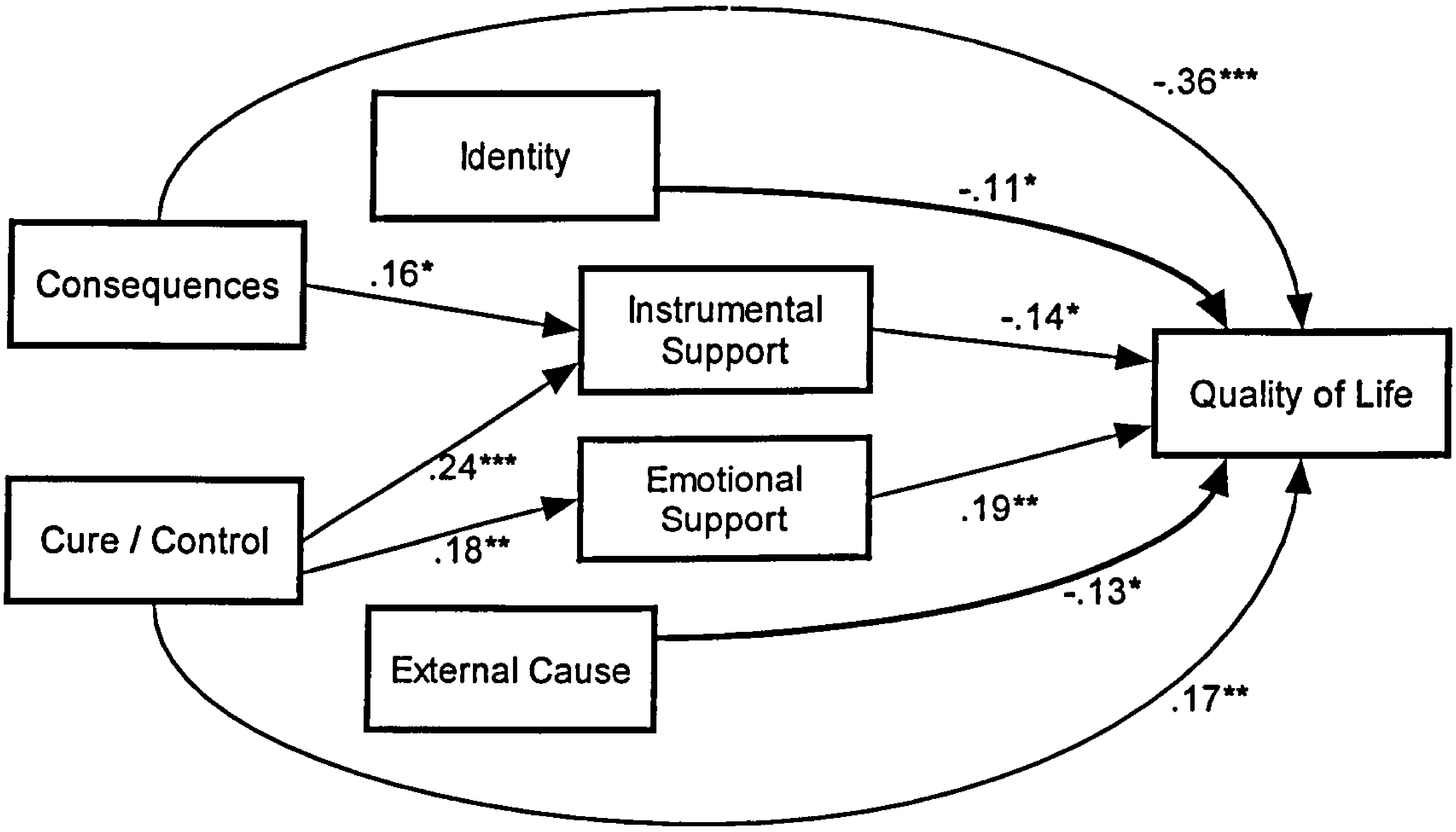
First examining the IBS model, both consequences and cure/control have direct influences on outcome: those who perceived few serious consequences and reported feelings of control over their illness reported greater quality of life. One coping strategy, acceptance, partially mediated the effect of the consequence representation. Those people who reported fewer serious consequences were more likely to accept the illness. When these variables were entered into a hierarchical regression, with the two illness representation components at the first step and acceptance at the second, acceptance added a significant 6% to the variance explained in perception of quality of life (R^2 change = 0.063, F(1, 203) = 19.06, $p<0.001$).

Figure 3a Path analysis predicting quality of life for the IBS sufferers



Adjusted R^2 = .32 F(3, 203) = 33.6***
**p<0.01 ***p<0.001

Figure 3b Path analysis predicting quality of life for the IBD sufferers



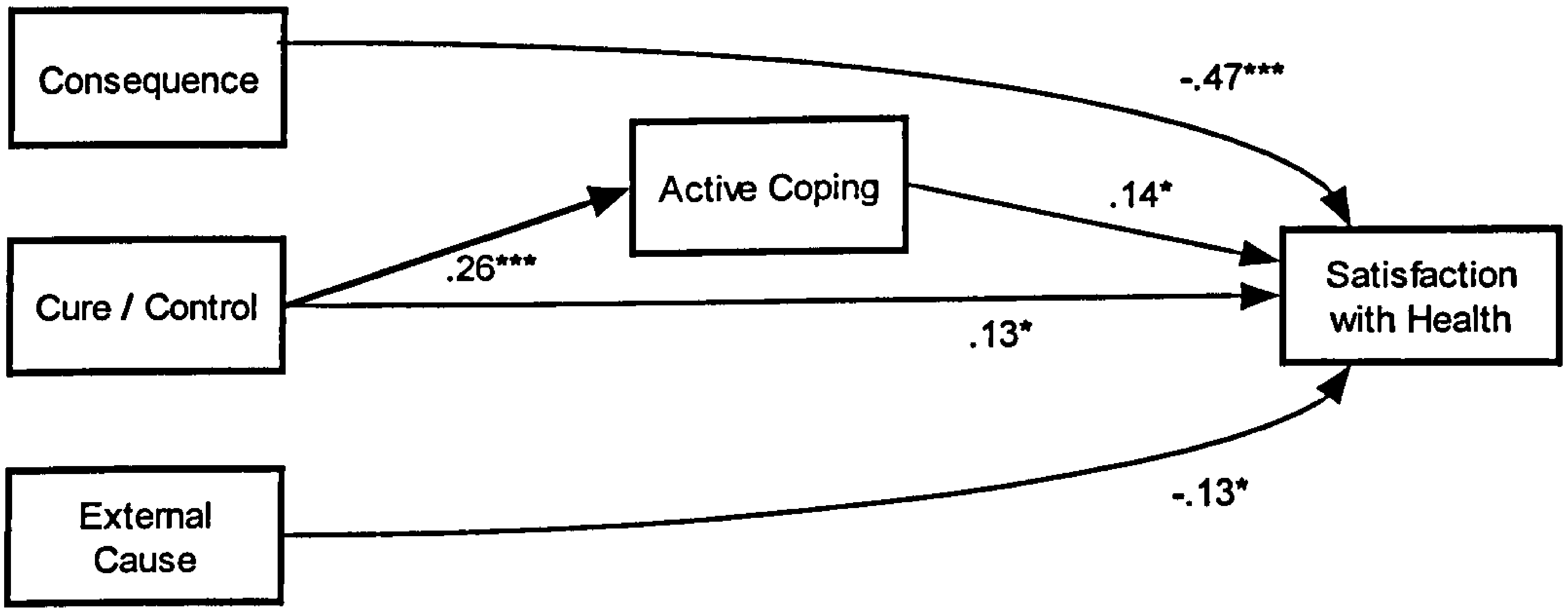
Adjusted $R^2 = .25$ $F(6, 260) = 15.9$***
*$p<0.05$ **$p<0.01$ ***$p<0.001$

The IBD model also shows a direct relationship between quality of life and the representation components of consequences and cure/control; however, this model also has direct paths from identity and external cause to outcome. Those who reported a good quality of life were likely to have perceived few serious consequences, reported strong feelings of control over their illness, perceived few symptoms and expressed a weak belief that the disease was caused by external factors.

Both the consequence and cure/control components were mediated by the coping strategies of seeking instrumental and emotional support: those who believed that IBD has serious consequences and who reported strong control beliefs were likely to seek out information about the illness, which was associated with poor perceived quality of life. Whether it is the seeking out of information that leads to a poorer quality of life, or whether the information received impacts negatively upon the consequences and control is not possible to determine with cross-sectional data of this type. Those with strong feelings of control were likely to seek emotional support, which is related to good perceived quality of life. When these variables were entered into a hierarchical regression, with the four illness representation components entered first and seeking emotional and instrumental support entered second, coping contributed a significant 2% of the variance explained in perception of quality of life (R^2 change = 0.021, F(2, 260) = 3.77, $p<0.05$).

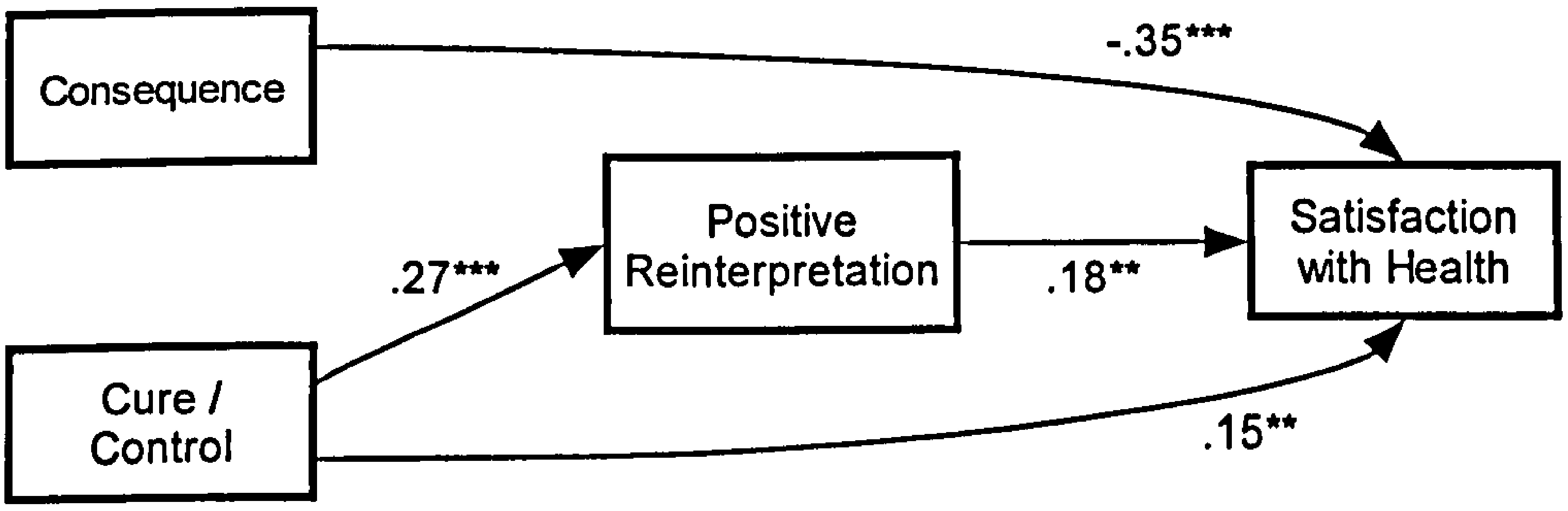
The second analysis examined the illness representation components and coping in relation to satisfaction with health for the IBS and IBD groups (Figure 4a and 4b).

Figure 4a Path analysis predicting satisfaction with health for the IBS Sufferers



Adjusted R^2 = .28 F(4, 202) = 21.2***
*$p<0.05$ **$p<0.01$ ***$p<0.001$

Figure 4b Path analysis predicting satisfaction with health for the IBD Sufferers



Adjusted R^2 = .19 F (3, 264) = 21.8***
*$p<0.05$ **$p<0.01$ ***$p<0.001$

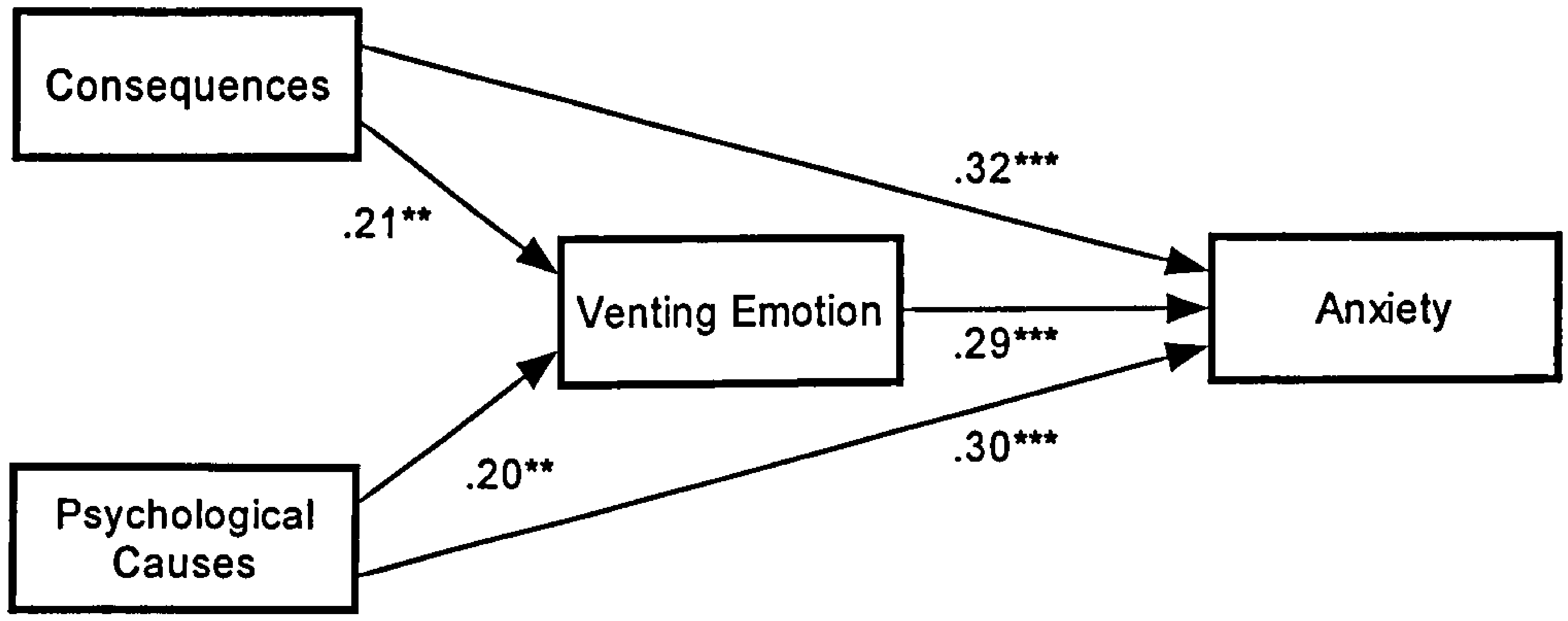
The IBS model accounted for 28% of the variance compared to 19% in the IBD model. Taking the IBS model first, those with strong feelings of control were likely to engage in active coping; active coping was related to greater satisfaction with health. The illness representation components of serious consequences, a belief in external cause, and feelings of control had direct relationships with satisfaction with health. Those people who reported few serious consequences and few external causal beliefs, but strong feelings of control, were more satisfied with their health. When these variables were entered into a hierarchical regression, with the illness components entered first and active coping second, coping added a significant 1.4% to the variance explained in satisfaction with health (R^2 change = 0.014, F(1, 202) = 4.05 $p<0.05$).

The IBD model was similar in that reporting few serious consequences and strong feelings of control were associated with greater satisfaction with health. The cure/control component was again mediated by an adaptive coping strategy, this time positive reinterpretation, which again was related positively to satisfaction with health. When these variables were entered into a hierarchical regression, with the two illness representation components entered first and positive reinterpretation entered second, coping added a significant 3% to the variance explained (R^2 change = 0.030, F(1, 264) = 9.89, $p<0.01$).

The third analysis examined how the representation components and coping strategies were related to anxiety (Figure 5a and 5b). The IBS model accounted for 40% of the variance, compared to 27% in the IBD model.

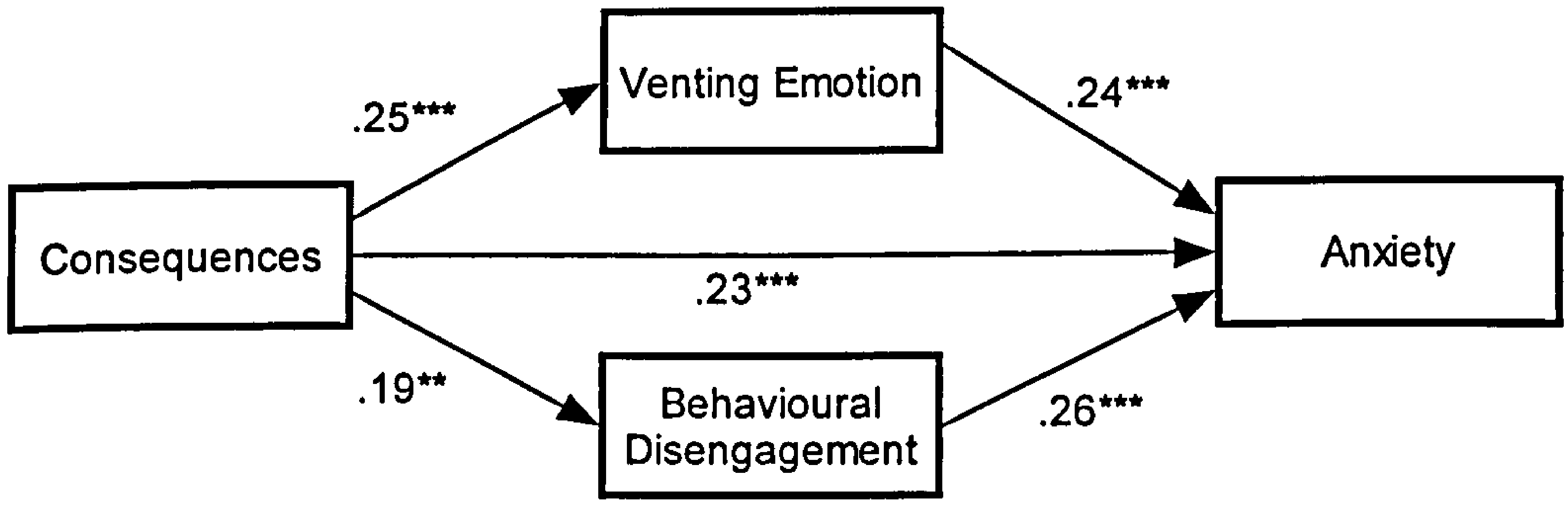
Beliefs that IBS was caused by psychological factors and reporting serious consequence beliefs were directly related to anxiety, and the effects of these two representation components were partially mediated by the coping strategy of venting emotions. When these variables were entered into a hierarchical regression, again with representation components entered first and coping entered second, venting emotions added a significant 7.4% to the variance explained in anxiety (R^2 change = 0.07, F(1, 203) = 25.4, $p<0.001$).

Figure 5a Path analysis predicting anxiety as a measure of psychological adjustment for the IBS sufferers



Adjusted $R^2 = .40$ F(3, 203) = 46.8***
**p<0.01 ***p<0.001

Figure 5b Path analysis predicting anxiety as a measure of psychological adjustment in IBD sufferers

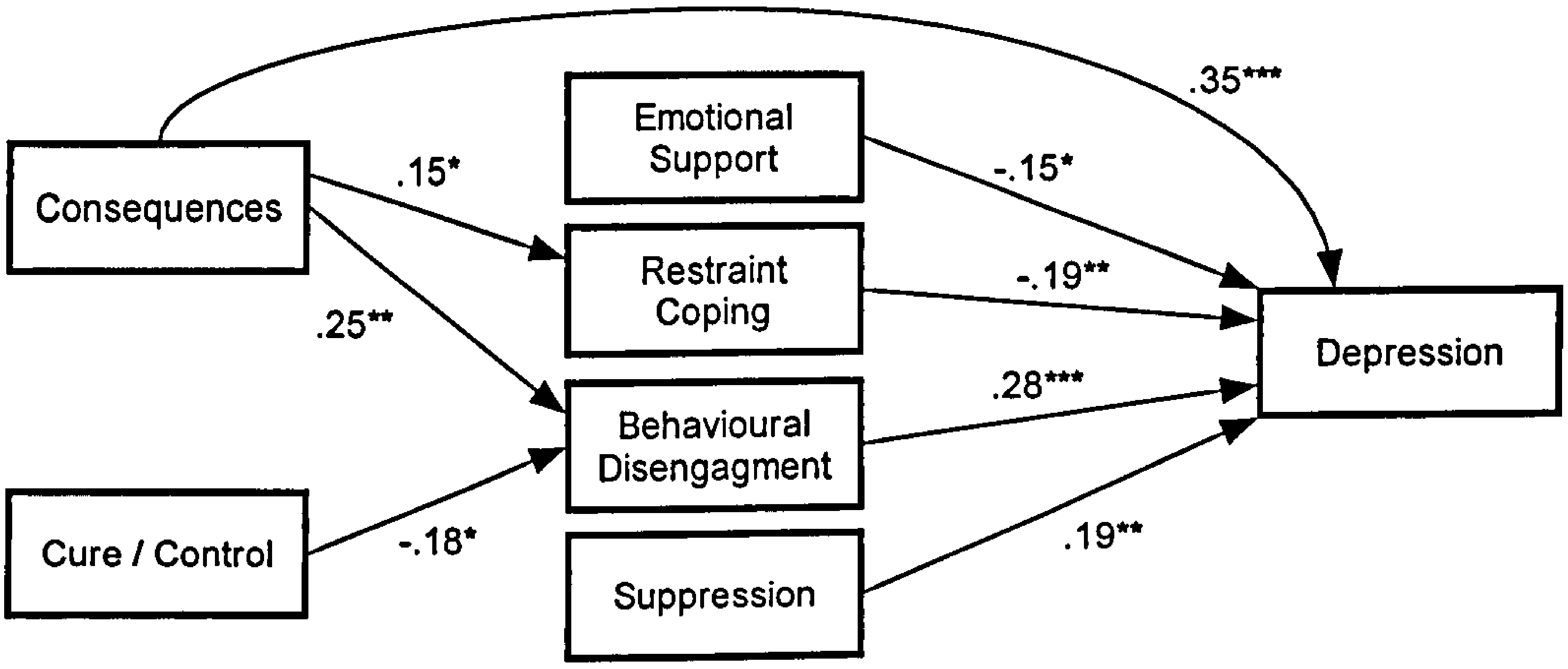


Adjusted $R^2 = .27$ F(3, 264) = 33.9***
**p<0.01 ***p<0.001

In the IBD model, the belief that IBD had serious consequences is directly related to anxiety. Those who believed that IBD had serious consequences were likely to vent their emotion and behaviourally disengage, both of which were related to anxiety. When these variables were entered into a hierarchical regression, with consequences entered first and venting emotions and behavioural disengagement entered second, coping added a significant 15% to the variance explained in anxiety (R^2 change = 0.15, F(2, 264) = 27.33, $p<0.001$).

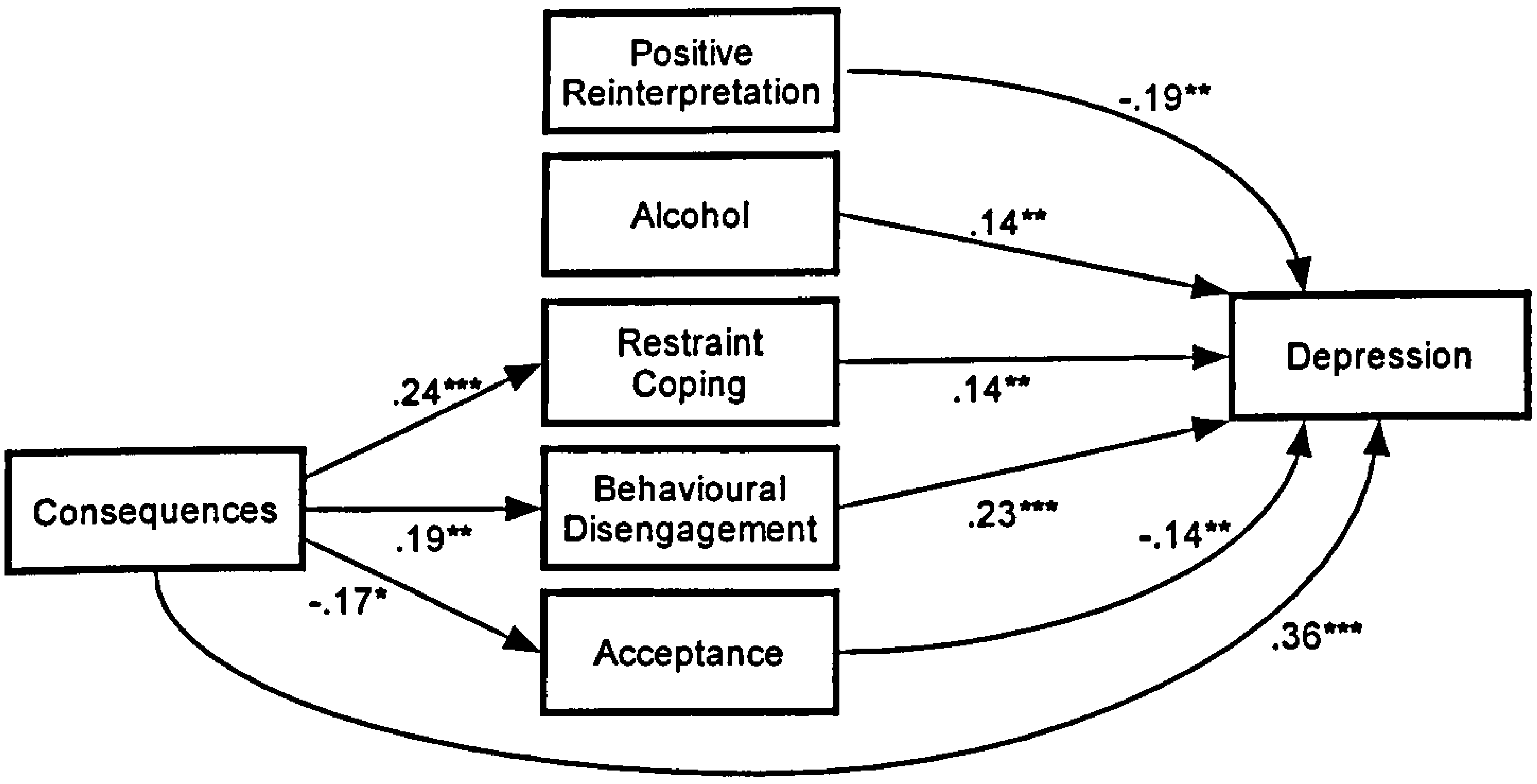
The final analysis examined depression as a measure of psychological adjustment (Figure 6a and 6b). The IBS model accounted for 30% of the variance, compared to 36% in the IBD model. For the IBS sufferers, those with weak control beliefs used behavioural disengagement; weak control beliefs led to behavioural disengagement which is associated with depression. Behavioural disengagement, along with restraint coping, partially mediated the effect of the consequences component - the reporting of serious consequences was also directly related to depression. The relationship between consequences, behavioural disengagement, and depression is relatively straightforward in that behavioural disengagement is identified with helplessness (Carver, Scheier and Weintraub, 1989) and reduces efforts to deal with the stressor. However, less straightforward is the relationship observed between consequences, restraint and depression. The belief in serious consequences is *positively* related to restraint coping, and restraint coping is *negatively* related to depression (showing an adaptive relationship). While restraint coping can be viewed as an avoidant coping strategy, Carver, Scheier and Weintraub, (1989) describe it as an *active* coping strategy "in the sense that the person's behaviour is focused on dealing effectively with the stressor, but it is also a passive strategy in the sense that using restraint means *not* acting" (p.269). In the context of depression restraint can be viewed as adaptive, however, restraint has earlier been shown to be associated with anxiety in IBS and depression in IBD, so this relationship should be interpreted with caution. Two coping strategies, seeking emotional support and suppression of competing activities were, independently of the representation components, contributors to the variance in depression. Once again all variables were entered into a hierarchical regression model with the representation components entered first and coping second. In the second step the four coping strategies added a significant 9.6% to the variance explained in depression (R^2 change = 0.096, F(4, 199) = 7.03, $p<0.001$).

Figure 6a Path analysis predicting depression as a measure of psychological adjustment in IBS sufferers



Adjusted R^2 = .30 F(6, 199) = 15.5***
*p<0.05 **p<0.01 ***p<0.001

Figure 6b Path analysis predicting depression as a measure of psychological adjustment in IBD sufferers



Adjusted R^2 = .36 F(6, 260) = 26.4***
*p<0.05 **p<0.01 ***p<0.001

The IBD model shows that restraint coping, behavioural disengagement and acceptance partially mediate the consequence representation component. However, here restraint coping was not associated with less depression; instead, along with behavioural disengagement it was associated with higher depression scores. Fewer serious consequence beliefs were associated with accepting IBD, which was related to lower depression scores.

Both alcohol and positive reinterpretation were independently of representation components associated with depression scores: using alcohol to cope was associated with high levels of depression, while positively reinterpreting the situation was associated with lower depression scores. When these variables were entered into a hierarchical regression, with consequences entered first and coping entered second, coping added a highly significant 17% to the variance explained in depression (R^2 change = 0.17, F(5, 260) = 14.59, $p<0.001$).

4. Further Analyses

4.1 The Role of Anxiety

Although anxiety has been used as an outcome measure in this research, it could be argued that it could be directing the cognitive representation of the illness. Anxiety has been measured in this study using the clinical "Hospital Anxiety and Depression Scale", and unsurprisingly, over one half of the IBS sufferers could be classified as clinically anxious, with 53.7% of this population of IBS sufferers scoring moderate to severe on the anxiety scale. This is unsurprising because the link between IBS and anxiety has been well established (Heaton et al. 1992; Creed et al. 1988). IBS researchers have shown that anxiety is more common than depression, and clinic patients have higher anxiety than those people who experience IBS yet who do not seek help for their symptoms. A cognitive-behavioural model of IBS has been suggested in which negative illness cognition and heightened anxiety interacts to maintain the experience of IBS. Toner et al. (1998) explain "cognitions such as "there must be a medical explanation for this pain" lead to certain behaviours (further medical consultations), increased attention and hypervigilance of bodily sensations and increased anxiety and arousal, which may lead to a heightened sensitivity to pain. During this process, sensations become amplified and are experienced as more noxious and intense, which may then lead to further thoughts that something must have been overlooked, leading to further physiological arousal and self scrutiny, which amplifies bodily sensations. These new sensations may be taken as confirmatory evidence of a physical cause. Independent of the original cause of the symptoms, cognitions about the illness and the associated anxiety serve to maintain and amplify symptoms" (p.219). More recently, a treatment manual for IBS describes a link between negative thought processes and the experience of anxiety, which is termed "bowel performance anxiety". The authors define this as "persistent, distressing apprehension about bowel symptoms in a public context, leading to avoidance of such situations or a heightened state of physiological arousal" (Toner et al. 2000, p. 115). The authors describe IBS patients as perfectionists with high levels of social desirability who "are likely to devote considerable attention to these symptoms and to make negative predictions with regard to the occurrence of the symptoms"(p. 116). It is possible therefore, that believing that an illness has serious consequences is directly related to the high anxiety levels exhibited by the IBS sufferers in this study. Therefore, the relationship between anxiety and consequences in predicting outcome was investigated further.

To determine how the consequence component differed by increasing anxiety, the IBS and IBD participants were separated into the four categories outlined earlier: normal anxiety; mild anxiety; moderate anxiety; and severe anxiety.

Table 21 Means and standard deviations of the consequence component by differing levels of anxiety for the IBS and IBD sufferers

	IBS		IBD	
	Mean	SD	Mean	SD
Normal Anxiety (0 – 7)	3.15	0.82	3.41	0.73
Mild Anxiety (8 – 10)	3.31	0.52	3.60	0.61
Moderate Anxiety (11 – 14)	3.57	0.63	3.78	0.57
Severe Anxiety (15 – 21)	3.91	0.56	4.21	0.47

It was observed that serious consequence beliefs increased with increasing levels of anxiety for both illness groups. Independent t-tests have shown that serious consequence beliefs increase significantly from those classified with moderate anxiety to those classified with severe anxiety (t (111) = -2.98, p<0.008 for IBS sufferers, and t (107) = -3.85, p<0.008 for IBD sufferers). A significant difference in consequence beliefs was also detected between those classified as having normal anxiety and those with severe anxiety (t(95) = -5.37, p<0.008 for IBS sufferers, and t(125) = -6.03, p<0.008) for IBD sufferers.

To determine whether the relationship of consequences and outcome (quality of life, satisfaction with health) differed as a function of anxiety, the interaction of consequences and anxiety was tested using hierarchical regression. While the beliefs in the serious consequences of illness and high anxiety scores were significant independent predictors of lower perceived quality of life and dissatisfaction with health, the interaction between the two predictor variables was not significant.

4.2 Multiple Investigations on Representation, Coping and Outcome

To examine whether the number of investigative tests had any impact upon the illness representation, coping and outcome of IBS and IBD sufferers, respondents were divided (by median split) into high and low investigations. The median number of investigations for IBS was four, and for the IBD group the median was five. A series of independent t-tests were computed. To control for Type I error, the Bonferoni adjustment was calculated to be p<0.002. No significant differences were detected for the IBD group.

However, reported physical quality of life was found to significantly differ for the IBS sufferers. Those who had experienced less than four investigations before IBS was diagnosed reported a significantly higher physical quality of life (t(204) = 3.34, p = 0.001). This relationship makes sense: those who experienced significant discomfort would be sent for more investigations. Three other relationships approached significance. Those IBS sufferers, who reported more than four investigations, reported that IBS had serious consequences, and reported a lower quality of life and satisfaction with health.

Table 22 Means and Standard deviations of the illness representation components and outcome measures for which a difference was detected: IBS sufferers

	Four or Fewer Investigations		Greater than Four Investigations				
	Mean	SD	Mean	SD	t	d.f.	sig
Physical QoL	13.5	3.0	12.0	3.1	3.3	207	.001
Consequences	3.4	0.7	3.6	0.6	-3.0	207	.003
General QoL	3.3	0.9	2.9	1.1	3.0	205	.003
Satisfaction	2.5	1.0	2.1	1.0	3.0	205	.003

Summary of Research Findings

This study was designed with three objectives. The first objective was to explore the relationships between the illness representation components of IBS and IBD sufferers. These relationships were compared to each other and to other illnesses reported in the literature. The second objective was to explore whether the representations of IBS and IBD sufferers can predict outcome. The third objective was to examine whether any links that may emerge between representations and outcome are mediated by coping.
In this section, each objective will be examined in turn.

The Illness Representations

A comparison of the means for the representation components of the two illness groups demonstrated that IBS sufferers have stronger psychological causal beliefs than IBD sufferers, and that IBD sufferers have greater chronic timeline beliefs than IBS sufferers. These were the only significant differences between the two illness groups, and both can be considered negative representation components because both are related to poor outcome. Strong psychological attributions were strongly associated with anxiety and depression for both IBS and IBD sufferers, dissatisfaction with health and a low quality of life (in psychological and social domains) for IBS sufferers, and a lower quality of life (in psychological, social and environmental domains) for IBD sufferers. A long timeline was related to a poor quality of life in general and in the physical and psychological domains for IBD sufferers, and weakly associated with dissatisfaction with health for the IBS sufferers. These differences may be due in part by the way the illness was explained to sufferers by health professionals, this difference will be examined in future studies using different populations of sufferers.

Univariate analyses demonstrated the interdependence of the illness representations in both patient groups. Similar patterns were found among the components of the IBS and IBD groups. The representation components of consequences and cure/control were significantly related to the other representations. Weaker control beliefs were related to the belief that the illness has serious consequences. Strong illness identity was related to a belief in serious consequences and weak feelings of control. A belief that the illness was caused by psychological factors was related to the reporting of serious consequences and the belief that the illness could be controlled. Reporting a chronic timeline was associated with a belief in serious consequences, and with weaker control beliefs.

In the IBS sample, stronger illness identity was related to the expectation that IBS would last a long time. Also a belief that IBS was caused by a germ/virus, pollution or poor medical care (i.e. external cause) was related to strong feelings of control. In the IBD sample, the belief that the illness was caused by external factors was related to beliefs about the serious consequences of IBD. Psychological causal beliefs were related to a short timeline and surprisingly, to external causal beliefs. Similar relationships between the representation components have been reported in CFS and MI patients (Moss-Morris, Petrie & Weinman, 1996; Petrie, Weinman, Sharpe & Buckley, 1996).

When comparing the patterns generated by the IBS and IBD sufferers to the CFS patients reported in the literature (Moss-Morris et al. 1996) similar relationships between avoidance behaviours and representations can be observed in the three patient groups. A belief in the serious consequences of the illness is related to both mental and behavioural disengagement in the IBS and IBD groups and just mental disengagement in the CFS group. A belief in the serious consequences of the illness is related to venting emotions in all three patient groups. The IBD and CFS sufferers who reported serious consequences were likely to report using suppression of competing activities. Restraint coping was not measured in the Moss-Morris study, however it was associated positively with a belief in the serious consequences of the illness in the IBS and IBD groups. In addition, similar associations between the representation component "cure/control", and four coping strategies: feelings of control over the illness are associated positively with active coping, planning and positive reinterpretation, and negatively with behavioural disengagement in the three illness groups. This makes sense in that a feeling of control encourages approach coping behaviours, while feelings of little control are associated with avoidance coping.

A belief that the illness will last a long time and weaker serious consequence beliefs are associated with acceptance in IBS sufferers. Also a chronic timeline, weaker beliefs in psychological causes and weaker control beliefs are associated with acceptance for IBD sufferers. Acceptance was not related significantly to any representation component or outcome measure in the CFS sample.

A belief that their illness was caused by emotional (or psychological) factors is associated with behavioural disengagement in IBS and CFS, the use of alcohol in IBS and IBD, and denial in IBD. Venting emotions is often considered a maladaptive coping strategy; a belief that the illness was caused by emotional factors is related to venting emotions in the IBS and IBD groups.

The aetiology of CFS is as uncertain as it is for IBS and IBD, however IBS and IBD sufferers are much more ready to believe that psychological factors may have played a part in causing their illness than the CFS sufferers. The majority of the CFS sample (Moss-Morris et al. 1996) agreed or strongly agreed that their CFS was due to physical (external) causes, whereas, the GI patient groups, IBS especially, favoured internal (psychological) causes. Whether this is a reflection of current medical thinking or the patients' own ideas regarding cause are unknown.

Stress was the most favoured psychological attribution, with 57.4% of IBS patients and 48.5% of IBD patients perceiving stress as the cause of their illness compared to 41% of CFS patients. Forty-five per cent of IBS sufferers, and 26% of IBD sufferers agreed or strongly agreed that their state of mind played a part in the development of their symptoms, compared to less than 12% in the CFS group.

Attributing illness to a germ or virus was the most favoured external attribution in the IBD group. Sixty-nine per cent of CFS sufferers report that a germ or

KENT TEMPLEMAN LIBRARY

virus caused their symptoms compared to 16.1% of IBS sufferers and 40.7% of IBD sufferers. Thirty per cent of CFS sufferers endorsed pollution as a cause of their illness compared to 7% of IBD sufferers and only 1.4% of the IBS sufferers. Thirty five per cent of the IBD group agreed that they developed their illness due to chance, compared to 19.8% of the IBS group and less than 12% of the CFS group. It is interesting to note that the organic GI group (IBD sufferers) were more likely to cite "chance" than the two functional groups (i.e. IBS and CFS). All three illnesses have poorly-defined aetiologies. As argued earlier these attributions may develop from physician explanations about the cause of the illness. If a physician cannot identify a specific illness, then he/she is more likely to suggest that emotional and / or psychological factors are causing illness. Citing "chance" is less pejorative and could possibly be more useful when answering questions about the cause of inflammation in a specific part of the GI tract.

As reported in Chapter 1, there is a firmly held belief by psychologists and the medical profession that those CFS sufferers who maintain that their CFS was caused by a germ or virus are relinquishing responsibility for their illness, and this is implicated as a possible maintaining factor. Moss-Morris, Petrie and Weinman (1996) strengthen this position by reporting that those CFS sufferers who cited *psychological* reasons for their illness (rather than a germ or virus), although reporting poorer psychological adjustment, scored higher on measures of vitality. However, strongly believing that psychological factors have caused illness is related to many negative coping strategies and outcome measures too. Psychological cause is related to a belief in the serious consequences of IBS and IBD. It is associated with the maladaptive and avoidant coping strategies, venting emotion, mental and behavioural disengagement, denial and using alcohol to cope. In addition, psychological causal beliefs were also associated with higher anxiety and depression scores and lower quality of life psychologically.

There is, however, an association between psychological cause beliefs and feelings of control over the illness. If the sufferer feels responsible in some way for their illness, it follows that they may feel they can control it, possibly by relaxation methods[1]. These feelings of control may contribute to poorer outcome over time if relaxation methods do not reduce the experience of symptoms. From the results presented here, it could be argued that the medical profession may be contributing to anxiety about illness status by placing so much emphasis on psychological factors as causal elements in IBS and IBD.

Predicting Outcome from Illness Representation

Univariate analyses of illness representation components and outcome measures revealed straightforward relationships for the IBS and IBD sufferers: a strong belief in the serious consequences of IBS was related to a lower perceived quality of life, less satisfaction with health, lower quality of life in all four domains, and greater anxiety and depression; strong control beliefs were associated with greater quality of life, more satisfaction with health, greater quality of life in the four domains and less depression. For the IBS sufferers, strong illness identity (high scores on the GI symptom inventory) was associated with a lower quality of life in general: lower quality of life in the physical, psychological and environmental domains, less satisfaction with health and more depression. Believing IBS to last for a long time is associated with dissatisfaction with health. The respondents who believed that their IBS was caused by psychological factors (stress, state of mind, own behaviour, other people) reported less satisfaction with health, lower quality of life in the psychological and social domains and higher scores for anxiety and depression. Those who believed that their IBS was caused by external factors (virus, pollution, poor medical care) reported a lower quality of life in the environmental domain. The IBD sufferers produced the same relationships as the IBS sufferers, although the magnitudes of the relationships were greater. More IBD relationships reached significance, however this could be attributed to the greater number of IBD participants.

---

[1] Although relaxation is often suggested to IBS and IBD sufferers, it does not always benefit individual patients.

This explanation seems likely when we examine the predictive models of the IBS and IBD sufferers. When the representation components were entered into standard regression models as criterion variables to predict the four outcome measures, (all the models significantly predicted outcome), the IBS models explained a greater amount of the variance in outcome than in the equivalent IBD model.

The biggest differences between the IBS and IBD models were detected when predicting anxiety. Here the representation components taken together explained 35% of the variance in anxiety, compared to 18% of variance explained in the IBD model. Four of the representation components independently contributed to the prediction of anxiety, and three of the relationships were identical for both the IBS and IBD models. Reporting that the illness was caused by psychological factors, that it has serious consequences and reporting weak control beliefs, helps to predict anxiety. The models differed slightly in the fourth independent predictor (however the fourth predictor only accounts for approximately 1.4% of the unique variance). Those IBS sufferers who cite external causes for their illness report less anxiety, whereas those IBD sufferers who report fewer GI symptoms report less anxiety.

The same three representation components were implicated in the prediction of depression: psychological causal attribution, serious consequence beliefs, and weak control beliefs. In the prediction of quality of life and satisfaction with health, only fewer serious consequence beliefs and strong control beliefs were associated with good outcome. The prediction of satisfaction with health produced a large difference in the variance explained for the two illness groups. The IBS model explained approximately 28% of the variance, compared to 18% in the equivalent IBD model. Much of the difference in these models can be attributed to the consequence component, which uniquely explained approximately 13% in the IBS model compared to only 6.8% in the IBD model. The second objective of this study was to explore whether the illness representations of IBS and IBD sufferers predict outcome, the data presented in this chapter suggests that they can.

Mediation of Representation Components by Coping

Instead of the multiple measures of quality of life two one item measures were chosen: "How do you rate your quality of life?" and "How satisfied are you with your health?" These two items are presented before any of the other quality of life statements and are presented in sequence so that the participant realises that they are both different concepts almost immediately. This is supported when we examine the response distribution of the answers to these statements. It is believed that the two items are clear enough in their concepts, and directly assess the participants' perception of these concepts.

After determining that the representation components can predict outcome, path analyses using multiple linear regression were computed to examine how much coping adds to the predictive models. Mediation was observed in the path analyses conducted. All eight models show that representations are partially mediated by coping strategies, and one demonstrated true mediation – weak cure / control beliefs were mediated by behavioural disengagement which then predicted depression for the IBS sufferers.

Direct paths were observed between the representation components and the four outcome variables: quality of life, satisfaction with health, anxiety and depression. The consequence component is the most strongly associated component. It has a direct path to outcome in every model.

When predicting quality of life, consequences and cure / control directly contributed to the variance explained in outcome for the IBS sufferers. For the IBD group, consequences and cure / control were joined by illness identity and external cause. Predicting satisfaction with health also showed consequence and cure / control as important predictors for both IBS and IBD, however the IBS model also showed external cause contributing to outcome. When predicting anxiety and depression, the consequence component was a very important predictor, only psychological causes showed another direct path for the IBS sufferers when predicting anxiety.

In the majority of cases, the consequence component was mediated by coping strategies. The effect of the serious consequence belief on outcome was mediated by a number of different coping strategies, most notably venting emotions, and behavioural disengagement. Both have been related to poorer psychological adjustment, slower recovery, and increased distress in other illness groups (e.g. Felton, Revenson and Hindrichsen, 1984; Moss-Morris, Petrie and Weinman, 1996). Few serious consequences were mediated by the adaptive coping strategies of acceptance and seeking instrumental support. Strong feelings of control were mediated by adaptive coping strategies - active coping, positive reinterpretation, seeking instrumental and emotional support. When predicting anxiety, the belief that IBS was caused by psychological factors was partially mediated by venting emotions.

Where mediation was detected, differences in the variance that coping explained was observed between the two illness groups. When predicting quality of life, coping contributed 6% of the 32% variance explained in the IBS model, compared to 2% of the 25% explained in the IBD model. For IBS sufferers, when predicting satisfaction with health, the model showed 30% of the variance in outcome is explained, and yet coping explained just 1.4%. In the corresponding IBD model, coping added 3% to the 19% variance explained. In the anxiety model, coping contributed just 7% of the variance, with consequences and a belief that IBS was caused by psychological factors explaining over 30% of the variance in anxiety. The corresponding IBD model only had one significant component predictor: consequences. It accounted for approximately 10% of the variance in outcome, and coping contributed 15% to the variance explained. In the depression models coping contributed approximately 10% in the IBS model compared to 17% in the IBD model. This data suggests that coping may be playing a larger role in the prediction of outcome for IBD sufferers than for IBS sufferers.

Comparison of the IBS and IBD models

The two sets of models are similar in that (1) the direct paths from representations to outcome are identical: a belief in serious consequences, strong illness identity, psychological causal beliefs, and weak control beliefs are all associated with a lower quality of life and poorer psychological adjustment, and (2) similar coping strategies appear in the models, with acceptance, positive reinterpretation and active coping leading to positive outcomes, and venting emotions, mental and behavioural disengagement leading to poorer outcomes.

The IBS models explained more of the variance in the perception of quality of life (32%, compared to 25% in the IBD model), satisfaction with health (30% compared to 19% in the IBD model), and anxiety (40% compared to 27%). When predicting depression the IBD model explained more of the variance (36% compared to 30% in the IBD model).

One large difference between the paired models was when predicting anxiety: here the IBS model explained 40% of the variance, compared to 27% in the IBD model. The greater amount of variance explained could be due in part to the additional representation component: psychological causes. Blaming oneself for the illness, and trying to control it by keeping emotions in check, will no doubt impact upon the amount of anxiety experienced. However, as stated earlier, many studies have reported that IBS sufferers score higher on measures of anxiety, and it could be that catastrophising cognitions are playing a part. This is a point to which I will return in the Discussion (Chapter 7). It was predicted that the IBS models would be more predictive than the IBD models since psychological factors are more readily implicated in functional illness. The models presented in this chapter support this prediction.

Anxiety

While serious consequence beliefs increased with increasing anxiety for both illness groups, the interaction between anxiety and consequences was not significant. Thus showing that serious consequence beliefs do not increase as a function of anxiety when predicting perceived quality of life or reported satisfaction with health.

Multiple Investigations upon Representation, Coping and Outcome

Those IBS sufferers who have experienced more investigations to rule out organic disease reported lower quality of life in the physical domain, reported lower perceived quality of life, reported more dissatisfaction with health, and reported greater serious consequence beliefs than those IBS sufferers diagnosed with fewer investigations. As reported in Chapter 2, IBS does not have objective symptom markers and there are many investigations available to the gastroenterologist to rule out organic disease. If a gastroenterologist refers the IBS sufferer for many and often quite unpleasant tests, then the belief that organic illness is present may be reinforced; the negative results may encourage the sufferer to believe that organic illness has been missed. There is extensive media coverage of mistakes and blunders within the overstretched NHS at present, which may promote beliefs like this. In addition, receiving negative results for each investigation provides no efficient "payback" for the invasive procedure, possibly leaving the sufferer feeling confused and perplexed. The data reported here supports the call for the positive diagnosis of IBS to be based upon symptom criteria as much as possible and to avoid repeated referrals for different procedures.

Limitations of the Current Study

This examination has been based on cross-sectional data, therefore we cannot be sure that the representations, coping behaviours and outcome variables are associated with each other in the direction presented here. It is possible that the poor quality of life and poor psychological adjustment experienced determine the illness beliefs and coping behaviours. Or indeed coping behaviours may directly influence the representation components.

This data will be compared to later studies in which longitudinal data has been collected to determine the effectiveness of cross-sectional designs in the evaluation of the commonsense model. It was predicted that the effect of the illness representation components on outcome would be partially mediated by coping behaviours. The cross-sectional data presented in this chapter support this hypothesis, however longitudinal analysis is needed before clear conclusions can be drawn.

Summary and Conclusion

This cross-sectional study has shown that: firstly, the representations of IBS and IBD sufferers are similar to each other, although IBS sufferers are likely to report stronger psychological causal beliefs; secondly, causal attributions of the two GI groups are more internal and emotional than the extensively reported external attributions of CFS sufferers (e.g. Moss-Morris et al. 1996); thirdly, the illness representation components can successfully predict outcome and consequences and cure / control are the strongest predictors; fourthly, partial mediation of the representation components was detected; fifthly, numerous investigations are related to poorer quality of life in general and in the physical domain, more dissatisfaction with health and more serious consequence beliefs; and finally, the IBS models are more predictive than the IBD models in predicting outcome using cross-sectional data.

Overall, this first cross-sectional study has provided evidence that the illness representation components are associated with coping strategies and measures of outcome. However, because the study was cross-sectional, causal direction could not be determined. Therefore, a prospective design in which representations are measured at Time 1 and coping and outcome are measured on subsequent occasions is needed. In study 2, outlined in the next chapter, a prospective longitudinal design is used.

Chapter 4

Illness Representation, Coping and Outcome of New Self-Help Group Members: A Longitudinal Study of IBS Sufferers

Introduction

As reported in Chapters 2 and 3, the majority of research investigating the commonsense model has recruited from self-help organisations. Chapter 3 presented a cross-sectional study that involved members of the IBS Network (and NACC - the National Association of Colitis and Crohn's Disease). The study showed that the illness representations of IBS sufferers were associated with quality of life, satisfaction with health and psychological adjustment. While the effect of the representation was sometimes mediated by coping behaviours, coping played a smaller part in the IBS models compared to the IBD models; thus, the representation components were stronger predictors of outcome than coping behaviours for IBS sufferers. The illness beliefs (representation components) of (serious) consequences and (weak) control were strong predictors of (poor) outcome for the IBS population. These representation components were related to each other, as well as the other representation components. Serious consequences and weak control beliefs were associated with strong illness identity and a long timeline. Believing that IBS was caused by psychological factors was associated with serious consequences, but *stronger* feelings of cure/control. A belief that IBS was caused by external factors (e.g. a virus) was associated with strong cure/control beliefs.

As this data was collected from established members of the IBS Network,[1] it is not possible to examine whether representation components were altered or shaped by the Network. Therefore, this study was designed so that representations, coping and outcome could be determined at the start of

---

[1] Although length of membership was not measured, it is expected that the majority of respondents will have been members for over one year

Network membership, and again eight months later[2]. All measures completed by participants in the cross-sectional study (Chapter 3) were selected again so that comparisons between studies could be made.

Hypotheses of the Study

From the data examined in Chapter 3, the study was designed to test three hypotheses.

1. The first concerns the relationships between the illness representation components of IBS sufferers before and after joining a self-help organisation. It is predicted that the representation components will change as sufferers receive both professional and lay information about their illness.
2. The second hypothesis was that both Time 1 and Time 2 representation components of the IBS sufferers will predict Time 2 outcome.
3. The third prediction was, that if representation components predict outcome, that these links are mediated by coping.

Design and Procedure

The IBS Network is a UK charitable support network providing information and support for approximately 3000 IBS sufferers. As a member of the Network, sufferers receive a quarterly newsletter, Gut Reaction (GR). GR started in 1991 as a two-page black and white newsletter. Since becoming a charity in 1996, the newsletter has been updated, now GR (also titled the Journal of the IBS Network) is printed in colour and runs to sixteen pages. Each issue carries a lead article, usually from medical practitioners, complementary therapists, or psychologists examining a range of topics related to the experience of IBS. Moreover, regular features include a question and answer page by a consultant gastroenterologist and analytical psychotherapist, an update of the latest research, and a letters page for sufferers to share their

---

[2] Eight months was chosen as a suitable timeframe, because it allows all participants to receive at least 2 newsletters

experiences of IBS. In addition, the newsletter runs cartoons (illustrated by a fellow sufferer), which provide a light-hearted look at the experience of IBS.

After consultation with the Network trustees, it was decided that the most effective way of recruiting for the study would be by placing an information sheet (see appendix B1) in the *new member welcome pack*[3]. A welcome pack is sent to a new member as soon as their £15 membership fee has been paid. The recruitment for this study took place over 5 months from January 2000 till May 2000, thus allowing till January 2001 for the last of the data collection.

Four hundred information sheets were delivered to the Network office for manual inclusion in the welcome packs for new members. Ninety-two people returned the information sheet, giving their consent for their participation in the study. At the end of the recruitment phase (May 2000), Network staff counted approximately 200 information sheets left in their office, thus showing a response rate of approximately 46%.

On the receipt of each information sheet, a Time 1 questionnaire (appendix B3) and letter (appendix B2) were sent out to respondents. Eighty-three people returned the Time 1 questionnaire (9 did not return the Time 1 questionnaire, these people were not contacted again). The first page of the Time 1 questionnaire asked respondents to write the date; it was made clear to the individual that the second questionnaire would be posted 8 months from that date.

The Time 2 letter (appendix B4) and questionnaire (appendix B5) were sent out eight months after the Time 1 questionnaire was completed. Most respondents (N=45) returned this questionnaire within two weeks (54.2%). If a questionnaire was not received one month after it was posted, a reminder

---

[3] Each welcome pack already contains several leaflets - promoting services provided by the network and also advice for those interested in obtaining more specific information, (e.g. fact sheets, recommended IBS self-help books, the IBS helpline number).

card was sent out explaining that the Time 1 information could not be used without the new information. If a questionnaire was not received 2 weeks after that date, a final reminder card was sent out. In total only 9 participants failed to complete the Time 2 questionnaire. No reasons for attrition were given. The data presented in this chapter is only for those individuals who participated in both waves of data collection (N = 74). The demographic details of the new member sample are presented in Table 1.

Participants

Once again the IBS gender bias is reflected in the sample here with 70% of the sample female. The age of the participants in this sample ranged from 19 to 87 with a mean age of 47.7. Fifty six percent of the sample was married and the majority of the sample was employed.

Table 1 Descriptive demographic information of the new members

	N	%
Sex		
Male	22	29.7
Female	52	70.3
Age		
0-20 years	2	2.7
21-30 years	8	10.8
31-40 years	21	28.4
41-50 years	12	16.2
51-60 years	11	14.9
61-70 years	12	16.2
70 + years	7	9.5
Not Reported	1	1.4
Marital Status		
Single	17	23.0
Married	42	56.8
Divorced	3	4.1
Widowed	4	5.4
Cohabiting	8	10.8
Occupation		
No Occupation	7	9.5
Retired	19	25.7
Manual	8	10.8
Administration	6	8.1
Professional	10	13.5
Student	1	1.4
Other	23	31.1

The self reported mean length of the illness was 11.2 years (SD = 11.2) and the time from diagnosis was 5.8 years (SD = 7.8). Fifty one percent of the sample had been diagnosed with IBS in the previous 2 years. Sick leave (over the last 12 months) ranged from 0-365. The mean was 24.4 (SD = 59.9) days and the median was 5 days. The mean days sick were quite high, however only 7 sufferers reported over 30 days taken as sick leave. This is reflected by the mode, which was zero, showing that the majority of respondents reported taking no sick days in response to their gastrointestinal symptoms. Those who stated that they had no occupation were asked whether this was connected to their illness. Four (non-working) IBS sufferers claimed that their symptoms were the reason why they were unemployed - reflecting the diversity of the IBS prognosis.

The participants were asked to estimate how often they had been to see their GP in the past year, responses ranged from 1 to 50. While the mean was 9.4 times (SD = 10.0), the modal response was 3 times.

The participants were asked to indicate which investigations they received before a diagnosis of IBS was given. Participants were presented with a list of nine common investigations; they were asked to tick those experienced. The same nine investigations from the first study were presented (barium meal, barium enema, colonoscopy, rectal examination, blood test, urine sample, stool sample, ultrasound scan and endoscopy). The responses were summed to give an investigations score ranging from 0 – 9, with high scores indicating more investigations. The IBS sufferers reported a mean of 3.0 (SD = 2.0) investigations. The four most frequently cited investigations reported by these IBS sufferers were a blood test (N = 46: 55.4%), rectal examination (N = 39: 47%), barium enema (N = 27: 32.5%) and stool sample (N=27: 32.5%).

Measures

All measures used in the previous study were selected again to examine the illness representation, coping and outcome of the new members.

Illness Representation

The Illness Perception Questionnaire (IPQ) ***(Weinman, Petrie, Moss-Morris and Horne, 1996)*** Lower scores indicate fewer reported consequences of the illness, weaker cure/control beliefs and a short timeline; high scores represent serious consequences, stronger cure/control beliefs and a longer timeline. Psychological cause and external cause were once again selected as the causal components. The same GI symptom measure was used to assess illness identity. For more detail regarding this measure, see Chapter 3.

Coping

COPE ***(Carver, Scheier and Weintraub, 1989)*** The scores for each of the 15 scales range from 4 -16, which indicates the extent to which the IBS sufferers typically employ this type of coping behaviour. The higher the score on each scale, the greater the extent to which the coping behaviour is typically employed by participants to cope with their symptoms. The COPE allows examination of individual coping behaviours as well as a combination of specific behaviours regarding approach and avoidance.

Outcome

WHOQOL-Bref ***(Division of Mental Health, WHO, Geneva, 1999)*** The two one-item measures supplied by the WHOQOL, "*How would you rate your quality of life?*" and "*How satisfied are you with your health?*" are retained as the quality of life and perceived health measures. Respondents rate their response on 5-point scales pertaining to how they have been feeling over the previous two weeks. Higher scores denote a higher quality of life and greater satisfaction with health.

The Hospital Anxiety and Depression Scale (HADS) ***(Zigmond and Snaith, 1983)*** Respondents were asked to respond to how they had been feeling over the last two weeks, on four-point scales. Higher scores indicate greater anxiety or depression.

Results

The results will be presented according to the hypotheses outlined on page 111.

1. The first hypothesis was concerned with the relationships between the representation components at the time of joining the self-help organisation and again, eight months later. Firstly, the Time 1 and Time 2 representation components of the IBS sufferers will be presented. Secondly, the Time 1 and Time 2 representation components will be compared statistically to determine change. Thirdly, relationships between the Time 1 and Time 2 components will be explored.
2. The second prediction was that the Time 1 and Time 2 representation components will predict outcome. Firstly, outcome measures from Time 1 and Time 2 will be examined and compared statistically. Secondly, the relationships between representation components and outcome are presented. Thirdly standard regression models are presented to examine the prediction of outcome by the Time 1 and Time 2 representation components.
3. The third hypothesis was that the links that emerge between representations and outcome will be mediated by coping. Firstly, the 15 coping behaviours are examined at the two Time points. Secondly, the relationships between the representation components and coping behaviours are presented. Thirdly, relationships between coping and outcome are presented. Fourthly, because of the limited number of participants the fifteen COPE scales are merged into three subscales (problem focused, emotion focused and avoidant coping) so that the coping data becomes more manageable. Finally, the theorised role of coping will be examined by path analysis using multiple linear regression.

1. The Illness Representations

1.1 The Representation Components

Illness Identity The three most frequently perceived symptoms at Time 1 (by reporting the experience of the symptom more than once every week) were wind (79.7%), bloating of the abdomen (63.5%), and rumblings and grumblings (54.1%). This symptom profile is consistent with the IBS sample from Chapter 3, only rumbling and grumbling and bloating were second and third respectively. At Time 2, the three most frequently perceived symptoms (by reporting the experience of the symptom more than once every week) were wind (67.6%), bloating of the abdomen (51.4%), and rumblings and grumblings (47.3%). The data here suggest that the most common symptoms are perceived less frequently at Time 2.

Causal attribution At Time 1, the most commonly reported causal attributions (where participants agreed or strongly agreed with the statement) were stress (67.6%), state of mind (43.2%) and diet (39.2%). After being a member of the IBS Network for eight months, the most commonly reported causal attributions for the new members were once again, stress (62.2%), state of mind (40.5%) and diet (31.1%). It is interesting to see that while the three most implicated causes are still implicated at Time 2, there are fewer people citing them as potential causes of IBS. The IBS Network does not endorse any particular cause of IBS; rather it takes the position that IBS is likely to result from interplay of many factors. Therefore, it could be argued that rigid ideas regarding the cause of IBS may become weaker with length of membership.

It was observed once again, that sufferers were more likely to disagree with a causal attribution rather than agree with one (no causal attribution produced a mean of 4 or above). Only "stress" (mean at Time 1 = 3.9, SD = 1.1; mean at Time 2 = 3.9, SD = 1.2) and "state of mind" (mean at Time 1 = 3.2, SD = 1.2; mean at Time 2 = 3.2, SD= 1.3) produced a mean above 3.

For analysis, the psychological cause (stress, state of mind, other people and own behaviour) and external cause (germ/virus, pollution, poor medical care) components used in the previous study were calculated for the new members.

1.2 Statistical Comparison of Time 1 and Time 2 Representation Components

Table 2 shows the means, standard deviations, and reliabilities for each of the illness representation components for both Time points. The data show that there were no significant differences between Time 1 and Time 2 representation components. Not as many serious consequences were reported at Time 2, however this is not a significant change after the Bonferoni adjustment was computed to control for type I errors (alpha is lowered to p<0.008). Note that the identity measure is higher than the other representations because it is summed, not averaged like the other components.

Table 2 Means, standard deviations, and alphas of the representation components for IBS sufferers

Representation Components	Time 1 Mean	SD	α	Time 2 Mean	SD	α	t values	df
GI Symptom Score	22.7	5.4	.35	22.0	6.0	.63	0.86	73
Psychological Cause	3.2	0.8	.62	3.0	0.9	.71	1.97	70
External cause	2.2	0.8	.53	2.1	0.8	.49	0.59	70
Timeline	3.8	0.8	.78	3.9	0.8	.82	-0.62	70
Consequences	3.4	0.7	.78	3.3	0.8	.81	2.06*	70
Cure / Control	3.3	0.7	.70	3.4	0.8	.80	-0.80	70

NB: Higher symptom scores indicate more perception of symptoms. A higher score on the causal representation components shows more agreement with the causal factor. Lower scores indicate a shorter timeline, fewer reported consequences and weaker cure/control beliefs.
*$p < 0.05$

1.3 Relationships Among Time 1 and Time 2 Representation Components

Univariate correlations were carried out on the Time 1 and Time 2 representation components (Table 3).

Table 3 Univariate relationships between the illness representation components at Time 1 and Time 2 for the IBS new members: Pearson's r

		(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)
(1)	Identity (T1)	1.0											
(2)	Identity (T2)	.38***	1.0										
(3)	Psychological Cause (T1)	.16	-.08	1.0									
(4)	Psychological Cause (T2)	-.07	-.10	.60***	1.0								
(5)	External Cause (T1)	.01	.20	-.05	-.07	1.0							
(6)	External Cause (T2)	-.10	.07	-.19	-.14	.65***	1.0						
(7)	Timeline (T1)	.09	.22	-.11	-.14	-.04	-.07	1.0					
(8)	Timeline (T2)	-.03	.33**	-.13	-.13	-.09	-.20	.47***	1.0				
(9)	Consequences (T1)	.03	.08	.25*	-.02	.06	-.05	.17	.22	1.0			
(10)	Consequences (T2)	.02	.34**	.24*	.10	.00	.02	.31	.38***	.67***	1.0		
(11)	Cure / Control (T1)	-.01	-.30*	.23	.31**	.02	-.01	-.29*	-.29*	-.23	-.15	1.0	
(12)	Cure / Control (T2)	.03	-.31**	.19	.27*	.01	-.12	-.27*	-.52***	-.13	-.38***	.62***	1.0

*p<.05, **p<.01, ***p<.001

It can be observed that representation components measured at Time 1 and again at Time 2 were strongly related to each other, (all $p<0.001$). An examination of the data demonstrated that relationships between the Time 2 measures were the strongest. At Time 2, long timeline beliefs were associated with serious consequence beliefs ($r= .38$, $p<0.001$), and weaker control beliefs ($r= -.52$, $p<0.001$). In addition, Time 2 measures of serious consequence beliefs were associated with weak feelings of control at Time 2 ($r= -.38$, $p<0.001$). Strong illness identity at Time 2 was significantly associated with the Time 2 components, long timeline ($r= .33$, $p<0.01$), serious consequences of IBS ($r= .34$, $p<0.01$), and weak perceived control ($r= -.31$, $p<0.01$). The belief that IBS was caused by psychological factors upon joining the Network (Time 1) was related to the belief that IBS has serious consequences (Time 1) upon joining ($r= .25$, $p<0.05$) and again 8 months later (Time 2) ($r= .24$, $p<0.05$). Citing that IBS has psychological causes at Time 2 was associated with strong control beliefs at Time 1 ($r= .31$, $p<0.01$) and Time 2 ($r= .27$, $p<0.05$).

2. Predicting Outcome

2.1 Statistical Comparison of Time 1 and Time 2 Outcome

An examination of the outcome measures shows that all four outcomes have changed in the expected direction (improvement), however only anxiety and depression have significantly changed (Table 5). At the adjusted alpha of $p=0.013$, (Bonferoni adjustment) anxiety scores have reduced significantly ($t\ (72)= 2.92$, $p=0.005$), and the reduction in depression is approaching significance ($t\ (72)= 2.53$, $p=0.014$).

Table 4 Means and standard deviations of the outcome measures for the IBS sufferers at Time 1 and Time 2

Outcome Measure	Time 1		Time 2			
	Mean	SD	Mean	SD	t value	df
General Quality of Life	3.3	0.94	3.5	1.1	-1.65	70
Satisfaction with Health	2.4	1.0	2.6	1.1	-1.23	70
Anxiety	10.8	4.5	9.3	4.2	2.92**	72
Depression	6.8	3.6	5.8	3.6	2.53*	72

General quality of life and satisfaction with health are single items, range 1-5. Anxiety and depression scores range 0-21 with higher scores indicating more psychological disturbance.
*p<0.05, **p<0.01

The Time 1 means (upon joining the IBS Network) are more closely related to the descriptive data from the cross-sectional study presented in Chapter 3 than are the Time 2 means. It would be expected that the Time 2 means would better resemble the cross-sectional data, as both come from established members of the IBS Network. It could be argued that this is a result of the smaller sample size, or possibly that over time the initial comforting effect of becoming a member may wear off. This same trend is reflected in the anxiety data: Time 1 anxiety scores more closely resemble those of the IBS Network members examined in the previous study. Time 1 data show that 51.3% of the participants could be classified as having moderate to severe anxiety, this figure drops to 36.5% at Time 2.

2.2 Relationships between Representation Components and Outcome Measures

Univariate correlations were computed between the Time 1 illness representation components and the four outcome measures at both Time points to examine how patients' views of their illness related to outcome measures over time. Because of the large number of relationships examined, only those that reach the more conservative significance level of $p<0.01$ will be presented.

The reporting of serious consequences at Time 1 was associated with a lower perceived quality of life at Time 1 ($r=-.46$, $p<0.001$). Strong control beliefs at Time 1 were associated with good quality of life at Time 1 ($r=.38$, $p=0.001$). Good quality of life at Time 1 was related to strong feelings of control at Time 2 ($r= .46$, $p<0.001$). Serious consequence beliefs at Time 1 were associated negatively with Time 2 quality of life ($r= -.39$, $p=0.001$). Serious consequence beliefs at Time 2 were associated negatively with Time 2 quality of life ($r= -.47$, $p<0.001$). Quality of life at Time 2 was associated positively with control beliefs at Time 1 ($r= .39$, $p=0.001$) and Time 2 ($r= .60$, $p<0.001$).

Reporting serious consequences of IBS at Time 1 was associated negatively with satisfaction with health at Time 1 ($r= -.52$, $p<0.001$). Strong feelings of control at Time 1 were associated positively with satisfaction with health at

Time 1 (r = .33, p<0.01). Satisfaction with health at Time 1 was associated with short timeline beliefs at Time 2 (r= -.34, p<0.01) and strong psychological causal beliefs at Time 2 (r= .30, p=0.01). Satisfaction with health at Time 2 was associated negatively with serious consequences at Time 1 (r= -.38, p=0.001) and Time 2 (r= -.53, p<0.001), and short timeline beliefs at Time 2 (r= -.37, p<0.01) and strong control beliefs at Time 2(r= .49, p<0.001).

Anxiety at Time 1 was associated positively with Time 1 psychological causal attributions (r= .31, p<0.01). Anxiety at Time 2 was associated positively with serious consequences at Time 2 (r= .31, p<0.01) and negatively with Time 2 control (r= -.34, p<0.01).

Depression at Time 1 was associated positively with long timeline beliefs at Time 1 (r= .32, p<0.01), serious consequences at Time 1 (r= .46, p<0.001) and Time 2 (r= .40, p<0.01), and negatively to control at Time 2 (r= -.34, p<0.01). Depression at Time 2 was associated positively with serious consequence beliefs at Time 1 (r=.35, p<0.01) and Time 2 (r= .36, p<0.01), and negatively to control beliefs at Time 2 (r= -.43, p<0.001).

2.3 Representation Components Predicting Outcome

One of the objectives for this study was to explore whether the illness representation could predict outcome as was shown in the previous study (Chapter 3). To this end a series of four regression models were computed. Each analysis is presented in pairs for each outcome measure, so that the Time 1 and Time 2 predictors (i.e. representation components) can be directly compared. These analyses are presented in Tables 5 - 12.

As can be observed in Table 5 below, the Time 2 representation components taken together accounted for more of the variance in general quality of life than the Time 1 components (22% compared to 44% of the variance accounted for). Few consequence beliefs and strong feelings of control were implicated in both models however the Time 2 representation components were stronger. Serious consequence beliefs alone explained 8.4% of the variance in the DV at Time 1, and 9% at Time 2 (sr^2). Strong control beliefs explained 6.8% of the variance at Time 1, which increased to 13.7% at Time 2, thus concurrent feelings of control may be important when evaluating quality of life.

Table 5 Predicting (Time 2) *general quality of life* from the Time 1 and Time 2 representation components

	Time 1			Time 2		
	B	β	*sr*	B	β	*sr*
Identity	.00	.06	.06	.00	.09	.08
Psychological Cause	.00	.06	.05	.11	.08	.08
External Cause	-.17	-.11	-.10	-.25	-.17	-.15
Timeline	-.18	-.13	-.12	.00	.02	.02
Consequences	-.47	-.32**	-.29	-.46	-.34**	-.30
Cure/Control	.49	.29*	.26	.65	.47***	.37
		ΔR^2 = .22			ΔR^2 =.44	
		F = 4.17**			F = 9.88***	
		d.f. = 6, 63			d.f. = 6, 63	

*p<.05, **p<.01, ***p<.001

Table 6 Predicting (Time 2) *satisfaction with health* from the Time 1 and Time 2 representation components

	Time 1			Time 2		
	B	β	*sr*	B	β	*sr*
Identity	.00	.00	.00	.00	-.02	-.02
Psychological Cause	.00	-.01	.00	.01	.04	.03
External Cause	-.27	-.17	-.16	-.19	-.12	-.11
Timeline	.00	-.06	-.06	-.16	-.12	-.09
Consequences	-.47	-.31*	-.28	-.54	-.39**	-.33
Cure/Control	.38	.22	.20	.37	.26*	.20
		ΔR^2 = .15			ΔR^2 =.35	
		F = 2.97*			F = 7.06***	
		d.f. = 6, 63			d.f. = 6, 63	

*p<.05, **p<.01, ***p<.001

As can be observed in Table 6 above, when predicting satisfaction with health, the Time 2 representation components predicted Time 2 outcome better than did the Time 1 representation components. The Time 2 model explained 35% of the variance in satisfaction with health compared to only 15% in the Time 1 model. The belief that IBS did not have serious consequences contributed 7.8% of the variance explained in the Time 1 model, which increased to 10.9% in the Time 2 model. Also strong control beliefs accounted for 4% of the variance explained in the Time 2 model. Serious consequence beliefs strongly predicted satisfaction with health.

Table 7 Predicting (Time 2) *anxiety* from the Time 1 and Time 2 representation components

	Time 1			Time 2		
	B	*β*	*sr*	B	*β*	*sr*
Identity	.00	.08	.08	.00	.04	.03
Psychological Cause	1.42	.27*	.24	.96	.19	.18
External Cause	.36	.07	.06	-.31	-.06	-.05
Timeline	.48	.09	.08	-.21	-.04	-.03
Consequences	.00	-.02	-.02	.82	.16	.14
Cure/Control	-1.91	-.29*	-.27	-1.86	-.35*	-.27
		$\Delta R^2 = .08$ *F* = 2.05 *(ns)* d.f. = 6, 65			$\Delta R^2 = .12$ *F* = 2.60* d.f. = 6, 65	

*p<.05, **p<.01, ***p<.001

Table 7 shows that the Time 1 components taken together could not predict anxiety. The Time 2 components taken together explained only 12% of the variance in anxiety, of which 7.3% was explained by weak control beliefs alone.

Table 8 shows that while both Time 1 and Time 2 models can significantly predict depression, the Time 2 components explained more of the variance, 14%, compared to 19%. The consequence component significantly explained 6.8% of the variance in the Time 1 model and 5.8% in the Time 2 model. However, the Time 2 model also shows the cure/control component explaining 10.2% of the variance in depression alone.

Table 8 Predicting (Time 2) *depression* from the Time 1 and Time 2 representation components

	Time 1			Time 2		
	B	*β*	*sr*	B	*β*	*sr*
Identity	.11	.17	.16	.00	.04	.03
Psychological Cause	.00	.01	.01	-.30	-.07	-.07
External Cause	.00	-.01	-.01	-.49	-.11	-.10
Timeline	.43	.09	.09	-.86	-.21	-.17
Consequences	1.40	.29*	.26	1.20	.28*	.24
Cure/Control	-1.10	-.20	-.18	-1.88	-.42**	-.32
		$\Delta R^2 = .14$ *F* = 2.89* d.f. = 6, 65			$\Delta R^2 = .19$ *F* = 3.85** d.f. = 6, 65	

*p<.05, **p<.01, ***p<.001

From the data presented here, it can be observed that the Time 2 representation components were better predictors of Time 2 outcome than were the Time 1 representation components. However, Time 1 representation components can help to predict quality of life, satisfaction with health and depression (but not anxiety).

3. Theorised Mediating Role of Coping

3.1 Statistical Comparison of Time 1 and Time 2 Coping Behaviour

Table 9 shows the means and standard deviations for each of the fifteen coping behaviours at both Time points. T-tests were computed to examine whether coping behaviours changed significantly from Time 1 to Time 2.

Table 9 Means and standard deviations and a statistical comparison of the coping behaviours employed by the IBS sufferers at Time 1 and Time 2

Coping Behaviour	Time 1 Mean	SD	Time 2 Mean	SD	t value	Df
Active Coping	11.9	3.0	11.8	3.0	0.38	71
Planning	11.2	3.2	10.7	3.3	1.43	71
Suppression	9.3	3.0	9.0	2.9	0.92	71
Restraint Coping	8.8	3.1	8.6	2.7	0.65	70
Instrumental Support	9.4	3.7	8.4	3.4	2.63**	71
Emotional Support	9.2	3.4	8.8	3.5	1.75	71
Positive Reinterpretation	8.4	3.5	8.5	3.2	-0.37	70
Acceptance	11.2	3.2	11.5	3.1	-0.93	71
Religion	6.9	4.3	7.1	4.3	-0.67	71
Venting Emotion	9.2	3.3	8.5	3.2	2.22*	71
Mental Disengagement	8.8	2.6	9.0	2.5	-0.68	71
Behavioural Disengagement	6.5	2.3	6.8	2.6	-1.04	71
Denial	6.2	2.4	6.2	2.2	0.00	71
Alcohol	5.3	2.4	5.6	2.7	-1.31	71
Humour	6.5	3.2	6.6	3.7	-0.21	71

*p<0.05 **p<0.01

Two marginally significant differences were found between the coping behaviours reported at Time 1 and Time 2: seeking instrumental support (t(71) = 2.63, p<0.01) and venting emotions (t (71) = 2.22, p<0.05), neither reached the adjusted alpha (Bonferoni adjustment). Both coping strategies decreased, in the eight months from joining the Network. Obtaining the newsletter every quarter may give the sufferer confidence that they are obtaining the latest information, and thus reduce the need to seek out more independent advice about IBS. In addition, the Network is set up in such a way that sufferers can talk to someone about their IBS (either another sufferer through the "befriender scheme", or a health professional via the IBS help line). Talking effectively to someone who understands IBS, or just having the reassurance that they can talk to someone who understands, may reduce the tendency to focus on and repeatedly vent the negative emotions that IBS encourages. It is possible that the more conservative significance levels calculated after the Bonferoni adjustment may be reached with a larger sample.

3.2 Relationships between Representation Components and Coping Behaviour

Once again, due to the large number of relationships analysed, only those significant at the more conservative level of p<0.01 will be presented. Strong identity at Time 1 was associated positively with active coping at Time 1 (r=.36, p<0.01). Serious consequences at Time 1 were related negatively to using humour to cope at Time 2 (r= -.38, p=0.001). Serious consequences at Time 2 were related negatively to active coping at Time 2 (r= -.34, p<0.01). Serious consequences at Time 2 were related positively to restraint coping at Time 2 (r = .34, p<0.01), and behavioural disengagement at Time 2 (r=.27, p<0.01). Long timeline beliefs at Time 1 were related positively to behavioural disengagement at Time 2 (r= .31, p<0.01). Strong control beliefs at Time 1 were related positively to active coping at Time 2 (r= .34, p<0.01), planning at Time 2 (r= .41, p<0.001), suppression at Time 2 (r=.39, p<0.01), positive reinterpretation at Time 1 (r= .41, p<0.001) and Time 2 (r= .44, p<0.001), and mental disengagement at Time 2 (r= .33, p<0.01). Strong control beliefs at Time 2 were related positively to planning at Time 2 (r= .31, p<0.01), positive reinterpretation at Time 2 (r= .40, p=0.001), and negatively to Time 2 behavioural disengagement (r= -.34, p<0.01). The beliefs in the psychological causes of IBS at Time 1 were related positively to the suppression of competing activities at Time 2 (r= .30, p=0.01). The belief that IBS was caused by psychological factors at Time 2 was related positively to Time 2 planning (r= .33, p<0.01) and positive reinterpretation (r= .32, p<0.01). External causal beliefs at Time 1 were related negatively to acceptance at Time 1 (r= -.31, p<0.01). External causal beliefs at Time 2 were related positively to Time 1 humour (r= .32, p<0.01).

3.3 Relationships between Coping Behaviours and Outcome Measures

Active coping at Time 2 was related positively to Time 2 quality of life (r= .33, p<0.01). Restraint coping at Time 1 was related positively to Time 1 depression (r= .38 p=0.001), and restraint coping at Time 2 was related positively to Time 1 depression (r= .36, p<0.01). Venting emotion at Time 1 was related to depression at Time 1 (r= .32, p<0.01). Denial at Time 2 was associated with Time 1 satisfaction with health (r=.42, p<0.001). Behavioural disengagement at Time 1 was related positively to anxiety at Time 1 (r=.48, p<0.001), depression at Time 1 (r= .52, p<0.001), and negatively to Time 2 quality of life (r= -.38, p=0.001). Behavioural disengagement at Time 2 was related negatively to Time 2 quality of life (r= -.48, p<0.001) and satisfaction with health (r= -.37, p=0.001), and positively to Time 2 anxiety (r=.32, p<0.01), Time 1 depression (r= .53, p<0.001), and Time 2 depression (r= .42, p<0.001). The use of humour to cope at Time 1 was related positively to satisfaction with health at Time 1 (r=.36, p<0.01), and negatively to depression at Time 2 (r= -.30, p=0.01). The use of humour at Time 2 was related to good quality of life (r= .35, p<0.01) and satisfaction with health (r= .48, p<0.001) both at Time 1, and less depression both at Time 1 (r= -.35, p<0.01) and Time 2 (r= -.34, p<0.01).

3.4 Combining Coping Behaviours

To assess the theorised mediating role of coping between representation components and outcome, a conservative number of variables had to be selected due to the small sample size. Therefore, coping behaviours were combined.

It was decided that categories based on judgements of adaptive and maladaptive strategies (as suggested by Carver, Scheier and Weintraub, 1989) should be avoided at this stage due to the exploratory nature of this research. Therefore three subscales, problem-focused coping, emotion-focused coping and avoidant coping, were thought to satisfactorily divide the 60 items relating to the 15 subscales.

Carver, Scheier and Weintraub (1989) introduce most of the thirteen[4] subscales as particular problem or emotion focused strategies, and so items were divided by their guidance. To check that these new categories made conceptual sense, an independent rater also divided the items into the same three categories. The criteria the independent rater was given were: Problem-focused defined those items which were directed at defining the problem, generating solutions, choosing between solutions and acting to solve the problem. Emotion-focused coping defined those items, which were directed at reducing emotional distress by emotional release and positive comparison. Avoidant coping was defined as those items, which were directed at avoiding or denying the problem. Items appeared exclusively in one of the three sub-scales.

Inter-rater reliability was 91.7%, initially. The discrepancy resulted from the issue of whether to include "focus on and venting of emotions" items into the emotion-focused coping scale; and one item from the behavioural disengagement scale - the item "I sleep more than usual" - was deemed by the independent rater as a problem-focused strategy rather than as avoidant coping. While no agreement about this item was reached, 98% was found after a discussion of the venting emotions issue. It was decided that the venting emotions items should be omitted from the emotion-focused scale because venting emotions was not associated with lessening the distress of IBS. The focus on the distress may exacerbate the distress and / or distract people from active coping efforts. In addition, the previous study (Chapter 3) has shown venting emotions to be related to poor outcome, therefore it was decided to omit venting emotions from this study. The scales were subjected to reliability analysis (an examination of the scale items can be found in Tables 10, 11 and 12).

---

[4] The two coping strategies of humour and drug/alcohol use were added later

Table 10 Theoretically derived problem-focused scale from the COPE subscales for the IBS patients

Item	COPE subscale
I concentrate my efforts on doing something about it	Active Coping
I take additional action to try and get rid of the problem	Active Coping
I take direct action to get around the problem	Active Coping
I do what has to be done, one step at a time	Active Coping
I make a plan of action	Planning
I try to come with a new strategy about what to do	Planning
I think about how might best handle the problem	Planning
I think hard about what steps to take	Planning
I try to get advice from someone about what to do	Seeking Instrumental Support
I talk to someone to find out more about the situation	Seeking Instrumental Support
I talk to someone who could do something concrete about the problem	Seeking Instrumental Support
I ask people who have had similar experiences what they did	Seeking Instrumental Support
I keep myself from getting distracted by other thoughts or activities	Suppression of Competing Activities
I focus on dealing with this problem and, if necessary, let other things slide a little	Suppression of Competing Activities
I try hard to prevent other things from interfering with my efforts at dealing with this	Suppression of Competing Activities
I put aside other activities in order to concentrate on this	Suppression of Competing Activities
I restrain myself from doing anything too quickly	Restraint Coping
I hold off doing anything about it until the situation permits	Restraint Coping
I make sure not to make matters worse by acting too soon	Restraint Coping
I force myself to wait for the right time to do something	Restraint Coping

Table 11 Theoretically derived emotion-focused scale from the COPE subscales for the IBS patients

Item	COPE subscale
I discuss my feelings with someone	Seeking Emotional Social Support
I try to get emotional support from friends or relatives	Seeking Emotional Social Support
I get sympathy and understanding from someone	Seeking Emotional Social Support
I talk to someone about how I feel	Seeking Emotional Social Support
I try to grow as a person as a result of the experience	Positive Reinterpretation and Growth
I try to see it in a different light, to make it seem more positive	Positive Reinterpretation and Growth
I look for something good in what is happening	Positive Reinterpretation and Growth
I learn something from the experience	Positive Reinterpretation and Growth
I accept the reality of the fact that it has happened	Acceptance
I learn to live with it	Acceptance
I get used to the idea that it has happened	Acceptance

Table 12 Theoretically derived avoidant coping scale from the COPE sub-scales for the IBS patients

Item	COPE subscale
I go to the cinema or watch television, to think about it less	Mental Disengagement
I turn to work or other substitute activities to take my mind off things	Mental Disengagement
I daydream about things other than this	Mental Disengagement
I sleep more than usual	Mental Disengagement
I admit to myself that I can't deal with it, and give up trying	Behavioural Disengagement
I give up the attempt to get what I want	
I just give up trying to reach my goal	Behavioural Disengagement
I reduce the amount of effort I'm putting into solving the problem	Behavioural Disengagement
I refuse to believe it has happened	Denial
I pretend that it hasn't really happened	Denial
I say to myself "this isn't real"	Denial
I act as though it hasn't even happened	
I use alcohol or drugs to make myself feel better	Alcohol/Drug Use
I try to lose myself for a while by drinking alcohol or taking drugs	Alcohol/Drug Use
I drink alcohol or take drugs, in order to think about it less	Alcohol/Drug Use
I use alcohol or drugs to help me get through it	Alcohol/Drug Use

All the items relating to active coping, planning, seeking instrumental support, suppression of competing activities and restraint coping were included for the problem-focused scale (alpha .86 at Time 1 and .84 at Time 2). All items related to seeking emotional support, positive reinterpretation and acceptance were included for the emotion-focused scale (alpha .70 at Time 1 and .74 at Time 2). For the avoidant coping scale, all the items from the sub-scales, denial, mental disengagement, behavioural disengagement and drug/alcohol use produced an alpha of .72 at Time 1 and .73 at Time 2. Scales were summed and then divided by the number of items so that they could be compared directly. A summary table below presents the means and standard deviations for the new scales.

Table 13 Means and standard deviations for the three new scales

	Problem Focused Coping (Time 1)	Problem Focused Coping (Time 2)	Emotion Focused Coping (Time 1)	Emotion Focused Coping (Time 2)	Avoidant Coping (Time 1)	Avoidant Coping (Time 2)
Mean	2.57	2.44	2.45	2.41	1.69	1.73
SD	0.53	0.56	0.55	0.55	0.38	0.40

Related t - tests were computed for each coping scale to examine differences over time. Both emotion-focused coping and avoidant coping were not significantly different from one another over time, however the data shows that the use of problem-focused behaviour reduced after being a member of the IBS Network for approximately 8 months (t (71) = 2.57, $p<0.05$).

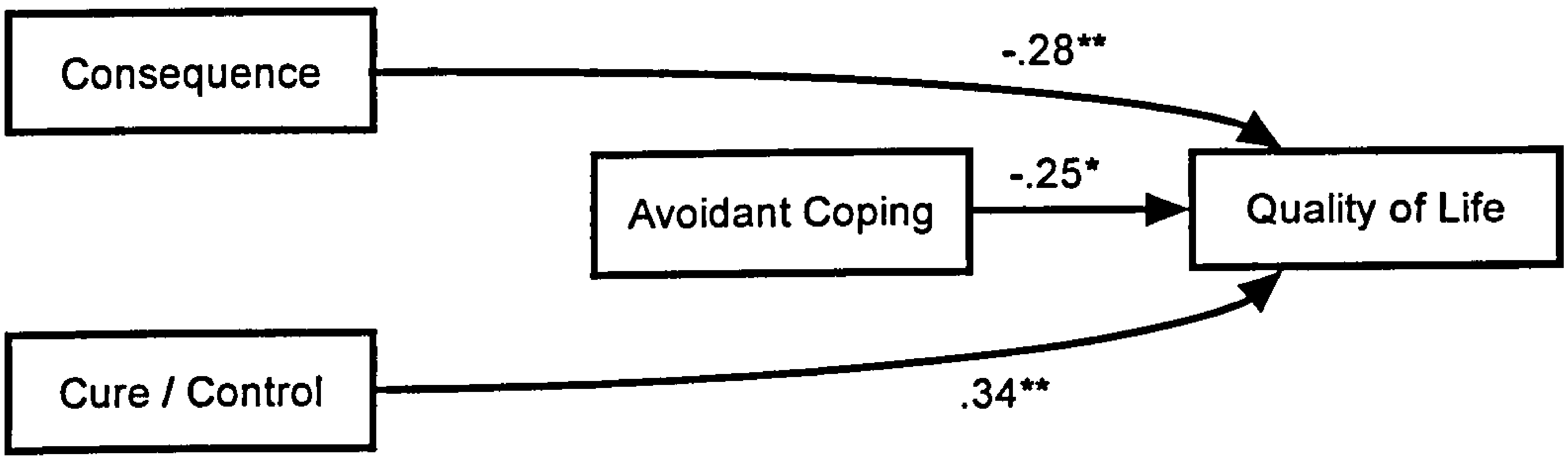
Avoidant coping is reported less frequently than both the emotion-focused and problem-focused scales. This difference was significant at both Time points (all $p<0.001$), however problem- and emotion-focused scales did not differ significantly.

3.5 Illness Representation, Coping and Outcome

The remaining analyses tested the possibility that the links between illness representations and outcome are mediated by coping behaviour. Each of the four outcomes, quality of life, satisfaction with health, anxiety and depression were examined by path analysis, using multiple linear regression. While the simultaneous measurement of representation, coping and outcome showed coping behaviours mediating the effect of the representation components upon outcome in the previous study (Chapter 3), the aim of this study was to examine if representations could predict outcome over time. Therefore, the path analyses presented here all examine whether representation components measured at Time 1 can predict outcome at Time 2. Path analyses are presented in pairs, the first model using coping measured at Time 1, the second model using coping measured at Time 2 (Figures 1 to 4).

The first analysis examined how Time 1 representation components and coping measured at Time 1 and Time 2 predict (Time 2) perceived quality of life. A comparison of the two models shows that the model examining Time 2 coping explained slightly more of the variance in outcome (28% compared to 31%). As can be observed in Figure 1a below, while the Time 1 representation components of consequence and cure / control independently predict Time 2 perceived quality of life, coping measured at Time 1 does not mediate this link. Here Time 1 avoidant coping is independently related to perceived quality of life. When coping from Time 2 is analysed instead of the Time 1 coping, avoidant coping mediates the Time 1 cure / control representation component. When these variables were entered into a hierarchical regression, with the two representation components entered at the first step, and Time 2 avoidant coping at the second, avoidant coping added a significant 9% to the variance explained in the perception of quality of life (R^2 change = .09, F (1, 66) = 9.16**).

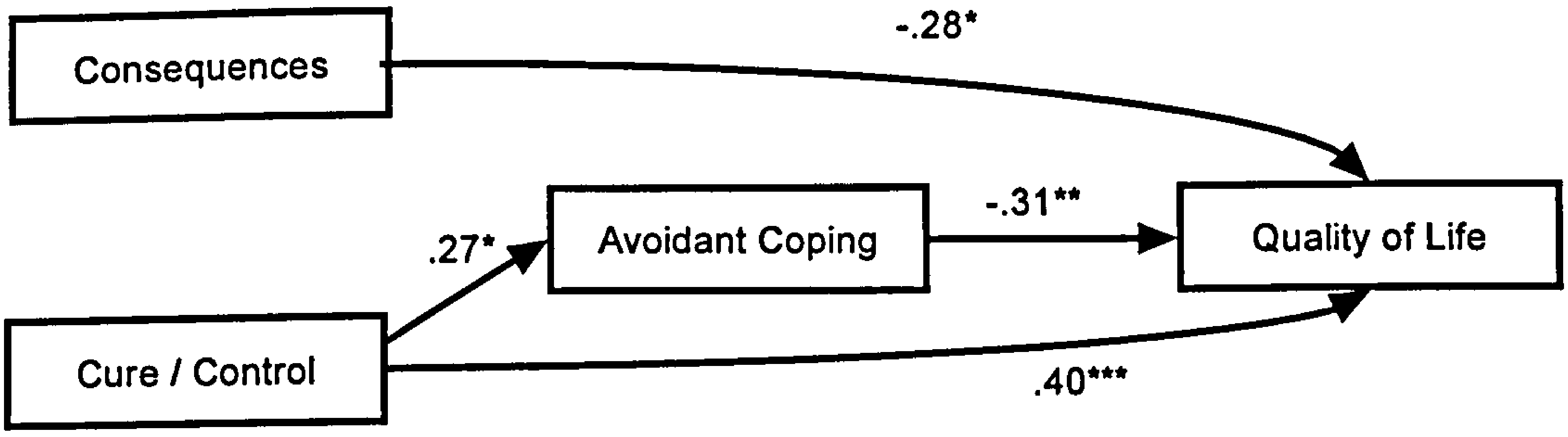
Figure 1a Predicting Time 2 quality of life from the Time 1 representation components and Time 1 coping behaviour



Adjusted R^2 = .28, F (3, 66) = 9.97***
*p<0.05 **p<0.01 ***p<0.001

No Mediation detected

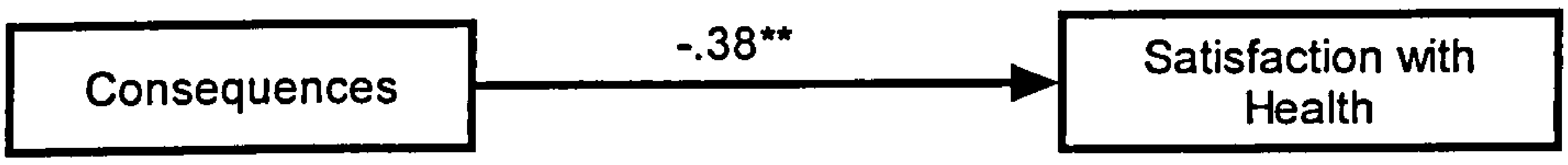
Figure 1b Predicting Time 2 quality of life from the Time 1 representation components and Time 2 coping behaviour



Adjusted R^2 =.31, F (3, 66) = 11.53***

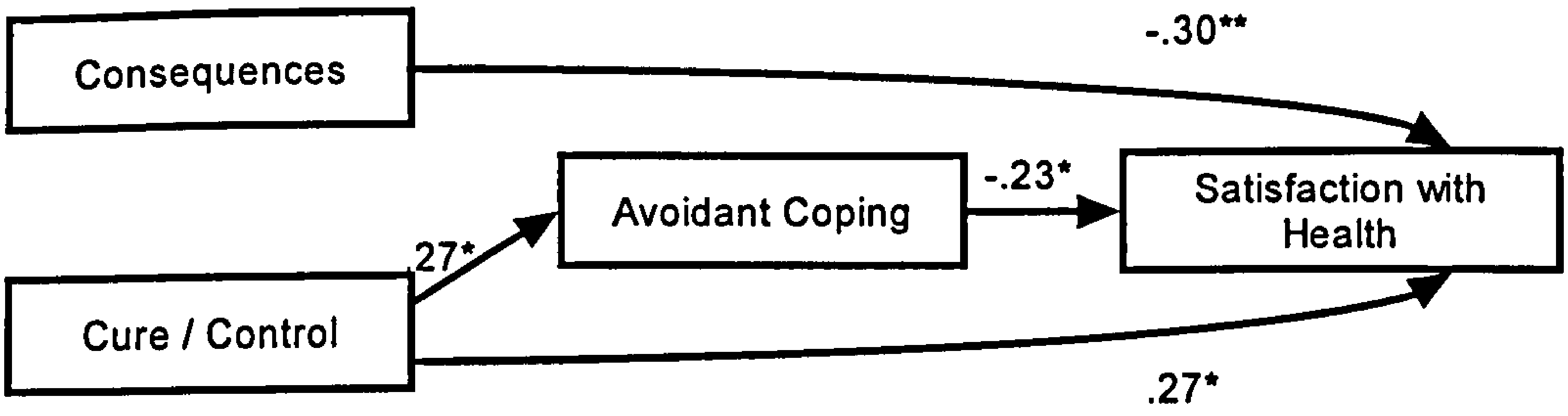
The second analyses examined how Time 1 representation components and coping measured at Time 1 and Time 2 predict (Time 2) perceived satisfaction with health. A comparison of the two models shows that the model in which Time 2 coping was examined explained more of the variance in outcome (13% compared to 21%). As can be observed in Figure 2a, only the Time 1 representation component of consequence significantly predicted Time 2 perceived satisfaction with health. Coping measured at Time 1 significantly predicted outcome but did not mediate this link. When coping from Time 2 is analysed instead of the Time 1 coping, consequence and the cure/control representation component have direct paths to outcome. Time 2 avoidant coping mediates the Time 1 cure / control representation component. When these variables were entered into a hierarchical regression, with the two representation components entered at the first step, and Time 2 avoidant coping at the second, Time 2 avoidant coping added a significant 5% to the variance explained in the perception of satisfaction with health (R^2 change = = .05, F (1, 66) = 4.36*).

Figure 2a Predicting Time 2 satisfaction with health from Time 1 representation components and Time 1 coping behaviour



Adjusted R^2 =.13, F (1, 68) = 11.45**

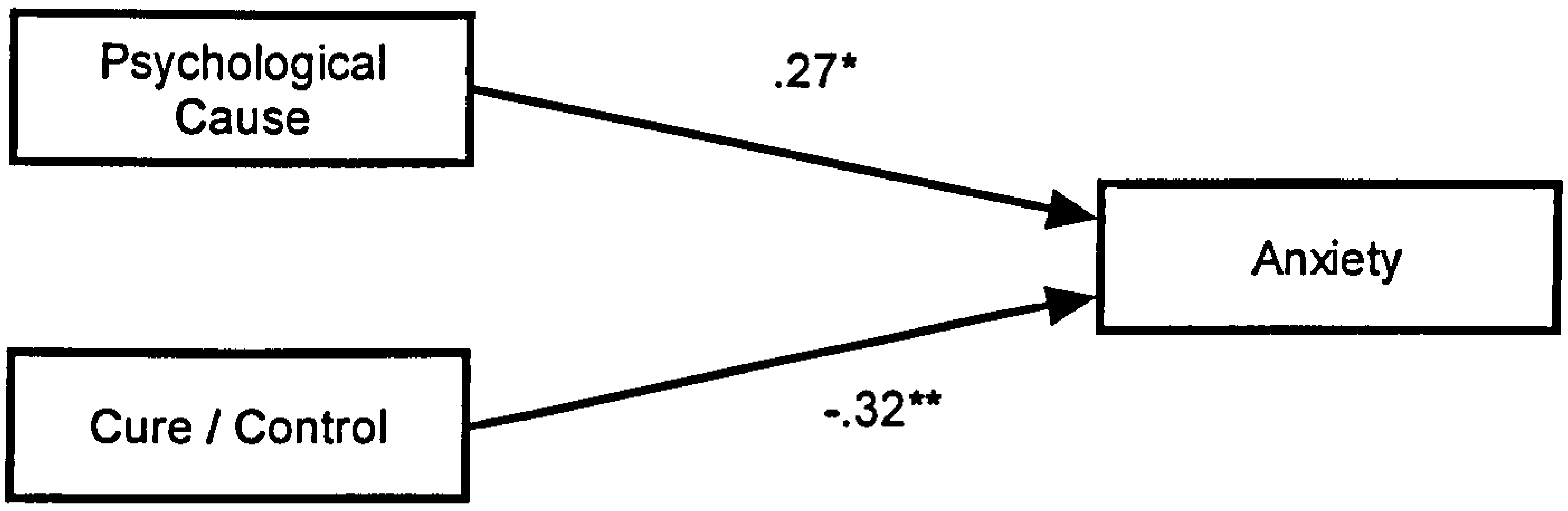
Figure 2b Predicting Time 2 satisfaction with health from Time 1 representation components and Time 2 coping behaviour



Adjusted R^2 =.21, F (3, 66) = 6.97***

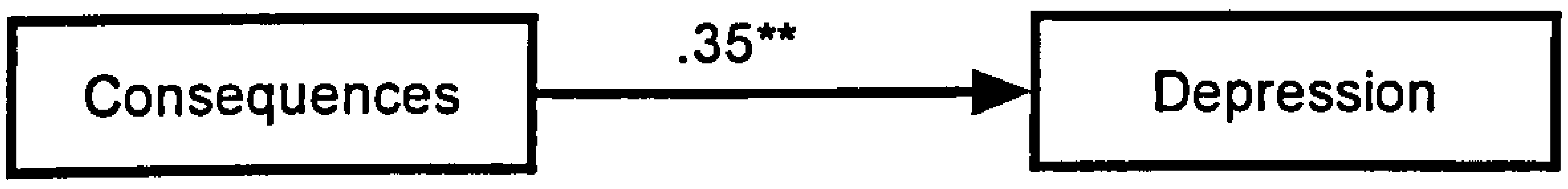
When predicting anxiety (Figure 3), neither Time 1 nor Time 2 coping produced significant effects. Believing that IBS was caused by psychological factors, and weak feelings of control upon joining the network, were related to later anxiety. The models are the same because coping behaviour measured at Time 1 and coping behaviour measured at Time 2 added nothing to the prediction of anxiety.

Figure 3 Predicting anxiety from Time 1 representation components



Adjusted R^2 = .12, F (2, 69) = 5.65**

Figure 4 Predicting depression from the Time 1 representation components



Adjusted R^2 = .11**, F (1, 70) = 9.61**

Again, when predicting depression (Figure 4), neither Time 1 nor Time 2 coping significantly predicted depression. Believing that IBS has serious consequences upon joining the network was related to later depression. The models are the same because coping behaviour measured at Time 1 and coping behaviour measured at Time 2 added nothing to the prediction of depression.

4. Further Analyses

4.2 The Role of Anxiety

As reported earlier in section 2.1, anxiety reduced significantly in the eight months from joining the IBS Network. Once again, to examine the effect of consequence and anxiety on measures of quality of life and satisfaction with health, anxiety was separated into the four clinical subgroups: normal anxiety; mild anxiety; moderate anxiety; and severe anxiety.

Table 14 Means and standard deviations of the consequence component by differing levels of anxiety for the IBS sufferers at both Time points

	Time 1		Time 2	
	Mean	SD	Mean	SD
Normal Anxiety (0 – 7)	3.27	0.67	3.29	0.76
Mild Anxiety (8 – 10)	3.41	0.63	3.04	0.96
Moderate Anxiety (11 – 14)	3.34	0.88	3.00	0.84
Severe Anxiety (15 – 21)	3.75	0.71	3.68	0.69

While the serious consequence beliefs did appear to increase with increasing severity of anxiety, the linear pattern that was displayed in the previous study (Chapter 3) was not present in this data. Some difference between the serious consequence beliefs was detected in the Time 2 data. Those IBS sufferers who, after being members of the IBS Network for approximately 8 months, could be classified as moderately anxious, had fewer serious consequence beliefs than those who could be classified as severely anxious (t (35) = -2.60, p=0.013). One slight difference was detected in the Time 1 data: those people who could be classified as severely anxious upon joining the IBS Network had more serious consequence beliefs than those with normal anxiety levels (as measured by the HADS) (t (34) = -2.07, p=0.046).

To determine whether the relationship between consequences and outcome (quality of life and satisfaction with health) differed as a function of anxiety, several hierarchical regression analyses were computed in which interaction terms were produced from the Time 1 and Time 2 data. Firstly, initial anxiety was examined with subsequent consequences, and secondly initial consequence beliefs were examined with subsequent anxiety for the two outcome measures. While none of the interaction terms were found to be significant predictors, both Time 1 and Time 2 consequence beliefs, and Time 2 anxiety significantly predicted outcome. Initial anxiety was a poor predictor of outcome. It could be argued that this is a result of the significant reduction in anxiety over the two Time points. The data here suggest that anxiety is not driving the consequence beliefs.

Summary of Research Findings

This study was designed with three hypotheses. The first prediction was that the representation components measured at Time 1 would change significantly by Time 2 because of the new information received after joining a self-help group. The second prediction was that both Time 1 and Time 2 representation components of the IBS sufferers, could predict Time 2 outcome. The third hypothesis was that if the representation components predicted outcome, that the links are mediated by coping. In this section, each hypothesis will be examined in turn.

Illness Representations at Time 1 and Time 2

Representation components measured at Time 1 changed very little at Time 2, showing the relative stability of the representation components. Each representation component measured at Time 1 was strongly correlated with the same measure at Time 2 ($p<0.001$). However, the relationships between the Time 1 components were rather limited. The belief that IBS was caused by psychological factors at Time 1 was related to Time 1 serious consequences. Time 1 timeline was related to Time 1 cure / control, so that a short timeline was related to strong feelings of control.

Time 1 cure / control was related to several Time 2 components: strong feelings of control at Time 1 were related to weak illness identity (i.e. a lower number of symptoms) at Time 2, a short timeline at Time 2, and a belief in the psychological causes of IBS at Time 2. Timeline at Time 1 was related to cure / control at Time 2 displaying the link between the belief in a short timeline and strong feelings of control over the illness. The initial (Time 1) belief that IBS was caused by psychological factors was related to Time 2 serious consequences. The remainder of the significant relationships concern only Time 2 measures. Relationships were observed between illness identity and timeline, consequences and control: those people who reported many symptoms were likely to have a long timeline, report serious consequences and have weak control beliefs. Relationships between cure / control, timeline, consequences and psychological causes were detected, such that those people with strong control beliefs were likely to express a short timeline, report few serious consequences, and report that IBS was caused by psychological factors. The belief that IBS has serious consequences at Time 2 was related to a long timeline and weak control beliefs. The relationships between the representation components uncovered in this study show similar relationships to those observed in Chapter 3.

Predicting Outcome from Time 1 and Time 2 Illness Representation

A series of standard regression models were computed to examine whether the illness representation components measured at Time 1 and Time 2 could predict Time 2 outcome. In summary, the Time 2 representation components explained more of the variance in Time 2 outcome than the Time 1 representation components. Once again, the serious consequences of IBS and weak control beliefs were significant unique predictors of poor quality of life, dissatisfaction with health and higher scores for anxiety and depression.

Even though the Time 1 components taken together could not explain any variance in anxiety in this study, the Time 1 component of cure / control explains the same amount of unique variance as the Time 2 component (7.8%). The prediction of anxiety in this study was different from the previous investigation. In the previous study (Chapter 3), the representation components taken together explained 35% of the variance when measured simultaneously. In this study, the Time 2 components (i.e. measured at the same time as outcome) explain only 12% of the variance in anxiety. This is likely to result from the stability of the representation components over time and the reduction in reported anxiety.

The data presented here demonstrate that the illness representation can predict outcome. The strength of the representation is so strong and stable that it can predict outcome 8 months later.

Mediation of Representation Components by Coping

Some mediation of coping was detected when predicting quality of life and satisfaction with health when coping was measured at the same time as the outcome measure. In two models the control component was partially mediated by avoidant coping. Those individuals who believe that they have control over their illness report good quality of life and satisfaction with health. However, those who report strong control and use avoidant coping to cope with their IBS have poorer quality of life and more dissatisfaction with health. When examining Time 1 representation components and Time 1 coping behaviour in predicting Time 2 outcome, coping did not significantly contribute to the prediction of satisfaction with health, and mediation was not detected for satisfaction with health or quality of life.

No mediation of coping was detected when predicting anxiety and depression, either when coping was measured at Time 1 or at Time 2. The data gathered here suggests that representation components are more predictive than coping behaviours.

Anxiety

While increasing anxiety levels appear to be related to more serious consequence beliefs, this relationship is not linear. In fact, initial anxiety was a poor predictor of outcome (quality of life and satisfaction with health). The data here suggest that anxiety is not driving the consequence beliefs, and that serious consequence beliefs, both initially and those measured after membership of the IBS Network for eight months are important when predicting outcome.

Limitations of Current Study

This examination has provided evidence that suggests that illness representation components stay relatively stable over time, and that the prior measurement of the representation components can predict future outcome. However, once again the participants in this study have been diagnosed with IBS for some time (approximately half of the sample were diagnosed with IBS in the previous two years), and all were members of a self-help group, which may influence the resulting representation. Therefore, it is likely that initial representation components and coping behaviour had been modified since diagnosis; changes in original representations may have already taken place.

Summary and Conclusion

This longitudinal study has shown: firstly that representation components and coping behaviour change very little after joining a self-help organisation; secondly, that Time 1 representation components can predict Time 2 outcome; thirdly, partial mediation of the representation components by Time 2 avoidant coping behaviours was detected for quality of life and satisfaction with health, but not for anxiety and depression.

Overall, this longitudinal study has provided evidence that representations and coping behaviours are relatively stable over time. However, because the participants in this study have experienced the symptoms of IBS for some time, and have been diagnosed with IBS for a long time, it could be argued that the representations, coping and outcome measured here have had time to be refined. Therefore, a prospective design in which the representation is measured as soon after diagnosis as possible, and measurement on a subsequent occasion, is required. In study 3, outlined in the next chapter (Chapter 5), a prospective longitudinal design is used in which the illness representation of IBS and IBD patients is measured within one month of diagnosis, and once again two months later.

Chapter 5

Illness Representation, Coping and Outcome of Secondary Care Patients: A Longitudinal Study of IBS and IBD Patients

Introduction

The data examined so far has concentrated on self-help group members. The first study has shown that the representations of IBS and IBD sufferers are similar to each other; similar patterns among the representation components are detected. While both groups of sufferers cited psychological factors more readily than external factors as a cause of their illness, IBS sufferers report this more strongly. The second study confirmed that the components of consequences and cure / control are the most predictive representation components of self-help group members. Representation components changed very little when sufferers joined a self-help group, and could predict outcome longitudinally. Later avoidant coping was found to partially mediate the effect of the prior control belief adding a small percentage to the variance explained in quality of life and satisfaction with health. The IBS models were more predictive than the IBD models and data collected simultaneously (i.e. cross-sectional) was found to be more predictive than prior measurement (i.e. longitudinal data).

In Chapters 3 and 4, the IBS sufferers examined had experienced IBS symptoms for an average of 14.1 years (SD = 11.8) and were diagnosed on average 7.9 years earlier (SD = 8.3). Similarly, the IBD patients examined in Chapter 3 had experienced GI symptoms for an average 13.2 years (SD = 11.9), and been diagnosed for 9.7 years (SD = 10.4). Leventhal et al. (1984) theorised that if patients/sufferers were unhappy with their appraisal of their health, attempts would be made to modify coping behaviour. If future appraisals were still unsatisfactory, then some modification of the illness representation would be made. It could be argued that the sufferers examined in Chapters 3 and 4 have extensively adapted their coping behaviours and their illness cognition in the time from diagnosis to measurement.

Another limitation of the studies presented in Chapters 3 and 4 is the population on which the research was carried out. Members of a self-help organisation receive advice and coping hints from fellow sufferers, which are often based on sufferers' unique experiences and not confirmed by independent research. Various substances (e.g. charcoal, Aloe Vera juice, pro-biotic yoghurts etc.) are introduced as "worked for me, may work for you"; advice of this nature may strengthen control beliefs. In addition, the individual experiences of IBS sufferers are published regularly. Sufferers often report their negative experiences of IBS (which are often quite serious). These reported negative life events might encourage positive outcomes in readers, as downward comparison may decrease serious consequence beliefs; alternatively, serious consequence beliefs may increase, as novel problems / situations are introduced. Comedic articles and cartoons provide a light-hearted look at the situations and problems of IBS, which may help decrease serious consequence beliefs. Perhaps, most important of all, being a member of an organisation reduces the isolation of living with an embarrassing illness; simply knowing that there are other people enduring the symptoms of IBS often gives comfort and promotes feelings of support.

These limitations regarding the population sampled, and the time from diagnosis, reduce the generalisability of this data. The main aim of the present study is to recruit newly diagnosed sufferers of IBS and IBD, in an effort to explore the illness representations as soon after diagnosis as possible, and again two months later. The IBS and IBD patients in this study were recruited from a local gastroenterology clinic. Patients who were attending the clinic for lower GI[1] problems, and with symptoms that were consistent with a diagnosis of either IBS or IBD, were informed of the study by their gastroenterologist. Those interested were introduced to me. After some discussion of the study, consent was obtained before diagnosis. When a diagnosis of either IBS or IBD was made the illness representation was measured (Time 1), and the illness representation, coping and outcome was

---

[1] Eliminating those with upper gastrointestinal illnesses such as hiatus hernia, gastritis (inflammation of the lining of the stomach), peptic ulcers and liver problems.

measured two months later (Time 2).

Hypotheses of the Study

The study was designed with three hypotheses.

1. It is predicted that the initial illness representation of IBS and IBD patients measured as soon after diagnosis as possible, will change in the following two months.
2. The second hypothesis was that both Time 1 and Time 2 representation components will predict outcome Time 2 outcome.
3. The third prediction was, that if representation components predict outcome, that these links are mediated by coping.

Design and Procedure

Two consultant gastroenterologists at the local hospital were contacted and invited to participate in research examining the illness cognitions of IBS and IBD patients. One gastroenterologist was interested. After consultation, the preliminary procedure was outlined. Ethical approval was sought from the East Kent Local Research Ethics Committee (LREC) in February 2000[2], and approved in May 2000. Once management approval was granted it was then possible to attend the twice-weekly gastroenterology clinic at the hospital, for the recruitment period of May to September 2000.

Recruiting Patients

Towards the end of consultations, the consultant gastroenterologist introduced the study to suitable patients[3]. Interested patients were led to a private room to hear more about the study from the researcher. Those patients who were interested in participating in the research took an information sheet (appendix C1), consent form (same as appendix A3), demographic Time 1 questionnaire (appendix C2) and prepaid envelope

---

[2] Although the application was submitted in February, the committee had to wait until April to see the application, due to a backlog of submissions. Changes in the procedure were required, and therefore the application was re-submitted and approved in May 2000.

[3] Suitable patients were deemed to be: those who were likely to receive a diagnosis of IBS or IBD, and those whom the gastroenterologist thought would be capable of completing questionnaires.

home with them[4]. Upon receiving a completed consent form, the medical secretary was contacted and asked either to provide detail regarding the date when the patient was next to see the gastroenterologist, or to state the date(s) of investigation(s), (e.g. colonoscopy, endoscopy, blood tests, barium enema).

Within a week of a patient seeing the gastroenterologist, the medical secretary was contacted so that a diagnosis could be obtained. In the cases where the patient was referred for investigation, the medical secretary was contacted approximately one week after the investigation had been due to take place. This allowed time for patient notes to be sent from the investigation unit and for the gastroenterologist to review the results of the investigation and to decide if further investigation was necessary. The information received was either that the patient required further investigation(s), or the date of the patient's next consultation with the consultant gastroenterologist.

As soon as a diagnosis of IBS or IBD was obtained from the medical secretary, the Time 2 letter (appendix C3) and questionnaire (the Illness Perception Questionnaire) was sent out to the patient (appendix C4)[5]. A note of the date was made upon receipt of the Time 2 questionnaire. The Time 3 letter and questionnaire was posted two months later (see appendix C5 and C6).

Of the 143 consent forms personally distributed, fifty were returned (response rate - almost 35%). This figure was surprisingly low. It was expected that the personal discussion regarding the study would ensure higher response rates, however this was not the case. Of those who returned their form, 40 patients (either IBS or IBD) completed both Time 1 and Time 2 data (76% of those

---

[4] Giving the patient over 24 hours to decide whether to participate – a condition of LREC approval.

[5] At the end of the study, it was noticed that no symptom inventory (to measure illness identity) was included with this questionnaire. This oversight meant that illness identity was not measured at time one.

who returned the consent form)[6]. The low number of patients recruited for this study prompted additional contact with the ethics committee, so that patient records could be examined.

Access to patient records was granted in August 2000. After examination of some 200 patient records, those patients with records in which the gastroenterologist's notes suggested possible IBS or IBD, and who were due to be seen by the gastroenterologist in the near future, were contacted. Fifteen patients were contacted by letter and invited to participate in the study (appendix C7); seven patients were recruited in this way. While consent was obtained from sixty patients in total, six were still waiting for investigations when the recruitment period ended (seven patients decided not to continue with the study; no reasons for attrition were given).

Participants

Table 1 contains the demographic information of the patients in this study. Unfortunately, recruitment proved extremely difficult; equal numbers of IBS and IBD patients could not be found. Approximately three quarters of the patients were IBS patients, making comparisons between the two patient groups limited.

Once again, the majority of the respondents were female (80%). Ages ranged from 21 to 75 with a mean age of 52.6 in the IBS sample; compared to 18 to 81, mean age 46.3 in the IBD group. The majority of both IBS and IBD patients were married and retired. IBS patients reported that they had experienced IBS symptoms for an average of 2.3 years (SD = 1.2), the reported mean length of the illness for the IBD patients was 1.6 years (SD = 11.1)[7]. Sick leave for the IBS patients (over the last 12 months) ranged from 0–20 days, with a mean of 10.3 (SD = 16.9), and a median of 5. For the IBD patients, sick leave ranged from 0–43 days with a mean of 12.4 (SD = 15.4)

---

[6] It should be noted that not all patients who returned their consent were later diagnosed as having either IBS or IBD.

[7] All patients completed baseline measures before being diagnosed with either IBS or IBD.

and a median of 8.5. No participant stated that they were unemployed due to problems with their illness. The participants were asked to estimate how often they had visited their GP in the past 12 months. IBS patients gave answers ranging from 1–20, mean of 5.9 (SD = 5.2); the IBD patients saw their GP between 3 and 10 times, with a mean of 6.2 (SD = 2.8); the IBS and IBD patients did not differ significantly from each other (t (27) = -.12, p>0.05).

Table 1 Demographic information about the secondary care patients

	IBS		IBD	
	N	%	N	%
Sex				
Male	7	20.0	7	58.3
Female	28	80.0	5	41.7
Age				
0-20 years	0	0.0	2	16.7
21-30 years	4	11.4	1	8.3
31-40 years	3	8.6	3	25.0
41-50 years	6	17.1	1	8.3
51-60 years	8	22.9	3	25.0
61-70 years	11	31.4	0	0.0
70+ years	3	8.6	2	16.7
Marital Status				
Single	4	11.4	4	33.3
Married	21	60.0	7	58.3
Divorced	3	8.6	0	0.0
Separated	1	2.9	0	0.0
Widowed	5	14.3	1	8.3
Cohabiting	1	2.9	0	0.0
Occupation				
No Occupation	5	14.3	0	0.0
Retired	14	40.0	3	25.0
Manual	6	17.1	2	16.7
Administration	6	17.1	2	16.7
Professional	2	5.7	2	16.7
Student	2	5.7	2	16.7
Other	0	0.0	1	8.3

Participants were asked which investigations they had (and were due to have before diagnosis). The most reported tests by the IBS patients were colonoscopy (48.6%) and endoscopy (45.7%). The majority of patients reported one test, with the mean 2.1 (SD = 1.4). This figure is lower than the means reported in the previous two studies (Chapter 3 was 3.7, and Chapter 4 was 3.0), which may result from the shorter length of time that these patients have experienced IBS symptoms. It could be argued that different investigations are preferred by different NHS Trusts, and therefore recruiting from just one Trust may produce a biased sample.

The majority of the IBD patients reported being investigated by colonoscopy (75%). The IBD patients cited similar profiles of investigations, however the majority of IBD patients were referred for three tests (the mean was 3.1 (SD = 0.8)). While this figure is lower than the number of investigations reported by the IBD sufferers recruited from the self-help organisation (4.8) (Chapter 3), it could be said to result from the shorter length of time these newly diagnosed IBD patients had experienced the symptoms of IBD and / or the specific geographical area from which the patients were recruited. However, a comparison of the IBS and IBD patients recruited in this study has shown that the IBD patients report significantly more investigations than the IBS patients ($t(44) = -2.13$, $p<0.05$).

Measures

Measures used in Chapters 3 and 4 were selected again to examine the illness representation, coping and outcome of the clinic patients.

Illness Representation

The Illness Perception Questionnaire (IPQ) ***(Weinman, Petrie, Moss-Morris and Horne, 1996)*** High scores indicate serious consequence beliefs, a long timeline and strong cure / control beliefs. Lower scores indicate fewer serious consequence beliefs, a short timeline, and weak cure / control beliefs. Psychological cause and external cause were selected as causal attribution components. The 10-item GI symptom measure was used as a measure of illness identity.

Coping

COPE ***(Carver, Scheier and Weintraub, 1989)*** The COPE provides 15 independent scales, and can also be combined to form problem focused, emotion focused and avoidant coping scores. The higher the score for each scale, or combined scale, the more that particular type of coping is typically employed by participants to cope with their symptoms.

Outcome

WHOQOL-Bref ***(Division of Mental Health, WHO, Geneva, 1999)*** Once again, the two one-item statements pertaining to quality of life ("How would you rate your quality of life?") and satisfaction with health ("How satisfied are you with your health?") were used as outcome measures. Scales range from 1–5, with higher scores representing a higher perceived quality of life and greater perceived satisfaction with health.

The Hospital Anxiety and Depression Scale (HADS) ***(Zigmond and Snaith, 1983)*** The HADS provides a measure of anxiety and depression. Higher scores indicate greater anxiety and depression.

Results

The results will be presented according to the hypotheses outlined on page 142.

1. The first hypothesis was concerned with the illness representations of IBS and IBD patients twice within the first few months of diagnosis. Firstly, the Time 1 and Time 2 representation components of the IBS and IBD sufferers will be presented. Secondly, the Time 1 and Time 2 representation components will be compared statistically. Thirdly, relationships between the Time 1 and Time 2 components will be explored.
2. The second hypothesis was that the early illness representations of the IBS patients will predict outcome 2 months later. Firstly, outcome measures are presented. Secondly, relationships between representation components and outcome measures will be explored. Thirdly, standard regression models will be conducted to examine whether the Time 1 and Time 2 representation components can predict outcome.

3. The third hypothesis was that, if representation components measured soon after IBS or IBD diagnosis can predict outcome, the links are mediated by coping. Due to the small sample size (N = 35), the coping subscales are combined once again. Firstly, relationships between the Time 1 and Time 2 representation components, coping subscales and outcome measures are explored. Then analysis regarding the mediation of representation components by coping will be examined. A conservative selection of variables will be taken and mediation tested directly, using the Sobel test.

1. The Initial Illness Representations

1.1 The Representation Components

Illness Identity The three most frequently perceived symptoms reported by IBS patients (by reporting the symptom more than once every week) were wind (65.7%), rumblings and grumblings (54.3%) and bloating of the abdomen (51.4%). The three most common symptoms reported by the IBD patients were wind (33.3%), rumblings and grumblings (33.3%), and diarrhoea (33.3%). Unfortunately, symptoms were only measured at Time 2 (two months from diagnosis), so no comparison over time can be made.

The most frequent symptoms reported by the IBS patients in this study were consistent with the pattern of symptoms reported in Chapters 3 and 4. The pattern of the three most frequent symptoms of IBD patients is consistent with the pattern reported in Chapter 3.

Causal attribution The most commonly reported causal attributions (where participants rated each specific cause as agree or strongly agree) for the IBS patients at the time of diagnosis were stress (45.8%), and chance (37.1%). State of mind, other people, own behaviour and diet all had the same level of agreement (34.3%). For the IBD patients, the most commonly reported causal factors were stress (41.7%), chance, (41.7%) and diet (25%). Two months from diagnosis, the pattern altered; the three most commonly reported causes for the IBS patients were stress (48.6%), state of mind (42.9%) and diet (25.7%); chance dropped to just 17.2% agreement. For the IBD patients at Time 2 the three most common causal factors were stress (50%), chance (50%) and state of mind (33.3%). The patterns reported here are similar to the patterns reported in Chapters 3 and 4.

Once again, IBS and IBD patients were more likely to disagree with a causal attribution than agree with one (while one attribution produced a mean of 4 at Time 1, this was reduced at Time 2). A series of related t-tests were computed to examine whether specific causal attributions changed over the two months from diagnosis. While no test reached the adjusted alpha of p=0.005, patients attributed IBS less to stress two months later (Time 1 mean 3.6 (SD = 1.0) reduced to 3.3 (SD =0.9) at Time 2, (t (33) = 2.54, p<0.05). In addition, both IBS and IBD patients showed a reduction in reporting their own behaviour as a cause: IBS patients attributed their own behaviour as a cause, (mean 3.6, SD=1.2) at Time 1, but this attribution was reduced (to 3.2, SD=1.0) at Time 2, (t (33) = 2.51, p<0.05). IBD patients reported their own behaviour as a cause more at Time 1, (mean 4.1, SD=0.8) than at Time 2 (3.2, SD=1.2), and this attribution had decreased significantly (t (10) = 3.19, p<0.05).

Individual causal attributions were not examined further. The same causal attributions from Chapter 3 and 4 were calculated for this study: psychological cause (stress, state of mind, other people and own behaviour); and external causes (germ/virus, pollution and poor medical care).

1.2 Statistical Comparison of the Representation Components

Table 2 displays the means, standard deviations, and reliability of each representation component for both the IBS and IBD patients at diagnosis and 2 months later. The cure / control scale has produced low alphas; however, since the Cronbach's alphas for the scales in study one (Chapter 3) were not problematic, low alphas here could be attributed to the small sample size.

Table 2 Means, standard deviations and alphas of the representation components for the IBS and IBD patients

Representation Components	Time 1			Time 2				
	Mean	SD	α	Mean	SD	α	t values	df
IBS Patients								
GI Symptom Score	----	----	----	21.9	7.1	.77	----	--
Psychological Causes	3.0	0.9	.78	2.8	0.8	.77	2.4*	34
External Causes	2.2	0.7	.59	2.4	0.6	.32	-2.0	34
Timeline	3.5	0.7	.75	3.5	0.7	.67	0.3	34
Consequences	2.7	0.8	.82	2.7	0.7	.88	-0.2	34
Cure / Control	3.3	0.5	.51	3.3	0.6	.59	-0.2	34
IBD Patients								
GI Symptom Score	----	----	----	19.8	5.9	.66	-----	--
Psychological Causes	2.7	0.9	.79	2.9	0.9	.72	-1.6	11
External Causes	1.7	0.5	.39	2.0	0.6	.57	-2.3*	11
Timeline	4.3	0.8	.90	4.3	0.6	.87	-0.4	11
Consequences	3.4	0.8	.84	3.0	0.8	.82	1.7	11
Cure / Control	3.2	0.7	.52	3.3	0.7	.44	-1.6	11

*$p<0.05$

Related t-tests show that the strength of the belief in a psychological attribution is lower at Time 2 for the IBS patients. For the IBD patients the belief in an external attribution increases two months after diagnosis. However, neither test reached the adjusted alpha level.

Independent t-tests were then computed between the IBS and IBD patient groups. A significant difference was detected for timeline beliefs at both Time 1 and Time 2 between the IBS and IBD patient groups. The IBD patients expect their illness to last for a long time and this belief is significantly stronger than the IBS patients' timeline beliefs at both Time points (t (45) = -2.9, p=0.006 for Time 1, and t (45) = -3.7, p=0.001 for Time 2). Another test approached significance, but did not reach the adjusted alpha (Bonferoni adjustment); IBD patients reported more serious consequence beliefs than the IBS patients at the time of diagnosis (t (45) = -2.6, p = 0.014). At Time 2, the serious consequence beliefs of the IBD patients reduced, showing less of a difference between the IBS and IBD serious consequence beliefs.

1.3 Relationships among the Illness Representations

Univariate correlations were computed for the IBS and IBD patients. As can be observed from the data presented in Table 3, few significant relationships were detected. Those significant relationships that were found displayed extremely high magnitudes. This was due to the low sample sizes in this study. Similar findings to study 2 (Chapter 4) were detected, in that the Time 1 and Time 2 measures were correlated with one another, except the IBD patients' rating of consequences at Time 1 and Time 2. This relationship did not reach significance. The means show that the IBD ratings of serious consequences reduced at Time 2.

More relationships that were significant were detected for the IBS patients; it is likely that this is due, once again, to the low IBD sample size. However, the relationships that emerged strongly suggest important relationships between the timeline and consequence components. In the IBS sample, both Time 1 and Time 2 timeline components are positively related to both Time 1 and Time 2 consequence components, such that the longer the timeline reported, the more severe the consequences reported, and vice versa. The IBD patients also show some support for this relationship, although the evidence is less pronounced: consequences at Time 1 were related to both Time 1 and Time 2 timeline (both $p<0.05$). Thus, long timeline cognition may encourage feelings of negativity about the illness, encouraging serious consequence beliefs. Timeline was also related to the symptoms perceived in the IBS patients. Strong illness identity was related positively to both Time 1 and Time 2 timeline, such that those who experienced more symptoms were also more likely to report a longer timeline at both Time points. A strong illness identity was also related to Time 2 serious consequence beliefs for the IBS patients. In addition, those IBD patients who reported that their illness was caused by external factors (germ/virus, pollution or poor medical care) reported a shorter timeline.

Table 3 Univariate relationships between the illness representation components at diagnosis (Time 1) and two months from diagnosis (Time 2) for the IBS and IBD patients: Pearson's r

	IBS Patients	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)
(1)	Identity (T2)	1.0										
(2)	Psychological Cause (T1)	-.17	1.0									
(3)	Psychological Cause (T2)	-.20	.84***	1.0								
(4)	External Cause (T1)	-.08	.03	.01	1.0							
(5)	External Cause (T2)	.02	-.01	-.04	.60***	1.0						
(6)	Timeline (T1)	.45**	-.19	-.23	-.09	-.06	1.0					
(7)	Timeline (T2)	.39*	-.27	-.29	-.21	-.21	.80***	1.0				
(8)	Consequences (T1)	.31	.29	.27	.18	-.06	.49**	.47**	1.0			
(9)	Consequences (T2)	.43**	.04	.00	.17	.22	.46**	.43*	.77***	1.0		
(10)	Cure / Control (T1)	.10	.01	.01	.15	.12	.08	-.02	-.06	-.05	1.0	
(11)	Cure / Control (T2)	.05	.17	.16	-.11	-.05	.02	.02	.02	-.20	.74***	1.0

	IBD Patients	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)
(1)	Identity (T2)	1.0										
(2)	Psychological Cause (T1)	.08	1.0									
(3)	Psychological Cause (T2)	-.08	.84**	1.0								
(4)	External Cause (T1)	-.22	.26	.20	1.0							
(5)	External Cause (T2)	.23	-.04	-.08	.75**	1.0						
(6)	Timeline (T1)	.13	-.23	-.36	-.70*	-.41	1.0					
(7)	Timeline (T2)	-.28	-.20	-.26	-.45	-.44	.76**	1.0				
(8)	Consequences (T1)	.24	.07	-.04	-.25	-.11	.64*	.63*	1.0			
(9)	Consequences (T2)	.58	.35	.33	-.26	.10	.35	.17	.54	1.0		
(10)	Cure / Control (T1)	-.14	.22	.21	.45	.40	-.10	-.12	.11	.05	1.0	
(11)	Cure / Control (T2)	-.15	.22	.19	.56	.42	-.13	-.13	.18	-.08	.94***	1.0

2. Predicting Outcome

2.1 Statistical Comparison of IBS and IBD Outcome Measures

As can be seen in table 4 below, none of the outcome measures differed significantly between the IBS and IBD patients. Both reported similar levels of satisfaction with their health and perceived quality of life. The IBS group did report higher levels of anxiety and depression. A difference in anxiety may have been observed if the IBD patient group was larger as this difference approached significance (t(45) = 1.98, p = .054).

Table 4 Means and standard deviations of the outcome measures for the IBS and IBD patients

Outcome Measure	IBS Mean	SD	IBD Mean	SD	t-value	df
General Quality of Life	3.8	1.0	3.8	0.8	-0.10	45
Satisfaction with Health	2.9	1.1	2.8	1.0	0.37	45
Anxiety	9.0	4.1	6.3	3.9	1.98	45
Depression	4.8	3.2	3.7	3.1	1.07	45

An analysis of the anxiety data shows that, while the IBS patients here score higher than the IBD patients for anxiety, this sample have a lower proportion of moderate and severe cases than the previous two studies. Sixty-two percent of the IBS patients score in the normal and mild range for anxiety; only 37.1% of the IBS patients could be classified as having moderate to severe anxiety. In the first study (Chapter 3), the percentage of sufferers who could be classified as having moderate to severe anxiety was 53.7%. In the second study (Chapter 4), of the new members sampled, 51.3% could have been classified with moderate to severe anxiety at Time 1, however this figure dropped to 36.5% after being a member of the IBS Network for eight months. IBS researchers have often reported that clinical samples of patients are more anxious and depressed than sufferers recruited from elsewhere, however this has not been supported by this sample in comparison to the anxiety and depression levels reported in the previous two chapters.

2.2 Relationships between Representation Components and Outcome

IBS Relationships Strong illness identity two months after diagnosis was related negatively to satisfaction with health (r= -.38, p<0.05). An initial belief at the time of diagnosis that IBS was caused by psychological factors was associated positively with anxiety (r= .38, p<0.05). A belief in the serious consequences of IBS at the time of diagnosis was related to a poor perception of quality of life (r= -.43, p<0.01), dissatisfaction with health, (r= -.42, p<0.05), and high scores for anxiety (r= .42, p<0.05) and depression (r= .44, p<0.01). The same four relationships were detected two months from diagnosis, although the relationships were stronger. A belief in the serious consequences of IBS two months from diagnosis was related to a poor perception of quality of life (r= -.54, p<0.001), dissatisfaction with health (r= -.64, p<0.001), and high scores for anxiety (r= .51, p<0.01) and depression (r= .59, p<0.001).

IBD Relationships Only two relationships were statistically significant for the IBD group. Illness identity (Time 2) was associated negatively with satisfaction with health (r= -.73, p<0.05), and the external causal attribution at Time 2 was associated positively with depression (r=.70, p<0.05).

2.3 Representation Components Predicting Outcome

To examine whether representation components (measured at the time of diagnosis, and two months from diagnosis) could predict early outcome, a series of eight regression models were computed. Because there were so few IBD patients, (N = 12), these patients were omitted from any further analysis. Each analysis is presented in pairs for each outcome measure, so that the Time 1 and Time 2 predictors can be directly compared. The cases to IVs ratio is small, but five cases per IV was considered acceptable in this exploratory study.

As can be seen from Table 5, the Time 1 components taken together fail to explain any variance in quality of life. The illness beliefs held two months after diagnosis account for approximately 24% of the variance in quality of life, with the belief that IBS has serious consequences accounting for 29% (semipartial correlation = -.54, zero order correlation = -.42, and beta = -.72). This larger unique variance (29% compared to 24% variance explained by all components) highlights the importance of the relationship between the consequence component and quality of life. As more unique variance is explained by the consequence component than the total model, this suggests that the other representation components could be little more than noise, and their inclusion serves to lower the variance explained.

Table 5 Predicting general quality of life from IBS patients' Time 1 and Time 2 representation components

Representation Components		Time 1			Time 2	
	B	β	*sr*	B	β	*sr*
Identity	----	---	---	.01	.12	.10
Psychological Cause	.08	.07	.06	.12	.09	.08
External Cause	-.07	-.06	-.05	.05	.03	.03
Timeline	.24	.17	.13	.22	.14	.11
Consequences	-.71	-.53	-.39	-.99	-.72**	-.54
Cure / Control	-.30	-.15	.15	-.49	-.29	-.27
		ΔR^2 =.09			ΔR^2 =.24	
		F = 1.70(ns)			F = 2.81*	
		d.f. = 5, 29			d.f. = 6, 28	

*p<0.05, **p<0.01

Table 6 Predicting satisfaction with health from IBS patients' Time 1 and Time 2 representation components

Representation Components		Time 1			Time 2	
	B	β	*sr*	B	β	*sr*
Identity	---	----	--	-.02	-.18	-.15
Psychological Cause	.28	.22	.19	.20	.13	.12
External Cause	.02	.02	.02	.30	.15	.14
Timeline	.16	.10	.08	.55	.32	.25
Consequences	-.79	-.52*	-.38	-1.12	-.71***	-.53
Cure / Control	.46	.21	.20	.20	.10	.10
		ΔR^2 =.13			ΔR^2 =.40	
		F = 2.03(ns)			F = 4.84**	
		d.f. = 5, 29			d.f. = 6, 28	

*p<0.05 **p<0.01 ***p<0.001

When predicting satisfaction with health (Table 6 above), the Time 2 representation components accounted for approximately 40% of the variance, while the Time 1 representation components failed to account for subsequent satisfaction with health. Both models once again highlight the importance of the consequence component. While the Time 1 representation components fail to account for the variance in outcome, the Time 1 consequences uniquely predicted 14% of the subsequent variance. When consequence is measured at the same time as satisfaction, the consequence component uniquely contributes 28% of the variance explained (semipartial correlation = -.53, zero order correlation =-.54 and beta = -.71).

When predicting anxiety from the representation components (Table 7), both the Time 1 components together and the Time 2 representation components taken together fail to account adequately for the variance in anxiety, although the Time 2 model can be considered marginally significant (p=0.056). The Time 2 consequence component uniquely accounts for 23% of the variance in anxiety (semipartial correlation = .48, zero-order correlation = .40 and beta = .64). Once again, the unique contribution of consequences explains more of the variance than when the components are taken together, which again could be attributed to the importance of the consequence component in comparison with the other representation components.

Table 7 Predicting anxiety from IBS patients' Time 1 and Time 2 representation components

Representation Components	Time 1			Time 2		
	B	β	*sr*	B	β	*sr*
Identity	-----	---	---	.00	-.01	-.01
Psychological Cause	1.25	.27	.23	.61	.11	.10
External Cause	-.60	-.11	-.10	-1.26	-.18	-.16
Timeline	-.14	-.03	-.02	-.90	-.15	-.11
Consequences	2.03	.37	.27	3.64	.64**	.48
Cure / Control	1.06	.13	.13	1.07	.15	.14
		ΔR^2 =.14			ΔR^2 =.19	
		F = 2.14(ns)			F =2.37†	
		d.f. = 5, 29			d.f. = 6, 28	

**p<0.01 † marginally significant

Table 8 Predicting depression from IBS patients' Time 1 and Time 2 representation components

Representation Components	Time 1			Time 2		
	B	β	*sr*	B	β	*sr*
Identity	---	---	---	-.02	-.07	-.06
Psychological Cause	.54	.15	.13	.56	.13	.12
External Cause	.07	.02	.02	.00	.00	.00
Timeline	-.33	-.08	-.06	.29	.06	.05
Consequences	1.78	.42	.31	2.53	.57**	.43
Cure / Control	-.97	-.15	-.15	-.56	-.10	-.10
		ΔR^2 =.12			ΔR^2 =.24	
		F = 1.88(ns)			F = 2.77*	
		d.f. = 5, 29			d.f. = 6, 28	

*p<0.05 **p<0.01

Finally, when predicting depression, the Time 2 components are once again better predictors than the Time 1 components. The Time 1 components fail to explain the variance in depression. The Time 2 components together explain approximately 24% of the variance in depression. Once again, consequence was the most important component, uniquely predicting 18% of the variance (semipartial correlation = .43, zero-order correlation = .47 and beta = .57).

The low number of patients recruited for this study means that we must interpret these results with caution, and replication is advised. However, the previous two studies (Chapters 3 and 4) have also shown the important role of consequences in predicting outcome, and it is likely therefore that those who report that IBS has many serious consequences report a lower quality of life, lower satisfaction with health and greater anxiety and depression. Even though fewer predictors were entered into the Time 1 models, the Time 2 models explained more variance in outcome. The results from this and the previous study (Chapter 4) suggest that the simultaneous measurement of consequences and the other components provide stronger predictions of outcome than the equivalent longitudinal models.

3. Theorised Mediating Role of Coping

3.1 Combining Coping Behaviours

To assess the theorised mediating role of coping between representation components and outcome, a conservative number of variables had to be selected due to the low sample size. Coping behaviours were combined using the same categories as in the previous chapter. However, some items were removed due to low alpha reliability.

The problem-focused scale remained the same as in the previous study. All the items relating to active coping, planning, seeking instrumental support, suppression of competing activities and restraint coping were included for the problem-focused scale (Cronbach's alpha .88).

Two acceptance items ("I get used to the idea that it has happened", and "I accept that it has happened and that it can't be changed") were removed from the emotion-focused scale to increase the reliability of the scale (Cronbach's alpha .86).

For the avoidant coping scale, all the items from the sub-scales: denial, mental disengagement, behavioural disengagement and drug/alcohol use produced a low alpha of .66, therefore items were removed until satisfactory scale reliability was detected (Cronbach's alpha .74). Table 10 contains the remaining items that make up the avoidant coping scale.

Table 9 Remaining items that comprise the avoidant coping scale (from the COPE sub-scales) for the IBS patients

Item	COPE subscale
I go to the cinema or watch television, to think about it less	Mental Disengagement
I admit to myself that I can't deal with it, and give up trying	Behavioural Disengagement
I just give up trying to reach my goal	Behavioural Disengagement
I reduce the amount of effort I'm putting into solving the problem	Behavioural Disengagement
I refuse to believe it has happened	Denial
I pretend that it hasn't really happened	Denial
I use alcohol or drugs to make myself feel better	Alcohol/Drug Use
I try to lose myself for a while by drinking alcohol or taking drugs	Alcohol/Drug Use
I drink alcohol or take drugs, in order to think about it less	Alcohol/Drug Use
I use alcohol or drugs to help me get through it	Alcohol/Drug Use

Scales were summed and then divided by the number of items so that the scales could be compared directly. A summary table below presents the means and standard deviations for the new scales.

Table 10 Means and standard deviations for the three new coping scales

	Problem-Focused Coping	Emotion-Focused Coping	Avoidant Coping
Mean	2.12	2.34	1.43
SD	0.55	0.65	0.42

As in Chapter 4, avoidant coping is used less than problem and emotion focused coping. Related t-tests were computed for each pair; all three scales were significantly different from each other. The largest difference emerged between emotion-focused coping and avoidant coping (t (34) = 7.13, p<0.001), and the smallest difference was found for problem and emotion focused coping (t (34) = -3.23, p<0.01). Problem-focused coping and avoidant coping were also significantly different from one another (t (34)= 6.62, p<0.001).

3.3 Relationships Between Representation Components, Coping and Outcome for the IBS patients

Univariate correlations were computed for the three coping subscales and the Time 1 and Time 2 representation components and the outcome measures. Only those significant relationships are presented here.

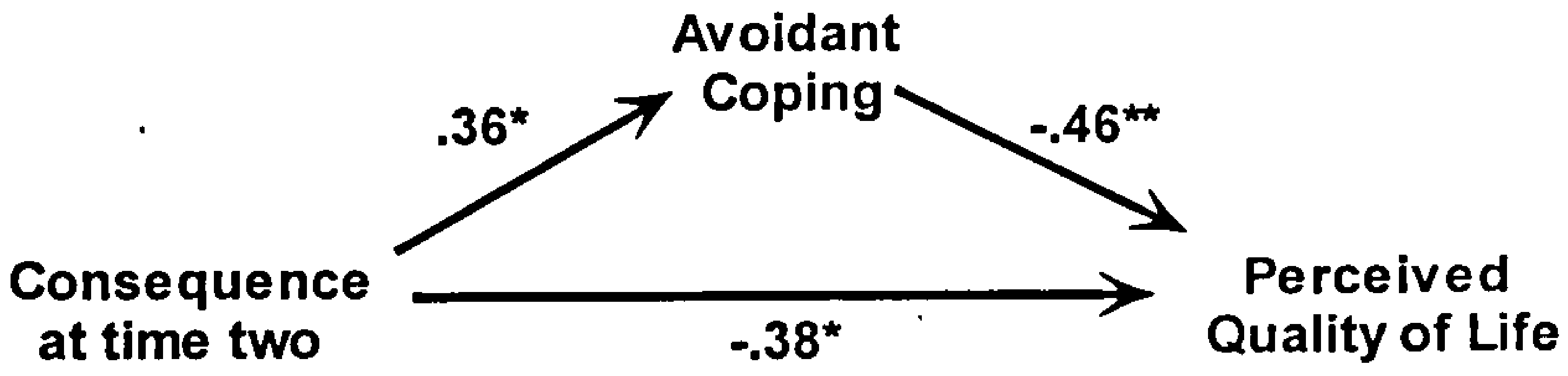
Time 1 timeline was associated positively with subsequent (Time 2) problem-focused ($r = .46$, $p<0.01$) and emotion-focused coping ($r= .47$, $p<0.01$). Time 2 timeline beliefs were associated positively with problem-focused strategies ($r= .37$, $p<0.05$). Serious consequences at Time 1 and Time 2 were associated positively with problem-focused coping ($r= .36$, $p<0.05$ and $r= .34$, $p<0.05$) (Time 1 and Time 2 respectively). However, Time 2 serious consequences were also associated positively with avoidant coping ($r= .36$, $p<0.05$). Only avoidant coping produced significant relationships with outcome measures: it was related negatively to quality of life ($r= -.60$, $p<0.001$), and positively to anxiety ($r= .47$, $p<0.01$) and depression ($r= .41$, $p<0.05$).

3.4 Mediation of Representation by Coping

Mediation can be said to occur when: the IV significantly affects the mediator, the IV significantly affects the DV in the absence of the mediator, the mediator has a significant unique effect on the DV, and the effect of the IV on the DV shrinks upon the addition of the mediator to the model (Baron and Kenny, 1986). These criteria can be used to judge informally whether mediation has occurred. However, mediation may be formally assessed using several methods which are available on-line. The Sobel test was employed here to test for mediation (http://quantrm2.psy.ohio-state.edu/kris/sobel/sobel.htm). This program was selected because it is conservative and easy to use, and often used in structural equation modelling. This programme calculates on-line a critical ratio as a test of whether the indirect effect of the IV on the DV via the mediator is significantly different from zero (i.e. treating the ratio as a z-test).

The small sample size ensured a conservative selection of predictors, in order to avoid Type I error. After examination of the correlational relationships, and the relationships from the previous two studies, serious consequences and avoidant coping were selected as the most important predictors of outcome. Mediation Analysis was conducted for each of the four outcome measures. Thus, eight tests were conducted (for both Time 1 and Time 2 consequences). Only one test reached marginal significance (p=0.06).

Figure 1 The mediated relationship between the representation component of consequences and perceived quality of life for the IBS sufferers



As Figure 1 shows, those patients who report that IBS had serious consequences two months after being diagnosed were likely to use avoidant coping. Both avoidant coping and serious consequence beliefs were related to lower perceived quality of life. While it could be argued that mediation has been detected, the results should be interpreted with caution due to the small sample size.

Summary of Research Findings

This study was designed with three predictions. The first was that the initial representation of IBS and IBD patients will change in the two months following diagnosis. The second prediction was that initial representations measured at the time of diagnosis will predict 2 month outcome. The third hypothesis was that coping will mediate the link between representation and outcome. In this section, each prediction will be discussed in turn.

The Illness Representations

The symptom patterns revealed in this study were consistent with the symptom patterns revealed in the earlier studies, with wind, rumblings and grumbling and bloating the most common in the IBS group, and wind, rumblings and grumblings, and diarrhoea the most common for the IBD group. Causal beliefs were also consistent with the studies presented in Chapters 3 and 4: both IBS and IBD groups cite psychological causes such as stress and state of mind more readily than external causes such as pollution or a virus. Once again, the IBD patients were more likely to cite chance than the IBS patients. At the time of diagnosis, 37 percent of the IBS patients agreed or strongly agreed that chance was a likely cause, however this figure drops to seventeen percent two months later. The IBD patients showed the opposite effect: forty one percent cited chance at the time of diagnosis, and this rose to fifty percent two months later.

Both IBS and IBD patient groups displayed a relationship between timeline and serious consequence beliefs, in that serious consequence beliefs were related to chronic timelines. Similar relationships to those reported in Chapters 3 and 4 were observed between the representation components in this study, but fewer significant relationships were detected. This may be a consequence of the small sample size.

A comparison of the means for the representation components of the two illness groups demonstrated that the IBD patients expect their illness to have a longer timeline than the IBS patients. This difference was evident at the time of diagnosis, and was still present two months later. This is unusual as both illnesses have similar prognoses: a chronic timeline with expectations of exacerbation and remission. At the time of diagnosis, the IBD patients also displayed more serious consequence beliefs. This could be due to the organic status of the illness. In the consultation in which IBD was diagnosed, it was likely that the gastroenterologist explained the possible treatment methods (e.g. surgery to remove the inflamed part of the bowel, or steroids to control the inflammation) if the disease was to flare up unremittingly. In comparison, the IBS patients would be told that they had to control it as best as possible.

An interesting point to note is the absence of the representation component of cure / control. In the previous two studies, this component has often helped in the prediction of outcome and has shown strong relationships with the consequence component. In this study the reliability of the cure / control was very poor; whether this was a result of the low sample size or the clinic population is as yet unknown.

It was predicted that the initial IBS and IBD representations would be significantly different from each other due to the different diagnoses the patients received from the gastroenterologist. Two differences were detected: the IBD patients expressed a longer timeline and more serious consequence beliefs.

Some changes were detected over time, however none of the changes were significant. The IBS patients showed a decrease in psychological causes and an increase in external causes. While the former is supported in study two (Chapter 4), the latter was not.

The IBD patients also displayed an increase in external causes: however, these patients displayed an increase in psychological causes too. Interesting to note is the decrease in the serious consequence beliefs of the IBD patients. At the time of diagnosis, the IBD patients displayed more serious consequence beliefs than the IBS patients. However, two months later these serious consequence beliefs were reduced. The serious consequence beliefs of the IBS patients were lower in this study than in the previous two studies. It could be that the more serious consequence beliefs observed in the previous two studies develop over time, when sufferers realised that there are limited treatments available to them. It was expected that the individual illness representation components would improve significantly for both IBS and IBD patients in the two months following diagnosis. The only change detected related to the change in psychological causes, which decreased in the IBS patients and increased in the IBD patients. This will be examined in more detail in the final study.

Illness Representation Predicting Outcome

Although none of the representation components changed significantly over the two months following diagnosis, the Time 2 components taken together were much better predictors of Time 2 outcome. Serious consequences measured at Time 2 was the only representation component to significantly predict Time 2 outcome. Even though some of the Time 1 models could not significantly predict Time 2 outcome, the Time 1 consequence component showed that it uniquely contributed to predicting outcome, thus showing once again how important the consequence component is to the representation of IBS. It was expected that the illness representation from Time 2 would explain more of the variance in outcome than the Time 1 representation. This prediction was supported.

Mediation of Representation by Coping

Due to the low sample size, consequence (measured at Time 1 and Time 2) was the only representation component to be investigated. Following the observed relationships between consequences and behavioural disengagement in the earlier studies, and after examining the relationships between the new coping scales, avoidant coping was chosen as the mediator. Eight mediating models were tested for each of the four outcomes. Mediation was detected for one model: in predicting quality of life, the belief in serious consequences was partly mediated by avoidant coping. Two other models showed some mediation: consequences at Time 2 were partly mediated by avoidant coping when predicting anxiety and depression, however the mediation in these models was not found to be significant. It was expected that the effect of the illness representation upon outcome would be partly mediated by coping, and this was supported in part in the prediction of quality of life.

Anxiety

Most of the literature pertaining to IBS and anxiety, shows that anxiety is highest in patients who have been referred to secondary care. However, the patients tested here show lower scores for anxiety and depression compared to the two previous studies (Chapters 3 and 4). It could be argued to be a consequence of the shorter amount of time these patients have had to cope with their symptoms. This will be examined further in the final study.

Summary and Conclusion

This small prospective study has shown that, at the time of diagnosis, the IBD patients express longer timeline beliefs and consequences that are more serious than patients diagnosed with IBS. Secondly, it has shown that causal beliefs change over the first couple of months from diagnosis. Thirdly, the simultaneous measurement of representation components provides better predictors of outcome than representation components measured before outcome measures. Fourthly, serious consequence beliefs are the most important of the representation components in predicting outcome. Finally, mediation of consequences by avoidant coping is observed when predicting quality of life.

The findings from this study provide interesting discussion points which will be examined more closely in the final study. The main limitation of this study was the small number of participants recruited. Unfortunately, both extra time and funding needed to travel to further clinics was not available. The final longitudinal study is concerned with patients recruited from primary care. In this population, some patients have undergone various tests and investigations; others have been diagnosed from their symptoms alone. As patients are recruited from around the country, and from their GP, this should provide a good representative sample.

Chapter 6

Illness Representation, Coping and Outcome in Primary Care Patients: A Longitudinal Study of IBS, IBD and CFS Patients

> *Almost all IBS research is done in tertiary care centres. Information gained from this research cannot automatically be extrapolated to the IBS population at large. While these patients may be largely depressed, abused, socially disadvantaged, or gut hyperactive, it does not follow that these are intrinsic features of IBS.*
>
> Grant Thompson, W. (1999)
>
> *If we are to understand more about this disorder it is essential that we study more representative patients.* Drossman, D. (1999)

Introduction

As reported in Chapters 2, 3, 4 and 5, the majority of research investigating the IBS has recruited from self-help organisations and tertiary care centres due to the relative ease of recruitment - sufferers are contacted *en masse* and there is limited input from other health professionals. As the opening quotations show, it is thought that this kind of research recruits sufferers who are not representative of the majority of IBS individuals.

The research presented in this thesis has shown first, that illness representation is related to outcome. Second, that the representation component of serious consequences is perhaps the most predictive component. Third, that the simultaneous measurement of the illness representation and outcome variables provides stronger relationships than the equivalent longitudinal model. Fourth, the representation components are partially mediated by coping. The representation components of serious consequences and weak control have been shown to have direct and indirect relationships with poor outcomes, with most of the indirect routes mediated by avoidant coping. Fifth, that the representations of IBS sufferers (a functional GI illness) are similar to those with IBD (an organic GI illness), with perhaps the most consistent difference being that IBS patients report significantly more anxiety than the IBD patients. Finally, IBS models have been shown to be more predictive than the IBD models; it is unknown whether this is a consequence of the functional status of IBS. Therefore, to control for bowel symptoms a third illness was tested in this study - chronic fatigue syndrome (CFS), which is a functional, non-GI disorder. CFS was investigated along with IBS and IBD in this final study.

Hypotheses of the Study

The study was designed with three hypotheses and an exploratory objective.

1. The first hypothesis was concerned with the relationships between representation components. It was predicted that the representation components would remain stable over 12 months (3 Time points).
2. The second prediction was that Time 1, Time 2 and Time 3 representation components will predict Time 3 outcome.
3. The third was, if Time 1, Time 2 and Time 3 representation components predict Time 3 outcome, that these links between them are mediated by coping.

A further exploratory objective of this study was to explore the illness representation, coping and outcome of another functional, non-gut illness to examine whether the patterns detected in IBS are attributable to IBS being (1) a functional disorder, (2) a disorder of the gut, or (3) both.

Design and Procedure

The data presented so far, may be influenced by: the membership of the Network, recent explanation of the illness by the gastroenterologist, or recently experiencing invasive investigations in order to detect physical disease. In the previous study (Chapter 5), the representation components were more positive than in studies one and two (Chapters 3 and 4). This finding was unexpected, as previous researchers have suggested that clinic patients are “likely to have the most severe bowel symptoms, co-existing psychiatric symptoms, and the most severe illness worries” (Creed, 1995, p.257). Therefore, it could be argued that being told that no organic disease is present initially protects the individual from constructing a negative representation of the illness. The more severe illness worries that have been observed in previous studies may develop after the diagnosis has been made and sufferers realise that there is little effective treatment. A sample was required then, where patients have been diagnosed for over six months, and are not members of a self-help organisation. In order to contact a sample of IBS patients who were not in secondary (also known as tertiary) care, or members of a self-help organisation, GPs from around Britain were contacted and asked to help recruit patients for this study.

Patients recruited from primary care are under-represented in the literature, perhaps due to the difficulties that primary care research presents. Due to the potential importance of this population, it was decided that a longitudinal study containing three Time points would be useful. The only entry criteria for this research were that patients had received a diagnosis of IBS (Manning criteria), IBD (defined as either colitis or Crohn's disease), or CFS (Oxford criteria).

Recruiting GPs

The time pressures on GPs are relatively well established, so before this study was submitted for ethical approval, it was decided to invite GPs to participate in this research, in order to assess the feasibility of the study. In order to obtain a random sample of GPs, one hundred and twenty two health authorities and boards across England and Wales[1] were contacted. Each health authority was asked to send lists of GP's in their area. Twelve health authorities required payment (which ranged from £5 + VAT, up to £70) for the list, and so were ignored. Of the seventy-seven health authorities that sent their GP lists[2], sixteen were selected at random[3].

All GP lists presented GP by practice. Each fourth GP was selected, (however only one GP from a practice was selected, and in the case where a large surgery is presented, I simply counted on a further four). There were large differences in the number of GPs sampled from each health authority

---

[1] From the web page http://www.tagish.co.uk/tagish/health/ha.htm

[2] 33 Health authorities refused to send a list, after hearing the nature of the research.

[3] Sixteen was decided as enough to begin with. Some lists were a lot longer than others, and these sixteen provided a large amount of information.

due to the area covered (a summary of the sampled GPs can be observed in Table 1). The selected GP's name and address were then entered into a data source for a mail merge.

Table 1 Geographical information regarding the sampled GPs and response rates per health authority

Health Authority / Board	**No. GP's sampled**	**No. GPs agreed to help**	**No. GPs declined**	**No reply**
Ayrshire & Arran Health Board	49	4	9	36 (73.5%)
North Bedfordshire Health Authority	45	5	15	25 (55.5%)
Cambridge & Huntingdon Health Authority	55	11	13	31 (56.4%)
East & North Hertfordshire Health Authority	66	11	15	40 (60.6%)
West Hertfordshire Health Authority	70	13	24	33 (47.1%)
Iechyd Morgannwg Health (South Wales)	65	8	14	43 (66.2%)
North Essex Health Authority	22	4	6	12 (54.5%)
Northumberland Health Authority	37	4	10	23 (62.2%)
North Yorkshire Health Authority	99	18	28	53 (53.5%)
Rotherham Health Authority	23	3	1	19 (82.6%)
Salford & Trafford Health Authority	57	11	15	31 (54.4%)
Solihull Health Authority	24	6	6	12 (50%)
Suffolk Health Authority	98	21	27	50 (51%)
Tees Health Authority	69	8	14	47 (68.1%)
Wigan & Bolton Health Authority	42	8	10	24 (57.1%)
Wolverhampton Health Authority	31	5	6	20 (64.5%)

Eight hundred and fifty two GPs were mailed and asked if they would be prepared to hand out information envelopes to their IBS, IBD and CFS patients, (a copy of the letter and reply letter are included in appendix D1). GPs were provided with a reply letter and reply envelope so that their contribution at this instance was minimal. One hundred and forty GPs from around the country agreed to help with the study, 16.4% of the GPs sampled.

Of the 213 who returned the reply letter, but declined to help, 20.5% said that they did not have the time, 5% had retired, 4.7% had left the practice, 3.2% were already involved in other studies, and 66.3% did not give a specific reason. A breakdown of response rates is presented in Table 1 above.

It was assumed that one hundred and forty GPs would give a reasonable return of patients, and so ethical approval was then sought. As a number of health authorities were involved in this research, ethical approval was first sought from a central committee. The South Thames Multi Research Ethics Committee (MREC) granted ethical approval in January 1999. Local approval was then sought from each of the 16 targeted health authorities. The length of time it took for local approval varied by each authority, lasting from February to July 1999. Only when local approval was granted could information envelopes be posted along with an explanatory letter (appendix D2) to each GP who agreed to help. Each information envelope contained a patient information sheet with a reply slip (appendix D3), two consent forms, (one for the patient to keep and one to return with the reply slip) and a pre-paid envelope. Each GP was sent five envelopes, along with a letter reminding them of the study (appendix D2) and a sample questionnaire.

Recruiting Patients

GPs were instructed to distribute information envelopes to patients they had diagnosed with IBS, IBD or CFS. The patients were left to decide whether to take part. Those interested in finding out more about the study returned the reply slips to me. Upon receiving a reply slip, a Time 1 letter and questionnaire was sent out (appendix D4 and D5).

Due to confidentiality issues and GP time pressures, GPs were not followed up and asked to state how many envelopes they had distributed. Therefore, it is not possible to know how many information envelopes were passed on to patients to assess a response rate. However, sixty-seven patients returned a reply slip saying they were interested in the research. All were sent a letter explaining the research and the commitment of the three time periods, a questionnaire and a prepaid envelope. Forty-three patients returned a completed questionnaire: 24 IBS, 10 IBD and 9 CFS. Due to the small response rate, it was decided that more GPs should be contacted.

To increase the number of health authorities contacted, local approval was sought from two local health authorities: East and West Kent. Two hundred GPs from East and West Kent were selected using the same procedure as before: sampling every fourth GP from a different practice. Then, one thousand and ninety one GPs from the previous 16 health authorities were selected from the GP lists used previously. Now the second listed GP in every surgery was contacted (in single run GP practices, the sole GP was contacted). If the GP second on the practice list had been selected previously, the first GP in the practice was selected. Each selected GP was then sent a letter (appendix D10) with five information envelopes[4].

Patients were sent the same information letter (appendix D3) and consent form as in the earlier phase. Fifty patients returned a completed Time 1 questionnaire: 21 IBS, 15 IBD, 15 CFS. Thus a total of 43 IBS, 27 IBD and 25 CFS Time 1 questionnaires were returned. The Time 2 letter and questionnaire (appendix D6 and D7) was sent 6 months later. The Time 3 letter and questionnaire (appendix D8 and D9) was sent 6 months after receiving the Time 2 questionnaire. If a questionnaire was not received one month after it was posted, a reminder card was sent out. If a questionnaire was not received two weeks after that date, a final reminder was sent out. Only 10 patients failed to complete the Time 2 and 3 measures. Five IBS patients dropped out (one lady was diagnosed as IBD and so not followed up, although she was given details of NACC). Three IBD patients dropped out (one lady reported that after having her appendix removed, her symptoms disappeared). In addition, two CFS patients (neither gave any reason for attrition) only completed the Time 1 measure. One IBS and two CFS patients failed to return the Time 3 questionnaire. This then gave the number of

---

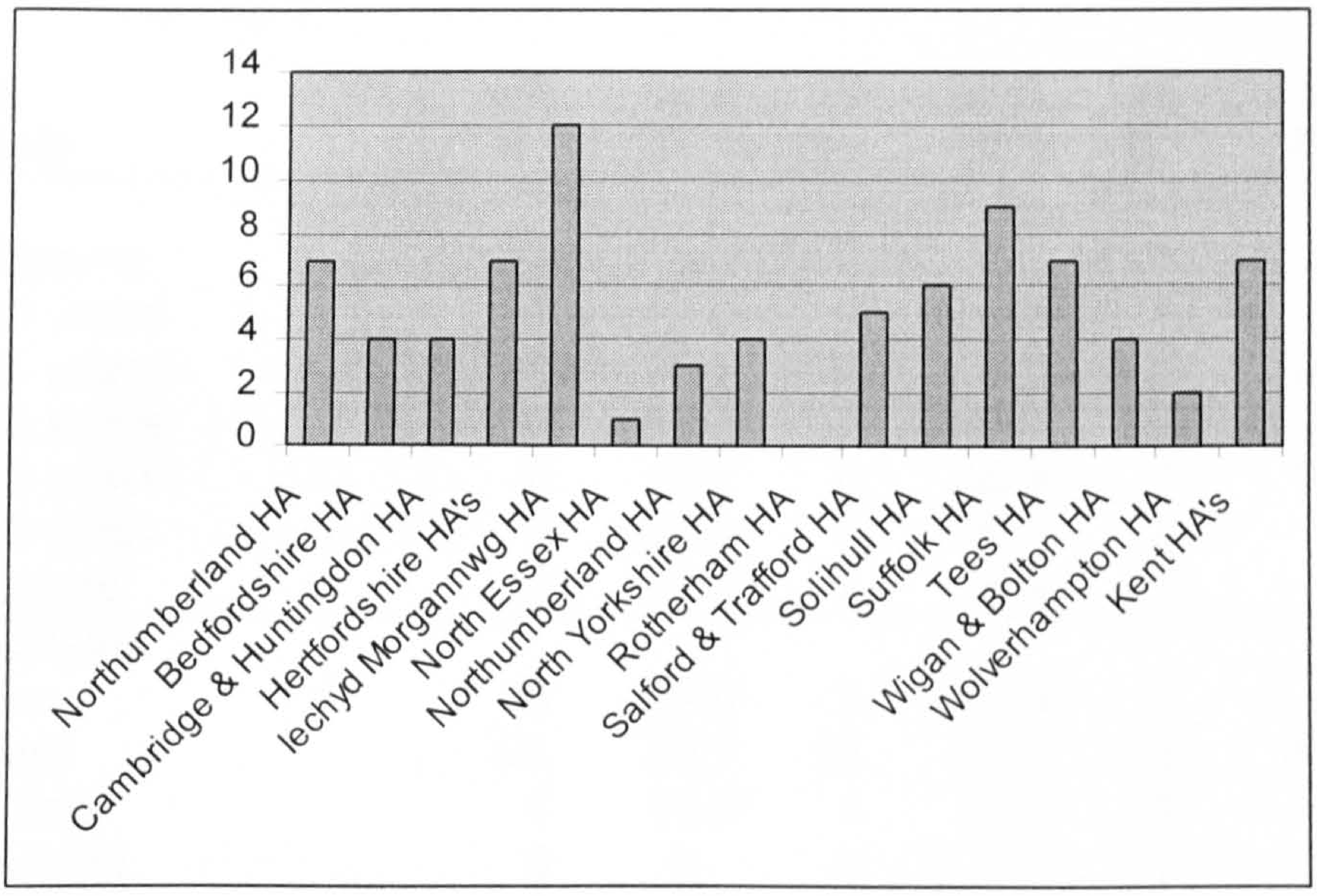
[4] If a similar response rate of 16% were achieved, then approximately 200 GP's would hand out at least one information envelope. This *cold calling* technique produced a similar number of people interested in the research: sixty-two patients returned the (colour coded) reply slip. This technique was less successful than the earlier method, of providing brief information and inviting the GPs to participate by returning a reply slip.

participants with data for all three Time points as: 37 IBS, 24 IBD, and 21 CFS. The data presented in this chapter is only for those 82 individuals who participated in all three Time points.

Participants

Although no information is available regarding which GPs gave out information envelopes to patients, Figure 1 below shows the geographical location from where patients were recruited. As can be seen, the majority of patients in this study were from South Wales and Suffolk.

Figure 1 Bar chart showing the number of patients recruited by each health authority



The demographic details of each of the eighty-two patients who participated in all three data collection points are presented in Table 2. In the IBS sample, ages ranged from 19 to 77 with a mean age of 47.7. Almost sixty percent of the sample was married and the majority were retired. The reported mean length of the illness was 8.9 years (SD = 8.4) and the time from diagnosis was 5.5 years (SD = 5.0).

The ages of the IBD patients ranged from 27 to 76, with a mean age of 50.8. The majority of the IBD patients were married and the majority were not working. The reported mean length of the illness was 13.6 years (SD = 11.1) and the time from diagnosis was 9.3 years (SD = 8.1).

In the CFS sample, ages ranged from 26 to 71, with a mean age of 45.9. As in the IBD sample, the majority of CFS patients were married and the majority were not working. The reported mean length of the illness was 10.1 years (SD = 9.9) and the time from diagnosis was 5.3 years (SD = 3.8). A one-way ANOVA on this data show that none of the groups were significantly different from each other.

Table 2 Demographic information of the primary care patients

	IBS		IBD		CFS	
	N	%	N	%	N	%
Sex						
Male	6	16.2	9	37.5	3	14.3
Female	31	83.4	15	62.5	18	85.7
Age						
0-20 years	1	2.7	0	0	0	0
21-30 years	7	18.9	1	4.2	1	4.8
31-40 years	6	16.2	2	8.3	6	28.6
41-50 years	6	16.2	10	41.7	8	38.1
51-60 years	6	16.2	5	20.8	3	14.3
61-70 years	9	24.3	4	16.7	2	9.5
70+ years	2	5.1	2	8.3	1	4.8
Marital Status						
Single	8	21.6	3	12.5	0	0
Married	22	59.5	16	66.7	13	61.9
Divorced	4	10.8	1	4.2	3	14.3
Separated	0	0	0	0	1	4.8
Widowed	3	8.1	3	12.5	2	9.5
Cohabiting	0	0	1	4.2	1	4.8
Divorced now cohabiting	0	0	0	0	1	4.8
Occupation						
No Occupation	6	16.2	7	29.2	13	61.9
Retired	9	24.3	3	12.5	3	14.3
Manual	6	16.2	1	4.2	2	9.5
Administration	5	13.5	3	12.5	0	0
Professional	6	16.2	5	20.8	1	4.8
Student	2	5.4	0	0	0	0
Other	3	8.1	5	20.8	2	9.5

Sick leave for the IBS patients (over the last 12 months) ranged from 0 – 60 days, with a mean of 8.4 (SD = 13.7), and a median of 4. The IBD sufferers reported a mean of 14.5 (SD = 42.2) and a median of 0.5, or half a day, with a range of 0 – 148 days. However, the mode for both IBS and IBD patients was zero. Of the four CFS patients who answered the questions regarding sick leave, the range of days taken as sick ranged from 8 – 365, with a mean of 168.8 (SD = 149.3), and a median of 151 days. However, the data pertaining to sick leave must be interpreted with caution as only one half of the IBS and IBD patients completed this question, and only four CFS patients (19% of the sample).

At Time 1, the patients were asked to estimate how often they had visited their GP in the past 12 months. Once again, this data should be interpreted with caution due to the large amount of missing data in response to this question. IBS patients gave their answers as anywhere between 1 – 50, mean 11.4 (SD = 13.2), the IBD patients saw their GP between 1 – 100 times, mean 15.9 (SD = 28.4), and the CFS patients estimated the frequency of GP visits as between 2 – 30, mean 11.1 (SD = 8.1).

At Time 1, the participants were asked to indicate which investigations they received before a diagnosis (either IBS, IBD or CFS) was given. Participants were presented with a list of nine common investigations; they were asked to tick those experienced. The investigations that the GI patients were presented with were: barium meal, barium enema, colonoscopy, rectal examination, blood test, urine sample, stool sample, ultrasound scan and endoscopy. The investigations that the CFS patients were presented with were: MRI scan, blood test, PET scan, CT scan, X-Ray, urine test, stool test and a liver function test. Responses were summed to give an investigations score ranging from 0 – 9, for the GI patients, and 0 – 8 for the CFS patients, (high scores indicating more investigations).

The IBS sufferers reported a mean of 3.14 (SD = 2.8) compared to the IBD group's mean of 4.96 (SD = 2.6) investigations. The IBD group reported significantly more investigations than the IBS sufferers ($t(59) = -2.60$, $p<0.05$). The CFS group reported a mean of 3.29 (SD = 1.5) investigations. While the IBD patients reported significantly more investigations than the CFS patients (t

(43) = 2.59, $p<0.05$), the two functional groups, the IBS and CFS patients, reported similar numbers of investigations (t (56) = -.23, $p>0.05$).

The three most frequent investigations for the IBS sufferers were a rectal examination (N = 18: 48.6%), blood test (N = 17: 45.9%), and a barium enema (N = 17: 45.9%). The four most frequent investigations for the IBD sufferers were a rectal examination (N= 19: 79.2%), barium enema (N = 16: 66.7%), colonoscopy (N = 16: 66.7%) and a blood test (N = 16: 66.7%). The three most frequent investigations for the CFS patients were a blood test (N = 21: 100%), urine test (N = 17: 81%) and x-ray (N = 11: 52.4%).

Measures

Illness Representations

The Illness Perception Questionnaire (IPQ) ***(Weinman, Petrie, Moss-Morris and Horne, 1996)*** This questionnaire was selected once again so that the illness representation components of cause, timeline, consequence and cure / control could be examined and compared to the same components in the earlier studies. Higher scores represent more agreement with cause, longer timeline beliefs, more severe consequences, and strong feelings of control.

To measure identity, the same ten-item symptom inventory was administered, a higher score on this scale representing more experience of the GI symptoms. A similar ten-item scale was produced for CFS symptoms. Here symptoms were based on the Oxford criteria for CFS and the most common CFS/ME symptoms reported in ME literature. The ten selected symptoms were: general muscle pain, tiredness, difficulty concentrating, fatigue, memory loss, joint pain, difficulty sleeping, reduced energy levels, exhaustion, headache. Participants rated their identification with each symptom from (0) “No experience of the symptom” to (4) “Experience the symptom more than once every week”. Higher scores indicate greater identification with the illness. As reported earlier, as symptom reports are the only means available to clinicians for diagnosing CFS, it was believed that illness identity based on the perception of frequency of CFS symptoms would be a valuable measure of this component. Cronbach's alpha for this scale yielded .59 for the CFS patients at Time 1, .57 at Time 2, and an acceptable .76 at Time 3. Four items were initially removed (difficulty concentrating, memory loss, difficulty sleeping and headache) to increase the reliability of the CFS identity scale, however, keeping all 10 items at all Time points provided the best Cronbach's alphas overall.

Coping

COPE ***(Carver, Scheier and Weintraub, 1989)*** This questionnaire was selected once more due to its flexibility in allowing examination of both individual and broader concepts of problem- and emotion focused strategies, and avoidant coping. A higher score on either the individual strategies or in the broader categories indicated greater use of that coping behaviour.

Outcome

WHOQOL-Bref ***(Division of Mental Health, WHO, Geneva, 1999)*** The two one-item statements were employed which measured the perceived rating of quality of life ("How would you rate your quality of life?") and satisfaction with health ("How satisfied are you with your health?"). Both statements are rated on a 1 – 5 scale, with higher scores representing better quality of life and more satisfaction with health.

The Hospital Anxiety and Depression Scale (HADS) ***(Zigmond and Snaith, 1983)*** This measure provides an assessment of anxiety and depression. Scores range from 0 – 21, with higher scores indicating greater anxiety and depression.

Results

The results will be presented according to the hypotheses outlined on page 166.

1. The first prediction was that the representation components will remain stable over 12 months. Firstly, the Time 1, Time 2 and Time 3 representation components of the IBS, IBD and CFS patients will be presented. Secondly, the Time 1, Time 2 and Time 3 representation components will be compared statistically within and between groups. Thirdly, relationships between the representation components over time will be explored.
2. The second hypothesis was that the Time 1, Time 2 and Time 3 representation components will predict outcome. Firstly, the individual outcome measures are examined and compared within and between patient groups. Secondly, relationships between representation components and outcome measures will be explored. Then analysis will focus on whether representation components from the different Time points predict future outcome.
3. The third hypothesis was that if the representation components measured 6 and 12 months earlier can predict Time 3 outcome, that these links are mediated by coping. Firstly the three subscales are incorporated once more so that the data becomes more manageable. Secondly, relationships between the Time 1, Time 2 and Time 3 representation components and coping subscales are explored, then relationships between the coping subscales and outcome measures are examined. Finally, analysis regarding the mediation of representation components by coping will be examined. A conservative selection of variables is taken and mediation tested directly, using the Sobel test.

1. The Illness Representations

1.1 The Representation Components

Illness identity At Time 1, the three most frequently perceived symptoms (by reporting the experience of the symptom more than once every week) for the

IBS patients were wind (73%), bloating of the abdomen (67.6%), and rumblings and grumblings (54.1%). For the IBD group, the three most frequently perceived symptoms were wind (58.3%), rumblings and grumblings (45.8%), and diarrhoea (37.5%). The CFS patients reported that they were likely to experience tiredness (95.2%), fatigue (90.5%) and reduced energy levels (90.5%) more than once every week.

At Time 2, the IBS patients reported similar symptom profiles: wind (73%), bloating of the abdomen (64.9%) and rumblings and grumblings (54.1%) as the three most frequently perceived symptoms. The IBD patients also reported a similar symptom pattern to the previous 6 months: rating wind (45.8%), rumblings and grumblings (33.3%) abdominal pain and bloating of the abdomen (25%) as the most frequently perceived symptoms. The CFS patients also reported similar symptoms to Time 1, however four symptoms were equally perceived: tiredness (90.5%), fatigue (90.5%), reduced energy levels (90.5%) and difficulty concentrating (90.5%) were all cited.

At Time 3, the IBS patients rated the most frequently experienced symptoms as wind (70.3%), bloating of the abdomen (59.5%) and incomplete evacuation (51.4%). This is the first time rumbling and grumbling has not been among the top three symptoms reported by IBS sufferers using this ten item scale. The IBD patients rated the most frequent symptoms as wind (66.7%), rumblings and grumblings (50%) and bloating of the abdomen (45.8%). While this pattern is similar across studies one and three (Chapters 3 and 5), here, diarrhoea was perceived more than once every week by only 37.5% of the primary care patients. Once again the CFS patients rated the most frequently perceived symptoms as tiredness (85.7%), fatigue (85.7%) and reduced energy levels (85.7%).

Table 3 presents the means and standard deviations for the identity scale at each Time point. While the IBS and CFS symptom scores vary very little over time (no significant differences were detected), the IBD identity scores varied significantly over the three Time points. The IBD patients reported fewer symptoms at Time 2, (from mean of 19.9 down to 17.2) ($t(23) = 2.31$, $p<0.05$)

and then greater symptoms (mean of 20.7) at Time 3, (t (23) = -2.35, $p < 0.05$). The difference between Time 1 and 3 however was non significant. One important difference in this primary care population is that the IBS patients are reporting more symptoms than the IBD patients, and this difference is significant at Time 2 (t (59) = 3.20, $p<0.01$), when the IBD patients are perceiving fewer symptoms. The CFS patients have significantly higher symptom scores than both GI groups (all $p<0.001$), however this could be attributed to a number of factors, such as the non-specific nature of symptoms such as fatigue and tiredness, or hyperawareness of symptoms, or the over-reporting / exaggerating symptom profiles. More research should be carried out with IBS and CFS patients.

Causal attribution Once again, the IBS and IBD patients in this study were more likely to disagree with causal attributions than agree with them. Only the psychological attribution of stress and state of mind produced means of over three. The largest agreement for the IBS patients at Time 1 (where participants agree or strongly agree with the statement) were stress (70.2%), state of mind (35.1%) and diet (32.4%). Similar patterns were reported at Time 2 and 3 with stress (falling to 64.8% at Time 2, and then rising to 67.5% at Time 3), state of mind (40.5% at both Time 2 and 3), and attributing diet as a causal factor of IBS grew in strength over the Time points (increasing to 35.1% and then 43.2% agreement).

The most commonly reported causal attributions for the IBD patients at Time 1 were stress (45.8%), chance (40.6%) and state of mind (25%). Whilst the beliefs in stress and chance strengthened over time (stress rose to 54.2% at Time 2 and reduced to 50% at Time 3; chance strengthened to 50% at Time 2 and then weakened by Time 3 41.7%), the belief that IBD was caused by a germ or virus increased. At Time 2, 29.1% of the participants agreed or strongly agreed that a germ or virus had caused their IBD. This belief remained salient at Time 3 (29.1%).

The causal beliefs of the CFS patients showed the often reported strong external belief in a germ or virus as the cause of symptoms, however, the other causal attributions were also remarkably similar to those of the IBD patients. At Time 1 the belief that CFS was caused by a germ or virus found 85.7% agreement among the CFS patients. This figure dropped to 71.5% agreement at Time 2, but rose again to 76.2% at Time 3. While it is often reported that CFS patients actively avoid psychological causal attributions, approximately half of the CFS patients in this study agreed or strongly agreed that stress was a causal factor in their CFS, with 51.1% agreement at Time 1, lowering to 47.6% agreement at Time 2, and increasing to 61% agreement at Time 3. While the belief that CFS was caused by poor medical care was the third most agreed upon causal attribution at Time 1 (28.5%), this attribution was eclipsed by chance which found 28.6% agreement at Time 2, and rose to 38.1% agreement at Time 3.

It is interesting to note that IBD and CFS patients were more likely to cite “chance” than the IBS group. It is possible that this results from information given by health professionals. With the belief by many, that CFS is an organic disorder awaiting objective measurement, chance or “bad luck” is a likely consideration.

1.2 Statistical Comparison of the Representation Components

One-way analysis of variance was used to calculate differences within and between patient groups. By combining the individual causal attributions into the psychological and external attributions demonstrates that the IBS patients attribute their illness to internal, emotional or psychological causes more than the IBD patients, and the CFS patients. The IBS patients cited psychological causes more strongly than the CFS patients ($p<0.05$ at Time 1 and 3, $p<0.001$ at Time 2). As expected, CFS patients agreed that external causes were responsible for causing their illness, significantly more so than either of the GI patient groups (all Time points for both GI illness comparisons $p<0.005$).

Table 3 Means and standard deviations of the illness representation components at the three Time points for the IBS, IBD and CFS patients

	IBS		IBD		CFS	
	Mean	SD	Mean	SD	Mean	SD
Identity (T1)	22.9	7.1	19.9	9.1	35.0	4.1
Identity (T2)	23.5	6.3	17.2	9.0	35.7	3.9
Identity (T3)	23.5	7.6	20.7	9.1	34.4	5.0
Psychological Cause (T1)	3.2	0.9	2.8	0.8	2.6	0.9
Psychological Cause (T2)	3.2	0.8	2.7	0.9	2.4	0.9
Psychological Cause (T3)	3.1	0.7	2.8	0.6	2.6	0.9
External Cause (T1)	2.2	0.7	2.6	0.6	3.2	0.7
External Cause (T2)	2.2	0.8	2.4	0.9	3.2	0.8
External Cause (T3)	2.2	0.7	2.6	0.6	3.2	0.6
Timeline (T1)	3.8	0.9	3.9	0.9	3.2	0.9
Timeline (T2)	3.8	0.7	3.8	0.7	3.3	1.1
Timeline (T3)	3.8	0.9	3.8	0.7	3.5	1.1
Consequences (T1)	3.0	0.9	3.2	0.9	4.1	0.6
Consequences (T2)	3.1	1.0	3.2	0.9	4.3	0.7
Consequences (T3)	3.0	1.0	3.4	0.8	4.1	0.6
Cure / Control (T1)	3.1	0.8	3.3	0.7	3.1	0.9
Cure / Control (T2)	3.0	0.8	3.5	0.7	3.4	0.9
Cure / Control (T3)	3.0	0.8	3.5	0.7	3.3	0.7

The CFS patients reported significantly more symptoms than the IBS and IBD patients at all three Time points (all p<0.001). However, as different symptom lists were used, this difference should be interpreted with caution. A difference was also detected for the consequence component: the CFS patients reported significantly more severe consequences than either of the GI illness groups (all Time points, p<0.001), however no differences were detected between the two GI groups.

Only one difference was detected between the IBS and IBD groups. As reported earlier, the IBS patients in this sample reported stronger illness identities than the IBD patients, and at Time 2 this difference was highly significant, (t(59) = 3.2, p =0.002).

No differences were detected within or between the patient groups when examining the representation components of timeline and cure / control, although the pattern of means suggests that the IBS and IBD patients have longer timeline beliefs than the CFS patients, and that the IBD patients have stronger feelings of control over their illness than the two functional groups.

1.3 Relationships among the Illness Representations

Univariate correlations were computed for the IBS, IBD and CFS patients over the three Time points, and are displayed in Tables 3, 4 and 5. Due to the large number of relationships to be examined only those relationships that reached the significance level of $p<0.01$ are described here. However, while this meant that not as many relationships reached significance, more relationships that were significant were detected for the IBS patients. While it could be argued that this is a result of the larger sample of IBS patients, CFS patients displayed more significant relationships than the IBD patients, even though there are more IBD than CFS patients. As expected, the same representation component measured at Time 1, Time 2 and Time 3 were highly associated with one another.

PAGE
MISSING
IN
ORIGINAL

Table 4 Univariate relationships between the illness representation components for all three Time points for the IBS patients: Pearson's r

		(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)	(13)	(14)	(15)	(16)	(17)	(18)
(1)	Identity (1)	1.0																	
(2)	Identity (2)	.82**	1.0																
(3)	Identity (3)	.78**	.86**	1.0															
(4)	Psychological C (1)	.04	-.02	.09	1.0														
(5)	Psychological C (2)	.03	-.04	.04	.84**	1.0													
(6)	Psychological C (3)	-.00	-.09	.02	.79**	.76**	1.0												
(7)	External Cause (1)	.10	.13	.09	-.10	-.11	-.14	1.0											
(8)	External Cause (2)	.05	-.01	-.07	-.07	-.19	-.10	.69**	1.0										
(9)	External Cause (3)	.00	-.01	.06	-.10	-.10	-.12	.68**	.52*	1.0									
(10)	Timeline (1)	**.43***	.35	.24	.20	.38	.24	.04	-.07	.07	1.0								
(11)	Timeline (2)	.21	.40	.38	.10	.08	.03	.20	.08	-.13	.36	1.0							
(12)	Timeline (3)	.18	.22	.18	.04	.14	.20	.19	.15	**.42***	.74**	.34	1.0						
(13)	Consequences (1)	.21	.37	.36	.27	.21	.27	**.58****	**.52***	.36	.24	**.42***	.39	1.0					
(14)	Consequences (2)	.14	.26	.25	.21	.16	.10	**.56****	**.58****	.30	.16	.40	.29	.84**	1.0				
(15)	Consequences (3)	.24	.35	.41	.24	.06	.20	**.45***	**.56****	.33	.08	**.43***	.34	.85**	.88**	1.0			
(16)	Cure / Control (1)	-.22	-.23	-.19	.10	.17	.06	-.39	**-.49***	-.23	-.04	-.21	-.11	-.33	-.29	-.35	1.0		
(17)	Cure / Control (2)	-.08	-.20	-.19	-.13	-.10	-.09	-.30	-.28	-.05	-.15	**-.53****	-.18	**-.46***	**-.51***	**-.47***	.57**	1.0	
(18)	Cure / Control (3)	-.08	-.16	-.21	-.04	-.07	.01	-.34	-.36	-.18	-.02	-.24	-.09	-.40	-.41	**-.43***	.71**	.71**	1.0

*p<0.01, **p<0.001

Table 5 Univariate relationships between the illness representation components for all three Time points for the IBD patients: Pearson's r

		(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)	(13)	(14)	(15)	(16)	(17)	(18)
(1)	Identity (1)	1.0																	
(2)	Identity (2)	.79**	1.0																
(3)	Identity (3)	.49	.68**	1.0															
(4)	Psychological C (1)	.38	.36	.50	1.0														
(5)	Psychological C (2)	.12	.08	**.65***	.32	1.0													
(6)	Psychological C (3)	.11	.10	.34	.65*	.20	1.0												
(7)	External Cause (1)	.03	.18	.37	.16	.01	.15	1.0											
(8)	External Cause (2)	.16	.24	**.55***	.25	.42	.13	.47	1.0										
(9)	External Cause (3)	-.25	-.21	.26	.16	.18	.30	.55*	.39	1.0									
(10)	Timeline (1)	.21	.36	.00	.29	-.25	.35	-.25	-.12	-.25	1.0								
(11)	Timeline (2)	.17	.14	.05	.37	-.10	.35	-.35	-.03	-.09	.68**	1.0							
(12)	Timeline (3)	.00	.13	-.03	-.08	-.05	-.08	-.22	-.20	-.11	.52	.48	1.0						
(13)	Consequences (1)	.41	.45	.34	**.61***	.14	.41	.00	.16	.09	.52	.49	.22	1.0					
(14)	Consequences (2)	.53	**.62***	**.59***	**.55***	.33	.38	.06	.09	-.09	.35	.33	.23	.77**	1.0				
(15)	Consequences (3)	.36	.48	.30	.41	-.01	.38	.09	.07	.18	.52	.41	.31	.92**	.70**	1.0			
(16)	Cure / Control (1)	.15	-.05	.18	.27	.30	.19	.24	.30	-.06	-.35	-.18	-.33	-.11	.02	-.23	1.0		
(17)	Cure / Control (2)	.34	.06	.21	.31	.28	.12	.38	.29	.20	-.25	-.26	-.35	.19	.24	.06	.63*	1.0	
(18)	Cure / Control (3)	-.09	-.20	-.19	-.05	.12	-.17	.10	.00	.19	-.40	-.50	-.51	-.10	-.13	-.23	.18	.34	1.0

*p<0.01, **p<0.001

Table 6 Univariate relationships between the illness representation components for all three Time points for the CFS patients: Pearson's r

		(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)	(9)	(10)	(11)	(12)	(13)	(14)	(15)	(16)	(17)	(18)
(1)	Identity (1)	1.0																	
(2)	Identity (2)	.71	1.0																
(3)	Identity (3)	.47	.78**	1.0															
(4)	Psychological C (1)	.10	-.31	-.17	1.0														
(5)	Psychological C (2)	-.12	-.26	-.29	.73**	1.0													
(6)	Psychological C (3)	-.21	-.33	-.12	.74**	.85**	1.0												
(7)	External Cause (1)	.32	.22	.07	.24	-.12	.04	1.0											
(8)	External Cause (2)	.38	.32	.20	.05	.19	.01	.47	1.0										
(9)	External Cause (3)	-.19	.19	-.21	.33	.36	.33	.62*	.41	1.0									
(10)	Timeline (1)	-.03	.03	.08	-.20	-.04	-.07	-.22	-.22	-.10	1.0								
(11)	Timeline (2)	.08	.25	.37	-.14	-.45	-.32	.12	-.28	-.23	.67*	1.0							
(12)	Timeline (3)	-.05	.07	.16	-.06	-.05	-.05	.02	-.02	.12	.73**	.68**	1.0						
(13)	Consequences (1)	**.64***	.53	.47	.27	-.05	-.02	**.55***	**.56***	.27	-.01	.25	.23	1.0					
(14)	Consequences (2)	.51	.54	.46	.25	.22	.18	.42	**.70****	.27	-.04	.05	.18	.80**	1.0				
(15)	Consequences (3)	.39	.29	.31	.42	.25	.20	**.55***	**.65***	.49	-.28	-.08	.07	.83**	.86**	1.0			
(16)	Cure / Control (1)	-.21	-.23	-.09	.42	.53	.47	-.11	-.01	.23	-.36	-.53	-.35	.12	.01	.29	1.0		
(17)	Cure / Control (2)	.10	-.10	-.05	.45	**.81****	.42	-.20	.28	.08	-.05	-.51	-.13	.10	.27	.35	.60*	1.0	
(18)	Cure / Control (3)	-.08	-.28	-.31	.54	**.75****	.53	-.04	.26	.21	-.36	**-.58***	-.30	.08	.15	.33	.66*	.79**	1.0

*p<0.01, **p<0.001

As significant relationships have been detected for the same representation components over the three Time points (i.e. a one year period), this demonstrates the stability of the representation components over time (see shaded boxes).

Both functional groups (IBS and CFS) showed external causes associated positively with serious consequences, while the IBD patients showed positive associations between the symptoms experienced, serious consequences and psychological causal attributions. The IBS patients displayed positive associations between timeline beliefs and serious consequences, and serious consequences were negatively associated with control beliefs. The CFS patients displayed positive associations between psychological causes and control, and weak control was positively associated with a long timeline.

2. Predicting Outcome

2.1 Statistical Comparison of IBS, IBD and CFS Outcome Measures

From observing the values in the table below, it can be seen that once again, the IBS patients score the highest for anxiety, the CFS patients score the highest for depression, and the CFS patients are more dissatisfied with their health than the GI patient groups.

Table 7 Means and standard deviations of the outcome measures for the IBS, IBD and CFS patients

	Time 1		Time 2		Time 3	
	Mean	SD	Mean	SD	Mean	SD
IBS Patients						
Quality of Life	3.5	0.9	3.3	1.0	3.5	0.9
Satisfaction with Health	2.8	1.1	2.8	1.1	3.0	0.9
Anxiety	10.4	4.4	10.6	4.7	10.0	4.9
Depression	5.9	4.1	6.0	4.5	5.6	4.2
IBD Patients						
Quality of Life	3.7	1.0	3.8	0.9	3.8	1.0
Satisfaction with Health	2.8	1.1	3.2	1.1	3.1	1.0
Anxiety	8.2	4.1	9.1	4.7	8.6	4.7
Depression	5.5	3.7	5.3	3.7	5.8	4.2
CFS Patients						
Quality of Life	2.7	1.1	3.1	1.0	3.3	1.1
Satisfaction with Health	1.4	0.6	1.8	0.7	1.8	1.1
Anxiety	9.3	4.3	9.2	4.3	8.6	4.8
Depression	8.9	3.6	7.9	3.4	7.9	4.6

One way repeated measures ANOVAs were calculated to examine the outcome measures over time. Only one variable showed a significant difference; the CFS patients rated their satisfaction with health as very poor at Time 1 and satisfaction increased at Time 2 (t (20) = -3.51, p = 0.002). As this was the only difference detected in the outcome measures over time, it suggests that outcomes are relatively stable within these primary care illness groups.

One way independent ANOVAs were used to examine differences between illness groups. Surprisingly anxiety did not differ significantly between the groups, however CFS patients did score significantly higher for depression at Time 1: between IBS and CFS (t (56) = -2.80, p = 0.007), and IBD and CFS (t (43) = -3.09, p = 0.003).

CFS patients reported significantly lower quality of life at Time 1 than IBS patients (t (56) = 3.35, p = 0.001) and IBD patients (t (43) = 3.31, p = 0.002). In addition, CFS patients rated their satisfaction with health lower than the IBS and IBD patients at each Time point, (IBS and CFS patients, Time 1 (t (56) = 5.15, p=0.000), Time 2 (t (56) = 3.69, p = 0.001), and Time 3 (t (56) = 4.19, p = 0.000); IBD and CFS patients, Time 1 (t (43) = 4.86, p = 0.000), Time 2 (t (43) = 4.90, p = 0.000), and Time 3 (t (43) = 4.17, p = 0.000)).

2.2 Relationships between Representation Components and Outcome for IBS, IBD and CFS Patients Over Time

Due to the considerable number of relationships that have been examined here, the illness representation components for each Time point for each illness group are presented first with the outcome measures of quality of life and satisfaction with health, and then with the outcome measures of anxiety and depression. Only those that reach the more conservative significance level of p<0.01 are presented.

Table 8 displays the relationships that emerged for the IBS patients. Firstly, the importance of the consequence component is observed. Reporting the serious consequences of IBS is related negatively to quality of life and satisfaction with health at Times 1, 2 and 3. Strong control beliefs are associated positively with good outcome: quality of life and satisfaction with health. Other relationships emerged: illness identity was associated negatively with outcome; a belief in the external causes of IBS was associated negatively with satisfaction with health; and a long timeline was associated negatively with quality of life.

Table 8 Relationships between illness representation components and outcome measures - Quality of life and satisfaction with health for the IBS patients over time: Pearson's r

	Q (t1)	Q (t2)	Q (t3)	S (t1)	S (t2)	S (t3)
Identity (T1)	-.52*	-.27	-.23	-.27	-.23	-.26
Identity (T2)	-.51*	-.33	-.22	-.21	-.17	-.38
Identity (T3)	-.40	-.38	-.26	-.26	-.24	-.51*
Psychological Cause (T1)	-.13	-.25	-.23	.01	-.06	-.10
Psychological Cause (T2)	-.06	-.20	-.13	.06	-.02	-.05
Psychological Cause (T3)	-.03	-.27	-.25	.02	-.09	-.09
External Cause (T1)	-.25	-.25	-.20	-.38	-.26	.02
External Cause (T2)	-.16	-.24	-.25	-.45*	-.25	-.01
External Cause (T3)	-.03	.08	-.16	-.18	.04	.20
Timeline (T1)	-.23	-.20	-.09	-.17	-.16	-.08
Timeline (T2)	-.22	-.51*	-.29	-.39	-.34	-.41
Timeline (T3)	-.04	-.13	-.17	-.14	-.05	-.05
Consequences (T1)	-.39	-.48*	-.43	-.55**	-.46*	-.33
Consequences (T2)	-.41	-.60**	-.37	-.60**	-.62**	-.37
Consequences (T3)	-.43*	-.52*	-.51*	-.62**	-.48*	-.50*
Cure / Control (T1)	.43*	.26	.35	.39	.19	.24
Cure / Control (T2)	.45*	.53*	.41	.55*	.38	.38
Cure / Control (T3)	.42*	.43*	.38	.49*	.29	.49*

*$p < 0.01$, **$p<0.001$

By exploring the same outcome measures with the IBD patients, fewer relationships reached significance levels, and of those that did, most concerned the relationship between poor outcome and serious consequence beliefs. In addition, a strong belief that IBD was caused by psychological factors was associated negatively with quality of life.

Even fewer relationships were detected for the CFS representation components (Table 10): satisfaction with health was associated negatively with serious consequence beliefs, and strong control beliefs were related positively to quality of life.

Table 9 Relationships between illness representation components and outcome measures - Quality of life and satisfaction with health for the IBD patients over time: Pearson's r

	Q (t1)	Q (t2)	Q (t3)	S (t1)	S (t2)	S (t3)
Identity (T1)	-.39	-.37	.02	-.34	-.30	.13
Identity (T2)	-.18	-.33	-.17	-.35	-.34	-.13
Identity (T3)	-.20	-.23	-.41	-.41	-.44	-.41
Psychological Cause (T1)	-.23	-.37	-.34	-.13	-.16	-.00
Psychological Cause (T2)	-.10	-.04	-.11	-.20	-.33	-.08
Psychological Cause (T3)	-.34	-.26	**-.60***	-.28	-.35	-.22
External Cause (T1)	-.02	-.07	-.20	.17	-.23	-.06
External Cause (T2)	.09	-.23	-.10	.07	-.46	-.18
External Cause (T3)	-.25	-.02	-.32	.02	-.25	-.20
Timeline (T1)	-.31	-.43	-.33	-.29	-.17	-.14
Timeline (T2)	-.31	-.47	-.33	-.17	-.19	-.30
Timeline (T3)	-.02	-.10	-.22	-.24	-.11	-.28
Consequences (T1)	**-.55***	**-.73****	-.46	-.52	-.52	-.20
Consequences (T2)	**-.63***	**-.60***	-.50	**-.69***	**-.60***	-.28
Consequences (T3)	**-.56***	**-.63***	-.53	-.52	-.47	-.31
Cure / Control (T1)	.30	.15	.13	.34	.04	.21
Cure / Control (T2)	-.20	.00	.24	.06	-.24	.36
Cure / Control (T3)	-.01	.07	.24	.24	.12	.42

*p < 0.01, **p < 0.001

Table 10 Relationships between illness representation components and outcome measures - Quality of life and satisfaction with health for the CFS patients over time: Pearson's r

	Q (t1)	Q (t2)	Q (t3)	S (t1)	S (t2)	S (t3)
Identity (T1)	-.06	-.10	-.10	-.28	-.19	-.34
Identity (T2)	-.37	-.18	.06	-.48	-.40	-.28
Identity (T3)	-.34	-.29	.07	-.44	-.30	-.19
Psychological Cause (T1)	.21	.01	-.01	.24	.09	-.03
Psychological Cause (T2)	.13	.10	.15	.20	.15	.02
Psychological Cause (T3)	.24	.19	.28	.28	.24	.13
External Cause (T1)	-.08	.19	-.04	-.18	-.13	-.09
External Cause (T2)	-.19	.09	.10	-.34	-.09	-.20
External Cause (T3)	.09	.37	.10	-.12	-.03	.10
Timeline (T1)	.07	-.22	-.19	.08	.17	-.18
Timeline (T2)	-.32	-.57	-.48	-.16	-.16	-.25
Timeline (T3)	-.24	-.27	-.51	-.02	-.10	-.18
Consequences (T1)	-.32	-.17	-.06	-.53	-.46	-.33
Consequences (T2)	-.52	-.29	-.08	**-.63***	-.39	-.40
Consequences (T3)	-.39	-.14	-.07	**-.60***	-.45	-.34
Cure / Control (T1)	.21	.39	**.61***	.24	.01	.34
Cure / Control (T2)	.13	.07	.22	.14	.22	.03
Cure / Control (T3)	.08	.14	.22	.22	.04	.01

*p < 0.01, **p < 0.001

When examining the relationships between the representation components and anxiety and depression over the three Time points, once again, the IBS patients display more relationships that are significant. Most associations concern the positive association between serious consequence beliefs and anxiety and depression over the three Time points (only one relationship, serious consequence beliefs and depression at Time 3 did not reach significance). Other interesting relationships showed illness identity associated positively with depression. Long timeline beliefs were associated with simultaneous and subsequent anxiety. Anxiety was associated negatively with subsequent control, and depression was associated negatively with simultaneous and subsequent control beliefs.

Table 11 Relationships between illness representation components and outcome measures – Anxiety and depression for the IBS patients over time: Pearson's r

	A (t1)	A (t2)	A (t3)	D (t1)	D (t2)	D (t3)
Identity (T1)	.34	.12	.09	.44*	.32	.24
Identity (T2)	.39	.26	.27	.34	.36	.28
Identity (T3)	.38	.36	.40	.36	.36	.36
Psychological Cause (T1)	.41	.41	.38	.42	.32	.29
Psychological Cause (T2)	.36	.45*	.35	.39	.36	.22
Psychological Cause (T3)	.33	.34	.27	.38	.32	.31
External Cause (T1)	.17	.11	.11	.25	.24	.01
External Cause (T2)	.11	.09	.12	.22	.26	.13
External Cause (T3)	.10	.12	.22	.18	.20	.21
Timeline (T1)	.37	.29	.22	.26	.29	.22
Timeline (T2)	.32	.44*	.44*	.08	.30	.22
Timeline (T3)	.29	.36	.38	.11	.28	.32
Consequences (T1)	.48*	.50*	.55**	.54*	.52*	.42*
Consequences (T2)	.44*	.56**	.58**	.48*	.55**	.37
Consequences (T3)	.48*	.51*	.63**	.50*	.50*	.53*
Cure / Control (T1)	-.39	-.24	-.16	-.37	-.38	-.32
Cure / Control (T2)	-.36	-.40	-.43*	-.31	-.43*	-.30
Cure / Control (T3)	-.40	-.43*	-.48*	-.38	-.42*	-.40

* $p < 0.01$, **$p < 0.001$

The IBD relationships between the representation components and anxiety and depression are presented in Table 12. Once again, the majority of the significant relationships concern serious consequence beliefs and poor simultaneous outcome (i.e. scoring higher on measures of anxiety and depression) for the IBD patients. In addition, the belief that IBD was caused by psychological factors was associated positively with later anxiety, and a belief that IBD was caused by external factors was associated positively with simultaneous depression. Strong illness identity was associated positively with concurrent depression.

Table 12 Relationships between illness representation components and outcome measures – Anxiety and depression for the IBD patients over time: Pearson's r

	A (t1)	A (t2)	A (t3)	D (t1)	D (t2)	D (t3)
Identity (T1)	.42	.37	.39	**.55***	.41	.37
Identity (T2)	.24	.37	.34	.32	.40	.38
Identity (T3)	.40	.51	.39	.34	.41	.36
Psychological Cause (T1)	.46	**.55***	.32	.31	.41	.24
Psychological Cause (T2)	.31	.36	.01	.15	.30	.07
Psychological Cause (T3)	.31	.25	.27	.36	.35	.38
External Cause (T1)	-.14	.10	.00	.15	.16	.14
External Cause (T2)	.20	.41	.20	.20	**.55***	.22
External Cause (T3)	.10	.01	.08	.36	.29	.27
Timeline (T1)	.28	.16	.30	.18	.28	.38
Timeline (T2)	.42	.43	.48	.21	.38	.26
Timeline (T3)	-.05	-.02	.07	.01	.17	.31
Consequences (T1)	**.54***	.51	.37	**.54***	**.70****	**.57***
Consequences (T2)	.47	.41	.30	.44	.52	.51
Consequences (T3)	.46	.44	.41	.51	**.65***	**.70****
Cure / Control (T1)	-.00	.21	-.19	-.03	-.06	-.27
Cure / Control (T2)	.15	.16	-.22	.31	.18	-.06
Cure / Control (T3)	-.29	-.47	-.49	-.02	-.14	-.21

*p < 0.01, **p < 0.001

The CFS patients demonstrated positive associations between long timeline beliefs and depression over time, also control beliefs were associated negatively with simultaneous depression.

Table 13 Relationships between illness representation components and outcome measures – Anxiety and depression for the CFS patients over time: Pearson's r

	A (t1)	A (t2)	A (t3)	D (t1)	D (t2)	D (t3)
Identity (T1)	-.01	-.17	-.26	.19	.03	-.12
Identity (T2)	-.17	-.31	-.30	.26	.16	-.06
Identity (T3)	-.14	-.16	-.19	.35	.27	.09
Psychological Cause (T1)	.53	.55	.34	-.14	-.08	-.04
Psychological Cause (T2)	.44	.50	.36	-.15	-.04	-.18
Psychological Cause (T3)	.49	.46	.33	-.16	-.22	-.12
External Cause (T1)	.34	.15	.27	.06	-.09	.13
External Cause (T2)	-.02	-.24	-.20	.16	-.05	-.23
External Cause (T3)	.21	.08	.15	-.25	-.25	-.03
Timeline (T1)	.18	-.02	-.09	.41	.31	.40
Timeline (T2)	.31	.10	.06	**.63***	.55	**.66***
Timeline (T3)	.41	.08	-.07	.47	.32	.54
Consequences (T1)	.18	.03	-.18	.14	.03	.01
Consequences (T2)	.33	.07	.00	.37	.29	.13
Consequences (T3)	.28	.23	.15	.15	.12	.10
Cure / Control (T1)	-.09	.36	.04	**-.57***	-.38	-.47
Cure / Control (T2)	.18	.26	.09	-.01	.04	-.23
Cure / Control (T3)	.04	.27	.11	-.16	-.18	-.31

p < 0.01, **p < 0.001

2.3 Representation Components Predicting Outcome

One of the objectives of this study was to examine whether the illness representation components measured at Time 1, 2 and 3, would predict Time 3 outcome. Therefore, a series of 12 multiple linear regression models were computed for each of the three illness groups, one for each outcome, with Time 1, 2, and 3 representation components as predictors. Only significant models are presented here.

Table 14 Predicting Time 3 satisfaction with health from the IBS patients' representations measured at Time 1, 2 and 3

	Time 1		Time 2		Time 3	
	β	*sr*	β	*sr*	β	*sr*
Illness Identity	-.20	-.18	-.20	-.18	-.31*	-.27
Psychological Cause	.05	.04	.08	.07	.04	.04
External Cause	.41	.31	.25	.18	.41**	.35
Timeline	.11	.09	-.13	-.10	-.02	-.02
Consequences	-.50*	-.36	-.32	-.21	-.36*	-.28
Cure / Control	.19	.17	.19	.14	.34*	.31
	$\Delta R^2 = .11$		$\Delta R^2 = .17$		$\Delta R^2 = .50$	
	F = 1.8 (ns)		*F* = 1.7 (ns)		*F* = 6.8***	
	d.f. = 6, 30		d.f. = 6, 29		d.f. = 6, 29	

*p<0.05, **p<0.01, ***p<0.001

Table 15 Predicting Time 3 anxiety from the IBS patients' representations measured at Time 1, 2 and 3

	Time 1		Time 2		Time 3	
	β	*sr*	β	*sr*	β	*sr*
Illness Identity	-.08	-.07	.04	.03	.17	.15
Psychological Cause	.19	.17	.21	.19	.17	.15
External Cause	-.26	-.19	-.19	-.14	-.01	.00
Timeline	.07	.06	.15	.12	.18	.15
Consequences	.62**	.44	.54*	.35	.34*	.26
Cure / Control	-.09	-.08	-.10	-.08	-.28	-.25
	$\Delta R^2 = .29$		$\Delta R^2 = .38$		$\Delta R^2 = .43$	
	F = 3.4*		*F* = 4.5**		*F* = 5.4**	
	d.f. = 6, 30		d.f. = 6, 29		d.f. = 6, 29	

*p<0.05, **p<0.01

Table 16 Predicting Time 3 depression from the IBS patients' representations measured at Time 1, 2 and 3

	Time 1		Time 2		Time 3	
	β	*sr*	β	*sr*	β	*sr*
Illness Identity	.08	.07	.22	.19	.17	.16
Psychological Cause	.14	.12	.17	.16	.23	.22
External Cause	-.39	-.29	-.01	-.01	.05	.04
Timeline	.05	.04	-.06	-.05	.11	.10
Consequences	.48*	.34	.24	.15	.26	.20
Cure / Control	-.31	-.27	-.15	-.12	-.25	-.22
	$\Delta R^2 = .24$		$\Delta R^2 = .06$		$\Delta R^2 = .30$	
	F = 2.9*		*F* = 1.3(ns)		*F* = 3.4*	
	d.f. = 6, 30		d.f. = 6, 29		d.f. = 6, 29	

Table 17 Predicting Time 3 quality of life from the IBD patients' representations measured at Time 1, 2 and 3

	Time 1		Time 2		Time 3	
	β	*sr*	β	*sr*	β	*sr*
Illness Identity	.33	-.12	.41	.29	-.22	-.20
Psychological Cause	-.12	-.14	.17	.13	-.42	-.35
External Cause	-.23	.08	-.33	-.27	-.19	-.18
Timeline	-.18	.08	.03	.03	-.26	-.20
Consequences	-.47	-.26	-.90*	-.55	-.20	-.17
Cure / Control	.00	.23	.45	.39	.03	.02
	$\Delta R^2 = .13$		$\Delta R^2 = .27$		$\Delta R^2 = .40$	
	F = 1.5 (ns)		F = 2.2(ns)		F = 3.4*	
	d.f. = 6, 15		d.f. = 6, 14		d.f. = 6, 15	

*p<0.05

Table 18 Predicting Time 3 depression from the IBD patients' representations measured at Time 1, 2 and 3

	Time 1		Time 2		Time 3	
	β	*sr*	β	*sr*	β	*sr*
Illness Identity	.15	.12	-.03	-.02	.12	.11
Psychological Cause	-.07	-.05	-.21	-.17	.13	.11
External Cause	.24	.22	.31	.25	.10	.09
Timeline	.10	.08	.01	.01	.23	.18
Consequences	.52	.30	.61	.37	.56*	.47
Cure / Control	-.19	-.14	-.17	-.14	.12	.10
	$\Delta R^2 = .28$		$\Delta R^2 = .08$		$\Delta R^2 = .40$	
	F = 2.3(ns)		F = 1.3(ns)		F = 3.4*	
	d.f. = 6, 15		d.f. = 6, 14		d.f. = 6, 16	

*p<0.05

Table 19 Predicting Time 3 depression from the CFS patients' representations measured at Time 1, 2 and 3

	Time 1		Time 2		Time 3	
	β	*sr*	β	*sr*	β	*sr*
Illness Identity	-.40	-.27	-.51*	-.39	-.28	-.21
Psychological Cause	.21	.18	-.20	-.11	.08	.06
External Cause	.12	.08	-.24	-.14	-.30	-.22
Timeline	.25	.21	.66*	.47	.49*	.45
Consequences	.13	.08	.60	.32	.41	.27
Cure / Control	-.55	-.39	.10	.06	-.37	-.25
	$\Delta R^2 = .15$		$\Delta R^2 = .46$		$\Delta R^2 = .14$	
	F = 1.5(ns)		F = 3.6*		F = 1.5(ns)	
	d.f. = 6, 13		d.f. = 6, 12		d.f. = 6, 14	

*p<0.05

Quality of life was not predicted by any of the three IBS or three CFS models. The IBD patients' illness representation measured at Time 3 could help predict Time 3 quality of life, however none of the components uniquely contributed to the 40% variance explained in quality of life.

Satisfaction with health was not successfully predicted by any of the IBD or CFS models. The Time 3 IBS model successfully accounted for approximately 50% of the variance, with four representation components: weak illness identity, strong belief in external causes, few serious consequence beliefs, and strong control beliefs uniquely contributing to this outcome.

Anxiety was not predicted by any of the IBD or CFS models however, the IBS models successfully explained 29%, 38% and 43% of the variance (Time 1, 2 and 3 respectively). In each model the unique significant predictor was the consequence component, in that the more severe the consequences reported, the more anxiety was experienced. When predicting depression, the IBS patients' representation components measured at Time 1 and Time 3 successfully explained some of the variance in outcome (24% and 30% respectively). While the Time 1 consequence component uniquely contributed 11.6% of the variance explained in the first model, no representation components uniquely contributed to the variance explained in the Time 3 components.

Depression was significantly predicted by the Time 1 and 3 IBS models; accounting for 24% and 30% of the variance. With consequences explaining 11.6% of the unique variance in the Time 1 model. The IBD patients' illness representation components measured at Time 3 significantly contributed to the prediction of depression, with approximately 40% of the variance explained, with consequences uniquely contributing 22.1%. When predicting subsequent depression from the CFS patients' representation of illness, only the Time 2 model reached significance. Interestingly, while the Time 2 components collectively accounted for approximately 46% of the variance in depression, Time 2 timeline uniquely accounted for 22.1% of the variance, in that those CFS patients who believed that CFS would last a long time at Time 2, scored higher on the depression inventory six months later.

In summary, while more Time 3 models were successful in predicting Time 3 outcome, it is interesting to note that the IBS patients' representation components measured at Time 1 and 2 predicted anxiety six and twelve months later. The IBS patients' representation components measured at Time 1 successfully predicted depression twelve months later. CFS patients' representation components measured at Time 2 could predict depression six months later.

3. Theorised Mediating Role of Coping Behaviour

3.1 Combining Coping Behaviours

Once again, the individual coping behaviours were combined into the same three scales of problem-focused coping, emotion-focused coping and avoidant coping in order to examine the role of coping in this study with the limited number of participants. This time all items that measure active coping, planning, seeking instrumental support, suppression of competing activities and restraint coping made up the problem focused scale. All items that assess seeking emotional social support, positive reinterpretation and growth and acceptance made up the emotion focused scale. All items relating to mental disengagement, behavioural disengagement, denial and alcohol / drug use were combined to make the avoidant coping scale. All but 9 of the 27 scales produced alphas over .70.

Table 20 Means, standard deviations and alphas of the merged problem-focused scale for the three patient groups

Coping Subscale	T1 Mean	T1 SD	T2 Mean	T2 SD	T3 Mean	T3 SD
IBS Patients	2.2	0.5	2.2	0.5	2.3	0.5
IBD Patients	2.4	0.6	2.2	0.6	2.4	0.6
CFS Patients	2.8	0.6	2.8	0.6	2.8	0.7

Table 21 Means, standard deviations and alphas of the merged emotion-focused scale for the three patient groups

Coping Subscale	T1 Mean	T1 SD	T2 Mean	T2 SD	T3 Mean	T3 SD
IBS Patients	2.4	0.5	2.4	0.5	2.4	0.6
IBD Patients	2.4	0.6	2.4	0.6	2.5	0.6
CFS Patients	2.9	0.5	3.0	0.5	2.8	0.5

Table 22 Means, standard deviations and alphas of the merged avoidant coping scale for the three patient groups

Coping Subscale	T1 Mean	T1 SD	T2 Mean	T2 SD	T3 Mean	T3 SD
IBS Patients	1.7	0.3	1.8	0.4	1.8	0.3
IBD Patients	1.7	0.3	1.6	0.4	1.6	0.4
CFS Patients	1.9	0.4	1.9	0.5	1.9	0.4

None of the coping behaviours varied significantly over the Time periods for any patient group. CFS patients reported using problem and emotion focused coping more often than the IBS patients ($p<0.001$) (although the difference in problem focused coping at Time 3 was $p=0.006$, and Time 3 emotion focused coping was $p = 0.004$). CFS patients also reported using emotion focused coping more than the IBD patients at Time 2 ($t(43) = -3.53$, $p = 0.001$).

3.3 Relationships between Representation Components and Coping Behaviour

Due to the large number of relationships that were examined, only those that reached the more conservative significance level of $p<0.01$ are considered here.

IBS When examining the relationships between the representation components and coping scales for the IBS patients, it was observed that none of the relationships between components and the problem focused scale reached significance. Four relationships were observed in which components and coping measures were taken simultaneously. Psychological causal factors at Time 1 were associated positively with emotion focused coping at Time 1 ($r =.46$, $p<0.01$). Serious consequences at Time 2, and long timeline beliefs at Time 2, were associated positively with Time 2 avoidant coping ($r= .54$, $p<0.01$ and $r =.44$, $p<0.01$ respectively). Serious consequence beliefs at Time 3 were negatively associated with Time 3 emotion focused coping ($r = -.44$, $p<0.01$). The remaining significant relationships concerned relationships over time, and the majority of these relationships showed the representation components predicting subsequent coping. Time 1 serious consequence beliefs and external causal beliefs were associated positively with Time 2 avoidant coping ($r = .54$, $p<0.01$ and $r = .47$, $p<0.01$ respectively). Time 2 serious consequence beliefs and external causal beliefs were associated negatively with Time 3 emotion focused coping ($r = -.49$, $p<0.01$ and $r = -.44$, $p<0.01$ respectively). One relationship was detected in which coping could be seen to influence representation: Time 2 avoidant coping was associated positively with Time 3 serious consequence beliefs ($r = .55$, $p<0.001$).

IBD The majority of the relationships that reached the conservative significance level of p<0.01 for the IBD patients, were when coping was measured before representation, however, simultaneous measurement also showed significant relationships. Time 1 illness identity was associated positively with Time 1 avoidant coping (r = .57, p<0.01). Time 3 external causal beliefs were associated negatively with Time 3 emotion focused coping (r = -.54, p<0.01). Time 1 illness identity was related positively with Time 3 avoidant coping (r = .62, p<0.01). This relationship between identity and avoidant coping is strengthened further when we observe that Time 1 avoidant coping is associated positively with Time 2 illness identity (r = .55, p<0.01). Time 1 emotion focused coping was associated positively to Time 2 timeline beliefs (r = .60, p<0.01), while Time 1 problem focused coping was negatively associated with Time 3 timeline beliefs (r = -.53, p<0.01).

CFS Fewer significant relationships were observed for the CFS patients, however this is likely to be a result of the low sample size. Time 3 avoidant coping was associated positively with Time 3 timeline beliefs (r = .56, p<0.01). Time 1 control beliefs were associated positively with problem focused coping at Time 2 (r = .57, p<0.01) and Time 3 (r = .57, p<0.01).

3.4 Relationships between Coping Behaviour and Outcome

Similar analyses were conducted between coping and outcome measures. Once again, due to the large number of relationships to be examined, only those that reached the more conservative significance level of p<0.01 will be examined here.

IBS Time 1 avoidant coping was associated positively with Time 1 anxiety (r = .52, p<0.01). Time 2 avoidant coping was associated positively with Time 2 anxiety (r = .49, p<0.01). Relationships were detected between coping and subsequent outcome: Time 2 problem focused coping was related negatively with Time 3 satisfaction with health (r = -.46, p<0.01), and Time 2 avoidant coping was associated positively with Time 3 anxiety (r = .49, p<0.01). The two remaining relationships concern outcome and subsequent coping behaviour: Time 2 depression was associated negatively with Time 3 problem focused coping (r = -.47, p<0.01). Time 2 satisfaction with health was associated positively with Time 3 emotion focused coping (r = .43, p<0.01).

IBD Many more relationships were detected for the IBD patients, however the majority concern those relationships measured simultaneously and those where coping was measured before outcome. Those IBD patients who reported using avoidant coping at Time 1 reported more anxiety at Time 1 (r= .52, p=0.01) and more depression at Time 1 (r = .57, p<0.01). Those patients who reported using problem-focused coping at Time 2 reported more anxiety at Time 2 (r = .60, p<0.01). Those patients who reported avoidant coping at Time 2 reported at lower quality of life (r = -.52, p<0.01) and lower satisfaction with health (r = -.53, p<0.01) at Time 2. Those IBD patients who reported avoidant coping at Time 3, reported higher anxiety at Time 3 (r = .64, p<0.01). Those who reported avoidant coping at Time 1 reported poorer subsequent outcomes: a lower quality of life at Time 2 (r = -.54, p<0.01), anxiety at Time 2 (r = .53, p<0.01), anxiety at Time 3 (r = .57, p<0.01), depression at Time 2 (r = .56, p<0.01), and depression at Time 3 (r = .53, p<0.01). A reciprocal relationship emerged in which anxiety at Time 1 was associated with avoidant coping at Time 3 (r = .65, p =0.001), anxiety at Time 2 was associated with Time 3 avoidant coping (r = .68, p<0.001), and a lower quality of life at Time 2 was associated with avoidant coping at Time 3 (r = -.53, p<0.01).

Only two relationships between coping and outcome emerged at the more conservative significance level for the CFS patients, and both demonstrated relationships between outcome and subsequent coping behaviour. Anxiety at Time 1 was associated with avoidant coping at Time 3 (r = .62, p<0.01), and anxiety at Time 2 was associated with avoidant coping at Time 3 (r = .60, p<0.01).

3.5 Mediation of Representation by Coping

Several tests of mediation were calculated based upon the temporal relationships reported in the previous section (3.4). After an examination of the IBS patients' data, the following four relationships were examined: Time 1 consequences, external cause, Time 2 consequences and timeline predicting anxiety at Time 3, being mediated by avoidant coping at Time 2. One test approached significance (p = 0.08) this is presented below.

Figure 2 The mediated relationship between the representation component of timeline and anxiety for the IBS patients

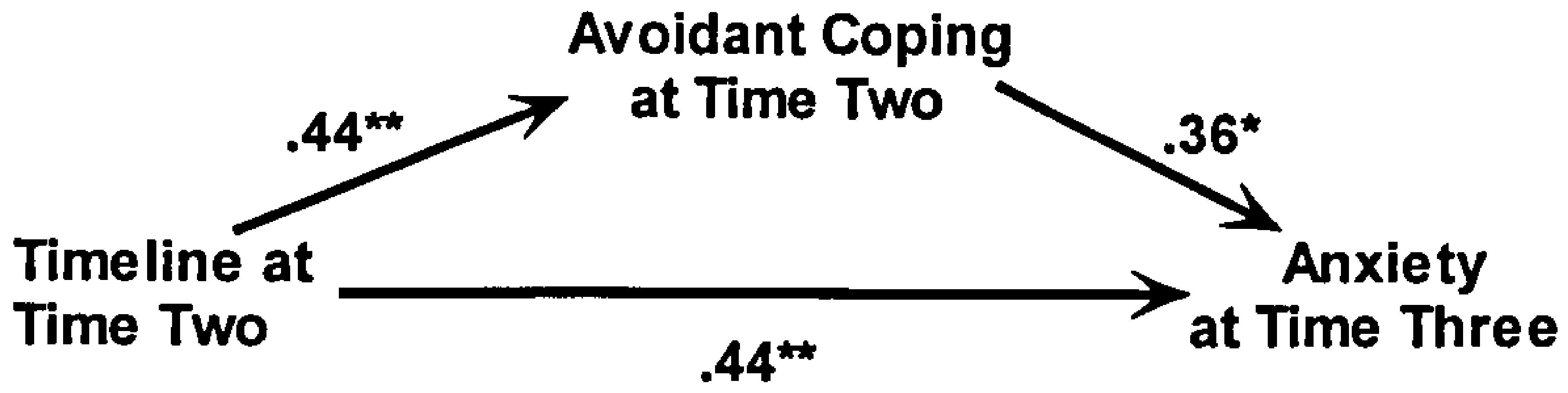


Figure 2 shows, those IBS patients who believe that IBS will last for a long time at Time 2 report more anxiety at Time 3. Also, those patients who expect IBS to last for a long time and who use avoidant coping report more subsequent anxiety. Mediation of the timeline belief was suggested by the Sobel test, with a marginal significance of p = 0.08.

Six relationships regarding the IBD patients data were examined. The first concerned the measurement of identity at Time 1, with avoidant coping and anxiety measured at Time 3. The remaining relationships examined identity at Time 1, being mediated by avoidant coping at Time 1, predicting: quality of life at Time 2, anxiety at Time 2, depression at Time 2, and anxiety and depression at Time 3. Only one relationship achieved marginal significance (p<0.08), this relationship is presented below.

Figure 3 The mediated relationship between the representation component of identity and anxiety for the IBD patients

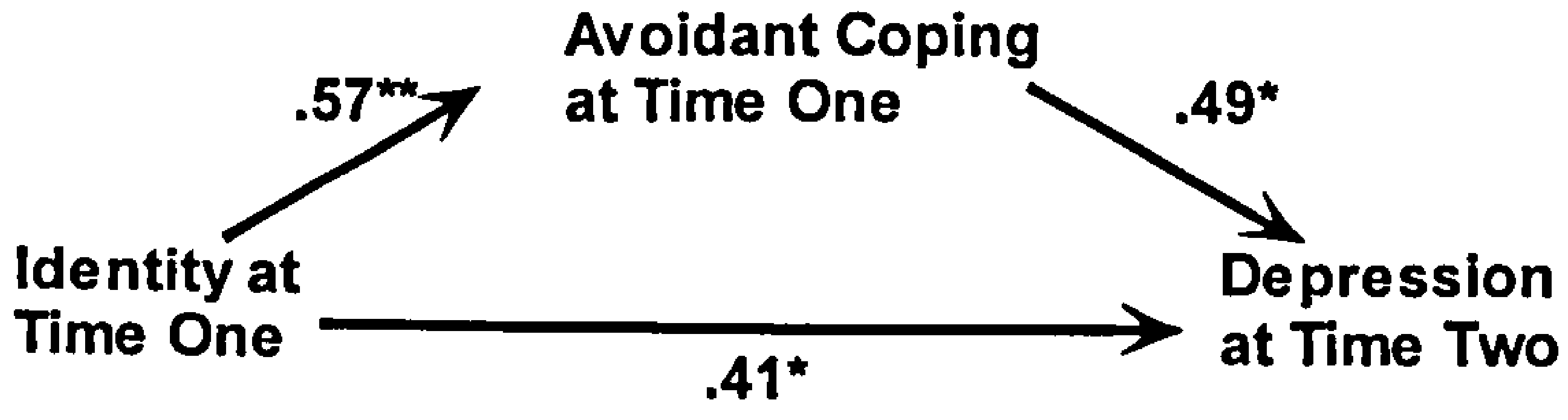


Figure 3 above shows that those patients who report that they experience many symptoms of IBD at Time 1, report more depression at Time 2. Also that those IBD patients with a strong illness identity are likely to cope with their symptoms by using avoidant coping procedures, which are also related to depression.

No relationships were examined using the CFS data due to the low sample size and lack of significant bivariate correlations between representation components, coping and outcome.

Discussion

This study was designed with three hypotheses. The first prediction was to explore the relationships between the illness representation components within and between IBS, IBD and CFS sufferers. The second hypothesis was to explore whether the illness representations of IBS, IBD and CFS sufferers can predict outcome. The third prediction was to examine whether any links that may emerge between representations and outcome are mediated by coping. In this discussion, each hypothesis will be examined in turn.

The Illness Representations

The IBS patients reported a stronger illness identity than the IBD patients for the first time in any of the previous studies in this thesis, and at Time 2 this difference was statistically significant. The IBD patients reported similar symptom levels at Time 1 and 3, and fewer symptoms at Time 2, a satisfactory reason for this cannot be determined. The CFS patients reported a stronger illness identity than both GI patient groups, however, the CFS symptom scale is different from the GI symptom scale, so these findings must be interpreted with caution.

Once again, the IBS and IBD patients cited stress as possible causal factors in their illness. Surprisingly, approximately half of the CFS patients also cited stress as a causal factor. This was unexpected as CFS researchers often report that CFS sufferers dismiss any involvement of psychological causal factors. IBD patients were more likely to cite "chance" as a causal factor than the IBS patients, and in this study, the CFS patients also cited chance as one of the causal factors. It could be argued that citing chance is more likely if patients believe that their illness is organic; IBS sufferers attribute their illness to psychological causes more strongly than the IBD and CFS patients.

The CFS patients reported more severe consequences than either of the two GI patient groups, even though the data contained here suggests that the IBS and IBD groups have longer timeline beliefs than the CFS group. The IBD patient group displayed stronger feelings of control over their illness than either of the two functional illness groups.

Examining relationships between the same representation components over time demonstrated that the stability of the components. Further, the strongest relationships were observed between representation components measured at the same time. Some of the more interesting relationships concerned relationships over time between the different representation components. The IBS patients' serious consequence beliefs were often related to preceding or subsequent long timeline beliefs, weak feeling of control and external causal beliefs. The IBD patients who reported psychological causal beliefs reported subsequent serious consequence beliefs, and those who reported that IBD was caused by psychological factors, and / or external factors and who reported that IBD had serious consequences reported strong illness identities six months later. Those CFS patients who reported that their illness was caused by psychological factors and who reported a short timeline, reported stronger subsequent feelings of control. Serious consequence beliefs and external causes were related to one another over time.

Illness Representation Predicting Outcome

The majority of the outcome measures observed remained relatively stable over the three Time points, with only CFS satisfaction with health improving significantly from Time 1 to Time 2. This is the first study in which the IBS sufferers did not report significantly more anxiety than the equivalent IBD group. However, the CFS sufferers reported more depression, a lower quality of life, and more dissatisfaction with their health than either of the GI patient groups.

Similar relationships observed previously have been observed with the primary care patients, in that strong illness identity, long timeline beliefs, serious consequence beliefs and weak control beliefs were associated with poor outcome: lower perceived quality of life, dissatisfaction with health, and higher scores on the anxiety and depression scales. Although little change was detected in the representation components and outcome measures over time, once again the most predictive models occurred when the representation components were measured at the same time as the outcome measures. However, the IBS representation components measured at Time 1 and 2 could predict anxiety six and twelve months later, and the Time 1 components could predict depression twelve months later. The CFS patients' representation components measured at Time 2, could predict depression six months later.

Theorised Mediating Role of Coping Behaviour

An examination of the coping behaviours over time revealed very little change, suggesting that the coping behaviours employed to deal with the symptoms of IBS, IBD or CFS, change very little over time. The IBS patients reported more humour at Time 3 than at Time 1, but this was the only difference detected. When comparing between illness groups, it was observed that the IBS patients reported more venting of emotion than the IBD patients, and that the CFS patients reported more positive reinterpretation than either of the GI illness groups. The two functional groups reported more behavioural disengagement than the IBD patients, and the difference was significant between the IBD and CFS patients at Time 1.

The individual coping behaviours were reduced once again to the three coping subscales of problem-focused coping, emotion-focused coping and avoidant coping, and the relationships between these scales and the representation components and outcome measures were examined. Once again it was observed that more relationships that were significant were observed when the measures were taken simultaneously; fewer relationships were observed over time. For the temporal relationships that were significant, a series of regression models were carried out to examine if mediation was likely. Where mediation was suspected, a series of tests of mediation were carried out using the Sobel on-line test.

Only one relationship approached partial mediation for the IBS patients: those who reported that they expected their IBS to last for a long time at Time 2, reported more avoidant coping at Time 2, and reported more subsequent anxiety (at Time 3). While there is a direct relationship between timeline beliefs at Time 2 and anxiety reported at Time 3, the effect of the timeline belief is partially mediated by avoidant coping.

Only one relationship approached partial mediation for the IBD patients: those who reported that they experienced many IBD symptoms at Time 1, reported more avoidant coping at Time 1, and reported more subsequent depression (at Time 2). While there is a direct relationship between illness identity at Time 1 and depression at Time 2, the effect of the illness identity is partially mediated by avoidant coping. No mediation of representation components by coping behaviour was suspected for the CFS relationships, and so no direct tests of mediation were carried out.

Similarities and differences between IBS, IBD and CFS

The similarities in the relationships between the representation components of both IBS and IBD groups have been demonstrated with primary care patients. However, once again the IBS models were found to be more predictive than the equivalent IBD models.

Similarities between the two functional groups were observed. Both IBS and CFS sufferers reported weaker control beliefs and more avoidance behaviour than the IBD sufferers did. However CFS models could not satisfactorily predict outcome, which was largely attributable to the low sample size, thus general conclusions regarding IBS pattern of relationships being attributable to its status as a gut disorder or a functional disorder cannot be made at this time. This will be discussed further in the next chapter.

Summary and Conclusion

This small longitudinal study has shown that in a sample of IBS, IBD and CFS patients who have been diagnosed with these illnesses for an average of 6.7 years (5.5 years, 9.3 years, and 5.3 years, IBS, IBD and CFS respectively), representation components and coping behaviours are fairly stable over a one year period. The study has reaffirmed the importance of the serious consequence component as an important predictor of outcome; however, the CFS patients studied here reported significantly more serious consequence beliefs than either GI illness group. Once again it has been observed that simultaneous measurement of representation, coping and outcome provide stronger relationships than when the illness representation is measured before coping and outcome. Finally, in line with the previous three studies (Chapters 3, 4 and 5), while partial mediation of coping has been observed, coping plays a much smaller part in predicting outcome than the illness representation. The illness representation components of the IBS patients could predict anxiety six and twelve months later. Also, the representation components could also successfully predict depression twelve months later.

The findings from this study have reaffirmed many of the main findings discussed in earlier chapters, and the inclusion of CFS as a further illness population to compare with the IBS patients, has shown that the functional groups show a poorer outcome than the organic patient group. The main limitation of the study was the relatively small number of patients who were recruited. It would have been preferable to have similar numbers in each illness group, however, recruitment proved difficult. While the sample size was smaller than desired, the study has provided a clear indication that an examination of the illness representations of IBS patients is warranted. The findings from all empirical chapters (3, 4, 5 and 6) will be discussed further in the final discussion chapter (Chapter 7).

Chapter 7
Discussion and Conclusions

The aim of the research in this thesis has been to examine the commonsense model of illness representation with IBS sufferers. Each study was designed around with three main predictions: the first concerned change in the representations over time; second, to determine whether the illness representation can predict simultaneous and subsequent outcome; and third, to examine whether coping mediates any links between the representation and outcome. The four studies examined the responses of IBS sufferers recruited from a self-help organisation (both established and new members), and from both primary and secondary care. These populations of IBS sufferers were examined separately because IBS researchers have long suggested that the secondary care patients usually recruited for research are not representative of IBS sufferers as a whole. Thus, by examining these populations separately, a clear picture regarding the role of illness representation in IBS emerges. In addition, to provide further information regarding the pattern of illness representation, coping and outcome in IBS, two further illnesses were also examined. First, patients diagnosed with inflammatory bowel disease (an organic GI illness) were examined in three studies to determine whether the IBS pattern can be attributed to the GI symptoms experienced. Second, one study examined the responses of chronic fatigue syndrome patients (a functional, non-GI illness) to determine whether the pattern of relationships observed with the IBS patients can be attributed more to its status as a functional illness.

This discussion chapter will review the evidence presented in this thesis. First, the patterns of relationships between the illness representation components were stable across the different populations of IBS sufferers and methodologies. Second, the illness representation of IBS sufferers predicted the outcomes of quality of life, satisfaction with health, anxiety, and depression - both cross-sectionally and longitudinally - and the consequence component was a strong independent predictor. Third, the link between representation and outcome was strong. Coping contributed little to the prediction of outcome, and there was little evidence of the mediation suggested by Leventhal's commonsense model. Finally, the pattern of relationships observed between the representation components of IBS sufferers shared a great deal with the pattern found in IBD sufferers – though the IBS models were more predictive than the equivalent IBD models, and coping was involved in more of the IBD models. Both IBS and CFS sufferers showed weaker control beliefs and more avoidance behaviour than did the IBD sufferers. However, CFS models could not satisfactorily predict outcome, which was largely attributable to the low sample size. Thus, general conclusions as to whether the IBS pattern of relationships was attributable to its status as a gut disorder or a functional disorder cannot be made at this time. The chapter concludes with a discussion of the potential implications of these findings, first in terms of Leventhal's theory, and second in terms of the potential improvements that might be implemented for the future management of IBS.

1. The Illness Representation

Cross-sectional relationships Overall, similar patterns of relationships detected in other illnesses (myocardial infarction, CFS and psoriasis) were observed for the IBS patients in the four studies (Petrie, Weinman, Sharpe and Buckley, 1996; Moss-Morris, Petrie and Weinman, 1996; Fortune, Richards, Main and Griffiths, 2000). Long timeline beliefs were associated with serious consequences, weak control, strong illness identity and external causal beliefs. Strong illness identity was associated with serious consequences and weak control beliefs. Serious consequence beliefs were associated with weak control and both psychological and external causal beliefs; however, psychological causal beliefs were also associated with strong control beliefs, a relationship that has also been reported with rheumatoid arthritis and chronic fatigue patients (Schiaffino and Revenson, 1992 and Moss-Morris et al. 1996 respectively). Serious consequences and weak control beliefs were involved in the majority of the significant associations detected, and these were the most often reported components in the illness representation literature since questionnaires were introduced.

Longitudinal relationships The three longitudinal studies showed that the representation components remained stable over time, and the same patterns of relationships identified in the cross-sectional data were observed. The stability of the components was illustrated most strongly in Chapter 4, as the representation components measured at the time of joining an IBS self-help group organisation did not change significantly within the first eight months of membership. Leventhal et al. (1984) argued that the illness representation is constantly being updated as new illness experience and illness knowledge is acquired, but this has not been supported in this research. The most likely explanation for the stability of the representation components observed here is that IBS is a chronic illness. Leventhal designed his commonsense model around common everyday, and mostly acute, illnesses. It is likely that the initial representation components generated by sufferers of chronic illness like IBS will remain unless challenged directly.

This position is given further support when we consider that the best supported longitudinal relationships were the associations involving the timeline representation component: long timeline beliefs were associated with serious consequences, weak control and strong illness identity in most studies. As the individual representation components were developed with the belief that the illness would last a long time, these pessimistic relationships are unlikely to go unchallenged as the sufferer continues to experience symptoms. The perception of IBS as a chronic illness may also reinforce these unhelpful relationships, thus maintaining the stability of the pattern.

The relationships discussed so far in this section may be explained using the symptom perception hypothesis. The symptom perception hypothesis (described by Watson and Pennebaker, 1989) suggests that anxious individuals focus their attention on their bodies, and that this focused attention is the prevailing factor in detecting new symptoms. New symptoms are identified which maintain the anxiety and increase the attention focus on the body. It could be argued that this symptom perception hypothesis was the foundation for the cognitive behavioural model proposed by Toner et al.

(1998; 2000). An examination of the data between the components suggests that we can interpret the components in a similar way. The expectation that the illness will last a long time and that little can be done to control the symptoms supports the serious consequence belief. This serious consequence belief directs patients' attention to their body in order to monitor symptoms, perhaps motivated by a need to reduce the serious consequences. In doing so, the patient is likely to maintain the awareness of their symptoms and to notice new symptoms more frequently than those patients who are less attentive to their body. Thus, the illness identity and the pattern of associations between the representation components are strengthened. As the perception of IBS is chronic, the relationships are likely to remain.

Differences observed between the different populations Not enough research has examined differences between IBS patients in primary and secondary care, yet it has been proposed that clinic patients are "likely to have the most severe bowel symptoms, co-existing psychiatric symptoms, and the most severe illness worries" (Creed, 1995, p. 257). Further, it has also been suggested that clinic patients are less likely than primary care patients to accept a psychological explanation of their symptoms and are more convinced they have organic disease (Jones et al. 2000, p.2). Small differences have been detected between the different IBS populations in this research and not all of these suppositions have been supported.

In the data reported here, clinic patients had the weakest belief in a psychological causal attribution and the strongest belief in an external causal attribution (2 months after the diagnosis of IBS), as expected. However, clinic patients reported the weakest illness identity, the shortest timeline, fewer consequence beliefs, and the strongest control beliefs of all the IBS populations examined. An illness representation of weak illness identity, short timeline, few consequences and weak control is related to good outcome. This is supported when we note that the clinic patients also scored lower than the other IBS sufferers on measures of anxiety and depression.

A likely explanation of why the clinic patients here do not fit the expected profile of reporting the most severe symptoms and most distress is the length of time the sufferers have been diagnosed with IBS. The clinic patients in this research were all diagnosed with IBS at the time of recruitment. However, the established members, the new members, and the patients managed in primary care had been diagnosed for an average of 9.9 years, 5.8 years and 5.5 years respectively. Guthrie et al. (1992) have shown that chronic attenders report significantly more frequent and severe symptoms, and report that the social consequences of their illness are much more striking than those of first time attenders. Thus, it is likely that the majority of research carried out in secondary care has used chronic attenders, and that several ineffective treatment methods will have been used.

Further, whilst it was expected that those sufferers recruited from a self-help organisation would have better adapted illness representations than those not in self-help groups, it was observed that the most serious consequences were reported by sufferers recruited from the IBS Network, both established and new members. This could be attributed to the reading of their fellow sufferers' experiences of IBS, as members have the opportunity to read about experiences/situations they may not have encountered, which may serve to increase illness worries.

- **The patterns of relationships between the illness representation components are stable across the different populations of IBS sufferers and methodologies.**
- **The pattern of relationships between these variables appears to strengthen over time.**

2. Predicting outcome from the illness representation

The outcome measures used in this research were quality of life, satisfaction with health, anxiety and depression. Both quality of life and satisfaction with health were one-item measures and were based entirely upon patient ratings. Anxiety and depression were measured with a validated and well-used clinical scale (the Hospital Anxiety and Depression Scale, also known as the HADS).

In each of the four studies multiple linear regression analysis was employed to examine the predictive power of the illness representation components for simultaneous and subsequent outcome. Overall, the most predictive models were observed when the representation components were measured at the same time as outcome: fifteen of the sixteen simultaneous models were significant, compared to only six of the sixteen prior models. However, while it can be concluded that the simultaneous models explained more of the variance in the four outcome measures, the variance explained differed considerably across studies, and the different populations predicted outcome in inconsistent ways.

Simultaneous models It could be argued that the models predicting satisfaction with health and anxiety were the most successful of the simultaneous models. The illness representation of the primary care patients explained 50% of the variance in satisfaction with health and 43% of the variance in anxiety, and the secondary care patients' illness representation explained 40% in both their models. The established self-help group members' illness representation explained 28% and 35% of the variance in satisfaction and anxiety respectively. The new members' illness representation explained 35% of the variance in satisfaction, but a notably smaller 12% of the variance in anxiety. This discrepancy can be explained when we note that anxiety reduced significantly within the first eight months of membership from Time 1 to Time 2, while the illness representation components remained stable.

In all but the new member model (predicting anxiety), the representation component of serious consequences was shown to be the most important and predictive component. Serious consequences were associated positively with anxiety and negatively with satisfaction with health. In fact, the simultaneous models of the clinic patients showed that the consequence component could explain more unique variance than the total variance, suggesting that the other components produced nothing more than noise.

Longitudinal models The fact that the simultaneous models were found to be more predictive than the longitudinal models is unsurprising when we consider that the commonsense model was developed as a dynamic feedback model, with the illness representation updated as new information is processed, or as appraisals of outcome are deemed unsatisfactory. However, as explained earlier, possibly because IBS was being perceived as a chronic illness, the representation components did not change significantly over the study periods. Thus, the illness representation could also predict outcome over time. Six of the sixteen models explained variance in outcome significantly, demonstrating the strength of the illness representation. The primary care patients showed that the illness representation measured at 12 and 6 months prior to the measurement of anxiety explained 29% and 38% of the variance. The illness representation of the primary care patients was also able to explain 24% of the variance in depression 12 months later. The illness representation of the new members measured at the time of joining the self-help group was able to predict quality of life, satisfaction with health, and depression (with 22%, 15% and 14% of the variance explained respectively) eight months later. As highlighted above, the anxiety reported by the new members decreased significantly after eight months' membership of the IBS Network, and the original illness representation was unable to predict later anxiety.

Once again the representation component, serious consequences, was found to be the most implicated and significant independent predictor of outcome: weak consequence beliefs were significant independent predictors of quality of life and satisfaction with health, and strong serious consequence beliefs were significant independent predictors of anxiety and depression.

- **The illness representation of IBS sufferers predicts outcome simultaneously and over time.**
- **The representation component, serious consequences, is highly predictive of outcome in both simultaneous and longitudinal models for IBS.**

3. The theorised mediating role of coping behaviours

Leventhal predicted that the link between the illness representation and outcome would be mediated by coping behaviours. The model was developed initially with the belief that the cognitive representation was directing problem-focused coping, and the emotional representation was directing emotion-focused coping. However, the data presented here show that the link between representation and outcome is strong and that coping does not contribute greatly to the prediction of outcome. When it does make a contribution, serious consequences, weak control and long timeline beliefs are partially mediated by avoidance coping behaviours.

The largest investigation of individual coping behaviours was reported in Chapter 3. This study demonstrated that the cognitive representation components had direct effects upon outcome, and that coping added very little to the prediction of outcome. One truly mediated relationship was detected, however: the link from the cure/control component to depression was mediated by behavioural disengagement. Those with weak control beliefs used the avoidant coping behaviour of behavioural disengagement, which was associated positively with depression. This study also indicated that, when partial mediation was detected, a variety of emotion, problem and avoidant coping behaviours mediated the links between the cognitive representation and outcome (not just problem-focused coping, as was initially theorised by Leventhal et al. (1984)).

Smaller samples were used in the three longitudinal studies, and the individual coping behaviours were therefore combined to reduce the number of variables entered into the analyses. Where coping did make a contribution to the link between representation and outcome, avoidant coping was the most implicated coping behaviour. This fits with previous IBS research that has reported that IBS patients cope with their illness by avoiding specific situations and using avoidance behaviour in general (Van Dulmen et al. 1984; Drossman et al. 1988). Avoidant coping has been shown by some researchers to benefit those in uncontrollable circumstances. For example, Meyerowitz (1983) studied women who had undergone mastectomies for breast cancer, and found that those who avoided thinking about cancer and minimised the impact of their illness showed less evidence of distress than those who did not use avoidance strategies). Avoidant coping has been related to poor outcome in the majority of the studies presented here, and in previous IBS research. Recent research has also demonstrated the potential importance of problem-focused coping in chronic IBS. For example, Chang et al. (2000) reported that, when IBS sufferers attempted to deal actively with their symptoms, problem-focused coping contributed to poor outcome. In situations where there is little perceived control, such as in chronic illness, it has been reported that emotion-focused coping strategies such as seeking emotional support are of more benefit to sufferers (Lazarus and Folkman, 1984). In this research, the effect of emotion-focused coping was weak, which may account for the poor outcomes observed. Emotion-focused coping was seen to add to the prediction of outcome when individual coping behaviours were studied (e.g. seeking social support, acceptance and positive reinterpretation were associated with positive outcomes). However, when coping behaviours were combined, very few relationships reached statistical significance. Of those that did, weak emotion-focused coping was associated with poor outcome and negative representation components.

- **There was little evidence that the link between illness representation and outcome was mediated by coping.**
- **On the one occasion that mediation did occur – through avoidant coping – the result was poorer outcome.**

4. Functional and organic illness

To determine whether the patterns observed for the representation components, coping and outcome were attributable to the status of IBS as (1) a functional illness or (2) a gut disorder, two further illnesses were examined alongside IBS: inflammatory bowel disease (IBD), and chronic fatigue syndrome (CFS). If the pattern found for IBS is similar to IBD, but different from CFS, then we could attribute the pattern to IBS' status as a gut disorder. If the pattern found for IBS is similar to CFS, but different from IBD, then we could attribute the pattern to IBS' status as a functional disorder. In fact, the pattern of relationships observed for IBS sufferers had similarities with both IBD and CFS, suggesting that the pattern of relationships observed in IBS is generated by both the symptoms experienced and by its functional status.

IBD was chosen as a suitable organic control for IBS because the symptoms of IBS and IBD are similar, though IBD sufferers may often experience the additional symptoms of gastrointestinal (GI) bleeding and weight loss. Further, patients with IBS, and with colitis and Crohn's disease (which together are referred to as inflammatory bowel disease) have the added discomfort of having an illness related to the bowel. When Leventhal introduced the illness identity component, he did not just refer to the concrete symptoms of the illness, but also the abstract label. The abstract label is important in most diseases, but when illness is connected to a part of the body that society deems distasteful, this component can be very influential indeed. In fact, it has been reported that social support can vary with the body part affected. For example, depending on the location of the cancer, cancer patients have received hesitant social support (Taylor and Dakof, 1987) or even aversion and avoidance (Dunkel-Schetter and Wortman, 1982).

Westerners find it extremely difficult to talk openly about gastrointestinal (GI) symptoms such as diarrhoea and flatulence, consequently, sufferers of chronic GI disorders are likely to feel unable to talk about their symptoms to others around them, and may feel shame about the uncontrollability of their symptoms. There may also be gender issues, since flatulence is not considered 'lady-like' and is the subject of 'schoolboy humour'. Because of this incongruity, female IBS sufferers may be magnifying the negative consequences of the illness and may believe that experiencing GI symptoms has bad ramifications. Thus, the important difference between IBS and IBD is that IBS is a functional illness (i.e. no physical abnormality is detected), and IBD is an organic illness (i.e. inflammation of the GI tract is observed).

Chronic fatigue syndrome (CFS) (also known as Myalgic Encephalitis or ME) does not share symptoms with IBS or IBD. CFS is classified as a functional illness. Both IBS and CFS are syndromes, where "syndrome" refers to a collection of symptoms, not a disease. There are many CFS sufferers who believe that the abstract illness label "CFS" trivialises the condition, and prefer to call their illness the more medical, although technically incorrect "ME".

As with IBS, there is no accepted theory regarding the cause of the CFS symptoms, and there is the often-controversial debate regarding the role of psychological factors in the cause and maintenance of the symptoms. As discussed earlier, when illness is attributed to external causes, it is often viewed as an accident, and the sufferer is viewed as a victim of dire circumstances. However, when illness is attributed to internal, psychological causes, it is perceived as being under the sufferer's voluntary control, and therefore support can be limited. This limited support can be further compounded if there is a suggestion that sufferers may be exaggerating their symptoms and / or associated distress. Ford (1986) reported that "the sick role caries with it many privileges and in addition to the exemption from responsibility, there is the unspoken obligation to be kind and sympathetic to such patients as well as assume some of their responsibilities for them" (p.406). Sufferers of functional illnesses have additional illness troubles, which may contribute to the developing illness representation. Thus, sufferers of both IBS and CFS were investigated in order to examine the patterns of the illness representation, coping and outcome, which may arise as a function of the illness' functional status.

The symptom profiles were similar in the two GI groups. The three most commonly perceived symptoms reported by IBS sufferers in all four studies were wind, rumbling and grumbling, and bloating. All three symptoms can be considered visible, and all have specific distresses associated with them. Firstly, wind can be both heard and smelt. Passing wind in public is socially unacceptable, and distressing to sufferers. Bloating may not be easily detected by others around the sufferer, but sufferers report feeling uncomfortable and unable to wear the clothes they want to. They may also experience problems with their body image as a consequence of their distended abdomens. Rumbling and grumbling (or burbulance) can occur frequently, both before and after eating, and many sufferers find the noises upsetting. IBD sufferers reported similar symptoms, but reported diarrhoea as one of their most frequently occurring symptoms. In the context of visibility, diarrhoea may be less visible to others, though sufferers still worry that frequent trips to the toilet will be noticed by other people around them. The CFS patients reported the strongest illness identity of all three patient groups in the final study – but, as different symptoms were used to measure the illness identity, they cannot be compared directly.

Overall, the IBS and IBD patients did not differ significantly in reported symptoms. Only one difference between the two illness groups was observed: at Time 2 the IBS primary care patients reported a stronger illness identity than the IBD patients. However, in the first study, with the established self-help group members, the IBD sufferers reported stronger illness identities. While it could be argued that there is little difference between the IBS and IBD illness identity, illness identity helped to explain variance in outcome in the IBD models but was not a significant independent predictor in the equivalent IBS models. Only one CFS model reached significance: the illness representation measured six months before was able to explain 46% of the variance in depression, with illness identity as a significant independent predictor. This supports the Moss-Morris et al (1996) research, which showed that the illness identity of CFS sufferers could significantly predict dysfunction, psychological adjustment, and vitality, with illness identity as a significant independent predictor. These findings indicate that it may not be the concrete symptoms themselves but the meaning of the symptoms, such as the serious consequences, that are more predictive for the IBS patients while the IBD and CFS patients implicate the actual symptoms more.

Overall, one of the greatest differences between the three patient groups was observed when examining the causal attribution. Both GI groups cited psychological causes more strongly than external causes and IBS patients cited psychological causes more strongly than the IBD patients. In contrast, the CFS patients agreed that external causes were responsible for causing their illness much more strongly than psychological causes. As reported earlier in Chapter 1, by making external causal attributions, the CFS patients were taking less responsibility for their illness. However, research has shown that breast cancer and renal failure patients who accept responsibility for their illness, and / or self-blame, tend to adjust better to illness (Timko and Janoff-Bulman, 1985; Witenberg et al. 1983). This is supported when we see that psychological cause is associated positively to control beliefs. It is likely that the GI symptoms experienced in both IBS and IBD are more readily associated with psychological processes because of the brain-gut connection: anxiety and anxiety provoking situations demonstrate the connection between stresses and symptoms almost immediately. If there is a psychological component / trigger involved in CFS, the link between stresses and symptoms is likely to be less immediate, and thus less clear. However, while psychological cause has been shown to be strongly associated with strong control beliefs, it has been involved in the prediction of anxiety in the IBS modes.

An examination of the individual causal beliefs demonstrates that, while stress figures highly in causal attribution for all patients, IBS patients cite stress most strongly. Further, both IBD and CFS patients are more likely to cite "chance" as a cause of illness. This could be attributed to the way that IBD is explained to the patient. Further, while it has often been reported that CFS patients are resistant to psychological processes involved in their illness, it follows that a "chance" attribution is more acceptable, and follows more along the lines of an organic illness.

The IBS and IBD patients expect their symptoms to last for a long time, and these beliefs are stronger in IBD patients. While few differences were detected in the study, the mean values suggest that the IBS and IBD patients have longer timeline beliefs than the CFS patients.

At the time of diagnosis, IBD patients reported more serious consequences than IBS patients, but this difference was short lived. As IBD patients adjusted to their illness, possibly finding out new information and refining their illness representation, the consequence component did not differ significantly between the GI patient groups. However, there was a trend to suggest that IBD sufferers reported more serious consequences than IBS patients. The CFS patients reported significantly more serious consequences than both GI groups. Thus, it cannot be concluded whether the IBS patients' weaker reporting of the serious consequences is due to the symptoms of the illness, or the illness' status as a functional illness. However, the consequences component has been shown to be the most important predictor of outcome, especially in the IBS sufferers. Turk and Rudy (1992) conducted a review of the cognitive processes in chronic pain patients and concluded that catastrophizing is the most important factor in poor coping and is strongly related to greater disability – having greater explanatory power than symptom variables. Petrie, Moss-Morris and Weinman (1995) conducted a study with 282 CFS sufferers from a self-help group in New Zealand and asked them "What would be the consequences of pushing yourself beyond your present physical state?" Respondents were separated into catastrophizers and non-catastrophizers. The differences between them could not be explained by differences in the length of symptoms or in the level of psychological adjustment. The authors argue that the critical factor is the meaning of the illness. The catastrophizers reported more disruption in home and social life.

Two areas where differences between the functional and organic groups are evident concern cure / control beliefs and coping behaviour. As expected, the IBD patients have stronger feelings of control than the two functional groups. This is unsurprising as IBD patients are offered practical help with their symptoms and are encouraged to attend outpatient appointments in order to check on the progression of their illness. However, IBS and CFS patients are often discouraged to return to health care providers. Further, both functional patient groups report significantly more behavioural disengagement than the IBD group. In an uncontrollable situation, avoidant coping could be argued to be adaptive, but, throughout this research, avoidant coping has been associated with poor outcomes.

While both IBS and IBD patients report more anxiety than depression, the IBS patients / sufferers reported significantly more anxiety than the equivalent IBD patients. The IBS patients scored highest on measures of anxiety. The CFS patients were significantly more dissatisfied with their health and scored significantly higher on measures of depression than either GI patient group.

When comparing the predictive power of the illness representation on outcome, the IBS models explained more of the variance than the equivalent IBD model. However, when coping was included in the IBD model, it almost doubled the variance explained and contributed more to outcome than in any of the IBS models. Thus, it can be concluded that the IBS illness representation components are stronger predictors of outcome and that coping plays a larger role in the equivalent IBD model.

Thus, overall, it is hard to conclude whether the pattern of IBS relationships observed here is determined by the status of IBS as a gut disorder or as a functional illness. The patterns observed in this research show that the IBS relationships are similar to the IBD relationships. However, the IBS models predict more variance in outcome than the corresponding IBD models, and coping explains a significant proportion of the variance in outcome in the IBD models. Thus, only subtle differences point to the strength of the illness representation for IBS sufferers compared to the IBD sufferers. Unfortunately, though, these differences cannot be attributed to the status of IBS as a functional illness, since comparing IBS and CFS has not shown clear similarities or differences. While both functional illnesses display weak control beliefs and more avoidance coping behaviour, these were the only similarities. Future researchers should re-examine the question by examining IBS and CFS along with other functional syndromes – for example, non-ulcer dyspepsia (a functional upper GI tract disorder), pre-menstrual syndrome (PMS), migraine, lower back pain, and chronic pain.

- **The pattern of relationships observed for IBS sufferers had similarities with both IBD and CFS, suggesting that the pattern of relationships observed in IBS is generated by both the symptoms experienced and by its functional status. More research comparing different functional and organic illnesses are encouraged.**

While I have drawn general conclusions from the different populations of IBS sufferers, the sample sizes vary considerably from study to study, and formal comparisons have not been made. Unfortunately, low recruitment is a common problem when using clinical samples, especially with psychological investigations. The time and money needed to increase the sample size to sufficient levels was unfortunately beyond the scope of this thesis.

5. Implications for theory

I believe this research has two implications for the commonsense model of illness representation. Firstly, when the commonsense model is used as a framework to examine chronic illness, it should not be considered a dynamic model. Secondly, the partial mediation of coping has been brought into question, and thus deserves greater attention from researchers.

The work in this thesis suggests that individuals with chronic illness develop their illness representation in the early stages of the illness, and that over time these patterns of relationships are strengthened. It is likely that the patterns and relationships between the different illness representations will remain unless challenged directly. Future researchers may be able to provide an insight into this stability of representation if patients with a chronic illness have an acute timeline. This would be an interesting area for future researchers to develop.

Secondly, the majority of recent research using the commonsense framework has ignored the role of coping in the model. While coping did not add to the prediction of outcome for the IBS sufferers, the predictive power of the IBD models increased significantly with the inclusion of coping. Also, avoidant coping was shown to be a significant predictor of outcome and to be associated with outcome measures in all three illnesses. It is thus an important factor in illness behaviour. Future researchers, especially those interested in designing effective interventions, should start to examine coping with different illnesses.

6. Implications for the management of IBS

The commonsense model does not tell us how to alter problematic representations. However, the research findings presented here have shown that (1) illness representations are formed early in the illness, (2) they remain stable over time, and (3) while the outcome and particular coping behaviours may change, it does not necessarily follow that the illness representation will change too (Chapter 4). For interventions to succeed, they must be holistic and integrative to reduce distress effectively. Interventions must provide a clear representation of both the concrete and abstract features of IBS, with effective criteria for describing coping behaviour and evaluating outcome.

It could be argued that those "unhelpful" illness representations - for example, long timeline, serious consequences and weak control beliefs - are strengthened over time and may contribute to the maintenance of symptom presentation in IBS. As the illness representation is likely to be developed very early on, it is clear that early intervention has the best chance of success. This adds further support to the calls for GPs to provide more effective reassurance to IBS patients at the earliest opportunity, preferably within the diagnostic consultation. Without effective reassurance, or addressing dysfunctional beliefs about the illness, it becomes too easy (or more likely) for the IBS sufferer to build their representation of their illness around the negative consequences of their illness. Identifying and correcting dysfunctional cognitions offers the real chance of increasing patient satisfaction and stimulating adequate coping behaviour, which may lower the further use of medical services. The benefit of this simple GP intervention is shown clearly by the work of van Dulmen et al. (1995; 1996a; 1997). These researchers have conducted a series of studies with functional bowel patients and have shown that when doctors perceive patients' cognitions correctly, dysfunctional somatic attributions were found to decrease and functional psychological attributions were found to increase (1995). In addition, positive changes to the patients' illness beliefs were associated with a better outcome in terms of improvement of the complaints 6 months later and to a reduction in the use of medical health services in primary care (1996a and 1997). Some people may argue that for GPs to address illness beliefs within the consultation may increase waiting times as the GP would have to spend longer with the patient. However, a necessary response could be that the time invested in the initial consultation should reduce further consultation and possibly referral rates in gastroenterology. Also, it is likely that once a GP has mastered a patient-centred attitude that this kind of consultation should not take up any more time than would normally be expected.

It is recognised that GPs have huge time pressures on them to accurately diagnose a range of illnesses, and thus may not want, or feel able to correctly perceive their patient's beliefs about their illness. Therefore three alternatives are proposed that future researchers may want to examine in more detail. First, the GP could discuss the issues that are embedded within the consequence scale (since this research shows this dimension to be the most predictive of poor outcome) and thus direct the dialogue of the consultation. Alternatively, these negative beliefs could be discussed in a patient information booklet, in an effort to give a balanced approach to the illness. Thirdly, the IPQ could be used on an individual basis, in which a trained person, (e.g. the practice nurse), encourages the patient to complete the IPQ. Then any dimension that reaches a certain cut off score (indicating a negative illness belief) should be easily identified, and the matter discussed within a supportive environment.

However, even when a patient's cognitions have been accurately identified and challenged there will be patients where it is not possible to alter dysfunctional or negative illness beliefs. Indeed a strong adherence to dysfunctional cognitions could buffer against any reassurance or interference. It is suggested then, that these patients could be offered more intensive or professional help such as cognitive-behavioural therapy (CBT). As outlined in Chapter 2, there have been several independent clinically controlled trials, which have shown that CBT is effective in helping IBS patients to cope with their condition. However this has not been matched with a clear understanding of how cognitive and or psychological variables interact with physical conditions to maintain symptoms. CBT involves helping the patient to recognise maladaptive patterns of thinking and behaviour. It encourages them to change how they interpret bodily sensations and changes in visceral function by seeing them, not so much as symptoms of disease, which need to be treated, but more as expression of anxiety. Treatment is essentially an exercise in the identification and solving of problems, which in turn facilitate greater control in the patient. The CBT model of IBS is special for many IBS researchers because it can be used to highlight how certain cognitions and underlying beliefs may lead to increased attention to bodily symptoms and sensations, increased arousal and a heightened sensitivity to pain and other symptoms. It takes into account how IBS symptoms may become perpetuated by interplay among biological, psychological and social factors. CBT insists that the patient takes some responsibility for the illness and helps him/her find more healthy ways of dealing with the underlying problem.

The research contained in this thesis suggests that therapy should try to disentangle or challenge the association between serious consequences and a long timeline belief. Patients will need to be aware that they have a chronic illness, but also practical advice in an effort to increase control beliefs. The serious consequence beliefs should be challenged, as they are not associated with good outcome. Serious consequence beliefs are associated with a poor perception of quality of life, dissatisfaction with health, anxiety and depression. Also it is likely that this relationship is mediated by avoidant coping behaviours such as behavioural and mental disengagement. It is extremely likely that avoiding coping with the illness and the negative thoughts about the potential consequences of the illness help maintain the poor prognosis. This is reflected in the ability of the consequence component to predict poor outcome over time. The key of CBT is to substitute negative, pessimistic thoughts for positive cognitions.

Future researchers could also explore the consequence dimension further because the IPQ was constructed for use with a variety of illnesses. Perhaps future researchers could interview patients to make the items more salient to IBS individuals (i.e how they see the consequences of their illness in terms of not being able to meet up with friends or the constant monitoring of the toilet situation). A similar approach to Petrie, Moss-Morris and Weinman (1995) could be used ("what would be the consequences of pushing yourself beyond your present physical state?").

The data from this thesis suggests that therapists who use CBT should try to reduce serious consequence beliefs and avoidant coping behaviour, and to encourage favorable emotion-focused behaviours. However, causal beliefs should be approached with caution because, although psychological causal beliefs are associated with strong control beliefs, they are also associated with serious consequences. To conclude, this research should help medical professionals to understand the importance of illness cognition in the course and/or maintenance of IBS.

7. Summary and Conclusion

The work in this thesis has shown, first, that the patterns of relationships observed between the representation components are similar across the different populations of IBS sufferers. Second, these relationships between the representation components are stable over time. Third, the illness representation is a powerful predictor of simultaneous and subsequent outcome. Fourth, the serious consequence representation component is the strongest individual predictor of outcome, in both simultaneous and longitudinal models. Fifth, the illness representation is such a strong predictor of outcome that coping adds very little to the explained variance. Sixth, avoidant coping and serious consequences are associated with poor outcome. Finally, the predictive power of the illness representation is stronger for IBS than IBD patients. Challenging the illness representation at an early stage in the illness may be an effective way of managing IBS patients in the future.

References

Abraham, C. and Sheeran, P. (1997). Cognitive representations and preventative health behaviour: A review. In K.J. Petrie and J.A. Weinman (Eds.), Perceptions of Health and Illness, (p.213-240). Amsterdam: Harwood Academic Publishers.

Abramson, L.Y., Seligman, M.E.P. and Teasdale, J. (1978). Learned helplessness in humans: Critique and reformulation. Journal of Abnormal Psychology, 87, 49-74.

Agreus, L., Svardsudd, K., Nyren, O. and Tibblin, G. (1995). Irritable bowel syndrome and dyspepsia in the general population: Overlap and lack of stability over time. Gastroenterology, 109, 671-680.

Ajzen, I. (1985). From intention to actions: a theory of planned behaviour. In J. Kuhl and J. Beckman (Eds.), Action Control: From Cognitions to Behaviour, (p.11-39). New York: Springer-Verlag.

Anderson, K.O., Dalton, C.B., Bradley, L.A. and Richter, J.E. (1989). Stress induces alteration of esophageal pressures in healthy volunteers and non cardiac chest patients. Digestive Diseases and Science, 34, 83-91.

Aziz, Q., Rothwell, J.C., Hamdy, S., Barlow, B. and Thompson, D.G. (1996). The topographic representation of espohageal motor function on the human cerebral cortex. Gastroenterology, 111, 855-862.

Baron, R.M. and Kenny, D.A. (1986). The moderator-mediator variable distinction in social psychological research: Conceptual, strategic and statistical considerations. Journal of Personality and Social Psychology, 51, 1173-1182.

Baumann, L., Cameron, L.D., Zimmerman, R. and Leventhal, H. (1989). Illness representations and matching labels with symptoms. Health Psychology, 8, 449-469.

Bennett, E.J., Kellow, J.E., Cowan, H., Scott, A.M., Shutter, B., Langeluddecke, P.M., Hoschl, R., Jones, M.P. and Tennant, C.C. (1992). Suppression of anger and gastric emptying in patients with functional dyspepsia. Scandinavian Journal of Gastroenterology, 27, 869-874.

Bennett, P. and Wilkinson, S. (1985). A comparison of psychological and medical treatment of the irritable bowel syndrome. British Journal of Clinical Psychology, 24, 215-216.

Blanchard, E.B., Scharff, L. and Payne, A. (1992). Prediction of outcome from cognitive-behavioural treatment of irritable bowel syndrome. Behaviour Research and Therapy, 30, 647-650.

Blanchard, E.B., Schwarz, S.P., Neff, D.F. and Gerardi, M.A. (1981). Prediction of outcome from the self-regulatory treatment of irritable bowel syndrome. Behaviour, Research and Therapy, 26, 187-190.

Bishop, G.D. (1987). Lay conceptions of physical symptoms. Journal of Applied Social Psychology, 17, 127-146.

Bishop, G.D. (1991). Understanding the understanding of illness. In J.A. Skelton and R.T. Croyle (Eds.), Mental Representation in Health and Illness, (p.32-59). New York: Springer-Verlag.

Bremner, J.D. (1999). Does stress damage the brain? Biological Psychiatry, 45, 797-805.

Bremner, J.D., Randel, P., Vermetten, E., Staib, L., Bronen, R.A., Maquire, C., Capelli, S., McCarthy, G., Innis, R.B. and Charney, DS. (1997). Magnetic resonance imaging-based measurement of hippocampal volume in posttraumatic stress disorder related to childhood physical and sexual abuse: A preliminary report. Biological Psychiatry, 41, 23-32.

Brown, G.W. (1984). Meaning, measurement and stress of life events. In Dohrenwend, B.S., Dohrenwend, B.P. (Eds.), Stressful Life Events: Their Nature and Effects. New York: Wiley.

Brown, S. and Williams, A. (1995). Woman's experiences of rheumatoid arthritis. Journal of Advanced Nursing, 21, 695-701.

Buick, D. (1997). Illness representations and breast cancer: Coping with radiation and chemotherapy. In K.J. Petrie and J.A. Weinman (Eds.), Perceptions of Health and Illness, (p.379-410). Amsterdam: Harwood Academic Publishers.

Cameron, L. (1997). Screening for cancer: Illness perceptions and illness worry. In K.J. Petrie and J.A. Weinman (Eds.), Perceptions of Health and Illness, (p.291-322). Amsterdam: Harwood Academic Publishers.

Cameron, L., Leventhal, E.A. and Leventhal, H. (1993). Symptom representations and affect as determinants of care seeking in a community dwelling adult sample population. Health Psychology, 12, 171-179.

Camilleri, M. and Choi, M.G. (1997). Review article: Irritable bowel syndrome. Alimentary Pharmacological Therapy, 11, 3-15.

Cannon, W.B. (1902). The movements of the intestine studied by means of roentgen rays. American Journal of Physiology, 6, 251-284.

Cannon, W.B. (1914) The interrealations of emotions as suggested by recent physiological researches. American Journal of Psychology, 25, 256.

Cannon, W.B. (1927). The James-Lange theory of emotions: A critical examination and an alternative. American Journal of Psychology, 39, 106-124.

Carver, C.S., Scheier, M.F. and Weintraub, J.K. (1989). Assessing coping strategies: A theoretically based approach. Journal of Personality and Social Psychology, 56, 267-283.

Cassileth, B.R. and Drossman, D.A. (1993). Psychosocial factors in gastrointestinal illness. Psychotherapy and Psychosomatics, 59, 131-143.

Chalder, T., Power, M. and Wessely, S. (1996). Chronic fatigue in the community: A question of attribution. Psychological Medicine, 26, 791-800.

Cheng, C., Hui, W.M., and Lam, S.K. (2000). Perceptual style and behavioural pattern of individuals with functional gastrointestinal disorders. Health Psychology, 19, 146-154.

Coffin, B., Azpiroz, F., Guarner, F. and Malagelada, J.R. (1994). Selective gastric hypersensitivity and reflux hyperreactivity in functional dyspepsia. Gastroenterology, 107, 1345-1351.

Corney, R.H., Stanton, R., Newell, R., Clare, A. and Fairclough, P. (1991). Behavioural psychotherapy in the treatment of irritable bowel syndrome. Journal of Psychosomatic Research, 35, 461-469.

Creed, F.H. (1999) The Relationship between psychosocial parameters and outcome in irritable bowel syndrome. American Journal of Medicine, 107, 74S-80S.

Creed, F.H. (1995) Psychological treatment of irritable bowel syndrome and abdominal pain. In R. Mayou, C. Bass and M. Sharpe (Eds.), Treatment of Functional Somatic Symptoms, (p.255-270). New York: Oxford University Press.

Creed, F.H., Craig, T. and Farmer, R.G. (1988). Functional abdominal pain, psychiatric illness and life events. Gut, 29, 235-242.

Croyle, R.T. and Barger, S.D. (1993). Illness cognition. In S. Maes, H. Leventhal and M. Johnston (Eds.), International Review of Health Psychology, vol. 2, (p.29-52). Sussex: John Wiley & Sons.

Croyle, R.T. and Jemmott, J.B.3rd (1991). Psychological reactions to risk factor testing. In J.A. Skelton and R.T. Croyle (Eds.), Mental Representation in Health and Illness, (p.85-107). New York: Springer-Verlag.

Dancey, C.P and Backhouse, S (1993). Towards a better understanding of patients with irritable bowel syndrome. Journal of Advanced Nursing, 18, 1443-1450.

Dancey, C.P. and Backhouse, S. (Eds.) (1997). IBS: A Complete Guide to Relief from Irritable Bowel Syndrome. London: Robinson.

Dancey, C.P., Fox, R.J. and Devins, G.M. (1999). The measurement of irritable bowel syndrome (IBS)-related misconceptions in people with IBS. Journal of Psychosomatic Research, 47, 269-276.

Dancey, C.P., Taghavi, M. and Fox, R.J. (1998). The relationship between daily stress and symptoms of irritable bowel: A time series approach. Journal of Psychosomatic Research, 44, 537-545.

Dancey, C.P., Whitehouse, A., Painter, J. and Backhouse, S. (1995). The relationship between hassles, uplifts and irritable bowel syndrome: A preliminary study. Journal of Psychosomatic Research, 39, 827-832.

Danivat, D., Tankeyoon, M. and Srirantanaban, A. (1988). Prevalence of irritable bowel syndrome in a non-western population. British Medical Journal, 196, 1710.

Deale, A., Chalder, T. and Wessely, S. (1998). Illness beliefs and treatment outcome in chronic fatigue syndrome. Journal of Psychosomatic Research, 45, 77-83.

Drossman, D.A. (1999). Biopsychosocial Approach to Functional Gastrointestinal Disorders. Paper presented at the 3rd international symposium on functional gastrointestinal disorders, Wisconsin, USA.

Drossman, D.A., Leserman, J., Nachman, G., Li, Z., Gluck, H., Toomey, T.C. and Mitchell, C.M. (1990). Sexual and physical abuse in woman with functional or organic gastrointestinal disorders. Annals of Internal Medicine, 113, 828-833.

Drossman, D.A., McKee, D.C., Sandler, R.S., Mitchell, C.M., Cramer, E.M., Lowman, B.C. and Burger, A.L. (1988). Psychosocial factors in the irritable bowel syndrome: A multivariate study of patients and non patients with irritable bowel syndrome. Gastroenterology, 95, 701-708.

Drossman, D.A., Li, Z., Leserman, J., Toomey, T.C. and Hu, Y.J. (1996). Health status by gastrointestinal diagnosis and abuse history. Gastroenterology, 110, 999-1007.

Drossman, D.A., Li, Z., Leserman, J., Toomey, T.C. and Hu, Y.J. (1997). Association of coping pattern and health status among female GI patients after controlling for GI disease type and abuse history: A prospective study. Gastroenterology, 112, 724.

van Dulmen, A.M., Fennis, J.F.M. and Bleijenberg, G. (1998). Toward effective reassurance in irritable bowel syndrome: The importance of attending to patients' complaint-related cognitions. Psychology, Health and Medicine, 3, 405-416.

van Dulmen, A.M., Fennis, J.F.M. and Bleijenberg, G. (1996b). Cognitive-behavioural group therapy for irritable bowel syndrome: effects and long-term follow-up. Psychosomatic Medicine, 58, 508-514.

van Dulmen, A.M., Fennis, J.F.M., Mokkink, H.G.A. and Bleijenberg, G. (1996a). The relationship between complaint-related cognitions in referred patients with irritable bowel syndrome and subsequent health care seeking behaviour in primary care. Family Practice, 13, (1), 12-17.

van Dulmen, A.M., Fennis, J.F.M., Mokkink, H.G.A., van der Velden, H.G.M. and Bleijenberg, G. (1994). Doctors' perception of patients' cognitions and complaints in irritable bowel syndrome at an out-patient clinic. Journal of Psychosomatic Research, 38, 581-590.

van Dulmen, A.M., Fennis, J.F.M., Mokkink, H.G.A., van der Velden, H.G.M. and Bleijenberg, G. (1997). Persisting improvement in complaint-related cognitions initiated during medical consultations in functional abdominal complaints. Psychological Medicine, 27, 725-729.

van Dulmen, A.M., Fennis, J.F.M., Mokkink, H.G.A., van der Velden, H.G.M. and Bleijenberg, G. (1995). Doctor-dependent changes in complaint-related cognitions and anxiety during medical consultations in functional abdominal complaints. Psychological Medicine, 25, 1011-1018.

Earll, L., Johnston, M. and Mitchell, E. (1993). Coping with motor neurone disease – an analysis using self-regulation theory. Palliative Medicine, 7, (suppl 2), 21-30.

Engel, G.L. (1977). The need for a new medical model: A challenge for biomedicine. Science, 196, 129-136.

Evans, P., Hucklebridge, F. and Clow, A. (2000). Mind, Immunity and Health: The Science of Psychoneuroimmunology. London: Free Association Books.

Festinger, L. (1964). Conflict, Decision, and Dissonance. Stanford CA: Stanford University Press.

Folkman, S. and Lazarus, R.S. (1980). An analysis of coping in a middle-aged community sample. Journal of Health and Social Behaviour, 21, 219-239.

Ford, M.J. (1986) Invited Review The Irritable Bowel syndrome. Journal of Psychosomatic Research, 30, 4, 399-410.

Ford, M.J., Miller, P.M., Eastwood, J. and Eastwood, M.A. (1987). Life events, psychiatric illness and the irritable bowel syndrome. Gut, 28, 160-165.

Fortune, D.G., Richards, H.L., Main, C.J. and Griffiths, C.E.M. (2000). Pathological worrying, illness perceptions and disease severity in patients with psoriasis. British Journal of Health Psychology, 5, 71-82.

Fowlie, S., Eastwood, M.A. and Prescott, R. (1992). Irritable bowel syndrome: The influence of psychological factors on the symptom complex. Journal of Psychosomatic Research, 36, 175-180.

Francis, C.Y., Morris, J. and Whorwell, P.J. (1997). The irritable bowel severity scoring system: a simple method of monitoring irritable bowel syndrome and its progress. Alimentary Pharmacology and Therapeutics, 11, 2, 395-401.

George, M.S. and Ketter, T.A. (1993). Post RM, SPECT and PET imaging in mood disorders. Journal of Clinical Psychiatry, 54, (suppl) 6-13.

Gomborone, J., Dewsnap, P., Libby, G. and Farthing, M. (1995). Abnormal illness attitudes in patients with irritable bowel syndrome. Journal of Psychosomatic Research, 39, 227-230.

Grant Thompson, W. (1999). Patient / Doctor Interaction. Paper presented at the 3rd international symposium on functional gastrointestinal disorders, Wisconsin, USA.

Greene, B. and Blanchard, E.B. (1995). Cognitive therapy for irritable bowel syndrome. Journal of Consulting and Clinical Psychology, 62, 576-582.

Guthrie, E., Creed F., Dawson, D. and Tomenson, B. (1991). A controlled trial of psychological treatment for the irritable bowel syndrome. Gastroenterology, 100, 450-457.

Guthrie, E., Creed F., Dawson, D. and Tomenson, B. (1993). A randomised controlled trial of psychotherapy in patients with refractory irritable bowel syndrome. British Journal of Psychiatry, 163, 315-321.

Hamdy, S., Aziz, Q., Crone, R., Rothwell, J.C., Hughes, D.G., Tallis, R.C. and Thompson, D.G. (1994). Explaining oropharyngeal dysphagia after unilateral hemispheric stroke. Lancet, 350, 686-692.

Hammer, J. and Talley, N.J. (1999). Diagnostic criteria for the irritable bowel syndrome. American Journal of Medicine, 107, (5A), 5S-11S.

Hampson, S.E. (1997). Illness representations and the self-management of diabetes. In K.J. Petrie and J.A. Weinman (Eds.), Perceptions of Health and Illness, (p.323-347). Amsterdam: Harwood Academic Publishers.

Hampson, S.E., Glasgow, R.E. and Strycker, L.A. (2000). Beliefs versus feelings: A comparison of personal models and depression for predicting multiple outcomes in diabetes. British Journal of Health Psychology, 5, 27-40.

Hampson, S.E., Glasgow, R.E. and Toobert, D.J. (1990). Personal models of diabetes and their relations to self-care activities. Health Psychology, 9, 632-646.

Hampson, S.E., Glasgow, R.E. and Zeiss, A. (1994). Personal models of osteoarthritis and their relation to self-management activities and quality of life. Journal of Behavioural Medicine, 17, 143-158.

Heaton, K.W., O'Donnell, L.J.D., Braddon, F.E.M., Mountford R.A, Hughes, A.O. and Cripps, P.J. (1992). Irritable bowel syndrome in a British urban community: Consulters and non-consulters. Gastroenterology, 102, 1962-1967.

Heaton, K.W., Ghosh, S. and Braddon, F.E.M. (1991). How bad are the symptoms and bowel dysfunction of patients with irritable bowel syndrome? A prospective, controlled study with special reference to stool form. Gut, 32, 73-79.

Heijmans, M. (1998). Coping and adaptive outcome in chronic fatigue syndrome: Importance of illness cognitions. Journal of Psychosomatic Research, 45, 39-51.

Heijmans, M. and de Ridder, D. (1998). Assessing illness representations of chronic illness: Explorations of their disease specific nature. Journal of Behavioural Medicine, 21, 485-503.

Heijmans, M., de Ridder, D. and Bensing, J. (1999). Dissimilarity in patients' and spouses' representations of chronic illness: Exploration of relations to patient adaptation. Psychology and Health, 14, 451-466.

Hinkle, L.E. (1973). The concept of "stress" in the biological and social sciences. Science, Medicine, and Man, 1, 31-48.

Holmes, T.H. and Rahe, R.H. (1967). The social readjustment rating scale. Journal of Psychosomatic Research, 11, 213-218.

Horne, R. (1998). Adherence to medication: A review of existing research. In L. Myers and K. Midence (Eds.), Adherence to Treatment in Medical Conditions, (p.25-50). Amsterdam: Harwood Academic Publishers.

Horne, R., James, D., Petrie, K., Weinman, J. and Vincent, R. (2000). Patients' interpretation of symptoms as a cause of delay in reaching hospital during acute myocardial infarction. Heart, 83, (4), 388-393.

van der Horst, H.E., van Dulmen, A.M., Schellevis, F.G., van Eijk, J.T.M., Fennis, J.F.M. and Bleijenberg, G. (1997). Do patients with irritable bowel syndrome in primary care really differ from outpatients with irritable bowel syndrome? Gut, 41, 669-674.

Houghton, L.A., Heyman, D.J. and Whorwell, P.J. (1996). Symptomatology, quality of life and features of irritable bowel syndrome – the effect of hypnotherapy. Alimentary Pharmacological Therapy, 10, 91-95.

Howard, N (1998). Irritable Bowel Syndrome. UK: Element Books Ltd.

James, W. (1884). What is emotion? Mind, 9, 188-205.

Janz, N.K. and Becker, M.H. (1984). The Health Belief Model: A decade later. Health Education Quarterly, 11, 1-47.

Jason, L.A., Taylor, R.R. and Stepanek, Z. (2001). Attitudes regarding chronic fatigue syndrome: The importance of a name. Journal of Health Psychology, 6, 1, 61-71.

Jenkins, C.D., Hurst, W.H. and Rose, R.M. (1979). Life changes: Do people really remember? Archives of General Psychiatry, 36, 370-384.

Jeong, H., Lee, H.R., Yoo, B.C. and Park, S.M. (1993). Manning criteria in irritable bowel syndrome: Its diagnostic significance. Korean Journal of Internal Medicine, 8, 34-39.

Johnson, J.E. and Leventhal, H. (1974). The effects of accurate expectations and behavioural instructions on reactions during a noxious medical examination. Journal of Personality and Social Psychology, 29, 710-718.

Johnston, M., Pollard, B. and Hennessey, P. (2000). Construct validation of the hospital anxiety and depression scale with clinical populations. Journal of Psychosomatic Research, 48, 579-584.

Jones, J., Boorman, J., Cann, P., Forbes, A., Gomborone, J., Keaton, K., Hungin, P., Kumar, D., Libby, G., Spiller, R., Read, N., Silk, D. and Whorwell, P. (2000). Guidelines for the management of the irritable bowel syndrome. Gut, 47, (suppl II), ii1 – ii19.

Jones, R. and Lydeard, S. (1992). Irritable bowel syndrome in the general population. British Medical Journal, 304, 87-90.

Kapoor, K.K., Nigam, P., Rastogi, C.K., Kumar, A. and Gupta, A.K. (1985). Clinical profile of irritable bowel syndrome. Indian Journal of Gastroenterology, 4, 15-16.

Kendall-Tackett, K.A. (2000). Physiological correlates of childhood abuse: Chronic hyperarousal in PTSD, depression and irritable bowel syndrome. Child Abuse and Neglect, 24, (6), 799-810.

Kennedy, T. and Jones, R. (1998). Gastro-oesophageal reflux symptoms in the community. Gastroenterology, 114, (suppl) A22.

Kettell, J., Jones, R. and Lydeard, S. (1992). Reasons for consultation in irritable bowel syndrome: symptoms and patient characteristics. British Journal of General Practice, 42, 459-461.

Künsebeck, H.W., Körber, J. and Fereyberger, H (1990). Quality of life in patients with inflammatory bowel disease. Psychotherapy and Psychosomatics, 54, 110-116.

Lazarus, R.S. and Folkman, S. (1984). Stress Appraisal and Coping. New York: Springer-Verlag.

Lacroix, J.M., Martin, B., Avendano, M. and Goldstein, R. (1991). Symptom schemata in chronic respiratory patients. Health Psychology, 10, 268-273.

Landrine, H. and Klonoff, E.A. (1992). Culture and health-related schemas: A review and proposal for interdisciplinary integration. Health Psychology, 11, 4, 267-276.

Lau, R.R. and Hartman, K.A. (1983). Common sense representations of common illnesses. Health Psychology, 2, 167-185.

Lau, R.R., Nernard, T.M. and Hartman, K.A. (1989). Further explorations of commonsense representations of common illnesses. Health Psychology, 8, 195-219.

Lembo, T., Fullerton, S., Diehl, D., Raeen, H., Munakata, J., Nailboff, B. and Mayer, E.A. (1996). Symptom duration in patients with irritable bowel syndrome. The American Journal of Gastroenterology, 91, (5), 898-905.

Leserman, J., Drossman, D.A., Li, Z., Toomey, T.C., Nachman, G. and Glogau, L. (1996). Sexual and physical abuse history in gastroenterology practice: How types of abuse impact health status. Psychosomatic Medicine, 58, 4-15.

Letson, S. and Dancey, C.P. (1996). Nurses' perceptions of irritable bowel syndrome and sufferers of IBS. Journal of Advanced Nursing, 23, 969-974.

Leventhal, H. (1970). Findings and theory in the study of fear communications. In L. Berkowitz (Ed.), Advances in Experimental Social Psychology. New York: Academic Press.

Leventhal, H. (1980). Toward a comprehensive theory of emotion. Advances in Experimental Social Psychology, 13, 139-207.

Leventhal, H. and Benyamini, Y. (1997). Lay beliefs about health and illness. In A. Baum, S. Newman, J. Weinman, R. West, C. McManus (Eds.), Cambridge Handbook of Psychology, Health and Medicine, (p.131-135). Cambridge: Cambridge University Press.

Leventhal, H. and Diefenbach, M. (1991). The active side of illness cognition. In, J.A. Skelton and R.T. Croyle (Eds.), Mental Representation in Health and Illness, (p.247-272). New York: Springer-Verlag.

Leventhal, H., Diefenbach, M. and Leventhal, E.A. (1992). Illness cognition: using commonsense to understand treatment adherence and affect cognition interactions. Cognition, Therapy and Research, 16, 143-163.

Leventhal, H., Meyer, D. and Nerenz, D. (1980). The Common Sense Representation of Illness Danger. In S. Rachman (Ed.), Contributions to Medical Psychology, (Vol. 2, p.7-30). Oxford: Pergamon.

Leventhal, H. and Nerenz, D.R. (1985). The assessment of illness cognition. In P.Karoly (Ed.), Measurement Strategies in Health Psychology, (p.517-553). New York: John Wiley.

Leventhal, H., Nerenz, D.R. and Straus, A. (1980). Self-regulation and the mechanisms for symptom appraisal. In D. Mechanic (Ed.), Psychosocial Epidemiology, (p.55-86). New York: Neale Watson.

Leventhal, H., Nerenz, D.R. and Steele, D.J. (1984). Illness representations and coping with health threats. In A. Baum, S.E. Taylor and J.E. Singer (Eds.), Handbook of Psychology and Health, (Vol. 4, p.219-252). Hillsdale, NJ: Erlbaum.

Leventhal, H., Zimmerman, R. and Gutmann, M. (1984). Compliance: A Self-Regulation Perspective. In D. Gentry (Ed.), Handbook of Behavioural Medicine, (p.369-436). New York: Guilford Press.

Lipowski, Z.J. (1986). Somatization: A borderland between medicine and psychiatry. Canadian Medical Association Journal, 135, 609-614.

Lydeard, S. and Jones, R.H. (1989). Factors affecting the decision to consult with dyspepsia: Comparison of consulters and non consulters. Journal of the Royal College of General Practitioners, 39, 495-498.

Lynch, P.M. and Zamble, E. (1989). A controlled behavioural treatment study of irritable bowel syndrome. Behaviour Therapy, 20, 509-523.

Manning, A.P., Thompson, W.G., Heaton, K.W. and Morris, A.F. (1978). Towards positive diagnosis of the irritable bowel. British Medical Journal, 2, 653-654.

Mayberg, H.S., Brannen, S.K., Mahurin, R.K., Jerabek, P.A., Brickman, J.S., Tekell, J.L., Silva, J.A., McGinnis, S., Glass, T.G., Martin, C.C. and Fox, P.T. (1997). Cingulate function in depression: A potential predictor of treatment response. Neuroreport, 8, 1057-1061.

McCarty, R. and Gold, P.E. (1996). Catecholamines, stress and disease: A psychobiological perspective. Psychosomatic Medicine, 58, 590-597.
Mearin, F., Cucala, M., Azpiroz, F. and Malagelada, J.R. (1991). The origin of symptoms on the brain gut axis in functional dyspepsia. Gastroenterology, 101, 999-1006.

Mendeloff, A.I., Monk, M., Seigel, C.I. and Lilienfeld, A. (1964). Illness experience and life stresses in patients with irritable colon and with ulcerative colitis: An epidemiologic study of ulcerative colitis and regional enteritis in Baltimore, 1960-1964. New England Journal of Medicine, 282, 14-17.

Mertz, H., Tanner, W.G., Kessler., D., Price., R. and Pickens, D. (1998). Functional MRI measurement of brain activity during rectal distension in normal volunteers and patients with irritable bowel syndrome. Gastroenterology, 114, A803.

Meyer, D., Leventhal, H. and Gutmann, M. (1985). Common-sense models of illness: The example of hypertension. Health Psychology, 4, 115-135.

Miller, S.M. (1987). Monitoring and blunting: Validation of a questionnaire to assess different styles for coping with stress. Journal of Personality and Social Psychology, 52, 345-353.

Miller, S.M. (1989). Cognitive informational styles in the process of coping with threat and frustration. Advances in Behaviour Research and Therapy, 11, 223-234.

Moss-Morris, R. (1997). The role of illness cognitions and coping in the aetiology and maintenance of chronic fatigue syndrome (CFS). In K.J. Petrie and J.A. Weinman (Eds.), Perceptions of Health and Illness, (p.411-440). Amsterdam: Harwood Academic Publishers.

Moss-Morris, R. and Petrie, K.J. (1996). Cognitive mechanisms in the maintenance of disability in chronic fatigue syndrome. Paper presented at the American Psychosomatic Society Annual Meeting, Williamsburg, USA.

Moss-Morris, R., Petrie, K.J. and Weinman, J. (1996). Functioning in chronic fatigue syndrome: Do illness perceptions play a regulatory role? British Journal of Health Psychology, 1, 15-25.

Murphy, H., Dickens, C., Creed, F. and Bernstein, R. (1999). Depression, illness perception and coping in rheumatoid arthritis. Journal of Psychosomatic Research, 46, 155-164.

Neff, D.F. and Blanchard, E.B. (1987). A multi-component treatment for irritable bowel syndrome. Behaviour Therapy, 18, 70-83.

Nerenz, D. and Leventhal, H. (1983). Self-regulation in chronic illness. In T.G. Burish and L.A. Bradley (Eds.), Coping with Chronic Disease. New York: Academic Press.

Nerenz, D., Leventhal, H., Love, R. and Ringler, K. (1984). Psychological aspects of cancer chemotherapy. International Review of Applied Psychology, 33, 51-55.

Nicassio, P.M. and Smith, T.W. (1995). Managing Chronic Illness: A Biopsychosocial Perspective. Washington, DC: American Psychological Association.

Norman, P. and Conner, C. (1996). The role of social cognition theories. In M. Conner and P. Norman (Eds.), Predicting Health Behaviour, (p.197-225). Buckingham: Open University Press.

Osborn, M. and Smith, J.A. (1998). The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis. British Journal of Health Psychology, 3, 65-83.

Payne, A. and Blanchard, E.B. (1995). A controlled comparison of cognitive therapy and self-help support groups in the treatment of irritable bowel syndrome. Journal of Consulting and Clinical Psychology, 63, 779-786.

Pennebaker, J.W. (1982). The Psychology of Physical Symptoms. New York: Springer-Verlag.

Pennebaker, J.W. and Skelton, J.A. (1981). Psychological parameters of physical symptoms. Personality and Social Psychology Bulletin, 4, 524-530.

Petrie, K.J., Weinman, J., Sharpe, N. and Buckley, J. (1996). Role of patients' views of their illness in predicting return to work and functioning after myocardial infarction: Longitudinal study. British Medical Journal, 312, 1191-1194.

Power, M., Bullinger, M., Harper, A. and The World Health Organization Quality of Life Group (1999). The World Health Organization WHOQOL-100: Tests of the universality of quality of life in 15 different cultural groups worldwide. Health Psychology, 18, 495-505.

Prohaska, T.R., Keller, M.L., Leventhal, E.A. and Leventhal, H. (1987). Impact of symptoms and aging attribution on emotions and coping. Health Psychology, 6, 495-514.

Rao, K.P., Gupta, S., Jain, A.K., Agrawal, A.K. and Gupta, J.P. (1993). Evaluation of Manning's criteria in the diagnosis of irritable bowel syndrome. Journal of the Association of Physicians of India, 41, 357-358.

Rao, S.S.C., Hatfield, R.A., Suls, J.M. and Chamberlain, M.J. (1998). Psychological and physical stress induce differential effects on human colonic motility. American Journal of Gastroenterology, 93, 985-990.

Rees, G., Davies, G.J., Parker, M. and Travan, M. (1994). Gastrointestinal symptoms and diet of members of an irritable bowel self help group. Journal of Royal Society of Health, 182-187.

Ringel, Y. and Drossman, D.A. (1999). From gut to brain and back – A new perspective into functional gastrointestinal disorders. Journal of Psychosomatic Research, 47, 205-210.

Rosenstock, I.M. (1974). Historical origins of the Health Belief Model. Health Education Monographs, 2, 328.

Rumsey, N. (1991). Group stress management programmes vs. pharmacological treatment in the treatment of the irritable bowel syndrome. In K.W. Keaton, F. Creed, N.L.M. Goeting (Eds.), Current Approaches Towards Confident Management of Irritable Bowel Syndrome. Lyme Regis, UK: Lyme Regis.

Salt, W.B. (1997). Irritable Bowel Syndrome & the Mind-Body Brain-Gut Connection. Ohio: Parkview Publishing.

Sandler, R.S., Drossman, D.A., Nathan, H.P. and McKee, D.C. (1984). Symptom complaints and health care seeking behaviour in subjects with bowel dysfunction. Gastroenterology, 87, 314-318.

Sarafino, E.P. (1994). Health Psychology: Biopsychosocial Interactions (2nd Edn). New York: John Wiley and Sons.

Schmulson, M.W and Chang, L. (1999) Diagnostic approach to the patient with irritable bowel syndrome. American Journal of Medicine, 107, (5A), 20S-26S.

Scharloo, M. and Kaptein, A.A. (1997). Measurement of illness perceptions in patients with chronic somatic illness: A review. In K.J. Petrie and J.A. Weinman (Eds.), Perceptions of Health and Illness, (p.103-154). Amsterdam: Harwood Academic Publishers.

Scharloo, M., Kaptein, A.A., Weinman, J., Bergman, W., Vermeer, B.J. and Rooijmans, H.G.M. (2000a). Patients' illness perceprtions and coping as predictors of functional status in psoriasis: A 1-year follow-up. British Journal of Dermatology, 142, (5), 899-907.

Scharloo, M., Kaptein, A.A., Weinman, J.A., Hazes, J.M., Breedveld, F.C. and Rooijmans, H.G. (1999). Predicting functional status in patients with rheumatoid arthritis. Journal of Rheumatology, 26, (8), 1686-1693.

Scharloo, M., Kaptein, A.A., Weinman, J., Hazes, J.M., Willems, L.N.A., Bergamn, W. and Roojimans, H.G.M. (1998). Illness perceptions, coping and functioning in patients with rheumatoid arthritis, chronic obstructive pulmonary disease and psoriasis. Journal of Psychosomatic Research, 44, 573-585.

Scharloo, M., Kaptein, A.A., Weinman, J.A., Willems, L.N. and Rooijmans, H.G. (2000b). Physical and psychological correlates of functioning in patients with chronic obstructive pulmonary disease. Journal of Asthma, 37, (1), 17-29.

Schiaffino, K.M. and Cea, C.D. (1995). Assessing chronic illness representations: The Implicit Models of Illness Questionnaire. Journal of Behavioural Medicine, 18, 531-548.

Schiaffino, K.M. and Revenson, T.A. (1992). The role of perceived self-efficacy, perceived control and causal attributions in adaptation to rheumatoid arthritis: Distinguishing mediator from moderator effects. Personality and Social Psychology Bulletin, 18, 709-718.

Schiaffino, K.M., Shawaryn, M.A. and Blum, D. (1998). Examining the impact of illness representations on psychological adjustment to chronic illness. Health Psychology,17, 3, 262-268.

Schwarz, E.D. and Perry, B.D. (1994). The post-traumatic response in children and adolescents. Psychiatric Clinics of North America, 17, 311-326.

Segal, F. and Walker, A.R. (1984). Irritable bowel syndrome in the black community. South African Medical Journal, 65, 72-73.

Seyle, H. (1956). The Stress of Life. New York: McGraw-Hill.

Seyle, H. (1976). Stress in Health and Disease. Reading MA: Butterworth.
Shaw, G., Srtgastava, E.D., Sadlier, M., Swann, P., James, J.Y. and Rhodes, J. (1991). Stress management for irritable bowel syndrome: A controlled trial. Digestion, 50, 36-42.

Sharpe, M., Hawton, K., Seagroatt, V. and Pasvol, G. (1992). Follow up of patients presenting with fatigue to an infectious diseases clinic. British Medical Journal, 305, 147-152.

Silverman, D.H., Munakata, J.A., Ennes, H., Mandelkern, M.A., Hoh, C.K. and Mayer, E.A. (1997). Regional cerebral activity in normal and pathological perception of visceral pain. Gastroenterology, 112, 64-72.

Skelton, J.A. and Croyle, R.T. (Eds.) (1991). Mental Representation in Health and Illness. New York: Springer-Verlag.

Skevington, S.M. (1999). Measuring quality of life in Britain: Introducing the WHOQOL-100. Journal of Psychosomatic Research, 47, 449-459.

Smith, J., Harre, R. and van Langenehove, L. (1995). Rethinking Psychology: Alternative Methods. London: Sage.

Stenner, P.H.D., Dancey, C.P, and Watts, S. (2000). The understanding of their illness amongst people with irritable bowel syndrome: A Q methodological study. Social Science and Medicine, 51, 439-452.

Suls, J. and Fletcher, B. (1985). The relative efficacy of avoidant and nonavoidant coping strategies: A meta analysis. Health Psychology, 4, 249-288.

Suls, J., Wan, C.K. And Blanchard, B. (1994). A multi-level data-analytic approach for evaluation of relationships between daily life stressors and symptomatology: Patients with irritable bowel syndrome. Health Psychology, 13, 103-113.

Svendsen, J.H., Munck, L.K. and Andersen, J.R. (1985) Irritable Bowel Syndrome: Prognosis and diagnostic safety. A 5-year follow-up study. Scandinavian Journal of Gastroenterology, 20, 415-418.

Tabachnick, B.G. and Fidell, L.S. (1996). Using Multivariate Statistics (3rd Edition). New York: HarperCollins.

Talley, N.J., Boyce, P.M. and Jones, M. (1997). Predictors of health care seeking for irritable bowel syndrome: A population based study. Gut, 41,394-398.

Talley, N.J., Boyce, P.M., Owen, B.K., Newman, P. and Paterson, K.J. (1995). Initial validation of a bowel symptom questionnaire and measurement of chronic gastrointestinal symptoms in Australians. Australian and New Zealand Journal of Medicine, 25, 302- 308.

Talley, N.J., Fett, S.L. and Zinsmeister, A.R. (1995a). Self-reported abuse and gastrointestinal disease in outpatients: Association with irritable bowel-type symptoms. American Journal of Gastroenterology, 90, 366-371.

Talley, N.J., Gabriel, S.E., Harmsen, W.S., Zinsmeister, A.R. and Evans, R.G. (1995b). Medical costs in community subjects with irritable bowel syndrome. Gastroenterology, 99, 1736-1741.

Talley, N.J., Phillips, S.F., Bruce, B.K., Melton, L.J. and Zinsmeister, A.R. (1990). Relation between personality characteristics and symptoms in non-ulcer dyspepsia and irritable bowel syndrome. Gastroenterology, 99, 327-333.

Talley, N.J., Phillips, S.F., Melton, L.J., Mulvihill, C., Wiltgen, C. and Zinsmeister, A.R. (1990). Diagnostic value of the Manning criteria in irritable bowel syndrome. Gut, 31, 77-81.

Talley, N.J., Weaver, A.L. Zinsmeister, A.R. and Melton, L.J. 3rd (1992). Onset and disappearance of gastrointestinal symptoms and functional gastrointestinal disorders. American Journal of Epidemiology, 136, 165-177.

Talley, N.J., Zinsmeister, A.R., van Dyke, C. and Melton, L.J. (1991). Epidemiology of colonic symptoms and the irritable bowel syndrome. Gastroenterology, 101, 927-934.

Taylor, S.E. (1983). Adjustment to threatening events: A theory of cognitive adaptation. American Psychologist, 38, 1161-1173.

Tennes, K. and Kreye, M. (1985). Children's adrenocortical responses to classroom activities and tests in elementary school. Psychosomatic Medcine, 47, 451-460.

Thompson, W.G. (1984). Gastrointestinal symptoms in the irritable bowel compared with peptic ulcer and inflammatory bowel disease. Gut, 25, 1089-1092.

Timko, C and Janoff-Bulman, R. (1985). Attributions, vulnerability and psychological adjustment: The case of breast cancer. Health Psychology, 4, 521-546.

Toner, B.B., Koyama, E., Garfinkel, P.E., Jeejeebhoy, K.N. and Di Gasbarro, I. (1992). Social desirability and irritable bowel syndrome. International Journal of Psychiatry in Medicine, 22, 1, 99-103.

Toner, B.B., Segal, Z.V., Emmott, S. and Myran, D. (2000). Cognitive-Behavioural Treatment of Irritable Bowel Syndrome: The Brain-Gut Connection. New York: The Guilford Press.

Toner, B.B., Segal, Z.V., Emmott, S., Myran, D., Ali, A., DiGasbarro, I. and Stuckless, N. (1998). Cognitive-behavioural group therapy for patients with irritable bowel syndrome. International Journal of Group Psychotherapy, 48, (2), 215-243.

Turk, D.C. and Rudy, T.E. (1992). Cognitive factors and persisting pain: a glimpse into Pandora's Box. Cognitive Therapy and Research,16, 99-122.

Turk, D.C., Rudy, T.E. and Salovey, P. (1986). Implicit models of illness. Journal of Behavioural Medicine, 9, (5), 453-474.

Turnbull, G.K., Aziz, Q., Hamdy, S., Barlow, J., Singh, K., Alani, S. and Thompson, D.G. (1994). Representation of the anal sphincter on human cerebral cortex. Gut, 35, (suppl): S30.

Vanner, S., Glenn, D. and Paterson, W. (1997), Diagnosing irritable bowel syndrome: Predictive values of Rome criteria. Gastroenterology, 112, A47;

Vercoulen, J., Swanink, C., Fennis, J., Galma, J., van der Meer, J. and Bleijenberg, G. (1996). Prognosis in chronic fatigue syndrome (CFS): A prospective study. Journal of Neurological and Neurosurgical Psychiatry, 60, 489-494.

Walker, E.A., Katon, W.J., Roy-Byrne, P.P., Jemelka, R.P. and Russo, J. (1993). Histories of sexual victimization in patients with irritable bowel syndrome or inflammatory bowel disease. American Journal of Psychiatry, 150, 1502-1506.

Watson, D. and Pennebaker, J.W. (1989). Health complaints, stress, and disease: Exploring the central role of negative affectivity. Psychological Review, 96, 234-254.

Weinman, J.A. (1997). The self-regulation model: What it is, how it has been tested and how it should be tested. Paper presented at the meeting of the Special Group in Health Psychology, Southampton.

Whitehead, W.E. (1994). Assessing the effects of stress on physical symptoms. Health Psychology, 13, 99-102.

Whitehead, W.E. (1996). Psychosocial aspects of functional gastrointestinal disorders. Gastroenterology Clinics of North America, 25, 21-34.

Whitehead, W.E., Bosmajian, L., Zonderman, A.B., Costa, P.T Jr. and Schuster, M.M. (1988). Symptoms of psychological distress associated with irritable bowel syndrome. Comparison of community and medical clinic samples. Gastroenterology, 95, 709-714.

Whitehead, W.E., Crowell, M.D., Robinson, J.C., Heller, B.R. and Schuster, M.M. (1992). Effects of stressful life events on bowel symptoms: Subjects with irritable bowel syndrome compared with subjects without bowel dysfunction. Gut, 33, 825-830.

Whorwell, P.J., Prior A. and Colgan, S.M. (1987). Hypnotherapy in severe irritable bowel syndrome. Gut, 28, 423-425.

Williams, D.A., Robinson, M.E. and Geisser, M.E. (1994). Pain beliefs: Assessment and utility. Pain, 36, 351-358.

Wills, T.A. (1981). Downward comparison principles in social psychology. Psychological Bulletin, 90, 381-397.

Wills, T.A. (1987). Downward comparison as a coping mechanism. In C.R. Snyder and C. Ford (Eds.), Coping with Negative Life Events: Clinical and Social-Psychological Perspectives, (p.243-268). New York: Plenum Press.

Wilson, A., Hickie, I., Lloyd, A., Hadzi-Pavlovic, D., Boughton, C., Dwyer, J. and Wakefield, D. (1994). Longitudinal study of outcome of chronic fatigue syndrome. British Medical Journal, 308, 756-759.

Witenberg, S.H., Blanchard, E.B., Suls, J., Tennen, H., McCoy, G. and McGoldrick, M.D. (1983). Perceptions of control and causality as predictors of compliance and coping in haemodialysis. Basic and Applied Social Psychology, 4, 319-336.

Wolf, S. (1981). The psyche and the stomach. Gastroenterology, 80, 605-608.

Wooley, S.C., Blackwell, B. and Winget, C. (1978). A learning theory model of chronic illness behaviour: Theory treatment and research. Psychosomatic Medicine, 40, 379-401.

Young, L.D., Richter J.E., Anderson, K.O., Bradley, L.A., Katz, P.O., McElveen, L., Obrecht, W.F., Dalton, L. and Synder, R.M. (1987). The effects of physiological and environmental stressors on peristaltic oesophageal contractions in healthy volunteers. Psychophysiology, 24, 132-141.

Zigmond, A.S. and Snaith, R.P. (1983). The hospital anxiety and depression scale. Acta Psychiatra Scandinavica, 67, 361-370.

Appendices

Please note that each questionnaire had to be reduced (by 19%) for binding purposes.

All versions of the questionnaire were included where possible, however in appendix D as all three questionnaires (over Time) were the same, only the IBS Time 2 and Time 3 versions are included.

Appendix A1

Adverts placed in The Journal of the IBS Network and NACCNews

Article published in The Journal of the IBS Network ("Gut Reaction")

I am a research student at the University of Kent at Canterbury. I am investigating the way being ill can affect people both physically and emotionally.

Coping with painful and / or embarrassing symptoms impact upon people in many ways and can often create feelings of uncertainty and frustration.

You may notice that your symptoms become more evident in times of stress, or sometimes when you are feeling more relaxed. As a psychology student I am interested in the way coping with your symptoms affects your thoughts and feelings about your IBS. The more we are able to understand about IBS, the more we may be able to help. The aim of my research is to help IBS sufferers to cope as successfully as possible with their illness.

I would like to invite you to take part in this research. I simply require IBS sufferers to complete my questionnaire booklet that contains several measures used by health psychologists within their research, none of which have so far focused on IBS. All the information I receive will be treated confidentially; no one will be able to identify any individual.

If you are interested in participating simply send your name and address to me at the address below. On receiving your letter I will send you an information letter, consent form, questionnaire booklet, and a pre-paid envelope. I regret that I cannot help with postage costs in the first instance.

I intend to publish my findings in relevant psychological and medical journals, and I hope this research will go some way to make a difference for future sufferers. Once my study is completed I will of course report my findings in GR.

Article published in the NACC Newsletter ("NACCNews")

I am a research student at the University of Kent at Canterbury. I am investigating the way being ill can affect people both physically and emotionally.

Coping with painful and / or embarrassing symptoms impact upon people in many ways and can often create feelings of uncertainty and frustration.

You may notice that your symptoms become more evident in times of stress, or sometimes when you are feeling more relaxed. As a psychology student I am interested in the way coping with your symptoms affects your thoughts and feelings about your IBD. The more we are able to understand about Colitis and Crohn's, the more we may be able to help. The aim of my research is to help IBD sufferers to cope as successfully as possible with their illness.

I would like to invite you to take part in this research. I simply require IBD sufferers to complete my questionnaire booklet that contains several measures used by health psychologists within their research. All the information I receive will be treated confidentially; no one will be able to identify any individual.

If you are interested in participating simply send your name and address to me at the address below. On receiving your letter I will send you an information letter, consent form, questionnaire booklet, and a pre-paid envelope. I regret that I cannot help with postage costs in the first instance.

I intend to publish my findings in relevant psychological and medical journals, and I hope this research will go some way to make a difference for future sufferers. Once my study is completed I will of course report my findings in a future edition of this newsletter.

Appendix A2

Information Letters for the IBS and IBD sufferers

(On University Headed Notepaper)
Claire L Rutter
Research Student
Dialling code for Canterbury:
01227 (UK) or +44 1227 (International)
Tel: 827147 direct line
764000 switchboard (ext.7147)
Fax: 827030
Email: C.L.Rutter@ukc.ac.uk

(Participant Name)
(Participant Address)

(Date)

Dear (Participant Name)

Thank you very much for replying to my request for help, I am very grateful for your co-operation.

As I stated in the advert, the aim of my research is to learn more about the way IBS affects your life and how your experiences affect your symptoms.

Most of the measures included in the questionnaire booklet require you to circle or tick your response. There are no right or wrong answers, and all your answers will be combined with other Network members. No one other than myself will ever see your individual questionnaire, however if there are some questions which you feel uneasy about answering, then please feel free to miss them out.

Please try not to spend too long on each question, it is often the case that the first answer is usually the most accurate.

There is room at the end of the booklet for you to comment on any treatments or therapies that may have helped you. Please state how important the Network has been in helping inform you of these treatments. How do you think the Network could be improved? Please feel free to write as little or as much as you feel like. I will then be able to pass on your anonymous comments to the Network.

If you still would like to participate, complete the consent form and questionnaire booklet. Then simply put them both in the prepaid envelope and send them back to me. Keep this letter and your consent form for your information.

I hope to have this data analysed by summer 2000, as soon as it is interpreted I will write an article for Gut Reaction to let you know my findings.

I look forward to receiving your completed questionnaire.

Thank you and best wishes.

Miss Claire Rutter
Research Student

(On University Headed Notepaper)
Claire L Rutter
Research Student
Dialling code for Canterbury:
01227 (UK) or +44 1227 (International)
Tel: 827147 direct line
764000 switchboard (ext.7147)
Fax: 827030
Email: C.L.Rutter@ukc.ac.uk

(Participant Name)
(Participant Address)

(Date)

Dear (Participant Name)

Thank you very much for replying to my request for help, I am very grateful for your co-operation.

As I stated in the advert, the aim of my research is to learn more about the way IBD affects your life and how your experiences affect your symptoms.

Most of the measures included in the questionnaire booklet require you to circle or tick your response. There are no right or wrong answers, and all your answers will be combined with other NACC members. No one other than myself will ever see your individual questionnaire, however if there are some questions which you feel uneasy about answering, then please feel free to miss them out.

Please try not to spend too long on each question; it is often the case that the first answer is usually the most accurate.

There is room at the end of the booklet for you to comment on any treatments or therapies that may have helped you. Please state how important NACC has been in helping inform you of these treatments. How do you think NACC could be improved? Please feel free to write as little or as much as you feel like. I will then be able to pass on your anonymous comments to NACC.

If you still would like to participate, complete the consent form and questionnaire booklet. Then simply put them both in the prepaid envelope and send them back to me. Keep this letter and your consent form for your information.

I hope to have this data analysed by Winter 2000, as soon as it is interpreted I will write an article for the quarterly newsletter to inform you of my findings.

I look forward to receiving your completed questionnaire.

Thank you and best wishes.

Miss Claire Rutter
Research Student

Appendix A3

Standard consent form(s) given to all participants in all studies

CONSENT FORM
(FOR YOU TO KEEP)

Project: Living with chronic illness

Name and contact address of researcher: Claire Rutter

Centre for Research in Health Behaviour
Department of Psychology
University of Kent at Canterbury
Canterbury
Kent CT2 7NP

Telephone: 01227 827147

Please tick box

☐ I confirm that I have read the accompanying information sheet

☐ I understand that my participation is voluntary and that I am under no obligation to complete the questionnaire booklet

☐ I agree to take part in this study

Name of participant ____________ Date ____________ Signature ____________

Name of Researcher ____________ Date ____________ Signature ____________

CONSENT FORM
(TO BE SENT BACK TO CLAIRE WITH THE COMPLETED QUESTIONNAIRE)

Project: Living with chronic illness

Name and contact address of researcher: Claire Rutter

Centre for Research in Health Behaviour
Department of Psychology
University of Kent at Canterbury
Canterbury
Kent CT2 7NP

Telephone: 01227 827147

Please tick box

- ☐ I confirm that I have read the accompanying information sheet
- ☐ I understand that my participation is voluntary and that I am under no obligation to complete the questionnaire booklet
- ☐ I agree to take part in this study

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Appendix A4

IBS and IBD Questionnaires

KENT
UNIVERSITY OF KENT
AT CANTERBURY ■■■■

Living with Irritable Bowel Syndrome
Questionnaire Booklet

Miss Claire Rutter
Research Student
Centre for Research in Health Behaviour
Department of Psychology
University of Kent at Canterbury
Canterbury
Kent CT2 7NP

☎ (01227) 827147

This booklet contains several questionnaires from the health and illness field. Most require you to circle or tick your preferred choice (i.e. the one that best describes the way you feel). **There are no right or wrong answers.** Although you may choose not to answer some questions, all answers will be treated in the **strictest confidence.** No one other than myself will see your completed questionnaires.
There is a space at the back for you to add anything else you feel is relevant. Please write freely. Also there are a few sections which ask you to write in your own words, if you run out of space please use the sheet at the back to continue.
Try not to spend too long thinking about specific questions. **Your initial choice for each question should take only a few seconds.** The whole booklet should take no longer than 50 minutes to complete.

Thank you for taking the time to complete this for me.

Best wishes

Miss Claire Rutter

Please Note: All questionnaires are confidential. No one will see your responses apart from the researcher named above.

© Claire Rutter
IBS/SHG

Section 1: Information About You

This section asks you for information regarding your personal situation. Please try and answer all questions. Answers are for statistical purposes only.

Male / Female (please circle)   Date of birth _____/_____/_____

Marital status (please circle)

Single   Married   Divorced   Separated   Widowed   Co-habiting

Number of children (with ages) ____________________

Please state highest academic qualification achieved ____________________

Occupation ____________________ If no occupation, is this due to your symptoms? Yes / No

Part time / Full time (please circle)   If part time, is this due to your symptoms? Yes / No

Please estimate how many days sick you have taken in the past year ____________

I first experienced bowel and related symptoms ________________ (As near to the date as possible)

I was diagnosed with Irritable Bowel Syndrome ________________ (As near to the date as possible)

I have been to the GP about my irritable bowel and related symptoms (approximately) ______________ times, and saw (please circle)

same GP / two GP's / 3 or more GP's

Before I was diagnosed with IBS I had the following tests / examinations; (please tick)

- ☐ Barium meal
- ☐ Barium enema
- ☐ Colonoscopy
- ☐ Rectal examination
- ☐ Blood test
- ☐ Urine sample
- ☐ Stool sample
- ☐ Ultra sound scan
- ☐ Other (please state)____________________

Please name the self help (Network, Association) you belong to ____________________

What benefit do you get out of belonging it? ____________________

____

____

Do you meet up with any other sufferers of IBS on a regular basis? Yes / No

If yes, how often do you meet, and how many people regularly attend? ____________

____

Section 2: Solving Problems

Please circle the response that best describes you

	Not at all True	Barely True	Moderately True	Exactly True
I can always manage to solve difficult problems if I try hard enough	1	2	3	4
If someone opposes me, I can find means and ways to get what I want	1	2	3	4
It is easy for me to stick to my aims and accomplish my goals	1	2	3	4
I am confident that I could deal efficiently with unexpected events	1	2	3	4
Thanks to my resourcefulness, I know how to handle unforeseen situations	1	2	3	4
I can solve most problems if I invest the necessary effort	1	2	3	4
I can remain calm when facing difficulties because I can rely on my coping abilities	1	2	3	4
When I am confronted with a problem, I can usually find several solutions	1	2	3	4
If I am in a bind, I can usually think of something to do	1	2	3	4
No matter what comes my way, I'm usually able to handle it	1	2	3	4

Section 3: Emotional Feelings

Please read each of the 21 statements
and for each one circle the response that best describes you.

When I feel angry (very annoyed)........	Almost Never	Sometimes	Often	Almost Always
I keep quiet	1	2	3	4
I refuse to argue or say anything	1	2	3	4
I bottle it up	1	2	3	4
I say what I feel	1	2	3	4
I avoid making a scene	1	2	3	4
I smother (cover up) my feelings	1	2	3	4
I hide my annoyance	1	2	3	4

When I feel unhappy (miserable)........	Almost Never	Sometimes	Often	Almost Always
I refuse to do anything about it	1	2	3	4
I hide my unhappiness	1	2	3	4
I put on a bold face	1	2	3	4
I keep quiet	1	2	3	4
I let others see how I feel	1	2	3	4
I smother (cover up) my feelings	1	2	3	4
I bottle it up	1	2	3	4

When I feel afraid (worried).......	Almost Never	Sometimes	Often	Almost Always
I let others see how I feel	1	2	3	4
I keep quiet	1	2	3	4
I refuse to say anything about it	1	2	3	4
I tell others about it	1	2	3	4
I say what I feel	1	2	3	4
I bottle it up	1	2	3	4
I smother (cover up) my feelings	1	2	3	4

© Claire Rutter

Section 4: Your Outlook in General

The following table has a list of statements that may or may not be true for you. There are no "correct" or "incorrect" answers. Answer according to your **own** feelings, rather than how you think "most people" would answer. Please circle the number in the appropriate column.

	Strongly Disagree 0	Disagree 1	Neutral 2	Agree 3	Strongly Agree 4
1. In uncertain times, I usually expect the best.	0	1	2	3	4
2. It's easy for me to relax	0	1	2	3	4
3. If something can go wrong for me, it will	0	1	2	3	4
4. I'm always optimistic about my future	0	1	2	3	4
5. I enjoy my friends a lot	0	1	2	3	4
6. It's important for me to keep busy	0	1	2	3	4
7. I hardly ever expect things to go my way	0	1	2	3	4
8. I don't get upset too easily	0	1	2	3	4
9. I rarely count on good things happening to me	0	1	2	3	4
10. Overall, I expect more good things to happen to me than bad	0	1	2	3	4

© Claire Rutter

Section 5: How you Rate your Feelings and Emotions

This scale consists of a number of words that describe different feelings and emotions. Read each item and then circle the best answer.

Please indicate to what extent you have felt this way during the past few weeks.

	1 Very Slightly	2 A Little	3 Moderately	4 Quite a Bit	5 Extremely
Interested	1	2	3	4	5
Distressed	1	2	3	4	5
Excited	1	2	3	4	5
Upset	1	2	3	4	5
Strong	1	2	3	4	5
Guilty	1	2	3	4	5
Scared	1	2	3	4	5
Hostile	1	2	3	4	5
Enthusiastic	1	2	3	4	5
Proud	1	2	3	4	5
Irritable	1	2	3	4	5
Alert	1	2	3	4	5
Ashamed	1	2	3	4	5
Inspired	1	2	3	4	5
Nervous	1	2	3	4	5
Determined	1	2	3	4	5
Attentive	1	2	3	4	5
Jittery	1	2	3	4	5
Active	1	2	3	4	5
Afraid	1	2	3	4	5

7

Section 6: Your Symptoms

Below is a list of Irritable Bowel symptoms that you may, or may not have been suffering from. Please rate each one for your experience of the symptom by placing a tick in the appropriate box.

	I have never experienced this symptom	Less than 3 or 4 times per year	Every month or so	Every week or so	More than once every week
Abdominal Pain	0	1	2	3	4
Diarrhoea	0	1	2	3	4
Bloating	0	1	2	3	4
Wind	0	1	2	3	4
Constipation	0	1	2	3	4
Blood in stools	0	1	2	3	4
Incomplete evacuation of the bowel	0	1	2	3	4
Passage of mucus	0	1	2	3	4
Incontinence	0	1	2	3	4
Rumbling and grumbling	0	1	2	3	4

Below is a list of common symptoms or bodily sensations. Most people have experienced most of them at one time or another. I am interested in finding out how prevalent each symptom is. Using the scale below, write beside each symptom the letter, which indicates how frequently you experience that symptom.

A	B	C	D	E
Have never or almost never experienced the symptom	Less than 3 or 4 times per year	Every month or so	Every week or so	More than once every week

	Symptoms	Your Response
1	Eyes water	
2	Itching or painful eyes	
3	Ringing in ears	
4	Temporary deafness or hard of hearing	
5	Lump in throat	
6	Choking sensation	
7	Sneezing spells	
8	Running nose	
9	Congested nose	
10	Bleeding nose	
11	Asthma or wheezing	
12	Coughing	

A Have never or almost never experienced the symptom	B Less than 3 or 4 times per year	C Every month or so	D Every week or so	E More than once every week

	Symptoms	Your Response
13	Out of breath	
14	Swollen ankles	
15	Chest pains	
16	Racing heart	
17	Cold hands or feet even in hot weather	
18	Leg cramps	
19	Insomnia	
20	Toothaches	
21	Upset stomach	
22	Indigestion	
23	Heartburn	
24	Severe pains or cramps in stomach	
25	Diarrhoea	
26	Constipation	
27	Haemorrhoids	
28	Swollen joints	
29	Stiff muscles	
30	Back pains	
31	Sensitive or tender skin	
32	Face flushes	
33	Severe itching	
34	Skin breaks out in a rash	
35	Acne or pimples on face	
36	Acne or pimples other than on face	
37	Boils	
38	Sweat even in cold weather	
39	Strong reactions to insect bites	
40	Headaches	
41	Sensation of pressure in head	
42	Hot flushes	
43	Chills	
44	Dizziness	
45	Feel faint	
46	Numbness or tingling in any part of body	
47	Twitching of eyelid	
48	Twitching other than eyelid	
49	Hands tremble or shake	
50	Stiff joints	
51	Sore muscles	
52	Sore throat	
53	Sunburn	
54	Nausea	

Section 7: Your Views about Your Irritable Bowel Syndrome (IBS)

I am interested in your own personal views of how you see your IBS. Please indicate how much you agree or disagree with the following statements about your IBS

	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
A germ or virus caused my IBS	1	2	3	4	5
My IBS was caused by poor medical care in the past	1	2	3	4	5
There is little that can be done to improve my IBS	1	2	3	4	5
My IBS is hereditary – it runs in my family	1	2	3	4	5
My IBS will last a short time	1	2	3	4	5
What I do can determine whether my IBS gets better or worse	1	2	3	4	5
My IBS has strongly affected the way I see myself as a person	1	2	3	4	5
Stress was a major factor in causing my IBS	1	2	3	4	5
My IBS is a serious condition	1	2	3	4	5
Pollution in the environment caused my IBS	1	2	3	4	5
It was just by chance that I developed IBS	1	2	3	4	5
My IBS has become easier to live with	1	2	3	4	5
My IBS has serious economic and financial consequences	1	2	3	4	5
My IBS has strongly affected the way others see me	1	2	3	4	5
My state of mind played a major part in causing my IBS	1	2	3	4	5
My treatments will be effective in curing my IBS	1	2	3	4	5
Diet played a major role in causing my IBS	1	2	3	4	5
My IBS is likely to be permanent rather than temporary	1	2	3	4	5
My IBS will improve in time	1	2	3	4	5
Recovery from my IBS is largely dependent on chance or fate	1	2	3	4	5
My IBS has had major consequences on my life	1	2	3	4	5
Other people played a large role in causing my IBS	1	2	3	4	5
There is a lot I can do to control my symptoms	1	2	3	4	5
My IBS will last for a long time	1	2	3	4	5
My IBS is largely due to my own behaviour	1	2	3	4	5
My IBS has not had much effect on my life	1	2	3	4	5

Section 8: Your Illness Knowledge

This page is concerned with what you know about your illness, and where this information came from. Do not worry about whether your answers are right or wrong. It is how you think about them that are important. Please try to answer as fully as possible.

In your own words tell me about the illness you have been diagnosed with, focusing specifically upon:

(i) Why do you think you suffer from this illness? ____________________

____

(ii) How serious is it? ____________________

____

(iii) What can you do to help alleviate your symptoms? ____________________

____

(iv) When some people are diagnosed with an illness like IBS, they actively seek out information about it. Please indicate (by circling) if you have gained information about your illness from the following sources:

Doctor	Yes / No	Television	Yes / No
Magazines	Yes / No	Radio	Yes / No
Self Help Book	Yes / No	Internet	Yes / No
Medical Journal	Yes / No	Friends/Family	Yes / No
Self Help Group	Yes / No		

Other (please state) ____________________

____

(v) Are you satisfied that your doctor explained your diagnosis to you as fully as possible?

1	2	3	4	5
Very Satisfied	Satisfied	Neither Satisfied nor Dissatisfied	Dissatisfied	Very Dissatisfied

(vi) After answering the above how confident are you that you know enough about your illness?

1	2	3	4	5
Very Confident	Confident	Neither Confident nor Unconfident	Unconfident	Very Unconfident

© Claire Rutter

Section 9: Your Attitudes Towards Doctors and Medicine

Please circle the appropriate number for each statement to show how strongly you agree or disagree with it. There are no right or wrong answers. I am interested just in your opinion.

		Strongly Disagree	Disagree	Tend to Disagree	Tend to Agree	Agree	Strongly Agree
1	All doctors are good doctors	1	2	3	4	5	6
2	Medicine is based on scientific principles	1	2	3	4	5	6
3	I only consult a doctor if I am at death's door	1	2	3	4	5	6
4	Medicines can do as much harm as good	1	2	3	4	5	6
5	I have absolute faith and confidence in all hospital doctors	1	2	3	4	5	6
6	The improved health of the nation is due to effective medicine	1	2	3	4	5	6
7	Doctors blame their patients if their treatment doesn't work	1	2	3	4	5	6
8	The advice of doctors is mainly common sense	1	2	3	4	5	6
9	No matter how long you have to wait and see a doctor, it's worth it	1	2	3	4	5	6
10	Medicine has cures for most diseases	1	2	3	4	5	6
11	Doctors are important in keeping us healthy	1	2	3	4	5	6
12	No two doctors will agree on what is wrong with a person	1	2	3	4	5	6
13	Many medicines are just placebos or sugar pills	1	2	3	4	5	6
14	Doctors are too ready to solve patients' problems by prescribing tranquillisers	1	2	3	4	5	6
15	Often the only purpose of tests is to make the doctor feel less anxious	1	2	3	4	5	6
16	Doctors know what's best for you	1	2	3	4	5	6
17	I don't like medical people	1	2	3	4	5	6
18	Most tests and investigations are done routinely rather than for a particular purpose	1	2	3	4	5	6
19	Medicine is the best profession a person can have	1	2	3	4	5	6

© Claire Rutter

Section 10: How You have been Feeling in the past TWO WEEKS

Please tick the response that best describes the way you have been feeling in the past two weeks

1. **I feel tense or "wound up":**
   - ☐ *Most of the time*
   - ☐ *A lot of the time*
   - ☐ *From time to time. occasionally*
   - ☐ *Not at all*

2. **I still enjoy the things I used to enjoy:**
   - ☐ *Definitely as much*
   - ☐ *Not quite so much*
   - ☐ *Only a little*
   - ☐ *Hardly at all*

3. **I get a sort of frightened feeling as if something awful is about to happen:**
   - ☐ *Very definitely and quite badly*
   - ☐ *Yes, but not too badly*
   - ☐ *A little, but it doesn t worry me*
   - ☐ *Not at all*

4. **I can laugh and see the funny side of things:**
   - ☐ *As much as I always could*
   - ☐ *Not quite so much now*
   - ☐ *Definitely not so much now*
   - ☐ *Not at all*

5. **Worrying thoughts go through my mind:**
   - ☐ *A great deal of the time*
   - ☐ *A lot of the time*
   - ☐ *From time to time. but not too often*
   - ☐ *Only occasionally*

6. **I feel cheerful:**
   - ☐ *Not at all*
   - ☐ *Not often*
   - ☐ *Sometimes*
   - ☐ *Most of the time*

7. **I can sit at ease and feel relaxed:**
   - ☐ *Definitely*
   - ☐ *Usually*
   - ☐ *Not often*
   - ☐ *Not at all*

8. I feel as if I am slowed down:

☐ *Nearly all of the time*
☐ *Very often*
☐ *Sometimes*
☐ *Not at all*

9. I get a sort of frightened feeling like "butterflies" in the stomach:

☐ *Not at all*
☐ *Occasionally*
☐ *Quite often*
☐ *Very often*

10. I have lost interest in my appearance:

☐ *Definitely*
☐ *I don't take as much care as I should*
☐ *I may not take as much care*
☐ *I take just as much care as ever*

11. I feel restless as if I have to be on the move:

☐ *Very much indeed*
☐ *Quite a lot*
☐ *Not very much*
☐ *Not at all*

12. I look forward with enjoyment to things:

☐ *As much as I ever did*
☐ *Rather less than I used to*
☐ *Definitely less than I used to*
☐ *Hardly at all*

13. I get sudden feelings of panic:

☐ *Very often indeed*
☐ *Quite often*
☐ *Not very often*
☐ *Not at all*

14. I can enjoy a good book or radio or TV programme

☐ *Often*
☐ *Sometimes*
☐ *Not often*
☐ *Very seldom*

Section 11: How You deal with Unpleasant Situations

In this section I want to know how you think you might react in some unpleasant situations. Tick as many statements as you want, that apply to you.

1. Vividly imagine that you are **afraid** of the dentist and have to get some dental work done. Which of the following would you do? Place a tick against **all** of the statements that apply to you.

_____ I would ask the dentist exactly what he was going to do

_____ I would take a tranquilliser or have a drink before going

_____ I would try to think about pleasant memories

_____ I would want the dentist to tell me when I would feel pain

_____ I would try to sleep

_____ I would watch all the dentists movements and listen for the sound of the drill

_____ I would watch the flow of water from my mouth to see if it contained blood

_____ I would do mental puzzles in my mind

2. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Tick **all** the statements that might apply to you.

_____ I would sit by myself and have as many daydreams and fantasies as I could

_____ I would stay alert and try to keep myself from falling asleep

_____ I would exchange life stories with the other hostages

_____ If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing

_____ I would watch every movement of my captors and keep an eye on their weapons

_____ I would try to sleep as much as possible

_____ I would think about how nice it's going to be when I get home

_____ I would make sure I knew where every possible exit was

© Claire Rutter

3. Vividly imagine that, due to a large drop in sales, it is rumoured that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about layoffs has been made and will be announced in several days. Tick **all** the statements that might apply to you.

_____ I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said

_____ I would review the list of duties for my present job and try to figure out if I had fulfilled them all

_____ I would go to the cinema to take my mind off things

_____ I would try to remember my arguments or disagreements I might have had with the supervisor that would have lowered his/her opinion of me.

_____ I would push all thoughts of being laid off out of my mind

_____ I would tell my partner that I'd rather not discuss my chances of being laid off

_____ I would try to think which employees in my department the supervisor might have thought had done the worst job

_____ I would continue doing my work as if nothing was happening

4. Vividly imagine that you are on an aeroplane, thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced all is well. Tick **all** of the statements that might apply to you.

_____ I would carefully read the information provided about the safety features in the plane and make sure I knew where the emergency exits were

_____ I would make small talk with the passenger beside me

_____ I would watch the end of the movie, even if I had seen it before

_____ I would call for the flight attendant and ask her exactly what the problem was

_____ I would order a drink or tranquilliser from the flight attendant

_____ I would listen carefully to the engines for unusual noises and would watch the crew to see if their behaviour was out of the ordinary

_____ I would talk to the passenger beside me about what might be wrong

_____ I would settle down and read a book or magazine or read a letter

Section 12: Coping with your IBS

This next section focuses upon the way you cope with your symptoms. Think about the times when your symptoms have been at their worst, and how you reacted to them. Now indicate the extent to which you did whatever each of the following statements says, using the key below.

1 = I usually don't do this at all. **2 = I usually do this a little bit.**

3 = I usually do this a medium amount. **4 = I usually do this a lot.**

1	I try to grow as a person as a result of the experience	
2	I turn to work or other substitute activities to take my mind off things	
3	I get upset and let my emotions out	
4	I try to get advice from someone about what to do	
5	I concentrate my efforts on doing something about it	
6	I say to myself "this isn't real"	
7	I put my trust in God	
8	I laugh about the situation	
9	I admit to myself that I can't deal with it, and give up trying	
10	I restrain myself from doing anything too quickly	
11	I discuss my feelings with someone	
12	I use alcohol or drugs to make myself feel better	
13	I get used to my symptoms	
14	I talk to someone to find out more about my symptoms	
15	I keep myself from getting distracted by other thoughts and activities	
16	I daydream about things	
17	I get upset and am really aware of it	
18	I seek God's help	
19	I make a plan of action	
20	I make jokes about it	
21	I accept my illness and that it can't be changed	
22	I hold off doing anything until the situation permits	

1 = I usually don't do this at all.
2 = I usually do this a little bit.
3 = I usually do this a medium amount.
4 = I usually do this a lot.

23	I try to get emotional support from friends and relatives	
24	I just give up trying to reach my goal	
25	I take additional action to try and get rid of the symptoms	
26	I try to lose myself for a while by drinking alcohol or taking drugs	
27	I refuse to believe it has happened	
28	I let my feelings out	
29	I try to see it in a different light, to make it seem more positive	
30	I talk to someone who can help	
31	I sleep more than usual	
32	I try to come up with a strategy about what to do	
33	I focus on dealing with this problem and, if necessary , let other things slide a little	
34	I get sympathy and understanding from someone	
35	I drink alcohol or take drugs, in order to think about it less	
36	I kid around about it	
37	I give up the attempt to get what I want	
38	I look for something good in what is happening	
39	I think about how I might best handle the problem	
40	I pretend that it hasn't really happened	
41	I make sure not to make matters worse by acting too soon	
42	I try hard to prevent other things from interfering with my efforts at dealing with this	
43	I go to the cinema or watch television to think about it less	
44	I accept the reality of the fact that I have this illness	
45	I ask people who have had similar experiences what they did	
46	I feel a lot of emotional distress and I find myself expressing those feelings a lot	
47	I take direct action to get around the illness	

© Claire Rutter

1 = I usually don't do this at all. 2 = I usually do this a little bit.
3 = I usually do this a medium amount. 4 = I usually do this a lot.

48	I try to find comfort in my religion	
49	I force myself to wait for the right time to do something	
50	I make fun of the situation	
51	I reduce the amount of effort I'm putting into solving the problem of illness	
52	I talk to someone about how I feel	
53	I use alcohol or drugs to help me get through it	
54	I learn to live with it	
55	I put aside other activities in order to concentrate on this	
56	I think hard about what steps to take	
57	I act as though I don't have an illness	
58	I do what has to be done, one step at a time	
59	I learn something from the experience of illness	
60	I pray more than usual	

Section 13: How You see your Quality of Life with Illness

The last questionnaire I would like you to complete concerns how you feel about your quality of life, health and other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the ONE** that appears most appropriate. This can often be your first response.
Please keep in mind your standards, hopes, pleasures and concerns. I ask that you think about your life **in the LAST TWO WEEKS**. Circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither Poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things **in THE LAST TWO WEEKS.**

		Not at all	A little	A moderate amount	Very much	An extreme amount
3	How much do you feel that pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
6	To what extent do you feel life to be meaningful?	1	2	3	4	5
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experienced or were able to do certain things **in the LAST TWO WEEKS.**

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	To what extent do you have enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

The following questions ask you to say **how good or satisfied** you have felt about various aspects of your life **over the LAST TWO WEEKS.**

		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things **in the LAST TWO WEEKS.**

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

		Not at all	Not much	A moderate amount	Very much	An extreme amount
27	How fed up do you feel?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
28	How satisfied are you with your level of happiness?	1	2	3	4	5

Section 14: Anything Else

Now please tell me anything else you feel is relevant here. Have any treatments or medications worked for you? Have any treatments made you feel worse?

Please use the rest of this sheet to finish questions, or attach additional sheets if necessary.

How long did this questionnaire take to complete? ___________ Today's date ___/____/___

Thank you very much for completing this booklet.

Now simply put this booklet into the pre-paid envelope and post it back to me.

Thank you once again for helping in my research.
Best wishes
Claire Rutter

© Claire Rutter
IBS/SHG

1

KENT
UNIVERSITY OF KENT
AT CANTERBURY ■■■■

Living with Inflammatory Bowel Disease Questionnaire Booklet

Miss Claire Rutter
Research Student
Centre for Research in Health Behaviour
Department of Psychology
University of Kent at Canterbury
Canterbury
Kent CT2 7NP

☎ (01227) 827147

This booklet contains several questionnaires from the health and illness field. Most require you to circle or tick your preferred choice (i.e. the one that best describes the way you feel). **There are no right or wrong answers.** Although you may choose not to answer some questions, all answers will be treated in the **strictest confidence**. No one other than myself will see your completed questionnaires.
There is a space at the back for you to add anything else you feel is relevant. Please write freely. Also there are a few sections which ask you to write in your own words, if you run out of space please use the sheet at the back to continue.
Try not to spend too long thinking about specific questions. Your initial choice for **each question should take only a few seconds**. It is hoped that the whole booklet should take no longer than 50 minutes to complete.

Thank you for taking the time to complete this for me.

Best wishes

Miss Claire Rutter

Please Note: All questionnaires are confidential. No one will see your responses apart from the researcher named above.

© Claire Rutter
IBD/SHG

Section 1: Information About You

This section asks you for information regarding your personal situation. Please try and answer all questions. Answers are for statistical purposes only.

Male / Female (please circle) Date of birth _____/_____/_____

Marital status (please circle)

Single Married Divorced Separated Widowed Co-habiting

No. of children (with ages)____

Please state highest academic qualification achieved ______________________

Occupation ______________________ If no occupation, is this due to your symptoms? Yes / No

Part time / Full time (please circle) If part time, is this due to your symptoms? Yes / No

Please estimate how many days sick you have taken in the past year __________

I first experienced my bowel and related symptoms ____________(As near to the date as possible)

I was diagnosed with Crohn's Disease / Ulcerative Colitis __________(As near to the date as possible)

I have been to the GP about my irritable bowel and related symptoms (approximately) __________ times, and saw (please circle)

same GP / two GP's / 3 or more GP's

Before I was diagnosed with IBD I had the following tests / examinations; (please tick)

- ☐ Barium meal
- ☐ Barium enema
- ☐ Colonoscopy
- ☐ Rectal examination
- ☐ Blood test
- ☐ Urine sample
- ☐ Stool sample
- ☐ Endoscopy
- ☐ Ultra sound scan
- ☐ Other (please state)____

Please name the self help (Association, Group) you belong to ____________________

What benefit do you get out of belonging to it? ____________________________

____

____

Do you meet up with any other sufferers of IBD on a regular basis? Yes / No
If yes, how often do you meet, and how many people regularly attend? ______________

____

Section 2: Solving Problems

Please circle the response that best describes you

	Not at all True	Barely True	Moderately True	Exactly True
I can always manage to solve difficult problems if I try hard enough	1	2	3	4
If someone opposes me, I can find means and ways to get what I want	1	2	3	4
It is easy for me to stick to my aims and accomplish my goals	1	2	3	4
I am confident that I could deal efficiently with unexpected events	1	2	3	4
Thanks to my resourcefulness, I know how to handle unforeseen situations	1	2	3	4
I can solve most problems if I invest the necessary effort	1	2	3	4
I can remain calm when facing difficulties because I can rely on my coping abilities	1	2	3	4
When I am confronted with a problem, I can usually find several solutions	1	2	3	4
If I am in a bind, I can usually think of something to do	1	2	3	4
No matter what comes my way, I'm usually able to handle it	1	2	3	4

Section 3: Emotional Feelings

Please read each of the 21 statements
and for each one circle the response that best describes you.

When I feel angry (very annoyed)…….	Almost Never	Sometimes	Often	Almost Always
I keep quiet	1	2	3	4
I refuse to argue or say anything	1	2	3	4
I bottle it up	1	2	3	4
I say what I feel	1	2	3	4
I avoid making a scene	1	2	3	4
I smother (cover up) my feelings	1	2	3	4
I hide my annoyance	1	2	3	4

When I feel unhappy (miserable)…….	Almost Never	Sometimes	Often	Almost Always
I refuse to do anything about it	1	2	3	4
I hide my unhappiness	1	2	3	4
I put on a bold face	1	2	3	4
I keep quiet	1	2	3	4
I let others see how I feel	1	2	3	4
I smother (cover up) my feelings	1	2	3	4
I bottle it up	1	2	3	4

When I feel afraid (worried)…….	Almost Never	Sometimes	Often	Almost Always
I let others see how I feel	1	2	3	4
I keep quiet	1	2	3	4
I refuse to say anything about it	1	2	3	4
I tell others about it	1	2	3	4
I say what I feel	1	2	3	4
I bottle it up	1	2	3	4
I smother (cover up) my feelings	1	2	3	4

Section 4: Your Outlook in General

The following table has a list of statements that may or may not be true for you. There are no "correct" or "incorrect" answers. Answer according to your **own** feelings, rather than how you think "most people" would answer. Please circle the number in the appropriate column.

	Strongly Disagree 0	**Disagree 1**	**Neutral 2**	**Agree 3**	**Strongly Agree 4**
1. In uncertain times, I usually expect the best.	0	1	2	3	4
2. It's easy for me to relax	0	1	2	3	4
3. If something can go wrong for me, it will	0	1	2	3	4
4. I'm always optimistic about my future	0	1	2	3	4
5. I enjoy my friends a lot	0	1	2	3	4
6. It's important for me to keep busy	0	1	2	3	4
7. I hardly ever expect things to go my way	0	1	2	3	4
8. I don't get upset too easily	0	1	2	3	4
9. I rarely count on good things happening to me	0	1	2	3	4
10. Overall, I expect more good things to happen to me than bad	0	1	2	3	4

Section 5: How you rate your Feelings and Emotions

This scale consists of a number of words that describe different feelings and emotions. Read each item and then circle the best answer.

Please indicate to what extent you have felt this way during the past few weeks.

	1 Very Slightly	2 A Little	3 Moderately	4 Quite a Bit	5 Extremely
Interested	1	2	3	4	5
Distressed	1	2	3	4	5
Excited	1	2	3	4	5
Upset	1	2	3	4	5
Strong	1	2	3	4	5
Guilty	1	2	3	4	5
Scared	1	2	3	4	5
Hostile	1	2	3	4	5
Enthusiastic	1	2	3	4	5
Proud	1	2	3	4	5
Irritable	1	2	3	4	5
Alert	1	2	3	4	5
Ashamed	1	2	3	4	5
Inspired	1	2	3	4	5
Nervous	1	2	3	4	5
Determined	1	2	3	4	5
Attentive	1	2	3	4	5
Jittery	1	2	3	4	5
Active	1	2	3	4	5
Afraid	1	2	3	4	5

Section 6: Your Symptoms

Below is a list of Inflammatory Bowel symptoms that you may, or may not have been suffering from. Please rate each one for your experience of the symptom by placing a tick in the appropriate box.

	I have never experienced this symptom	**Less than 3 or 4 times per year**	**Every month or so**	**Every week or so**	**More than once every week**
Abdominal Pain	0	1	2	3	4
Diarrhoea	0	1	2	3	4
Bloating	0	1	2	3	4
Wind	0	1	2	3	4
Constipation	0	1	2	3	4
Blood in stools	0	1	2	3	4
Incomplete evacuation of the bowel	0	1	2	3	4
Passage of mucus	0	1	2	3	4
Incontinence	0	1	2	3	4
Rumbling and grumbling	0	1	2	3	4

Below is a list of common symptoms or bodily sensations. Most people have experienced most of them at one time or another. I am interested in finding out how prevalent each symptom is. Using the scale below, write beside each symptom the letter, which indicates how frequently you experience that symptom.

A	**B**	**C**	**D**	**E**
Have never or almost never experienced the symptom	**Less than 3 or 4 times per year**	**Every month or so**	**Every week or so**	**More than once every week**

	Symptoms	Your Response
1	Eyes water	
2	Itching or painful eyes	
3	Ringing in ears	
4	Temporary deafness or hard of hearing	
5	Lump in throat	
6	Choking sensation	
7	Sneezing spells	
8	Running nose	
9	Congested nose	
10	Bleeding nose	
11	Asthma or wheezing	
12	Coughing	

A Have never or almost never experienced the symptom	B Less than 3 or 4 times per year	C Every month or so	D Every week or so	E More than once every week

	Symptoms	Your Response
13	Out of breath	
14	Swollen ankles	
15	Chest pains	
16	Racing heart	
17	Cold hands or feet even in hot weather	
18	Leg cramps	
19	Insomnia	
20	Toothaches	
21	Upset stomach	
22	Indigestion	
23	Heartburn	
24	Severe pains or cramps in stomach	
25	Diarrhoea	
26	Constipation	
27	Haemorrhoids	
28	Swollen joints	
29	Stiff muscles	
30	Back pains	
31	Sensitive or tender skin	
32	Face flushes	
33	Severe itching	
34	Skin breaks out in a rash	
35	Acne or pimples on face	
36	Acne or pimples other than on face	
37	Boils	
38	Sweat even in cold weather	
39	Strong reactions to insect bites	
40	Headaches	
41	Sensation of pressure in head	
42	Hot flushes	
43	Chills	
44	Dizziness	
45	Feel faint	
46	Numbness or tingling in any part of body	
47	Twitching of eyelid	
48	Twitching other than eyelid	
49	Hands tremble or shake	
50	Stiff joints	
51	Sore muscles	
52	Sore throat	
53	Sunburn	
54	Nausea	

© Claire Rutter

Section 7: Your Views about Your Inflammatory Bowel Disease (IBD)

I am interested in your own personal views of how you see your IBD. Please indicate how much you agree or disagree with the following statements about your IBD

	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
A germ or virus caused my IBD	1	2	3	4	5
My IBD was caused by poor medical care in the past	1	2	3	4	5
There is little that can be done to improve my IBD	1	2	3	4	5
My IBD is hereditary – it runs in my family	1	2	3	4	5
My IBD will last a short time	1	2	3	4	5
What I do can determine whether my IBD gets better or worse	1	2	3	4	5
My IBD has strongly affected the way I see myself as a person	1	2	3	4	5
Stress was a major factor in causing my IBD	1	2	3	4	5
My IBD is a serious condition	1	2	3	4	5
Pollution in the environment caused my IBD	1	2	3	4	5
It was just by chance that I developed IBD	1	2	3	4	5
My IBD has become easier to live with	1	2	3	4	5
My IBD has serious economic and financial consequences	1	2	3	4	5
My IBD has strongly affected the way others see me	1	2	3	4	5
My state of mind played a major part in causing my IBD	1	2	3	4	5
My treatments will be effective in curing my IBD	1	2	3	4	5
Diet played a major role in causing my IBD	1	2	3	4	5
My IBD is likely to be permanent rather than temporary	1	2	3	4	5
My IBD will improve in time	1	2	3	4	5
Recovery from my IBD is largely dependent on chance or fate	1	2	3	4	5
My IBD has had major consequences on my life	1	2	3	4	5
Other people played a large role in causing my IBD	1	2	3	4	5
There is a lot I can do to control my symptoms	1	2	3	4	5
My IBD will last for a long time	1	2	3	4	5
My IBD is largely due to my own behaviour	1	2	3	4	5
My IBD has not had much effect on my life	1	2	3	4	5

11

Section 8: Your Illness Knowledge

This page is concerned with what you know about your illness, and where this information came from. Do not worry about whether your answers are right or wrong. It is how you think about them that is important. Please try to answer as fully as possible.

In your own words tell me about the illness you have been diagnosed with, focusing specifically upon:

(i) Why do you think you suffer from this illness? ____________________

____

(ii) How serious is it? ____________________

____

(iii) What can you do to help alleviate your symptoms? ____________________

____

(iv) When some people are diagnosed with an illness like IBD, they actively seek out information about it. Please indicate (by circling) if you have gained information about your illness from the following sources;

Doctor	Yes / No	Television	Yes / No
Magazines	Yes / No	Radio	Yes / No
Self Help Book	Yes / No	Internet	Yes / No
Medical Journal	Yes / No	Friends/Family	Yes / No
Self Help Group	Yes / No		

Other (please state) ____________________

____

(v) Are you satisfied that your doctor explained your diagnosis to you as fully as possible?

1	2	3	4	5
Very Satisfied	Satisfied	Neither Satisfied nor Dissatisfied	Dissatisfied	Very Dissatisfied

(vi) After answering the above how confident are you that you know enough about your illness?

1	2	3	4	5
Very Confident	Confident	Neither Confident nor Unconfident	Unconfident	Very Unconfident

Section 9: Your Attitudes Towards Doctors and Medicine

Please circle the appropriate number for each statement to show how strongly you agree or disagree with it. There are no right or wrong answers, I am interested just in your opinion

		Strongly Disagree	Disagree	Tend to Disagree	Tend to Agree	Agree	Strongly Agree
1	All doctors are good doctors	1	2	3	4	5	6
2	Medicine is based on scientific principles	1	2	3	4	5	6
3	I only consult a doctor if I am at death's door	1	2	3	4	5	6
4	Medicines can do as much harm as good	1	2	3	4	5	6
5	I have absolute faith and confidence in all hospital doctors	1	2	3	4	5	6
6	The improved health of the nation is due to effective medicine	1	2	3	4	5	6
7	Doctors blame their patients if their treatment doesn't work	1	2	3	4	5	6
8	The advice of doctors is mainly common sense	1	2	3	4	5	6
9	No matter how long you have to wait and see a doctor, it's worth it	1	2	3	4	5	6
10	Medicine has cures for most diseases	1	2	3	4	5	6
11	Doctors are important in keeping us healthy	1	2	3	4	5	6
12	No two doctors will agree on what is wrong with a person	1	2	3	4	5	6
13	Many medicines are just placebos or sugar pills	1	2	3	4	5	6
14	Doctors are too ready to solve patients problems by prescribing tranquillisers	1	2	3	4	5	6
15	Often the only purpose of tests is to make the doctor feel less anxious	1	2	3	4	5	6
16	Doctors know what's best for you	1	2	3	4	5	6
17	I don't like medical people	1	2	3	4	5	6
18	Most tests and investigations are done routinely rather than for a particular purpose	1	2	3	4	5	6
19	Medicine is the best profession a person can have	1	2	3	4	5	6

Section 10: How You have been feeling in the past TWO WEEKS.

Please tick the response that best describes the way you have been feeling in the past two weeks

1. **I feel tense or "wound up":**
   - ☐ *Most of the time*
   - ☐ *A lot of the time*
   - ☐ *From time to time, occasionally*
   - ☐ *Not at all*

2. **I still enjoy the things I used to enjoy:**
   - ☐ *Definitely as much*
   - ☐ *Not quite so much*
   - ☐ *Only a little*
   - ☐ *Hardly at all*

3. **I get a sort of frightened feeling as if something awful is about to happen:**
   - ☐ *Very definitely and quite badly*
   - ☐ *Yes, but not too badly*
   - ☐ *A little, but it doesn't worry me*
   - ☐ *Not at all*

4. **I can laugh and see the funny side of things:**
   - ☐ *As much as I always could*
   - ☐ *Not quite so much now*
   - ☐ *Definitely not so much now*
   - ☐ *Not at all*

5. **Worrying thoughts go through my mind:**
   - ☐ *A great deal of the time*
   - ☐ *A lot of the time*
   - ☐ *From time to time, but not too often*
   - ☐ *Only occasionally*

6. **I feel cheerful:**
   - ☐ *Not at all*
   - ☐ *Not often*
   - ☐ *Sometimes*
   - ☐ *Most of the time*

7. **I can sit at ease and feel relaxed:**
   - ☐ *Definitely*
   - ☐ *Usually*
   - ☐ *Not often*
   - ☐ *Not at all*

© Claire Rutter

8. I feel as if I am slowed down:

☐ *Nearly all of the time*
☐ *Very often*
☐ *Sometimes*
☐ *Not at all*

9. I get a sort of frightened feeling like "butterflies" in the stomach:

☐ *Not at all*
☐ *Occasionally*
☐ *Quite often*
☐ *Very often*

10. I have lost interest in my appearance:

☐ *Definitely*
☐ *I don't take as much care as I should*
☐ *I may not take as much care*
☐ *I take just as much care as ever*

11. I feel restless as if I have to be on the move:

☐ *Very much indeed*
☐ *Quite a lot*
☐ *Not very much*
☐ *Not at all*

12. I look forward with enjoyment to things:

☐ *As much as I ever did*
☐ *Rather less than I used to*
☐ *Definitely less than I used to*
☐ *Hardly at all*

13. I get sudden feelings of panic:

☐ *Very often indeed*
☐ *Quite often*
☐ *Not very often*
☐ *Not at all*

14. I can enjoy a good book or radio or TV programme:

☐ *Often*
☐ *Sometimes*
☐ *Not often*
☐ *Very seldom*

Section 11: How You deal with Unpleasant Situations

In this section I want to know how you think you might react in some unpleasant situations. Tick as many statements as you want, that apply to you.

1. Vividly imagine that you are **afraid** of the dentist and have to get some dental work done. Which of the following would you do? Place a tick against **all** of the statements that apply to you.

_____ I would ask the dentist exactly what he was going to do

_____ I would take a tranquilliser or have a drink before going

_____ I would try to think about pleasant memories

_____ I would want the dentist to tell me when I would feel pain

_____ I would try to sleep

_____ I would watch all the dentists movements and listen for the sound of the drill

_____ I would watch the flow of water from my mouth to see if it contained blood

_____ I would do mental puzzles in my mind

2. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Tick **all** the statements that might apply to you.

_____ I would sit by myself and have as many daydreams and fantasies as I could

_____ I would stay alert and try to keep myself from falling asleep

_____ I would exchange life stories with the other hostages

_____ If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing

_____ I would watch every movement of my captors and keep an eye on their weapons

_____ I would try to sleep as much as possible

_____ I would think about how nice it's going to be when I get home

_____ I would make sure I knew where every possible exit was

3. Vividly imagine that, due to a large drop in sales, it is rumoured that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about layoffs has been made and will be announced in several days. Tick **all** the statements that might apply to you.

_____ I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said

_____ I would review the list of duties for my present job and try to figure out if I had fulfilled them all

_____ I would go to the cinema to take my mind off things

_____ I would try to remember my arguments or disagreements I might have had with the supervisor that would have lowered his/her opinion of me.

_____ I would push all thoughts of being laid off out of my mind

_____ I would tell my partner that I'd rather not discuss my chances of being laid off

_____ I would try to think which employees in my department the supervisor might have thought had done the worst job

_____ I would continue doing my work as if nothing was happening

4. Vividly imagine that you are on an aeroplane, thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced all is well. Tick **all** of the statements that might apply to you.

_____ I would carefully read the information provided about the safety features in the plane and make sure I knew where the emergency exits were

_____ I would make small talk with the passenger beside me

_____ I would watch the end of the movie, even if I had seen it before

_____ I would call for the flight attendant and ask her exactly what the problem was

_____ I would order a drink or tranquilliser from the flight attendant

_____ I would listen carefully to the engines for unusual noises and would watch the crew to see if their behaviour was out of the ordinary

_____ I would talk to the passenger beside me about what might be wrong

_____ I would settle down and read a book or magazine or read a letter

Section 12: Coping with your IBD

This next section focuses upon the way you cope with your symptoms. Think about the times when your symptoms have been at their worst, and how you reacted to them. Now indicate the extent to which you did whatever each of the following statements says, using the key below.

1 = I usually don't do this at all.	**2 = I usually do this a little bit.**
3 = I usually do this a medium amount.	**4 = I usually do this a lot.**

1	I try to grow as a person as a result of the experience	
2	I turn to work or other substitute activities to take my mind off things	
3	I get upset and let my emotions out	
4	I try to get advice from someone about what to do	
5	I concentrate my efforts on doing something about it	
6	I say to myself "this isn't real"	
7	I put my trust in God	
8	I laugh about the situation	
9	I admit to myself that I can't deal with it, and give up trying	
10	I restrain myself from doing anything too quickly	
11	I discuss my feelings with someone	
12	I use alcohol or drugs to make myself feel better	
13	I get used to my symptoms	
14	I talk to someone to find out more about my symptoms	
15	I keep myself from getting distracted by other thoughts and activities	
16	I daydream about things	
17	I get upset and am really aware of it	
18	I seek God's help	
19	I make a plan of action	
20	I make jokes about it	
21	I accept my illness and that it can't be changed	
22	I hold off doing anything until the situation permits	

1 = I usually don't do this at all.
2 = I usually do this a little bit.
3 = I usually do this a medium amount.
4 = I usually do this a lot.

23	I try to get emotional support from friends and relatives	
24	I just give up trying to reach my goal	
25	I take additional action to try and get rid of the symptoms	
26	I try to lose myself for a while by drinking alcohol or taking drugs	
27	I refuse to believe it has happened	
28	I let my feelings out	
29	I try to see it in a different light, to make it seem more positive	
30	I talk to someone who can help	
31	I sleep more than usual	
32	I try to come up with a strategy about what to do	
33	I focus on dealing with this problem and, if necessary , let other things slide a little	
34	I get sympathy and understanding from someone	
35	I drink alcohol or take drugs, in order to think about it less	
36	I kid around about it	
37	I give up the attempt to get what I want	
38	I look for something good in what is happening	
39	I think about how I might best handle the problem	
40	I pretend that it hasn't really happened	
41	I make sure not to make matters worse by acting too soon	
42	I try hard to prevent other things from interfering with my efforts at dealing with this	
43	I go to the cinema or watch television to think about it less	
44	I accept the reality of the fact that I have this illness	
45	I ask people who have had similar experiences what they did	
46	I feel a lot of emotional distress and I find myself expressing those feelings a lot	
47	I take direct action to get around the illness	

1 = I usually don't do this at all. 2 = I usually do this a little bit.
3 = I usually do this a medium amount. 4 = I usually do this a lot.

48	I try to find comfort in my religion	
49	I force myself to wait for the right time to do something	
50	I make fun of the situation	
51	I reduce the amount of effort I'm putting into solving the problem of illness	
52	I talk to someone about how I feel	
53	I use alcohol or drugs to help me get through it	
54	I learn to live with it	
55	I put aside other activities in order to concentrate on this	
56	I think hard about what steps to take	
57	I act as though I don't have an illness	
58	I do what has to be done, one step at a time	
59	I learn something from the experience of illness	
60	I pray more than usual	

Section 13: How You see your Quality of Life with Illness

The last questionnaire I would like you to complete concerns how you feel about your quality of life, health and other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the ONE** that appears most appropriate. This can often be your first response.
Please keep in mind your standards, hopes, pleasures and concerns. I ask that you think about your life **in the LAST TWO WEEKS**. Circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither Poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things **in the LAST TWO WEEKS.**

		Not at all	A little	A moderate amount	Very much	An extreme amount
3	How much do you feel that pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
6	To what extent do you feel life to be meaningful?	1	2	3	4	5
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experienced or were able to do certain things **in the LAST TWO WEEKS.**

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	To what extent do you have enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

The following questions ask you to say **how good or satisfied** you have felt about various aspects of your life **over the LAST TWO WEEKS.**

		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things **in the LAST TWO WEEKS.**

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

		Not at all	Not much	A moderate amount	Very much	An extreme amount
27	How fed up do you feel?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
28	How satisfied are you with your level of happiness?	1	2	3	4	5

Section 14: Anything Else

Now please tell me anything else you feel is relevant here. Have any treatments, or medications worked for you? Have any treatments made you feel worse?

Please use the rest of this sheet to finish questions, or attach additional sheets.

How long did this booklet take to complete?____________Today's date _____/_____/____

Thank you very much for completing this booklet.

Now simply put this booklet into the pre-paid envelope and post it back to me.

Thank you once again for helping in my research.
Best wishes
Claire Rutter

© Claire Rutter

Appendix B1

Information Sheet included in the New Member Packs (2 sided)

Research Request

Hello there, new member. My name is Claire and I am a research student and a trustee of the IBS Network. I would like to invite you to participate in some research that I am carrying out in conjunction with the IBS Network. As a new member we would like to know what you expect from the Network and to ask you eight months later if we are meeting standards. Also in terms of my research, I will ask you to complete questionnaire measures that are concerned with the way being ill can affect people both physically and emotionally over time. I would like to determine if your attitude to IBS changes over the eight months from joining. The aim of my research is to help sufferers cope successfully with their illness. The more we understand about IBS, the more we may be able to help.

If you are interested in participating with this research, all you will be asked to do is to complete two questionnaire booklets, one now, and one in eight months from now. All the information you give will be treated in the strictest confidence; no one other than myself will ever see your completed answers. Once the research is completed I will write a short report for the Network incorporating all comments on ways to improve our services. Also, I will write a detailed article about the results of my research to be read by our members. All answers will be combined no one person will ever be identified in any article or report.

If you would like to participate, please fill in your personal details below, and complete the questions about the Network overleaf. There is also some spare space for you to make any other comments you think may be relevant to us. Once you have completed the sections on this letter, please send this sheet to:

**Miss Claire Rutter, Centre for Research in Health Behaviour,
Department of Psychology, University of Kent at Canterbury,
Canterbury, Kent CT2 7NP**

Once I receive this form from you I will then send you the first questionnaire booklet with a prepaid envelope. The second questionnaire booklet (and another prepaid envelope) will then be posted to you eight months later.

Please participate if you can, your feedback about the Network will help us to keep improving its services to its members.

Name ____

Address ____

____

____

Some questions about the Network

Where did you learn about the Network? ______________________________

How do you think we should spread the word of the Network? ____________

____

Do you think the membership fee is reasonable? Yes / No (please circle)

If No, please state what you think is reasonable ________________________

What do you expect to gain from becoming a member?

____

____

Are you interested in meeting other IBS sufferers? Yes / No (please circle)

If Yes, would you be interested in joining one of our local self help groups ran for and by IBS sufferers? Yes / No (please circle)

If Yes, would you like me to send you contact names and addresses of groups closest to you? Yes / No (please circle)

Are you a member of any other self-help group / organisation? Yes / No (please circle)

If Yes, please state which ____

Now please feel free to add any comments you feel appropriate

____

____

____

____

____

____

____

Appendix B2

Information letter to the new member

(on University Headed notepaper)
Claire L Rutter
Research Student
Dialling code for Canterbury:
01227 (UK) or +44 1227 (International)
Tel: 827147 direct line
764000 switchboard (ext.7147)
Fax: 827030
Email: C.L.Rutter@ukc.ac.uk

(Participant Name)
(Participant Address)

(Date)

Dear (Participant Name)

Thank you very much for completing the research request form.

As reported in the request form, my research hopes to address the way that people feel when they live with a chronic illness such as IBS. I am interested in your physical functioning (i.e. how your symptoms may affect your daily routine), and your attitude towards your illness. Also I want to try and understand the role of self-help groups, such as the IBS Network, in helping people cope with their illness. As a trustee of the Network I want to understand the benefits provided for IBS sufferers, and to identify any areas for improvement.

If you would like to help with this research, please complete the questionnaire booklet provided and send it back to me in the (postage paid) envelope provided. I will send you a follow-up questionnaire eight months later. The follow-up questionnaire will ask more specific questions about your views of the Network, however please feel free to add any comments and expectations about the Network that you may already have in section 14.

I hope the information contained here has gone some way in encouraging you to take part. If you have any other questions please contact me. I will be happy to take your calls.

Thank you and best wishes.

Miss Claire Rutter
Research Student

Appendix B3

Time 1 Questionnaire

IBS Network
LOGO

KENT
UNIVERSITY OF KENT
AT CANTERBURY

Living with Irritable Bowel Syndrome Questionnaire Booklet

Miss Claire Rutter
Research Student
Centre for Research in Health Behaviour
Department of Psychology
University of Kent at Canterbury
Canterbury
Kent CT2 7NP

☎ (01227) 827147

This booklet contains several questionnaires from the health and illness field. Most require you to circle or tick your preferred choice (i.e. the one that best describes the way you feel). **There are no right or wrong answers.** Although you may choose not to answer some questions, all answers will be treated in the **strictest confidence.** No one other than myself will see your completed questionnaires.
There is a space at the back for you to add anything else you feel is relevant. Please write freely. Also there are a few sections which ask you to write in your own words, if you run out of space please use the sheet at the back to continue.
Try not to spend too long thinking about specific questions. Your initial choice for **each question should take only a few seconds.** The whole booklet should take no longer than 50 minutes to complete.

Thank you for taking the time to complete this for me.

Best wishes

Miss Claire Rutter

Please Note: *All questionnaires are confidential. No one will see your responses apart from the researcher named above.*

© Claire Rutter
IBS Network Time One

Section 1: Information About You

This section asks you for information regarding your personal situation. Please try and answer all questions.

Name ____________________

Address ____________________

____

This information is needed so that I can send you the next questionnaire in 6 months time. It will not be passed on to any one else.

Male / Female (please circle) Date of birth ____/____/____

Marital status (please circle)

Single Married Divorced Separated Widowed Co-habiting

Number of children (with ages) ____________________

Please state highest academic qualification achieved ____________________

Occupation ____________ If no occupation, is this due to your symptoms? Yes / No

Part time / Full time (please circle) If part time, is this due to your symptoms? Yes / No

Please estimate how many days sick you have taken in the past year ________

I first experienced bowel and related symptoms ____________ (As near to the date as possible)

I was diagnosed with Irritable Bowel Syndrome ____________ (As near to the date as possible)

I have been to the GP about my irritable bowel and related symptoms (approximately) ________ times, and saw (please circle)

same GP / two GP's / 3 or more GP's

Before I was diagnosed with IBS I had the following tests / examinations; (please tick)

☐ Barium meal
☐ Barium enema
☐ Colonoscopy
☐ Rectal examination
☐ Blood test
☐ Stool sample
☐ Ultra sound scan
☐ Other (please state)____________________

Today's date ____/____/____

You will be sent the second questionnaire booklet in eight months of this date.

© Claire Rutter

Section 2: Solving Problems

Please circle the response that best describes you

	Not at all True	Barely True	Moderately True	Exactly True
I can always manage to solve difficult problems if I try hard enough	1	2	3	4
If someone opposes me, I can find means and ways to get what I want	1	2	3	4
It is easy for me to stick to my aims and accomplish my goals	1	2	3	4
I am confident that I could deal efficiently with unexpected events	1	2	3	4
Thanks to my resourcefulness, I know how to handle unforeseen situations	1	2	3	4
I can solve most problems if I invest the necessary effort	1	2	3	4
I can remain calm when facing difficulties because I can rely on my coping abilities	1	2	3	4
When I am confronted with a problem, I can usually find several solutions	1	2	3	4
If I am in a bind, I can usually think of something to do	1	2	3	4
No matter what comes my way, I'm usually able to handle it	1	2	3	4

Section 3: Emotional Feelings

Please read each of the 21 statements
and for each one circle the response that best describes you.

When I feel angry (very annoyed)…….	Almost Never	Sometimes	Often	Almost Always
I keep quiet	1	2	3	4
I refuse to argue or say anything	1	2	3	4
I bottle it up	1	2	3	4
I say what I feel	1	2	3	4
I avoid making a scene	1	2	3	4
I smother (cover up) my feelings	1	2	3	4
I hide my annoyance	1	2	3	4

When I feel unhappy (miserable)…….	Almost Never	Sometimes	Often	Almost Always
I refuse to do anything about it	1	2	3	4
I hide my unhappiness	1	2	3	4
I put on a bold face	1	2	3	4
I keep quiet	1	2	3	4
I let others see how I feel	1	2	3	4
I smother (cover up) my feelings	1	2	3	4
I bottle it up	1	2	3	4

When I feel afraid (worried)…….	Almost Never	Sometimes	Often	Almost Always
I let others see how I feel	1	2	3	4
I keep quiet	1	2	3	4
I refuse to say anything about it	1	2	3	4
I tell others about it	1	2	3	4
I say what I feel	1	2	3	4
I bottle it up	1	2	3	4
I smother (cover up) my feelings	1	2	3	4

© Claire Rutter

Section 4: Your Outlook in General

The following table has a list of statements that may or may not be true for you. There are no "correct" or "incorrect" answers. Answer according to your **own** feelings, rather than how you think "most people" would answer. Please circle the number in the appropriate column.

	Strongly Disagree 0	**Disagree 1**	**Neutral 2**	**Agree 3**	**Strongly Agree 4**
1. In uncertain times, I usually expect the best.	0	1	2	3	4
2. It's easy for me to relax	0	1	2	3	4
3. If something can go wrong for me, it will	0	1	2	3	4
4. I'm always optimistic about my future	0	1	2	3	4
5. I enjoy my friends a lot	0	1	2	3	4
6. It's important for me to keep busy	0	1	2	3	4
7. I hardly ever expect things to go my way	0	1	2	3	4
8. I don't get upset too easily	0	1	2	3	4
9. I rarely count on good things happening to me	0	1	2	3	4
10. Overall, I expect more good things to happen to me than bad	0	1	2	3	4

Section 5: How you Rate your Feelings and Emotions

This scale consists of a number of words that describe different feelings and emotions. Read each item and then circle the best answer.

Please indicate to what extent you have felt this way during the past few weeks.

	1 Very Slightly	2 A Little	3 Moderately	4 Quite a Bit	5 Extremely
Interested	1	2	3	4	5
Distressed	1	2	3	4	5
Excited	1	2	3	4	5
Upset	1	2	3	4	5
Strong	1	2	3	4	5
Guilty	1	2	3	4	5
Scared	1	2	3	4	5
Hostile	1	2	3	4	5
Enthusiastic	1	2	3	4	5
Proud	1	2	3	4	5
Irritable	1	2	3	4	5
Alert	1	2	3	4	5
Ashamed	1	2	3	4	5
Inspired	1	2	3	4	5
Nervous	1	2	3	4	5
Determined	1	2	3	4	5
Attentive	1	2	3	4	5
Jittery	1	2	3	4	5
Active	1	2	3	4	5
Afraid	1	2	3	4	5

© Claire Rutter

Section 6: Your Symptoms

Below is a list of Irritable Bowel symptoms that you may, or may not have been suffering from. Please rate each one for your experience of the symptom by placing a tick in the appropriate box.

	I have never experienced this symptom	Less than 3 or 4 times per year	Every month or so	Every week or so	More than once every week
Abdominal Pain	0	1	2	3	4
Diarrhoea	0	1	2	3	4
Bloating	0	1	2	3	4
Wind	0	1	2	3	4
Constipation	0	1	2	3	4
Blood in stools	0	1	2	3	4
Incomplete evacuation of the bowel	0	1	2	3	4
Passage of mucus	0	1	2	3	4
Incontinence	0	1	2	3	4
Rumbling and grumbling	0	1	2	3	4

Below is a list of common symptoms or bodily sensations. Most people have experienced most of them at one time or another. I am interested in finding out how prevalent each symptom is. Using the scale below, write beside each symptom the letter, which indicates how frequently you experience that symptom.

A Have never or almost never experienced the symptom	B Less than 3 or 4 times per year	C Every month or so	D Every week or so	E More than once every week

	Symptoms	Your Response
1	Eyes water	
2	Itching or painful eyes	
3	Ringing in ears	
4	Temporary deafness or hard of hearing	
5	Lump in throat	
6	Choking sensation	
7	Sneezing spells	
8	Running nose	
9	Congested nose	
10	Bleeding nose	
11	Asthma or wheezing	
12	Coughing	

A **Have never or almost never experienced the symptom**	**B** **Less than 3 or 4 times per year**	**C** **Every month or so**	**D** **Every week or so**	**E** **More than once every week**

	Symptoms	Your Response
13	Out of breath	
14	Swollen ankles	
15	Chest pains	
16	Racing heart	
17	Cold hands or feet even in hot weather	
18	Leg cramps	
19	Insomnia	
20	Toothaches	
21	Upset stomach	
22	Indigestion	
23	Heartburn	
24	Severe pains or cramps in stomach	
25	Diarrhoea	
26	Constipation	
27	Haemorrhoids	
28	Swollen joints	
29	Stiff muscles	
30	Back pains	
31	Sensitive or tender skin	
32	Face flushes	
33	Severe itching	
34	Skin breaks out in a rash	
35	Acne or pimples on face	
36	Acne or pimples other than on face	
37	Boils	
38	Sweat even in cold weather	
39	Strong reactions to insect bites	
40	Headaches	
41	Sensation of pressure in head	
42	Hot flushes	
43	Chills	
44	Dizziness	
45	Feel faint	
46	Numbness or tingling in any part of body	
47	Twitching of eyelid	
48	Twitching other than eyelid	
49	Hands tremble or shake	
50	Stiff joints	
51	Sore muscles	
52	Sore throat	
53	Sunburn	
54	Nausea	

Section 7: Your Views about Your Irritable Bowel Syndrome (IBS)

I am interested in your own personal views of how you see your IBS. Please indicate how much you agree or disagree with the following statements about your IBS

	Strongly Agree	**Agree**	**Neither Agree or Disagree**	**Disagree**	**Strongly Disagree**
A germ or virus caused my IBS	1	2	3	4	5
My IBS was caused by poor medical care in the past	1	2	3	4	5
There is little that can be done to improve my IBS	1	2	3	4	5
My IBS is hereditary – it runs in my family	1	2	3	4	5
My IBS will last a short time	1	2	3	4	5
What I do can determine whether my IBS gets better or worse	1	2	3	4	5
My IBS has strongly affected the way I see myself as a person	1	2	3	4	5
Stress was a major factor in causing my IBS	1	2	3	4	5
My IBS is a serious condition	1	2	3	4	5
Pollution in the environment caused my IBS	1	2	3	4	5
It was just by chance that I developed IBS	1	2	3	4	5
My IBS has become easier to live with	1	2	3	4	5
My IBS has serious economic and financial consequences	1	2	3	4	5
My IBS has strongly affected the way others see me	1	2	3	4	5
My state of mind played a major part in causing my IBS	1	2	3	4	5
My treatments will be effective in curing my IBS	1	2	3	4	5
Diet played a major role in causing my IBS	1	2	3	4	5
My IBS is likely to be permanent rather than temporary	1	2	3	4	5
My IBS will improve in time	1	2	3	4	5
Recovery from my IBS is largely dependent on chance or fate	1	2	3	4	5
My IBS has had major consequences on my life	1	2	3	4	5
Other people played a large role in causing my IBS	1	2	3	4	5
There is a lot I can do to control my symptoms	1	2	3	4	5
My IBS will last for a long time	1	2	3	4	5
My IBS is largely due to my own behaviour	1	2	3	4	5
My IBS has not had much effect on my life	1	2	3	4	5

Section 8: Your Illness Knowledge

This page is concerned with what you know about your illness, and where this information came from. Do not worry about whether your answers are right or wrong. It is how you think about them that are important. Please try to answer as fully as possible.

In your own words tell me about the illness you have been diagnosed with, focusing specifically upon:

(i) Why do you think you suffer from this illness? ______________________________

____

(ii) How serious is it? ______________________________

____

(iii) What can you do to help alleviate your symptoms? ______________________________

____

(iv) When some people are diagnosed with an illness like IBS, they actively seek out information about it. Please indicate (by circling) if you have gained information about your illness from the following sources:

Doctor	Yes / No	Television	Yes / No
Magazines	Yes / No	Radio	Yes / No
Self Help Book	Yes / No	Internet	Yes / No
Medical Journal	Yes / No	Friends/Family	Yes / No
Self Help Group	Yes / No		

Other (please state) ______________________________

____

(v) Are you satisfied that your doctor explained your diagnosis to you as fully as possible?

1	2	3	4	5
Very Satisfied	Satisfied	Neither Satisfied nor Dissatisfied	Dissatisfied	Very Dissatisfied

(vi) After answering the above how confident are you that you know enough about your illness?

1	2	3	4	5
Very Confident	Confident	Neither Confident nor Unconfident	Unconfident	Very Unconfident

Section 9: Your Attitudes Towards Doctors and Medicine

Please circle the appropriate number for each statement to show how strongly you agree or disagree with it. There are no right or wrong answers. I am interested just in your opinion.

		Strongly Disagree	Disagree	Tend to Disagree	Tend to Agree	Agree	Strongly Agree
1	All doctors are good doctors	1	2	3	4	5	6
2	Medicine is based on scientific principles	1	2	3	4	5	6
3	I only consult a doctor if I am at death's door	1	2	3	4	5	6
4	Medicines can do as much harm as good	1	2	3	4	5	6
5	I have absolute faith and confidence in all hospital doctors	1	2	3	4	5	6
6	The improved health of the nation is due to effective medicine	1	2	3	4	5	6
7	Doctors blame their patients if their treatment doesn't work	1	2	3	4	5	6
8	The advice of doctors is mainly common sense	1	2	3	4	5	6
9	No matter how long you have to wait and see a doctor, it's worth it	1	2	3	4	5	6
10	Medicine has cures for most diseases	1	2	3	4	5	6
11	Doctors are important in keeping us healthy	1	2	3	4	5	6
12	No two doctors will agree on what is wrong with a person	1	2	3	4	5	6
13	Many medicines are just placebos or sugar pills	1	2	3	4	5	6
14	Doctors are too ready to solve patients' problems by prescribing tranquillisers	1	2	3	4	5	6
15	Often the only purpose of tests is to make the doctor feel less anxious	1	2	3	4	5	6
16	Doctors know what's best for you	1	2	3	4	5	6
17	I don't like medical people	1	2	3	4	5	6
18	Most tests and investigations are done routinely rather than for a particular purpose	1	2	3	4	5	6
19	Medicine is the best profession a person can have	1	2	3	4	5	6

Section 10: How You have been Feeling in the past TWO WEEKS

Please tick the response that best describes the way you have been feeling in the past two weeks

1. I feel tense or "wound up":

- ☐ *Most of the time*
- ☐ *A lot of the time*
- ☐ *From time to time, occasionally*
- ☐ *Not at all*

2. I still enjoy the things I used to enjoy:

- ☐ *Definitely as much*
- ☐ *Not quite so much*
- ☐ *Only a little*
- ☐ *Hardly at all*

3. I get a sort of frightened feeling as if something awful is about to happen:

- ☐ *Very definitely and quite badly*
- ☐ *Yes, but not too badly*
- ☐ *A little, but it doesn't worry me*
- ☐ *Not at all*

4. I can laugh and see the funny side of things:

- ☐ *As much as I always could*
- ☐ *Not quite so much now*
- ☐ *Definitely not so much now*
- ☐ *Not at all*

5. Worrying thoughts go through my mind:

- ☐ *A great deal of the time*
- ☐ *A lot of the time*
- ☐ *From time to time, but not too often*
- ☐ *Only occasionally*

6. I feel cheerful:

- ☐ *Not at all*
- ☐ *Not often*
- ☐ *Sometimes*
- ☐ *Most of the time*

7. I can sit at ease and feel relaxed:

- ☐ *Definitely*
- ☐ *Usually*
- ☐ *Not often*
- ☐ *Not at all*

8. I feel as if I am slowed down:

- ☐ *Nearly all of the time*
- ☐ *Very often*
- ☐ *Sometimes*
- ☐ *Not at all*

9. I get a sort of frightened feeling like "butterflies" in the stomach:

- ☐ *Not at all*
- ☐ *Occasionally*
- ☐ *Quite often*
- ☐ *Very often*

10. I have lost interest in my appearance:

- ☐ *Definitely*
- ☐ *I don't take as much care as I should*
- ☐ *I may not take as much care*
- ☐ *I take just as much care as ever*

11. I feel restless as if I have to be on the move:

- ☐ *Very much indeed*
- ☐ *Quite a lot*
- ☐ *Not very much*
- ☐ *Not at all*

12. I look forward with enjoyment to things:

- ☐ *As much as I ever did*
- ☐ *Rather less than I used to*
- ☐ *Definitely less than I used to*
- ☐ *Hardly at all*

13. I get sudden feelings of panic:

- ☐ *Very often indeed*
- ☐ *Quite often*
- ☐ *Not very often*
- ☐ *Not at all*

14. I can enjoy a good book or radio or TV programme

- ☐ *Often*
- ☐ *Sometimes*
- ☐ *Not often*
- ☐ *Very seldom*

© Claire Rutter

Section 11: How You deal with Unpleasant Situations

In this section I want to know how you think you might react in some unpleasant situations. Tick as many statements as you want, that apply to you.

1. Vividly imagine that you are **afraid** of the dentist and have to get some dental work done. Which of the following would you do? Place a tick against **all** of the statements that apply to you.

_____ I would ask the dentist exactly what he was going to do

_____ I would take a tranquilliser or have a drink before going

_____ I would try to think about pleasant memories

_____ I would want the dentist to tell me when I would feel pain

_____ I would try to sleep

_____ I would watch all the dentists movements and listen for the sound of the drill

_____ I would watch the flow of water from my mouth to see if it contained blood

_____ I would do mental puzzles in my mind

2. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Tick **all** the statements that might apply to you.

_____ I would sit by myself and have as many daydreams and fantasies as I could

_____ I would stay alert and try to keep myself from falling asleep

_____ I would exchange life stories with the other hostages

_____ If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing

_____ I would watch every movement of my captors and keep an eye on their weapons

_____ I would try to sleep as much as possible

_____ I would think about how nice it's going to be when I get home

_____ I would make sure I knew where every possible exit was

© Claire Rutter

3. Vividly imagine that, due to a large drop in sales, it is rumoured that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about layoffs has been made and will be announced in several days. Tick **all** the statements that might apply to you.

_____ I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said

_____ I would review the list of duties for my present job and try to figure out if I had fulfilled them all

_____ I would go to the cinema to take my mind off things

_____ I would try to remember my arguments or disagreements I might have had with the supervisor that would have lowered his/her opinion of me.

_____ I would push all thoughts of being laid off out of my mind

_____ I would tell my partner that I'd rather not discuss my chances of being laid off

_____ I would try to think which employees in my department the supervisor might have thought had done the worst job

_____ I would continue doing my work as if nothing was happening

4. Vividly imagine that you are on an aeroplane, thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced all is well. Tick **all** of the statements that might apply to you.

_____ I would carefully read the information provided about the safety features in the plane and make sure I knew where the emergency exits were

_____ I would make small talk with the passenger beside me

_____ I would watch the end of the movie, even if I had seen it before

_____ I would call for the flight attendant and ask her exactly what the problem was

_____ I would order a drink or tranquilliser from the flight attendant

_____ I would listen carefully to the engines for unusual noises and would watch the crew to see if their behaviour was out of the ordinary

_____ I would talk to the passenger beside me about what might be wrong

_____ I would settle down and read a book or magazine or read a letter

Section 12: Coping with your IBS

This next section focuses upon the way you cope with your symptoms. Think about the times when your symptoms have been at their worst, and how you reacted to them. Now indicate the extent to which you did whatever each of the following statements says, using the key below.

1 = I usually don't do this at all.
2 = I usually do this a little bit.
3 = I usually do this a medium amount.
4 = I usually do this a lot.

1	I try to grow as a person as a result of the experience	
2	I turn to work or other substitute activities to take my mind off things	
3	I get upset and let my emotions out	
4	I try to get advice from someone about what to do	
5	I concentrate my efforts on doing something about it	
6	I say to myself "this isn't real"	
7	I put my trust in God	
8	I laugh about the situation	
9	I admit to myself that I can't deal with it, and give up trying	
10	I restrain myself from doing anything too quickly	
11	I discuss my feelings with someone	
12	I use alcohol or drugs to make myself feel better	
13	I get used to my symptoms	
14	I talk to someone to find out more about my symptoms	
15	I keep myself from getting distracted by other thoughts and activities	
16	I daydream about things	
17	I get upset and am really aware of it	
18	I seek God's help	
19	I make a plan of action	
20	I make jokes about it	
21	I accept my illness and that it can't be changed	
22	I hold off doing anything until the situation permits	

© Claire Rutter

1 = I usually don't do this at all.
2 = I usually do this a little bit.
3 = I usually do this a medium amount.
4 = I usually do this a lot.

23	I try to get emotional support from friends and relatives	
24	I just give up trying to reach my goal	
25	I take additional action to try and get rid of the symptoms	
26	I try to lose myself for a while by drinking alcohol or taking drugs	
27	I refuse to believe it has happened	
28	I let my feelings out	
29	I try to see it in a different light, to make it seem more positive	
30	I talk to someone who can help	
31	I sleep more than usual	
32	I try to come up with a strategy about what to do	
33	I focus on dealing with this problem and, if necessary , let other things slide a little	
34	I get sympathy and understanding from someone	
35	I drink alcohol or take drugs, in order to think about it less	
36	I kid around about it	
37	I give up the attempt to get what I want	
38	I look for something good in what is happening	
39	I think about how I might best handle the problem	
40	I pretend that it hasn't really happened	
41	I make sure not to make matters worse by acting too soon	
42	I try hard to prevent other things from interfering with my efforts at dealing with this	
43	I go to the cinema or watch television to think about it less	
44	I accept the reality of the fact that I have this illness	
45	I ask people who have had similar experiences what they did	
46	I feel a lot of emotional distress and I find myself expressing those feelings a lot	
47	I take direct action to get around the illness	

© Claire Rutter

1 = I usually don't do this at all.	2 = I usually do this a little bit.
3 = I usually do this a medium amount.	4 = I usually do this a lot.

48	I try to find comfort in my religion	
49	I force myself to wait for the right time to do something	
50	I make fun of the situation	
51	I reduce the amount of effort I'm putting into solving the problem of illness	
52	I talk to someone about how I feel	
53	I use alcohol or drugs to help me get through it	
54	I learn to live with it	
55	I put aside other activities in order to concentrate on this	
56	I think hard about what steps to take	
57	I act as though I don't have an illness	
58	I do what has to be done, one step at a time	
59	I learn something from the experience of illness	
60	I pray more than usual	

Section 13: How You see your Quality of Life with Illness

The last questionnaire I would like you to complete concerns how you feel about your quality of life, health and other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the ONE** that appears most appropriate. This can often be your first response.
Please keep in mind your standards, hopes, pleasures and concerns. I ask that you think about your life **in the LAST TWO WEEKS**. Circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither Poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

© Claire Rutter

The following questions ask about **how much** you have experienced certain things **in THE LAST TWO WEEKS.**

		Not at all	A little	A moderate amount	Very much	An extreme amount
3	How much do you feel that pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
6	To what extent do you feel life to be meaningful?	1	2	3	4	5
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experienced or were able to do certain things **in the LAST TWO WEEKS.**

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	To what extent do you have enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

The following questions ask you to say **how good or satisfied** you have felt about various aspects of your life **over the LAST TWO WEEKS.**

		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things **in the LAST TWO WEEKS.**

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

		Not at all	Not much	A moderate amount	Very much	An extreme amount
27	How fed up do you feel?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
28	How satisfied are you with your level of happiness?	1	2	3	4	5

Section 14: Anything Else

Now please tell me anything else you feel is relevant here. Have any treatments or medications worked for you? Have any treatments made you feel worse?

Please use the rest of this sheet to finish questions, or attach additional sheets if necessary.

How long did this questionnaire take to complete? ___________

Thank you very much for completing this booklet.

Now simply put this booklet into the pre-paid envelope and post it back to me. I will contact you again in six months from now.

Thank you once again for helping in my research.
Best wishes
Claire Rutter

© Claire Rutter

Appendix B4

Time 2 letter to the new member

(On University Headed Notepaper)
Claire L Rutter
Research Student
Dialling code for Canterbury:
01227 (UK) or +44 1227 (International)
Tel: 827147 direct line
764000 switchboard (ext.7147)
Fax: 827030
Email: C.L.Rutter@ukc.ac.uk

(Participant Name)
(Participant Address)

(Date)

Dear (Participant Name)

Hello again, it has now been eight months since I received the first completed questionnaire from you. Please find the stage two questionnaire enclosed. This is the last part of this research.

All of the measures that you completed in the first questionnaire 8 months ago are included here again. This is to determine if and how your attitudes to your IBS have changed since becoming a member of the Network.

Also, in the first stage of the research I asked you what you expect from the Network, now I would like to determine whether you feel the Network is living up to these expectations. This questionnaire gives you the opportunity for you to indicate whether you believe the Network is doing everything it can to meet standards.

Once I have received and analysed all of the stage two data I will submit an article to Gut Reaction to let you know my findings.

If you have any questions about this research, please contact me. I will be happy to take your calls.

I look forward to receiving your completed questionnaire

Thank you and best wishes.

Miss Claire Rutter
Research Student

Appendix B5

Time 2 Questionnaire

KENT
UNIVERSITY OF KENT
AT CANTERBURY ■■■■

Living with Irritable Bowel Syndrome Questionnaire Booklet

Miss Claire Rutter
Research Student
Centre for Research in Health Behaviour
Department of Psychology
University of Kent at Canterbury
Canterbury
Kent CT2 7NP

☎ (01227) 827147

Hello again. It is now eight months since you completed my first questionnaire booklet. You may realise that this booklet contains similar measures that you completed 8 months ago, please complete these measures. This is the only way we can tell how your circumstances have changed.
Remember, there are no right or wrong answers. Although you may choose not to answer some questions, all answers will be treated in the **strictest confidence.** No one other than myself will see your completed questionnaires.
Included this time are a number of questions about the Network. Now you have been a member for 8 months, you will have an idea of what our magazine is like, and you may have ideas about how it can be improved, this is your opportunity to have your views heard.
Once again the whole booklet should take no longer than 50 minutes to complete.

Thank you for taking the time to complete this for me.

Best wishes

Miss Claire Rutter

<u>Please Note:</u> All questionnaires are confidential. No one will see your responses apart from the researcher named above.

Your Name ____

Section 1: Your Views of the Network

Please rate how helpful you have found the following services provided by the Network by circling your response in the appropriate column. If you have not used a service please place a tick in the shaded "Not Used" column presented first.

Network Service	**Not used**	**Extremely unhelpful**	**Unhelpful**	**Neither helpful or unhelpful**	**Helpful**	**Extremely helpful**
Local Self Help Group (run by sufferers)		1	2	3	4	5
Therapeutic Package (16 week programme run by qualified therapists)		1	2	3	4	5
Befrienders Scheme		1	2	3	4	5
Penfriends		1	2	3	4	5
Telephone Contacts		1	2	3	4	5
IBS Helpline		1	2	3	4	5
Network Webpage		1	2	3	4	5
Fact Sheets		1	2	3	4	5
Membership "can't wait" Card		1	2	3	4	5

If you have attended a local Self Help Group or the Therapeutic Package, what are your views of these? How can they be improved? ____

____

____

____

____

Please state how useful/helpful you find Gut Reaction (the quarterly newsletter of the Network) (please circle one)

Very useful/helpful   Useful/helpful   Neither   Not useful/unhelpful   Very unhelpful

Please state how you find the format (i.e. the layout) of Gut Reaction (please circle one)

Very Satisfactory   Satisfactory   Neither   Unsatisfactory   Very Unsatisfactory

Please state how you would improve the format and/or content of Gut Reaction

____

____

____

____

____

Is the Network value for money? Yes / No (please circle)

Why? ____________________

Will you be renewing your membership of the Network? Yes / No (please circle)

Why? ____________________

In what ways do you think the Network can be improved? ____________________

How many people do you know with IBS? ____________________

Would you recommend the Network to others? Yes / No (please circle)

Why? ____________________

What have you learnt about IBS from the IBS Network? ____________________

After becoming a member of the Network, have you sought more information about IBS from other sources outside of the Network? If so what sources and why? ____________________

How do you feel your attitudes towards IBS developed over these last eight months? ____________________

Please feel free to add any further comments here about the Network. There will be further opportunity to make your comments about the Network at the end of this booklet.

Now I would like you to complete the same measures as before.

Section 2: Solving Problems

Please circle the response that best describes you

	Not at all True	Barely True	Moderately True	Exactly True
I can always manage to solve difficult problems if I try hard enough	1	2	3	4
If someone opposes me, I can find means and ways to get what I want	1	2	3	4
It is easy for me to stick to my aims and accomplish my goals	1	2	3	4
I am confident that I could deal efficiently with unexpected events	1	2	3	4
Thanks to my resourcefulness, I know how to handle unforeseen situations	1	2	3	4
I can solve most problems if I invest the necessary effort	1	2	3	4
I can remain calm when facing difficulties because I can rely on my coping abilities	1	2	3	4
When I am confronted with a problem, I can usually find several solutions	1	2	3	4
If I am in a bind, I can usually think of something to do	1	2	3	4
No matter what comes my way, I'm usually able to handle it	1	2	3	4

Section 3: Emotional Feelings

Please read each of the 21 statements
and for each one circle the response that best describes you.

When I feel angry (very annoyed).......	Almost Never	Sometimes	Often	Almost Always
I keep quiet	1	2	3	4
I refuse to argue or say anything	1	2	3	4
I bottle it up	1	2	3	4
I say what I feel	1	2	3	4
I avoid making a scene	1	2	3	4
I smother (cover up) my feelings	1	2	3	4
I hide my annoyance	1	2	3	4

When I feel unhappy (miserable).......	Almost Never	Sometimes	Often	Almost Always
I refuse to do anything about it	1	2	3	4
I hide my unhappiness	1	2	3	4
I put on a bold face	1	2	3	4
I keep quiet	1	2	3	4
I let others see how I feel	1	2	3	4
I smother (cover up) my feelings	1	2	3	4
I bottle it up	1	2	3	4

When I feel afraid (worried).......	Almost Never	Sometimes	Often	Almost Always
I let others see how I feel	1	2	3	4
I keep quiet	1	2	3	4
I refuse to say anything about it	1	2	3	4
I tell others about it	1	2	3	4
I say what I feel	1	2	3	4
I bottle it up	1	2	3	4
I smother (cover up) my feelings	1	2	3	4

© Claire Rutter

Section 4: Your Outlook in General

The following table has a list of statements that may or may not be true for you. There are no "correct" or "incorrect" answers. Answer according to your **own** feelings, rather than how you think "most people" would answer. Please circle the number in the appropriate column.

	Strongly Disagree 0	**Disagree 1**	**Neutral 2**	**Agree 3**	**Strongly Agree 4**
1. In uncertain times, I usually expect the best.	0	1	2	3	4
2. It's easy for me to relax	0	1	2	3	4
3. If something can go wrong for me, it will	0	1	2	3	4
4. I'm always optimistic about my future	0	1	2	3	4
5. I enjoy my friends a lot	0	1	2	3	4
6. It's important for me to keep busy	0	1	2	3	4
7. I hardly ever expect things to go my way	0	1	2	3	4
8. I don't get upset too easily	0	1	2	3	4
9. I rarely count on good things happening to me	0	1	2	3	4
10. Overall, I expect more good things to happen to me than bad	0	1	2	3	4

Section 5: How you Rate your Feelings and Emotions

This scale consists of a number of words that describe different feelings and emotions. Read each item and then circle the best answer.

Please indicate to what extent you have felt this way during the past few weeks.

	1 Very Slightly	**2 A Little**	**3 Moderately**	**4 Quite a Bit**	**5 Extremely**
Interested	1	2	3	4	5
Distressed	1	2	3	4	5
Excited	1	2	3	4	5
Upset	1	2	3	4	5
Strong	1	2	3	4	5
Guilty	1	2	3	4	5
Scared	1	2	3	4	5
Hostile	1	2	3	4	5
Enthusiastic	1	2	3	4	5
Proud	1	2	3	4	5
Irritable	1	2	3	4	5
Alert	1	2	3	4	5
Ashamed	1	2	3	4	5
Inspired	1	2	3	4	5
Nervous	1	2	3	4	5
Determined	1	2	3	4	5
Attentive	1	2	3	4	5
Jittery	1	2	3	4	5
Active	1	2	3	4	5
Afraid	1	2	3	4	5

Section 6: Your Symptoms

Below is a list of Irritable Bowel symptoms that you may, or may not have been suffering from. Please rate each one for your experience of the symptom by placing a tick in the appropriate box.

	I have never experienced this symptom	**Less than 3 or 4 times per year**	**Every month or so**	**Every week or so**	**More than once every week**
Abdominal Pain	0	1	2	3	4
Diarrhoea	0	1	2	3	4
Bloating	0	1	2	3	4
Wind	0	1	2	3	4
Constipation	0	1	2	3	4
Blood in stools	0	1	2	3	4
Incomplete evacuation of the bowel	0	1	2	3	4
Passage of mucus	0	1	2	3	4
Incontinence	0	1	2	3	4
Rumbling and grumbling	0	1	2	3	4

Below is a list of common symptoms or bodily sensations. Most people have experienced most of them at one time or another. I am interested in finding out how prevalent each symptom is. Using the scale below, write beside each symptom the letter, which indicates how frequently you experience that symptom.

A	**B**	**C**	**D**	**E**
Have never or almost never experienced the symptom	**Less than 3 or 4 times per year**	**Every month or so**	**Every week or so**	**More than once every week**

	Symptoms	**Your Response**
1	Eyes water	
2	Itching or painful eyes	
3	Ringing in ears	
4	Temporary deafness or hard of hearing	
5	Lump in throat	
6	Choking sensation	
7	Sneezing spells	
8	Running nose	
9	Congested nose	
10	Bleeding nose	
11	Asthma or wheezing	
12	Coughing	

© Claire Rutter

A Have never or almost never experienced the symptom	B Less than 3 or 4 times per year	C Every month or so	D Every week or so	E More than once every week

	Symptoms	Your Response
13	Out of breath	
14	Swollen ankles	
15	Chest pains	
16	Racing heart	
17	Cold hands or feet even in hot weather	
18	Leg cramps	
19	Insomnia	
20	Toothaches	
21	Upset stomach	
22	Indigestion	
23	Heartburn	
24	Severe pains or cramps in stomach	
25	Diarrhoea	
26	Constipation	
27	Haemorrhoids	
28	Swollen joints	
29	Stiff muscles	
30	Back pains	
31	Sensitive or tender skin	
32	Face flushes	
33	Severe itching	
34	Skin breaks out in a rash	
35	Acne or pimples on face	
36	Acne or pimples other than on face	
37	Boils	
38	Sweat even in cold weather	
39	Strong reactions to insect bites	
40	Headaches	
41	Sensation of pressure in head	
42	Hot flushes	
43	Chills	
44	Dizziness	
45	Feel faint	
46	Numbness or tingling in any part of body	
47	Twitching of eyelid	
48	Twitching other than eyelid	
49	Hands tremble or shake	
50	Stiff joints	
51	Sore muscles	
52	Sore throat	
53	Sunburn	
54	Nausea	

Section 7: Your Views about Your Irritable Bowel Syndrome (IBS)

I am interested in your own personal views of how you see your IBS. Please indicate how much you agree or disagree with the following statements about your IBS

	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
A germ or virus caused my IBS	1	2	3	4	5
My IBS was caused by poor medical care in the past	1	2	3	4	5
There is little that can be done to improve my IBS	1	2	3	4	5
My IBS is hereditary – it runs in my family	1	2	3	4	5
My IBS will last a short time	1	2	3	4	5
What I do can determine whether my IBS gets better or worse	1	2	3	4	5
My IBS has strongly affected the way I see myself as a person	1	2	3	4	5
Stress was a major factor in causing my IBS	1	2	3	4	5
My IBS is a serious condition	1	2	3	4	5
Pollution in the environment caused my IBS	1	2	3	4	5
It was just by chance that I developed IBS	1	2	3	4	5
My IBS has become easier to live with	1	2	3	4	5
My IBS has serious economic and financial consequences	1	2	3	4	5
My IBS has strongly affected the way others see me	1	2	3	4	5
My state of mind played a major part in causing my IBS	1	2	3	4	5
My treatments will be effective in curing my IBS	1	2	3	4	5
Diet played a major role in causing my IBS	1	2	3	4	5
My IBS is likely to be permanent rather than temporary	1	2	3	4	5
My IBS will improve in time	1	2	3	4	5
Recovery from my IBS is largely dependent on chance or fate	1	2	3	4	5
My IBS has had major consequences on my life	1	2	3	4	5
Other people played a large role in causing my IBS	1	2	3	4	5
There is a lot I can do to control my symptoms	1	2	3	4	5
My IBS will last for a long time	1	2	3	4	5
My IBS is largely due to my own behaviour	1	2	3	4	5
My IBS has not had much effect on my life	1	2	3	4	5

Section 8: Your Illness Knowledge

This page is concerned with what you know about your illness, and where this information came from. Do not worry about whether your answers are right or wrong. It is how you think about them that are important. Please try to answer as fully as possible.

In your own words tell me about the illness you have been diagnosed with, focusing specifically upon:

(i) Why do you think you suffer from this illness? ______________________

____

(ii) How serious is it? ______________________

____

(iii) What can you do to help alleviate your symptoms? ______________________

____

(iv) When some people are diagnosed with an illness like IBS, they actively seek out information about it. Please indicate (by circling) if you have gained information about your illness from the following sources:

Doctor	Yes / No	Television	Yes / No
Magazines	Yes / No	Radio	Yes / No
Self Help Book	Yes / No	Internet	Yes / No
Medical Journal	Yes / No	Friends/Family	Yes / No
Self Help Group	Yes / No		

Other (please state) ______________________

____

(v) Are you satisfied that your doctor explained your diagnosis to you as fully as possible?

1	2	3	4	5
Very Satisfied	Satisfied	Neither Satisfied nor Dissatisfied	Dissatisfied	Very Dissatisfied

(vi) After answering the above how confident are you that you know enough about your illness?

1	2	3	4	5
Very Confident	Confident	Neither Confident nor Unconfident	Unconfident	Very Unconfident

© Claire Rutter

Section 9: Your Attitudes Towards Doctors and Medicine

Please circle the appropriate number for each statement to show how strongly you agree or disagree with it. There are no right or wrong answers. I am interested just in your opinion.

		Strongly Disagree	**Disagree**	**Tend to Disagree**	**Tend to Agree**	**Agree**	**Strongly Agree**
1	All doctors are good doctors	1	2	3	4	5	6
2	Medicine is based on scientific principles	1	2	3	4	5	6
3	I only consult a doctor if I am at death's door	1	2	3	4	5	6
4	Medicines can do as much harm as good	1	2	3	4	5	6
5	I have absolute faith and confidence in all hospital doctors	1	2	3	4	5	6
6	The improved health of the nation is due to effective medicine	1	2	3	4	5	6
7	Doctors blame their patients if their treatment doesn't work	1	2	3	4	5	6
8	The advice of doctors is mainly common sense	1	2	3	4	5	6
9	No matter how long you have to wait and see a doctor, it's worth it	1	2	3	4	5	6
10	Medicine has cures for most diseases	1	2	3	4	5	6
11	Doctors are important in keeping us healthy	1	2	3	4	5	6
12	No two doctors will agree on what is wrong with a person	1	2	3	4	5	6
13	Many medicines are just placebos or sugar pills	1	2	3	4	5	6
14	Doctors are too ready to solve patients' problems by prescribing tranquillisers	1	2	3	4	5	6
15	Often the only purpose of tests is to make the doctor feel less anxious	1	2	3	4	5	6
16	Doctors know what's best for you	1	2	3	4	5	6
17	I don't like medical people	1	2	3	4	5	6
18	Most tests and investigations are done routinely rather than for a particular purpose	1	2	3	4	5	6
19	Medicine is the best profession a person can have	1	2	3	4	5	6

Section 10: How You have been Feeling in the past TWO WEEKS

Please tick the response that best describes the way you have been feeling in the past two weeks

1. I feel tense or "wound up":

☐ *Most of the time*
☐ *A lot of the time*
☐ *From time to time, occasionally*
☐ *Not at all*

2. I still enjoy the things I used to enjoy:

☐ *Definitely as much*
☐ *Not quite so much*
☐ *Only a little*
☐ *Hardly at all*

3. I get a sort of frightened feeling as if something awful is about to happen:

☐ *Very definitely and quite badly*
☐ *Yes, but not too badly*
☐ *A little, but it doesn't worry me*
☐ *Not at all*

4. I can laugh and see the funny side of things:

☐ *As much as I always could*
☐ *Not quite so much now*
☐ *Definitely not so much now*
☐ *Not at all*

5. Worrying thoughts go through my mind:

☐ *A great deal of the time*
☐ *A lot of the time*
☐ *From time to time, but not too often*
☐ *Only occasionally*

6. I feel cheerful:

☐ *Not at all*
☐ *Not often*
☐ *Sometimes*
☐ *Most of the time*

7. I can sit at ease and feel relaxed:

☐ *Definitely*
☐ *Usually*
☐ *Not often*
☐ *Not at all*

8. I feel as if I am slowed down:

☐ *Nearly all of the time*
☐ *Very often*
☐ *Sometimes*
☐ *Not at all*

9. I get a sort of frightened feeling like "butterflies" in the stomach:

☐ *Not at all*
☐ *Occasionally*
☐ *Quite often*
☐ *Very often*

10. I have lost interest in my appearance:

☐ *Definitely*
☐ *I don't take as much care as I should*
☐ *I may not take as much care*
☐ *I take just as much care as ever*

11. I feel restless as if I have to be on the move:

☐ *Very much indeed*
☐ *Quite a lot*
☐ *Not very much*
☐ *Not at all*

12. I look forward with enjoyment to things:

☐ *As much as I ever did*
☐ *Rather less than I used to*
☐ *Definitely less than I used to*
☐ *Hardly at all*

13. I get sudden feelings of panic:

☐ *Very often indeed*
☐ *Quite often*
☐ *Not very often*
☐ *Not at all*

14. I can enjoy a good book or radio or TV programme

☐ *Often*
☐ *Sometimes*
☐ *Not often*
☐ *Very seldom*

© Claire Rutter

Section 11: How You deal with Unpleasant Situations

In this section I want to know how you think you might react in some unpleasant situations. Tick as many statements as you want, that apply to you.

1. Vividly imagine that you are **afraid** of the dentist and have to get some dental work done. Which of the following would you do? Place a tick against **all** of the statements that apply to you.

_____ I would ask the dentist exactly what he was going to do

_____ I would take a tranquilliser or have a drink before going

_____ I would try to think about pleasant memories

_____ I would want the dentist to tell me when I would feel pain

_____ I would try to sleep

_____ I would watch all the dentists movements and listen for the sound of the drill

_____ I would watch the flow of water from my mouth to see if it contained blood

_____ I would do mental puzzles in my mind

2. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Tick **all** the statements that might apply to you.

_____ I would sit by myself and have as many daydreams and fantasies as I could

_____ I would stay alert and try to keep myself from falling asleep

_____ I would exchange life stories with the other hostages

_____ If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing

_____ I would watch every movement of my captors and keep an eye on their weapons

_____ I would try to sleep as much as possible

_____ I would think about how nice it's going to be when I get home

_____ I would make sure I knew where every possible exit was

3. Vividly imagine that, due to a large drop in sales, it is rumoured that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about layoffs has been made and will be announced in several days. Tick **all** the statements that might apply to you.

_____ I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said

_____ I would review the list of duties for my present job and try to figure out if I had fulfilled them all

_____ I would go to the cinema to take my mind off things

_____ I would try to remember my arguments or disagreements I might have had with the supervisor that would have lowered his/her opinion of me.

_____ I would push all thoughts of being laid off out of my mind

_____ I would tell my partner that I'd rather not discuss my chances of being laid off

_____ I would try to think which employees in my department the supervisor might have thought had done the worst job

_____ I would continue doing my work as if nothing was happening

4. Vividly imagine that you are on an aeroplane, thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced all is well. Tick **all** of the statements that might apply to you.

_____ I would carefully read the information provided about the safety features in the plane and make sure I knew where the emergency exits were

_____ I would make small talk with the passenger beside me

_____ I would watch the end of the movie, even if I had seen it before

_____ I would call for the flight attendant and ask her exactly what the problem was

_____ I would order a drink or tranquilliser from the flight attendant

_____ I would listen carefully to the engines for unusual noises and would watch the crew to see if their behaviour was out of the ordinary

_____ I would talk to the passenger beside me about what might be wrong

_____ I would settle down and read a book or magazine or read a letter

Section 12: Coping with your IBS

This next section focuses upon the way you cope with your symptoms. Think about the times when your symptoms have been at their worst, and how you reacted to them. Now indicate the extent to which you did whatever each of the following statements says, using the key below.

1 = I usually don't do this at all.
2 = I usually do this a little bit.
3 = I usually do this a medium amount.
4 = I usually do this a lot.

1	I try to grow as a person as a result of the experience	
2	I turn to work or other substitute activities to take my mind off things	
3	I get upset and let my emotions out	
4	I try to get advice from someone about what to do	
5	I concentrate my efforts on doing something about it	
6	I say to myself "this isn't real"	
7	I put my trust in God	
8	I laugh about the situation	
9	I admit to myself that I can't deal with it, and give up trying	
10	I restrain myself from doing anything too quickly	
11	I discuss my feelings with someone	
12	I use alcohol or drugs to make myself feel better	
13	I get used to my symptoms	
14	I talk to someone to find out more about my symptoms	
15	I keep myself from getting distracted by other thoughts and activities	
16	I daydream about things	
17	I get upset and am really aware of it	
18	I seek God's help	
19	I make a plan of action	
20	I make jokes about it	
21	I accept my illness and that it can't be changed	
22	I hold off doing anything until the situation permits	

1 = I usually don't do this at all. 2 = I usually do this a little bit.

3 = I usually do this a medium amount. 4 = I usually do this a lot.

23	I try to get emotional support from friends and relatives	
24	I just give up trying to reach my goal	
25	I take additional action to try and get rid of the symptoms	
26	I try to lose myself for a while by drinking alcohol or taking drugs	
27	I refuse to believe it has happened	
28	I let my feelings out	
29	I try to see it in a different light, to make it seem more positive	
30	I talk to someone who can help	
31	I sleep more than usual	
32	I try to come up with a strategy about what to do	
33	I focus on dealing with this problem and, if necessary , let other things slide a little	
34	I get sympathy and understanding from someone	
35	I drink alcohol or take drugs, in order to think about it less	
36	I kid around about it	
37	I give up the attempt to get what I want	
38	I look for something good in what is happening	
39	I think about how I might best handle the problem	
40	I pretend that it hasn't really happened	
41	I make sure not to make matters worse by acting too soon	
42	I try hard to prevent other things from interfering with my efforts at dealing with this	
43	I go to the cinema or watch television to think about it less	
44	I accept the reality of the fact that I have this illness	
45	I ask people who have had similar experiences what they did	
46	I feel a lot of emotional distress and I find myself expressing those feelings a lot	
47	I take direct action to get around the illness	

1 = I usually don't do this at all. 2 = I usually do this a little bit.

3 = I usually do this a medium amount. 4 = I usually do this a lot.

48	I try to find comfort in my religion	
49	I force myself to wait for the right time to do something	
50	I make fun of the situation	
51	I reduce the amount of effort I'm putting into solving the problem of illness	
52	I talk to someone about how I feel	
53	I use alcohol or drugs to help me get through it	
54	I learn to live with it	
55	I put aside other activities in order to concentrate on this	
56	I think hard about what steps to take	
57	I act as though I don't have an illness	
58	I do what has to be done, one step at a time	
59	I learn something from the experience of illness	
60	I pray more than usual	

Section 13: How You see your Quality of Life with Illness

The last questionnaire I would like you to complete concerns how you feel about your quality of life, health and other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the ONE** that appears most appropriate. This can often be your first response.
Please keep in mind your standards, hopes, pleasures and concerns. I ask that you think about your life **in the LAST TWO WEEKS**. Circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither Poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things **in THE LAST TWO WEEKS.**

		Not at all	A little	A moderate amount	Very much	An extreme amount
3	How much do you feel that pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
6	To what extent do you feel life to be meaningful?	1	2	3	4	5
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experienced or were able to do certain things **in the LAST TWO WEEKS.**

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	To what extent do you have enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

The following questions ask you to say **how good or satisfied** you have felt about various aspects of your life **over the LAST TWO WEEKS.**

		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things **in the LAST TWO WEEKS.**

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

		Not at all	Not much	A moderate amount	Very much	An extreme amount
27	How fed up do you feel?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
28	How satisfied are you with your level of happiness?	1	2	3	4	5

Since joining the Network how many times have you been back to see your GP with IBS related symptoms?

____________ times

Section 14: Anything Else

Now please tell me anything else you feel is relevant here. Have any treatments or medications worked for you? Have any treatments made you feel worse?

Please feel free to add any more comments or suggestions about ways in which you think the Network can be improved

How long did this questionnaire take to complete? ____________

Thank you very much for completing this booklet. Please check that you have entered your name at the top of section one so that I can match this questionnaire with your previous questionnaire. Now simply put this booklet into the pre-paid envelope and post it back to me.

Thank you once again for helping in my research. Your help is invaluable to me. I look forward to reporting my results in a future edition of Gut Reaction.
Best wishes
Claire Rutter

© Claire Rutter

PAGE
MISSING
IN
ORIGINAL

Appendix C1

Information sheet given to new attenders at the outpatient clinic

(On University Headed Notepaper)
Claire L Rutter
Research Student
Dialling code for Canterbury:
01227 (UK) or +44 1227
(International)
Tel: 827147 direct line
764000 switchboard
(ext.7147)
Fax: 827030
Email: C.L.Rutter@ukc.ac.uk

Hello
My name is Claire, and I am a PhD student conducting research in health psychology with Dr Barton. My research is concerned with the way being ill can affect people both physically and emotionally. The aim of this research is to help sufferers cope successfully with their illness. The more we understand the processes that accompany illness the more we may be able to help.

I would like to invite you to participate in this research. If you decide to participate you will be asked to complete questionnaires at home. You will be asked to complete a maximum of three questionnaires over the following months: the stage two questionnaire should take approximately 5 minutes, and the stage three questionnaire should not take longer than 20 minutes to complete. The stage one questionnaire that you have been given today should take no longer than 10 minutes to complete. It may be the case that you are asked only to complete the first questionnaire; this depends on how the research progresses. For each stage of the study you will receive a prepaid envelope so that you can post completed questionnaires back to me.

Even if you decide to complete the first questionnaire you are under no obligation to participate any further. Participation is completely voluntary and if you decide not to take part this will not affect your medical care now or in the future.

Experiencing gastrointestinal symptoms and entering a gastroenterology clinic can be a stressful time for many patients. This research recognises these issues and would like to investigate this experience.

If you would like to participate please complete both consent forms and the stage one questionnaire given to you. Once completed place the consent form (researcher copy) and the stage one questionnaire into the prepaid envelope you were given. **All the information you give will be confidential. No one other than myself will ever see your completed questionnaires. The data from all questionnaires will be combined with other patients so no one will ever be able to identify any individual.**

By giving your consent you are under no obligation to continue in this research if you do not wish. You are free to withdraw at any time.

If you need to discuss any of the above please do not hesitate to contact me.

Thank you and best wishes
Claire Rutter

Appendix C2

Time 1 Questionnaire – before diagnosis (given to all patients)

KENT
UNIVERSITY OF KENT
AT CANTERBURY

Stage One Questionnaire

Most of the measures contained in this booklet ask you to circle or tick your preferred choice (i.e. the one that best describes the way you feel). **Try not to spend too long thinking about specific questions, your initial choice for each question should take no more than a few seconds. This questionnaire booklet should take around 15 minutes to complete.**

There are no right or wrong answers.

No one other than the researcher (named below) will see your completed answers. Your data will be combined with other patients so no one will ever be able to identify any individual.

Researcher: Miss Claire Rutter

This small questionnaire booklet is designed to ask you questions about the symptoms you experience. Try and answer as accurately as possible.

1. Please list the symptoms that you are experiencing

______________ ______________ ______________

______________ ______________ ______________

______________ ______________ ______________

2. Next to each symptom please write how long (approximately) you have been experiencing these problems.

3. Please try to explain why you think you suffer from these symptoms.

____

____

____

____

____

4. How long was it from the first experience of your symptoms to your appointment with your GP?

______________ days / weeks / months (please delete as appropriate)

5. How long was it from seeing your GP, to your first appointment with a gastroenterologist?

______________ days / weeks / months (please delete as appropriate)

6. Have you been happy with the service provided?

Yes / No Why?______________________________________

____

7. Now I would like you to think back to the time before you consulted your GP. What was the most important reason for your attendance?

____

8. Do you know of anybody, friends/family/casual acquaintances that have suffered from any gastrointestinal illnesses?

Yes / No

If yes, please state what this / these person(s) was diagnosed with.

9. What investigation(s) have you had already?

10. What investigation(s) are you expecting to have in the future?

11. Do you have any worries about any of the investigations?

12. Is there anything you think that could be done to decrease your worries about these investigations?

Thank you for answering the above questions. I hope these will help us to understand the experiences of people in your situation better.
Now I would like you to complete a series of short measures.

Below is a list of common symptoms or bodily sensations. Most people have experienced most of them at one time or another. I am interested in finding out how prevalent each symptom is. Using the scale below, write beside each symptom the letter that indicates how frequently you experience that symptom.

A **Have never or almost never experienced the symptom**	**B** **Less than 3 or 4 times per year**	**C** **Every month or so**	**D** **Every week or so**	**E** **More than once every week**

	Symptoms	Your Response
1	Eyes water	
2	Itching or painful eyes	
3	Ringing in ears	
4	Temporary deafness or hard of hearing	
5	Lump in throat	
6	Choking sensation	
7	Sneezing spells	
8	Running nose	
9	Congested nose	
10	Bleeding nose	
11	Asthma or wheezing	
12	Coughing	
13	Out of breath	
14	Swollen ankles	
15	Chest pains	
16	Racing heart	
17	Cold hands or feet even in hot weather	
18	Leg cramps	
19	Insomnia	
20	Toothaches	
21	Upset stomach	
22	Indigestion	
23	Heartburn	
24	Severe pains or cramps in stomach	
25	Diarrhoea	
26	Constipation	
27	Haemorrhoids	
28	Swollen joints	
29	Stiff muscles	
30	Back pains	
31	Sensitive or tender skin	
32	Face flushes	
33	Severe itching	
34	Skin breaks out in a rash	
35	Acne or pimples on face	
36	Acne or pimples other than on face	
37	Boils	
38	Sweat even in cold weather	
39	Strong reactions to insect bites	

A Have never or almost never experienced the symptom	B Less than 3 or 4 times per year	C Every month or so	D Every week or so	E More than once every week

40	Headaches	
41	Sensation of pressure in head	
42	Hot flushes	
43	Chills	
44	Dizziness	
45	Feel faint	
46	Numbness or tingling in any part of body	
47	Twitching of eyelid	
48	Twitching other than eyelid	
49	Hands tremble or shake	
50	Stiff joints	
51	Sore muscles	
52	Sore throat	
53	Sunburn	
54	Nausea	

Please tick the response that best describes you

	Not at all True	Barely True	Moderately True	Exactly True
I can always manage to solve difficult problems if I try hard enough				
If someone opposes me, I can find means and ways to get what I want				
It is easy for me to stick to my aims and accomplish my goals				
I am confident that I could deal efficiently with unexpected events				
Thanks to my resourcefulness, I know how to handle unforeseen situations				
I can solve most problems if I invest the necessary effort				
I can remain calm when facing difficulties because I can rely on my coping abilities				
When I am confronted with a problem, I can usually find several solutions				
If I am in a bind, I can usually think of something to do				
No matter what comes my way, I'm usually able to handle it				

Please read each of the 21 statements and for each one tick the response that best describes you.

When I feel angry (very annoyed)…….	Almost Never	Sometimes	Often	Almost Always
I keep quiet				
I refuse to argue or say anything				
I bottle it up				
I say what I feel				
I avoid making a scene				
I smother (cover up) my feelings				
I hide my annoyance				

When I feel unhappy (miserable)…….	Almost Never	Sometimes	Often	Almost Always
I refuse to do anything about it				
I hide my unhappiness				
I put on a bold face				
I keep quiet				
I let others see how I feel				
I smother (cover up) my feelings				
I bottle it up				

When I feel afraid (worried)…….	Almost Never	Sometimes	Often	Almost Always
I let others see how I feel				
I keep quiet				
I refuse to say anything about it				
I tell others about it				
I say what I feel				
I bottle it up				
I smother (cover up) my feelings				

The following table has a list of statements that may or may not be true for you. There are no "correct" or "incorrect" answers. Answer according to your own feelings, rather than how you think "most people" would answer. Please place a tick in the appropriate column.

	Strongly Disagree 0	Disagree 1	Neutral 2	Agree 3	Strongly Agree 4
1. In uncertain times, I usually expect the best.					
2. It's easy for me to relax					
3. If something can go wrong for me, it will					
4. I'm always optimistic about my future					
5. I enjoy my friends a lot					
6. It's important for me to keep busy					
7. I hardly ever expect things to go my way					
8. I don't get upset too easily					
9. I rarely count on good things happening to me					
10. Overall, I expect more good things to happen to me than bad					

This scale consists of a number of words that describe different feelings and emotions. Read each item and then tick the best answer.

Please indicate to what extent you have felt this way during the past few weeks.

	1 Very Slightly	**2 A Little**	**3 Moderately**	**4 Quite a Bit**	**5 Extremely**
Interested					
Distressed					
Excited					
Upset					
Strong					
Guilty					
Scared					
Hostile					
Enthusiastic					
Proud					
Irritable					
Alert					
Ashamed					
Inspired					
Nervous					
Determined					
Attentive					
Jittery					
Active					
Afraid					

In this section I want to know how you think you might react in some unpleasant situations. Tick as many statements as you want, that apply to you.

1. Vividly imagine that, due to a large drop in sales, it is rumoured that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about layoffs has been made and will be announced in several days. Tick **all** the statements that might apply to you.

_____ I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said

_____ I would review the list of duties for my present job and try to figure out if I had fulfilled them all

_____ I would go to the cinema to take my mind off things

_____ I would try to remember my arguments or disagreements I might have had with the supervisor that would have lowered his/her opinion of me.

_____ I would push all thoughts of being laid off out of my mind

_____ I would tell my partner that I'd rather not discuss my chances of being laid off

_____ I would try to think which employees in my department the supervisor might have thought had done the worst job

_____ I would continue doing my work as if nothing was happening

2. Vividly imagine that you are on an aeroplane, thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced all is well. Tick **all** of the statements that might apply to you.

_____ I would carefully read the information provided about the safety features in the plane and make sure I knew where the emergency exits were

_____ I would make small talk with the passenger beside me

_____ I would watch the end of the movie, even if I had seen it before

_____ I would call for the flight attendant and ask her exactly what the problem was

_____ I would order a drink or tranquilliser from the flight attendant

_____ I would listen carefully to the engines for unusual noises and would watch the crew to see if their behaviour was out of the ordinary

_____ I would talk to the passenger beside me about what might be wrong

_____ I would settle down and read a book or magazine or read a letter

3. Vividly imagine that you are **afraid** of the dentist and have to get some dental work done. Which of the following would you do? Place a tick against **all** of the statements that apply to you.

_____ I would ask the dentist exactly what he was going to do

_____ I would take a tranquilliser or have a drink before going

_____ I would try to think about pleasant memories

_____ I would want the dentist to tell me when I would feel pain

_____ I would try to sleep

_____ I would watch all the dentists movements and listen for the sound of the drill

_____ I would watch the flow of water from my mouth to see if it contained blood

_____ I would do mental puzzles in my mind

4. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Tick **all** the statements that might apply to you.

_____ I would sit by myself and have as many daydreams and fantasies as I could

_____ I would stay alert and try to keep myself from falling asleep

_____ I would exchange life stories with the other hostages

_____ If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing

_____ I would watch every movement of my captors and keep an eye on their weapons

_____ I would try to sleep as much as possible

_____ I would think about how nice it's going to be when I get home

_____ I would make sure I knew where every possible exit was

Thank you for taking the time to complete this questionnaire. If you are interested in completing the stage two and three questionnaires please enter your name and address here:

Name______________________________ Address_______________________

____

<u>If you have not provided your name and address I can not contact you.</u>

Thank you for your help.

Appendix C3

Time 2 letter to clinic patients (IBS Version only)

(On university headed notepaper)
Claire L Rutter
Research Student
Dialling code for Canterbury:
01227 (UK) or +44 1227
(International)
Tel: 827147 direct line
764000 switchboard
(ext.7147)
Fax: 827030
Email: C.L.Rutter@ukc.ac.uk

(Patient Name)
(Patient Address)

(Date)

Dear (Patient Name)

Thank you for returning the stage one questionnaire. Dr Barton has informed me that he has given you a diagnosis of IBS. I hope things are not too bad for you at the moment. I am writing to ask if you would like to continue with my research.

I have included the stage two questionnaire, which should not take any longer than 5 minutes to complete. If you would like to continue, please complete the enclosed questionnaire and send it back in the prepaid envelope provided. I will send you the stage three questionnaire approximately 2 months after a receiving the stage two questionnaire enclosed today. The final stage three questionnaire should take about 20 minutes to complete and concludes the current research.

Remember that your participation is completely voluntary and if you decide not to take part this will not affect your medical care now or in the future.

Whatever you decide, it would really help me if you would complete the reply slip contained here (please use block capitals) and send it to me in the prepaid envelope provided (with the stage two questionnaire).

Thank you and best wishes.

Miss Claire Rutter
Research Student

Centre for Research in Health Behaviour, Department of Psychology, University of Kent at Canterbury, Canterbury, Kent CT2 7NP

✂--

Please tick as appropriate;

☐ I do not wish to participate any further with this research.

☐ I would like to continue with this research, please send me the stage three measures. I have completed the stage two measure. (The stage two measure is enclosed).

Name ____________________ Address ______________________________

Please feel free to add any comments you may have about this research

Appendix C4

Time 2 Questionnaire IBS and IBD version

UNIVERSITY OF KENT
AT CANTERBURY

Stage Two Measure

Thank you for participating in this research.

The scale below tries to assess your thoughts and feelings about the illness you have been diagnosed with.

There are no right or wrong answers. I am just interested in how you view your illness.

No one other than the researcher (named below) will see your completed answers. Your data will be combined with other patients so no one will ever be able to identify any individual.

Researcher: Miss Claire Rutter

I am interested in your own personal views of how you see your illness. Please indicate how much you agree or disagree with the following statements about your illness

		Strongly Agree	**Agree**	**Neither Agree or Disagree**	**Disagree**	**Strongly Disagree**
1	A germ or virus caused my IBS					
2	My IBS was caused by poor medical care in the past					
3	There is little that can be done to improve my IBS					
4	My IBS is hereditary – it runs in my family					
5	My IBS will last a short time					
6	What I do can determine whether my IBS gets better or worse					
7	My IBS has strongly affected the way I see myself as a person					
8	Stress was a major factor in causing my IBS					
9	My IBS is a serious condition					
10	Pollution in the environment caused my IBS					
11	It was just by chance that I developed IBS					
12	My IBS has become easier to live with					
13	My IBS has serious economic and financial consequences					
14	My IBS has strongly affected the way others see me					
15	My state of mind played a major part in causing my IBS					
16	My treatments will be effective in curing my IBS					
17	Diet played a major role in causing my IBS					
18	My IBS is likely to be permanent rather than temporary					
19	My IBS will improve in time					
20	Recovery from my IBS is largely dependent on chance or fate					
21	My IBS has had major consequences on my life					
22	Other people played a large role in causing my IBS					
23	There is a lot I can do to control my symptoms					
24	My IBS will last for a long time					
25	My IBS is largely due to my own behaviour					
26	My IBS has not had much effect on my life					

NAME ______________________________

KENT
UNIVERSITY OF KENT
AT CANTERBURY

Stage Two Measure

Thank you for participating in this research.

The scale below tries to assess your thoughts and feelings about the illness you have been diagnosed with.

There are no right or wrong answers. I am just interested in how you view your illness.

No one other than the researcher (named below) will see your completed answers. Your data will be combined with other patients so no one will ever be able to identify any individual.

Researcher: Miss Claire Rutter

I am interested in your own personal views of how you see your illness. Please indicate how much you agree or disagree with the following statements about your illness

		Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
1	A germ or virus caused my IBD					
2	My IBD was caused by poor medical care in the past					
3	There is little that can be done to improve my IBD					
4	My IBD is hereditary – it runs in my family					
5	My IBD will last a short time					
6	What I do can determine whether my IBD gets better or worse					
7	My IBD has strongly affected the way I see myself as a person					
8	Stress was a major factor in causing my IBD					
9	My IBD is a serious condition					
10	Pollution in the environment caused my IBD					
11	It was just by chance that I developed IBD					
12	My IBD has become easier to live with					
13	My IBD has serious economic and financial consequences					
14	My IBD has strongly affected the way others see me					
15	My state of mind played a major part in causing my IBD					
16	My treatments will be effective in curing my IBD					
17	Diet played a major role in causing my IBD					
18	My IBD is likely to be permanent rather than temporary					
19	My IBD will improve in time					
20	Recovery from my IBD is largely dependent on chance or fate					
21	My IBD has had major consequences on my life					
22	Other people played a large role in causing my IBD					
23	There is a lot I can do to control my symptoms					
24	My IBD will last for a long time					
25	My IBD is largely due to my own behaviour					
26	My IBD has not had much effect on my life					

NAME ________________________________

Appendix C5

Time 3 letter to clinic patients

(On University headed notepaper)
Claire L Rutter
Research Student
Dialling code for Canterbury:
01227 (UK) or +44 1227 (International)
Tel: 827147 direct line
764000 switchboard (ext.7147)
Fax: 827030
Email:
C.L.Rutter@ukc.ac.uk

(Patient Name)
(Patient Address)

(Date)

Dear (Patient Pame)

Thank you for completing the stage two questionnaire. It has now been approximately two months since I received this from you. I have enclosed the final stage three questionnaire; I hope you decide to complete this research. This questionnaire should take no longer than 20 minutes to complete. This is the final questionnaire, that I need from you to complete my research.

As I mentioned previously, I will write to you when I have analysed my data to inform you of my findings (in approximately July 2001, at which point I should have submitted my thesis), at this time I should also be able to tell you where I expect to publish my research.

If you have any questions about this research, please feel free to contact me.

Also if you have a change of address between now and the summer, please let me know, I like to make sure that everyone who helps me is kept informed of my research.

Thank you for participating in my research, your help has been invaluable to me.

Best wishes

Miss Claire Rutter
Research Student

Appendix C6

Time 3 Questionnaire (IBS and IBD versions)

UNIVERSITY OF KENT
AT CANTERBURY

Stage Three Measures

Thank you for continuing to participate in this research.

These last measures contained in this booklet once again ask you to circle or tick your preferred choice (i.e. the one that best describes the way you feel). **Try not to spend too long thinking about specific questions, your initial choice for each question should take no more than a few seconds.**

There are no right or wrong answers.

No one other than the researcher (named below) will see your completed answers. Your data will be combined with other patients so no one will ever be able to identify any individual.

Researcher: Miss Claire Rutter

This section asks you for information regarding your personal situation. Please try and answer all questions. Answers are for statistical purposes only.

Name____________________ Male / Female (please circle) Date of birth ____/____/____

Marital status (please circle)

Single Married Divorced Separated Widowed Co-habiting

Number of children (with ages)____

Please state highest academic qualification achieved _______________________

Occupation __________________________ If no occupation, is this due to your symptoms? Yes / No

Part time / Full time (please circle) If part time, is this due to your symptoms? Yes / No

Please estimate how many days sick you have taken in the past year _______

I first experienced bowel and related symptoms _____________(As near to the date as possible)

I was diagnosed with Irritable Bowel Syndrome _____________(As near to the date as possible)

I have been to the GP about my irritable bowel and related symptoms (approximately) _____________ times, and saw (please circle)

same GP / two GP's / 3 or more GP's

Below is a list of Irritable Bowel symptoms that you may, or may not have been suffering from. Please rate each one for your experience of the symptom by placing a tick in the appropriate box.

	I have never experienced this symptom	**Less than 3 or 4 times per year**	**Every month or so**	**Every week or so**	**More than once every week**
Abdominal Pain					
Diarrhoea					
Bloating					
Wind					
Constipation					
Blood in stools					
Incomplete evacuation of the bowel					
Passage of mucus					
Incontinence					
Rumbling and grumbling					

Please tick the appropriate box of each statement to show how strongly you agree or disagree with it. There are no right or wrong answers. I am interested just in your opinion.

		Strongly Disagree	**Disagree**	**Tend to Disagree**	**Tend to Agree**	**Agree**	**Strongly Agree**
1	All doctors are good doctors						
2	Medicine is based on scientific principles						
3	I only consult a doctor if I am at death's door						
4	Medicines can do as much harm as good						
5	I have absolute faith and confidence in all hospital doctors						
6	The improved health of the nation is due to effective medicine						
7	Doctors blame their patients if their treatment doesn't work						
8	The advice of doctors is mainly common sense						
9	No matter how long you have to wait and see a doctor, it's worth it						
10	Medicine has cures for most diseases						
11	Doctors are important in keeping us healthy						
12	No two doctors will agree on what is wrong with a person						
13	Many medicines are just placebos or sugar pills						
14	Doctors are too ready to solve patients' problems by prescribing tranquillisers						
15	Often the only purpose of tests is to make the doctor feel less anxious						
16	Doctors know what's best for you						
17	I don't like medical people						
18	Most tests and investigations are done routinely rather than for a particular purpose						
19	Medicine is the best profession a person can have						

You have already completed this scale (the stage two measure), but I would like you to complete it again so that I can see if your attitudes have changed in the intervening time.

	Strongly Agree	**Agree**	**Neither Agree or Disagree**	**Disagree**	**Strongly Disagree**
A germ or virus caused my IBS					
My IBS was caused by poor medical care in the past					
There is little that can be done to improve my IBS					
My IBS is hereditary – it runs in my family					
My IBS will last a short time					
What I do can determine whether my IBS gets better or worse					
My IBS has strongly affected the way I see myself as a person					
Stress was a major factor in causing my IBS					
My IBS is a serious condition					
Pollution in the environment caused my IBS					
It was just by chance that I developed IBS					
My IBS has become easier to live with					
My IBS has serious economic and financial consequences					
My IBS has strongly affected the way others see me					
My state of mind played a major part in causing my IBS					
My treatments will be effective in curing my IBS					
Diet played a major role in causing my IBS					
My IBS is likely to be permanent rather than temporary					
My IBS will improve in time					
Recovery from my IBS is largely dependent on chance or fate					
My IBS has had major consequences on my life					
Other people played a large role in causing my IBS					
There is a lot I can do to control my symptoms					
My IBS will last for a long time					
My IBS is largely due to my own behaviour					
My IBS has not had much effect on my life					

Please tick the response that best describes the way you have been feeling in the past two weeks

1. **I feel tense or "wound up":**
   - ☐ *Most of the time*
   - ☐ *A lot of the time*
   - ☐ *From time to time, occasionally*
   - ☐ *Not at all*
2. **I still enjoy the things I used to enjoy:**
   - ☐ *Definitely as much*
   - ☐ *Not quite so much*
   - ☐ *Only a little*
   - ☐ *Hardly at all*
3. **I get a sort of frightened feeling as if something awful is about to happen:**
   - ☐ *Very definitely and quite badly*
   - ☐ *Yes, but not too badly*
   - ☐ *A little, but it doesn't worry me*
   - ☐ *Not at all*
4. **I can laugh and see the funny side of things:**
   - ☐ *As much as I always could*
   - ☐ *Not quite so much now*
   - ☐ *Definitely not so much now*
   - ☐ *Not at all*
5. **Worrying thoughts go through my mind:**
   - ☐ *A great deal of the time*
   - ☐ *A lot of the time*
   - ☐ *From time to time, but not too often*
   - ☐ *Only occasionally*
6. **I feel cheerful:**
   - ☐ *Not at all*
   - ☐ *Not often*
   - ☐ *Sometimes*
   - ☐ *Most of the time*
7. **I can sit at ease and feel relaxed:**
   - ☐ *Definitely*
   - ☐ *Usually*
   - ☐ *Not often*
   - ☐ *Not at all*

8. **I feel as if I am slowed down:**
   - ☐ *Nearly all of the time*
   - ☐ *Very often*
   - ☐ *Sometimes*
   - ☐ *Not at all*

9. **I get a sort of frightened feeling like "butterflies" in the stomach:**
   - ☐ *Not at all*
   - ☐ *Occasionally*
   - ☐ *Quite often*
   - ☐ *Very often*

10. **I have lost interest in my appearance:**
    - ☐ *Definitely*
    - ☐ *I don't take as much care as I should*
    - ☐ *I may not take as much care*
    - ☐ *I take just as much care as ever*

11. **I feel restless as if I have to be on the move:**
    - ☐ *Very much indeed*
    - ☐ *Quite a lot*
    - ☐ *Not very much*
    - ☐ *Not at all*

12. **I look forward with enjoyment to things:**
    - ☐ *As much as I ever did*
    - ☐ *Rather less than I used to*
    - ☐ *Definitely less than I used to*
    - ☐ *Hardly at all*

13. **I get sudden feelings of panic:**
    - ☐ *Very often indeed*
    - ☐ *Quite often*
    - ☐ *Not very often*
    - ☐ *Not at all*

14. **I can enjoy a good book or radio or TV programme**
    - ☐ *Often*
    - ☐ *Sometimes*
    - ☐ *Not often*
    - ☐ *Very seldom*

This next section focuses upon the way you cope with your symptoms. Think about the times when your **symptoms have been at their worst, and how you reacted to them**. Now indicate the extent to which you did whatever each of the following statements says, using the key below.

1 = I usually don't do this at all.	2 = I usually do this a little bit.
3 = I usually do this a medium amount.	4 = I usually do this a lot.

1	I try to grow as a person as a result of the experience	
2	I turn to work or other substitute activities to take my mind off things	
3	I get upset and let my emotions out	
4	I try to get advice from someone about what to do	
5	I concentrate my efforts on doing something about it	
6	I say to myself "this isn't real"	
7	I put my trust in God	
8	I laugh about the situation	
9	I admit to myself that I can't deal with it, and give up trying	
10	I restrain myself from doing anything too quickly	
11	I discuss my feelings with someone	
12	I use alcohol or drugs to make myself feel better	
13	I get used to my symptoms	
14	I talk to someone to find out more about my symptoms	
15	I keep myself from getting distracted by other thoughts and activities	
16	I daydream about things	
17	I get upset and am really aware of it	
18	I seek God's help	
19	I make a plan of action	
20	I make jokes about it	
21	I accept my illness and that it can't be changed	
22	I hold off doing anything until the situation permits	

1 = I usually don’t do this at all. 2 = I usually do this a little bit.

3 = I usually do this a medium amount. 4 = I usually do this a lot.

23	I try to get emotional support from friends and relatives	
24	I just give up trying to reach my goal	
25	I take additional action to try and get rid of the symptoms	
26	I try to lose myself for a while by drinking alcohol or taking drugs	
27	I refuse to believe it has happened	
28	I let my feelings out	
29	I try to see it in a different light, to make it seem more positive	
30	I talk to someone who can help	
31	I sleep more than usual	
32	I try to come up with a strategy about what to do	
33	I focus on dealing with this problem and, if necessary , let other things slide a little	
34	I get sympathy and understanding from someone	
35	I drink alcohol or take drugs, in order to think about it less	
36	I kid around about it	
37	I give up the attempt to get what I want	
38	I look for something good in what is happening	
39	I think about how I might best handle the problem	
40	I pretend that it hasn’t really happened	
41	I make sure not to make matters worse by acting too soon	
42	I try hard to prevent other things from interfering with my efforts at dealing with this	
43	I go to the cinema or watch television to think about it less	
44	I accept the reality of the fact that I have this illness	
45	I ask people who have had similar experiences what they did	
46	I feel a lot of emotional distress and I find myself expressing those feelings a lot	
47	I take direct action to get around the illness	

1 = I usually don't do this at all.	2 = I usually do this a little bit.
3 = I usually do this a medium amount.	4 = I usually do this a lot.

48	I try to find comfort in my religion	
49	I force myself to wait for the right time to do something	
50	I make fun of the situation	
51	I reduce the amount of effort I'm putting into solving the problem of illness	
52	I talk to someone about how I feel	
53	I use alcohol or drugs to help me get through it	
54	I learn to live with it	
55	I put aside other activities in order to concentrate on this	
56	I think hard about what steps to take	
57	I act as though I don't have an illness	
58	I do what has to be done, one step at a time	
59	I learn something from the experience of illness	
60	I pray more than usual	

The last measure I would like you to complete concerns how you feel about your quality of life, health and other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the ONE** that appears most appropriate. This can often be your first response.
Please keep in mind your standards, hopes, pleasures and concerns. I ask that you think about your life **in the last two weeks**. Circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither Poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things **in the last two weeks.**

		Not at all	A little	A moderate amount	Very much	An extreme amount
3	How much do you feel that pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
6	To what extent do you feel life to be meaningful?	1	2	3	4	5
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experienced or were able to do certain things **in the last two weeks.**

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	To what extent do you have enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

The following questions ask you to say **how good or satisfied** you have felt about various aspects of your life **over the last two weeks.**

		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things **in the last two weeks.**

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

		Not at all	Not much	A moderate amount	Very much	An extreme amount
27	How fed up do you feel?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
28	How satisfied are you with your level of happiness?	1	2	3	4	5

Thank you very much for participating in this research, without your help research like this could not be carried out. I will write to you in autumn 2001 to inform you of my findings and to tell you where I expect to publish this research.

I wish you well in the future. Thanks once again!

Claire

KENT
UNIVERSITY OF KENT
AT CANTERBURY

Stage Three Measures

Thank you for continuing to participate in this research.

These last measures contained in this booklet once again ask you to circle or tick your preferred choice (i.e. the one that best describes the way you feel). **Try not to spend too long thinking about specific questions, your initial choice for each question should take no more than a few seconds.**

There are no right or wrong answers.

No one other than the researcher (named below) will see your completed answers. Your data will be combined with other patients so no one will ever be able to identify any individual.

Researcher: Miss Claire Rutter

This section asks you for information regarding your personal situation. Please try and answer all questions. Answers are for statistical purposes only.

Name ____________________ Male / Female (please circle) Date of birth _____/_____/_____

Marital status (please circle)

Single Married Divorced Separated Widowed Co-habiting

Number of children (with ages) ____

Please state highest academic qualification achieved ________________________________

Occupation ____________________________ If no occupation, is this due to your symptoms? Yes / No

Part time / Full time (please circle) If part time, is this due to your symptoms? Yes / No

Please estimate how many days sick you have taken in the past year ________

I first experienced bowel and related symptoms ______________(As near to the date as possible)

I was diagnosed with Inflammatory Bowel Disease ________________ (As near to the date as possible)

I have been to the GP about my bowel and related symptoms (approximately) ____________ times, and saw (please circle)

same GP / two GP's / 3 or more GP's

Below is a list of Inflammatory bowel symptoms that you may, or may not have been suffering from. Please rate each one for your experience of the symptom by placing a tick in the appropriate box.

	I have never experienced this symptom	**Less than 3 or 4 times per year**	**Every month or so**	**Every week or so**	**More than once every week**
Abdominal Pain					
Diarrhoea					
Bloating					
Wind					
Constipation					
Blood in stools					
Incomplete evacuation of the bowel					
Passage of mucus					
Incontinence					
Rumbling and grumbling					

Please tick the appropriate box of each statement to show how strongly you agree or disagree with it. There are no right or wrong answers. I am interested just in your opinion.

		Strongly Disagree	**Disagree**	**Tend to Disagree**	**Tend to Agree**	**Agree**	**Strongly Agree**
1	All doctors are good doctors						
2	Medicine is based on scientific principles						
3	I only consult a doctor if I am at death's door						
4	Medicines can do as much harm as good						
5	I have absolute faith and confidence in all hospital doctors						
6	The improved health of the nation is due to effective medicine						
7	Doctors blame their patients if their treatment doesn't work						
8	The advice of doctors is mainly common sense						
9	No matter how long you have to wait and see a doctor, it's worth it						
10	Medicine has cures for most diseases						
11	Doctors are important in keeping us healthy						
12	No two doctors will agree on what is wrong with a person						
13	Many medicines are just placebos or sugar pills						
14	Doctors are too ready to solve patients' problems by prescribing tranquillisers						
15	Often the only purpose of tests is to make the doctor feel less anxious						
16	Doctors know what's best for you						
17	I don't like medical people						
18	Most tests and investigations are done routinely rather than for a particular purpose						
19	Medicine is the best profession a person can have						

You have already completed this scale (the stage two measure), but I would like you to complete it again so that I can see if your attitudes have changed in the intervening time.

	Strongly Agree	**Agree**	**Neither Agree or Disagree**	**Disagree**	**Strongly Disagree**
A germ or virus caused my IBD					
My IBD was caused by poor medical care in the past					
There is little that can be done to improve my IBD					
My IBD is hereditary – it runs in my family					
My IBD will last a short time					
What I do can determine whether my IBD gets better or worse					
My IBD has strongly affected the way I see myself as a person					
Stress was a major factor in causing my IBD					
My IBD is a serious condition					
Pollution in the environment caused my IBD					
It was just by chance that I developed IBD					
My IBD has become easier to live with					
My IBD has serious economic and financial consequences					
My IBD has strongly affected the way others see me					
My state of mind played a major part in causing my IBD					
My treatments will be effective in curing my IBD					
Diet played a major role in causing my IBD					
My IBD is likely to be permanent rather than temporary					
My IBD will improve in time					
Recovery from my IBD is largely dependent on chance or fate					
My IBD has had major consequences on my life					
Other people played a large role in causing my IBD					
There is a lot I can do to control my symptoms					
My IBD will last for a long time					
My IBD is largely due to my own behaviour					
My IBD has not had much effect on my life					

Please tick the response that best describes the way you have been feeling in the past two weeks

1. **I feel tense or "wound up":**
   - ☐ *Most of the time*
   - ☐ *A lot of the time*
   - ☐ *From time to time, occasionally*
   - ☐ *Not at all*
2. **I still enjoy the things I used to enjoy:**
   - ☐ *Definitely as much*
   - ☐ *Not quite so much*
   - ☐ *Only a little*
   - ☐ *Hardly at all*
3. **I get a sort of frightened feeling as if something awful is about to happen:**
   - ☐ *Very definitely and quite badly*
   - ☐ *Yes, but not too badly*
   - ☐ *A little, but it doesn't worry me*
   - ☐ *Not at all*
4. **I can laugh and see the funny side of things:**
   - ☐ *As much as I always could*
   - ☐ *Not quite so much now*
   - ☐ *Definitely not so much now*
   - ☐ *Not at all*
5. **Worrying thoughts go through my mind:**
   - ☐ *A great deal of the time*
   - ☐ *A lot of the time*
   - ☐ *From time to time, but not too often*
   - ☐ *Only occasionally*
6. **I feel cheerful:**
   - ☐ *Not at all*
   - ☐ *Not often*
   - ☐ *Sometimes*
   - ☐ *Most of the time*
7. **I can sit at ease and feel relaxed:**
   - ☐ *Definitely*
   - ☐ *Usually*
   - ☐ *Not often*
   - ☐ *Not at all*

8. I feel as if I am slowed down:

☐ *Nearly all of the time*
☐ *Very often*
☐ *Sometimes*
☐ *Not at all*

9. I get a sort of frightened feeling like "butterflies" in the stomach:

☐ *Not at all*
☐ *Occasionally*
☐ *Quite often*
☐ *Very often*

10. I have lost interest in my appearance:

☐ *Definitely*
☐ *I don't take as much care as I should*
☐ *I may not take as much care*
☐ *I take just as much care as ever*

11. I feel restless as if I have to be on the move:

☐ *Very much indeed*
☐ *Quite a lot*
☐ *Not very much*
☐ *Not at all*

12. I look forward with enjoyment to things:

☐ *As much as I ever did*
☐ *Rather less than I used to*
☐ *Definitely less than I used to*
☐ *Hardly at all*

13. I get sudden feelings of panic:

☐ *Very often indeed*
☐ *Quite often*
☐ *Not very often*
☐ *Not at all*

14. I can enjoy a good book or radio or TV programme

☐ *Often*
☐ *Sometimes*
☐ *Not often*
☐ *Very seldom*

This next section focuses upon the way you cope with your symptoms. Think about the times when your **symptoms have been at their worst, and how you reacted to them**. Now indicate the extent to which you did whatever each of the following statements says, using the key below.

1 = I usually don't do this at all.	2 = I usually do this a little bit.
3 = I usually do this a medium amount.	4 = I usually do this a lot.

1	I try to grow as a person as a result of the experience	
2	I turn to work or other substitute activities to take my mind off things	
3	I get upset and let my emotions out	
4	I try to get advice from someone about what to do	
5	I concentrate my efforts on doing something about it	
6	I say to myself "this isn't real"	
7	I put my trust in God	
8	I laugh about the situation	
9	I admit to myself that I can't deal with it, and give up trying	
10	I restrain myself from doing anything too quickly	
11	I discuss my feelings with someone	
12	I use alcohol or drugs to make myself feel better	
13	I get used to my symptoms	
14	I talk to someone to find out more about my symptoms	
15	I keep myself from getting distracted by other thoughts and activities	
16	I daydream about things	
17	I get upset and am really aware of it	
18	I seek God's help	
19	I make a plan of action	
20	I make jokes about it	
21	I accept my illness and that it can't be changed	
22	I hold off doing anything until the situation permits	

1 = I usually don’t do this at all.
2 = I usually do this a little bit.
3 = I usually do this a medium amount.
4 = I usually do this a lot.

23	I try to get emotional support from friends and relatives	
24	I just give up trying to reach my goal	
25	I take additional action to try and get rid of the symptoms	
26	I try to lose myself for a while by drinking alcohol or taking drugs	
27	I refuse to believe it has happened	
28	I let my feelings out	
29	I try to see it in a different light, to make it seem more positive	
30	I talk to someone who can help	
31	I sleep more than usual	
32	I try to come up with a strategy about what to do	
33	I focus on dealing with this problem and, if necessary , let other things slide a little	
34	I get sympathy and understanding from someone	
35	I drink alcohol or take drugs, in order to think about it less	
36	I kid around about it	
37	I give up the attempt to get what I want	
38	I look for something good in what is happening	
39	I think about how I might best handle the problem	
40	I pretend that it hasn’t really happened	
41	I make sure not to make matters worse by acting too soon	
42	I try hard to prevent other things from interfering with my efforts at dealing with this	
43	I go to the cinema or watch television to think about it less	
44	I accept the reality of the fact that I have this illness	
45	I ask people who have had similar experiences what they did	
46	I feel a lot of emotional distress and I find myself expressing those feelings a lot	
47	I take direct action to get around the illness	

1 = I usually don't do this at all.	2 = I usually do this a little bit.
3 = I usually do this a medium amount.	4 = I usually do this a lot.

48	I try to find comfort in my religion	
49	I force myself to wait for the right time to do something	
50	I make fun of the situation	
51	I reduce the amount of effort I'm putting into solving the problem of illness	
52	I talk to someone about how I feel	
53	I use alcohol or drugs to help me get through it	
54	I learn to live with it	
55	I put aside other activities in order to concentrate on this	
56	I think hard about what steps to take	
57	I act as though I don't have an illness	
58	I do what has to be done, one step at a time	
59	I learn something from the experience of illness	
60	I pray more than usual	

The last measure I would like you to complete concerns how you feel about your quality of life, health and other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the ONE** that appears most appropriate. This can often be your first response.
Please keep in mind your standards, hopes, pleasures and concerns. I ask that you think about your life **in the last two weeks**. Circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither Poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things **in the last two weeks.**

		Not at all	A little	A moderate amount	Very much	An extreme amount
3	How much do you feel that pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
6	To what extent do you feel life to be meaningful?	1	2	3	4	5
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experienced or were able to do certain things **in the last two weeks.**

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	To what extent do you have enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

The following questions ask you to say **how good or satisfied** you have felt about various aspects of your life **over the last two weeks.**

		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things **in the last two weeks.**

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

		Not at all	Not much	A moderate amount	Very much	An extreme amount
27	How fed up do you feel?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
28	How satisfied are you with your level of happiness?	1	2	3	4	5

Thank you very much for participating in this research, without your help research like this could not be carried out. I will write to you in autumn 2001 to inform you of my findings and to tell you where I expect to publish this research.

I wish you well in the future. Thanks once again!

Claire

Appendix C7

Initial letter and reply slip to patients identified in patient records

(On hospital headed paper)

Dr Sebastian Barton MA MD MRCP
Consultant Gastroenterologist
East Kent Hospitals NHS Trust
Kent and Canterbury Hospital
Ethelbert Road
Canterbury
CT1 3NG

(Patient name)
(Patient address)

(Date)

Dear (Patient name)

I am writing to inform you about research I am collaborating on with a researcher from the University of Kent at Canterbury. **If you are not interested in participating in this research, please ignore this letter; you will not be contacted again.**

Claire Rutter is in the final year of her PhD thesis in health psychology. Her research is concerned with the experience of bowel symptoms; the effect symptoms have on patients' lives, and the role of stress on symptoms. The aim of the research is to help sufferers of gastrointestinal disorders cope as successfully as possible with their illness. The research involves simply completing questionnaires at your own home.

Your name has been selected from patient records because your gastrointestinal symptoms are, or have been, investigated by us. If you decide to participate or simply wish to find out more information about the research, simply complete the reply letter and place it in the prepaid envelope enclosed. On receipt of this reply letter, Claire will send you information about the research and a questionnaire booklet.

You may be asked to complete a maximum of three questionnaires over the following months; all of which should take no longer than 20 minutes to complete. For each stage of the study you will receive a prepaid envelope so that you can post the completed questionnaire back to Claire with no cost to yourself.

Participation is completely voluntary and if you decide not to take part this will not affect your medical care now or in the future. Even if you decide to complete the first questionnaire you are under no obligation to participate any further.

All the information you give will be confidential. No one other than Claire Rutter will ever see your completed questionnaires. The data from all questionnaires will be combined with other patients so no one will ever be able to identify any individual.

If you need to discuss any of the above please do not hesitate to contact Claire on 01227 827147, she would be happy to answer any questions you may have.

Yours sincerely

Dr Sebastian Barton MA MD MRCP
Consultant Gastroenterologist

Reply Letter

Please send me more details about the questionnaire based study, and the stage one questionnaire.

I understand that I am under no obligation to participate further.

Name ____

Address ____

____

____

____

Please feel free to add any comments you feel necessary below

Appendix D1

Initial letter and reply letter to GPs

(on University Headed Notepaper)

Claire L Rutter
Research Student
Dialling code for Canterbury:
01227 (UK) or +44 1227 (International)
Tel: 827147 direct line
764000 switchboard (ext.7147)
Fax: 827030
Email: C.L.Rutter@ukc.ac.uk

(GP Name)
(GP Address)

(Date)

Dear Dr (Name)

I am writing to you to ask for your help. I am a PhD student conducting research into Irritable Bowel Syndrome, Inflammatory Bowel Disease, and Chronic Fatigue Syndrome.

I am interested in how patients diagnosed with these organic and functional illnesses compare in the way they think and feel about their diagnoses, and to see if these factors have any bearing on future reported symptoms, and other outcome measures.

My reason for writing to you is to ask whether you might be able to help recruit patients for my study. I only require your help in finding patients with whom a diagnosis of IBS, IBD or CFS is imminent. Patients who agree to participate will simply be asked to complete a questionnaire booklet on four occasions.

It is hoped that once you have seen patients who you diagnose with IBS, IBD or CFS, you could give them a brief information sheet about the study, which includes a reply slip. This way the patient is left to decide whether or not to participate, by contacting me. This establishment of initial contact is all I ask of you.

Your help is crucial to my research. I "sampled" your name from a GP list obtained from your Health Authority. It is my aim to make this study as representative as possible, by gaining a national representative sample of newly diagnosed patients with IBS, IBD and CFS, and to chart their progress over 18 months or even longer.

I realise that you will not see many patients with these illnesses, so any help you can provide will be very much appreciated. If you agree to help me, I will send 10 information sheets (a sample attached), which you can keep in your surgery and give out to patients with IBS, IBD and CFS.

If you can help with this research please use the reply letter and envelope provided. I will then be able to provide you with more detailed information regarding the questionnaires I will be using and about my preparation for ethical approval, as well as the 10 information sheets. After this contact I will only need to contact you towards the end of the study to ask how many sheets you have given out, so I can assess a response rate.

It is hoped that this research will go some way to help patients manage their illness. Please help if you can.
Thank you for your time.

Yours sincerely,
Claire Rutter
Research Student.

(GP Name)
(GP address)

Miss Claire Rutter
Centre for Research in Health Behaviour
Department of Psychology
University of Kent at Canterbury
Canterbury
Kent
CT2 7NP

Dear Claire

☐ I would like to help in your research. Please send me 10 patient information sheets.

☐ I do not wish to help in your research

Please tick as appropriate.

Please feel free to add any comments about the study;

____

____

____

____

____

____

____

____

Signed ____________________ Date ______________

Appendix D2

Letter to GPs who agreed to help

(on University Headed Notepaper)
Claire L Rutter
Research Student
Dialling code for Canterbury:
01227 (UK) or +44 1227
Tel: 827147 direct line
764000 switchboard (ext.7147)
Fax: 827030
Email: C.L.Rutter@ukc.ac.uk

(GP Name)
(GP Address)

(Date)

Dear Dr (Name)

Re: Questionnaire Study

Thank you for replying to my original letter dated July 98. I am sorry I have taken so long to reply to you, but I have had a little trouble setting the study up. I hope you are still interested in helping me recruit patients for my questionnaire study.

As you may remember I am interested in how patients diagnosed with irritable bowel syndrome, chronic fatigue syndrome and inflammatory bowel disease compare in the way they think and feel about their diagnoses, and to see if these factors have any bearing on future reported symptoms, and other outcome measures. (If you have lost the original letter then please contact me, as I will be happy to give you another copy).

All I require is for you to hand out information envelopes. Each envelope contains; an information sheet, which includes a reply slip; a consent form; and a prepaid envelope. Included with this letter are 5 such information envelopes that I am hoping that you can distribute to suitable patients.

On distributing these envelopes, I am obviously trying to keep instructions fairly similar, so I hope that you can say something along the lines of *"Here is an envelope containing information about a study that a PhD student wanted me to hand out to sufferers of IBS / CFS / IBD. I am only giving out these envelopes, it's up to you whether you want to participate or not."*

My inclusion criteria are;

- IBS sufferers how have been diagnosed with the Rome criteria
- CFS sufferers who have been diagnosed with the Oxford criteria
- IBD sufferers who have had a positive diagnosis of Crohn's disease or colitis after investigative techniques
- Patients should only be included if they have received their diagnosis within the last 6 months
- Only patients who can give their informed consent

Patients who agree to participate will simply be asked to complete a questionnaire booklet on four occasions, (this is included so that you have a copy).

The study has been passed by your Local Research Ethics Committee.

Your help is crucial to my research, and I really appreciate your help in this task. Please feel free to contact me if you ever have any questions about this study, I will be pleased to talk to you. Also if you require more than 5 information envelopes, I will be happy to send more to you. Unless I hear from you, I will contact you towards the end of the study to ask how many envelopes you have given out, so I can assess a response rate.

Yours sincerely,

Claire Rutter
Research Student.

Appendix D3

Information letter to primary care patients contained in information envelope

Claire L Rutter
Research Student
Centre for Research in Health Behaviour
Department of Psychology
University of Kent at Canterbury
Canterbury
Kent CT2 7NP

Tel: 01227 764000 switchboard (ext. 7147)
01227 827147 (direct line)

Hello

My name is Claire, and I am asking for your help.
I am a PhD student conducting research in health psychology. My research is concerned with the way being ill can affect people both physically and emotionally over a period of time. The aim of this research is to help sufferers cope successfully with their illness. The more we understand about illness the more we may be able to help.

I would like you to take part in this research. All you have to do is to fill out a questionnaire booklet which tries to assess illness severity, daily function, relative anxiety level, and the different coping procedures used. I will also want to know if any treatments you use, or are prescribed, help you control your symptoms in any way.

Because of the nature of illness and the symptoms that different disorders have, I am comparing the responses from people suffering from Inflammatory Bowel Disease (which includes Crohn's Disease and Colitis), Irritable Bowel Syndrome and Chronic Fatigue Syndrome (also known as ME).

All the information you give will be confidential. No one other than myself will see your completed questionnaires.
If you are interested in taking part, or just require more information, please fill in the reply slip at the bottom of this page (please use block capitals), and send it to me, using the envelope attached.

You will be under no obligation, and you may drop out at any time. **Please feel free to contact me I will try to answer all your questions and queries.**
Thank you for taking the time to read this.
Best wishes
Claire Rutter

Please keep this sheet for your information

✂ ---

Please tick as appropriate;

☐ Please send me more details plus the first set of questionnaires

☐ Please send me more details of the study only

Please tick as appropriate; I suffer from

☐ Irritable Bowel Syndrome (IBS)

☐ Crohn's Disease or Ulcerative Colitis (IBD)

☐ Chronic Fatigue Syndrome (CFS, or ME)

Name………………………………………Address for correspondence……………………………

……

Please note all responders will be sent addresses of the appropriate self help organisations;

- **The IBS Network**
- **The National Association of Colitis and Crohn's Disease (NACC)**
- **Action for ME**

Appendix D4

Time 1 letter to primary care patients

(On University Headed Notepaper)
Claire L Rutter
Research Student
Dialling code for Canterbury:
01227 (UK) or +44 1227
(International)
Tel: 827147 direct line
764000 switchboard (ext.7147)
Fax: 827030
Email: C.L.Rutter@ukc.ac.uk

(Participant Name)
(Participant Address)

(Date)

Dear (Participant Name)

Thank you very much for sending me your reply slip to my request letter.

As I said in the previous letter, my research hopes to address the way that people feel when they are diagnosed with chronic illnesses. I am interested in your physical functioning, (i.e. how your symptoms may affect your daily routine), and your emotional responses to being ill (i.e. how your symptoms make you feel).

It has recently been suggested that these two processes work together for some people, so that when the painful and tiresome symptoms decrease, positive emotions increase, and vice versa. Although this may seem obvious to the sufferer, there is a need for this research to be actually carried out.

Since I intend to publish my findings in the relevant psychological and medical journals, it is hoped that this research will go some way to make a difference for future sufferers.

If you want to take part in the first phase of this study please complete the questionnaire booklet and send it back in the (postage paid) envelope provided. If you want to take part in the rest of the study you simply need to complete the last section, which asks you for your name and address. If you do not complete this section, I will not contact you again.

All information you can give is vital, but remember that you do not have to fill in every question, please miss out any you feel uncomfortable about.

I hope the information contained here has gone some way in encouraging you to take part. If you have any other questions please contact me. I will be happy to take your calls.

I would just like to state once more that you are free to drop out at any time, and to miss out any questions you feel uneasy about. The information you give will not be passed on to your GP, and your participation will not affect any future treatment you may have.

Thank you for your time.

Best wishes

Claire Rutter

Appendix D5

Time 1 Questionnaire (IBS, IBD and CFS version)

1

KENT
UNIVERSITY OF KENT
AT CANTERBURY ■■■■

Living with Irritable Bowel Syndrome
Questionnaire Booklet

Miss Claire Rutter
Research Student
Centre for Research in Health Behaviour
Department of Psychology
University of Kent at Canterbury
Canterbury
Kent CT2 7NP

☎ (01227) 827147

This booklet contains several questionnaires from the health and illness field. Most require you to circle or tick your preferred choice (i.e. the one that best describes the way you feel). **There are no right or wrong answers.** Although you may choose not to answer some questions, all answers will be treated in the **strictest confidence**. No one other than myself will see your completed questionnaires.
There is a space at the back for you to add anything else you feel is relevant. Please write freely. Also there are a few sections which ask you to write in your own words, if you run out of space please use the sheet at the back to continue.
Try not to spend too long thinking about specific questions. Your initial choice for **each question should take only a few seconds**. The whole booklet should take no longer than 50 minutes to complete.

Thank you for taking the time to complete this for me.

Best wishes

Miss Claire Rutter

<u>Please Note:</u> All questionnaires are confidential. No one will see your responses apart from the researcher named above.

© Claire Rutter
IBS/GP/1

Section 1: Information About You

This section asks you for information regarding your personal situation. Please try and answer all questions. Answers are for statistical purposes only.

Male / Female (please circle) Date of birth _____/_____/_____

Marital status (please circle)

Single Married Divorced Separated Widowed Co-habiting

Number of children (with ages) ________________________________

Please state highest academic qualification achieved ________________________

Occupation ____________________ If no occupation, is this due to your symptoms? Yes / No

Part time / Full time (please circle) If part time, is this due to your symptoms? Yes / No

Please estimate how many days sick you have taken in the past year ____________

I first experienced bowel and related symptoms ________________(As near to the date as possible)

I was diagnosed with Irritable Bowel Syndrome ________________(As near to the date as possible)

I have been to the GP about my irritable bowel and related symptoms (approximately) ____________ times, and saw (please circle)

same GP / two GP's / 3 or more GP's

Before I was diagnosed with IBS I had the following tests / examinations; (please tick)

☐ Barium meal
☐ Barium enema
☐ Colonoscopy
☐ Rectal examination
☐ Blood test
☐ Urine sample
☐ Stool sample
☐ Ultra sound scan
☐ Other (please state)________________________________

____

Today's date _____/_____/_____

© Claire Rutter

Section 2: Solving Problems

Please tick the response that best describes you

	Not at all True	Barely True	Moderately True	Exactly True
I can always manage to solve difficult problems if I try hard enough				
If someone opposes me, I can find means and ways to get what I want				
It is easy for me to stick to my aims and accomplish my goals				
I am confident that I could deal efficiently with unexpected events				
Thanks to my resourcefulness, I know how to handle unforeseen situations				
I can solve most problems if I invest the necessary effort				
I can remain calm when facing difficulties because I can rely on my coping abilities				
When I am confronted with a problem, I can usually find several solutions				
If I am in a bind, I can usually think of something to do				
No matter what comes my way, I'm usually able to handle it				

© Claire Rutter

Section 3: Emotional Feelings

Please read each of the 21 statements
and for each one tick the response that best describes you.

When I feel angry (very annoyed)…….	Almost Never	Sometimes	Often	Almost Always
I keep quiet				
I refuse to argue or say anything				
I bottle it up				
I say what I feel				
I avoid making a scene				
I smother (cover up) my feelings				
I hide my annoyance				

When I feel unhappy (miserable)…….	Almost Never	Sometimes	Often	Almost Always
I refuse to do anything about it				
I hide my unhappiness				
I put on a bold face				
I keep quiet				
I let others see how I feel				
I smother (cover up) my feelings				
I bottle it up				

When I feel afraid (worried)…….	Almost Never	Sometimes	Often	Almost Always
I let others see how I feel				
I keep quiet				
I refuse to say anything about it				
I tell others about it				
I say what I feel				
I bottle it up				
I smother (cover up) my feelings				

© Claire Rutter

Section 4: Your Outlook in General

The following table has a list of statements that may or may not be true for you. There are no "correct" or "incorrect" answers. Answer according to your **own** feelings, rather than how you think "most people" would answer. Please place a tick in the appropriate column.

	Strongly Disagree 0	Disagree 1	Neutral 2	Agree 3	Strongly Agree 4
1. In uncertain times, I usually expect the best.					
2. It's easy for me to relax					
3. If something can go wrong for me, it will					
4. I'm always optimistic about my future					
5. I enjoy my friends a lot					
6. It's important for me to keep busy					
7. I hardly ever expect things to go my way					
8. I don't get upset too easily					
9. I rarely count on good things happening to me					
10. Overall, I expect more good things to happen to me than bad					

Section 5: How you Rate your Feelings and Emotions

This scale consists of a number of words that describe different feelings and emotions. Read each item and then tick the best answer.

Please indicate to what extent you have felt this way during the past few weeks.

	1 Very Slightly	**2 A Little**	**3 Moderately**	**4 Quite a Bit**	**5 Extremely**
Interested					
Distressed					
Excited					
Upset					
Strong					
Guilty					
Scared					
Hostile					
Enthusiastic					
Proud					
Irritable					
Alert					
Ashamed					
Inspired					
Nervous					
Determined					
Attentive					
Jittery					
Active					
Afraid					

© Claire Rutter

Section 6: Your Symptoms

Below is a list of Irritable Bowel symptoms that you may, or may not have been suffering from. Please rate each one for your experience of the symptom by placing a tick in the appropriate box.

	I have never experienced this symptom	Less than 3 or 4 times per year	Every month or so	Every week or so	More than once every week
Abdominal Pain					
Diarrhoea					
Bloating					
Wind					
Constipation					
Blood in stools					
Incomplete evacuation of the bowel					
Passage of mucus					
Incontinence					
Rumbling and grumbling					

Below is a list of common symptoms or bodily sensations. Most people have experienced most of them at one time or another. I am interested in finding out how prevalent each symptom is. Using the scale below, write beside each symptom the letter, which indicates how frequently you experience that symptom.

A	B	C	D	E
Have never or almost never experienced the symptom	Less than 3 or 4 times per year	Every month or so	Every week or so	More than once every week

	Symptoms	Your Response
1	Eyes water	
2	Itching or painful eyes	
3	Ringing in ears	
4	Temporary deafness or hard of hearing	
5	Lump in throat	
6	Choking sensation	
7	Sneezing spells	
8	Running nose	
9	Congested nose	
10	Bleeding nose	
11	Asthma or wheezing	
12	Coughing	

A Have never or almost never experienced the symptom	B Less than 3 or 4 times per year	C Every month or so	D Every week or so	E More than once every week

	Symptoms	Your Response
13	Out of breath	
14	Swollen ankles	
15	Chest pains	
16	Racing heart	
17	Cold hands or feet even in hot weather	
18	Leg cramps	
19	Insomnia	
20	Toothaches	
21	Upset stomach	
22	Indigestion	
23	Heartburn	
24	Severe pains or cramps in stomach	
25	Diarrhoea	
26	Constipation	
27	Haemorrhoids	
28	Swollen joints	
29	Stiff muscles	
30	Back pains	
31	Sensitive or tender skin	
32	Face flushes	
33	Severe itching	
34	Skin breaks out in a rash	
35	Acne or pimples on face	
36	Acne or pimples other than on face	
37	Boils	
38	Sweat even in cold weather	
39	Strong reactions to insect bites	
40	Headaches	
41	Sensation of pressure in head	
42	Hot flushes	
43	Chills	
44	Dizziness	
45	Feel faint	
46	Numbness or tingling in any part of body	
47	Twitching of eyelid	
48	Twitching other than eyelid	
49	Hands tremble or shake	
50	Stiff joints	
51	Sore muscles	
52	Sore throat	
53	Sunburn	
54	Nausea	

© Claire Rutter

Section 7: Your Views about Your Irritable Bowel Syndrome (IBS)

I am interested in your own personal views of how you see your IBS. Please indicate how much you agree or disagree with the following statements about your IBS

	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
A germ or virus caused my IBS					
My IBS was caused by poor medical care in the past					
There is little that can be done to improve my IBS					
My IBS is hereditary – it runs in my family					
My IBS will last a short time					
What I do can determine whether my IBS gets better or worse					
My IBS has strongly affected the way I see myself as a person					
Stress was a major factor in causing my IBS					
My IBS is a serious condition					
Pollution in the environment caused my IBS					
It was just by chance that I developed IBS					
My IBS has become easier to live with					
My IBS has serious economic and financial consequences					
My IBS has strongly affected the way others see me					
My state of mind played a major part in causing my IBS					
My treatments will be effective in curing my IBS					
Diet played a major role in causing my IBS					
My IBS is likely to be permanent rather than temporary					
My IBS will improve in time					
Recovery from my IBS is largely dependent on chance or fate					
My IBS has had major consequences on my life					
Other people played a large role in causing my IBS					
There is a lot I can do to control my symptoms					
My IBS will last for a long time					
My IBS is largely due to my own behaviour					
My IBS has not had much effect on my life					

Section 8: Your Illness Knowledge

This page is concerned with what you know about your illness, and where this information came from. Do not worry about whether your answers are right or wrong. It is how you think about them that are important. Please try to answer as fully as possible.

In your own words tell me about the illness you have been diagnosed with, focusing specifically upon:

(i) Why do you think you suffer from this illness? ____________________

____

(ii) How serious is it? ____________________

____

(iii) What can you do to help alleviate your symptoms? ____________________

____

(iv) When some people are diagnosed with an illness like IBS, they actively seek out information about it. Please indicate (by circling) if you have gained information about your illness from the following sources:

Doctor	Yes / No	Television	Yes / No
Magazines	Yes / No	Radio	Yes / No
Self Help Book	Yes / No	Internet	Yes / No
Medical Journal	Yes / No	Friends/Family	Yes / No
Self Help Group	Yes / No		

Other (please state) ____________________

____

(v) Are you satisfied that your doctor explained your diagnosis to you as fully as possible?

1	2	3	4	5
Very Satisfied	Satisfied	Neither Satisfied nor Dissatisfied	Dissatisfied	Very Dissatisfied

(vi) After answering the above how confident are you that you know enough about your illness?

1	2	3	4	5
Very Confident	Confident	Neither Confident nor Unconfident	Unconfident	Very Unconfident

Section 9: Your Attitudes Towards Doctors and Medicine

Please tick the appropriate box of each statement to show how strongly you agree or disagree with it. There are no right or wrong answers. I am interested just in your opinion.

		Strongly Disagree	**Disagree**	**Tend to Disagree**	**Tend to Agree**	**Agree**	**Strongly Agree**
1	All doctors are good doctors						
2	Medicine is based on scientific principles						
3	I only consult a doctor if I am at death's door						
4	Medicines can do as much harm as good						
5	I have absolute faith and confidence in all hospital doctors						
6	The improved health of the nation is due to effective medicine						
7	Doctors blame their patients if their treatment doesn't work						
8	The advice of doctors is mainly common sense						
9	No matter how long you have to wait and see a doctor, it's worth it						
10	Medicine has cures for most diseases						
11	Doctors are important in keeping us healthy						
12	No two doctors will agree on what is wrong with a person						
13	Many medicines are just placebos or sugar pills						
14	Doctors are too ready to solve patients' problems by prescribing tranquillisers						
15	Often the only purpose of tests is to make the doctor feel less anxious						
16	Doctors know what's best for you						
17	I don't like medical people						
18	Most tests and investigations are done routinely rather than for a particular purpose						
19	Medicine is the best profession a person can have						

© Claire Rutter

Section 10: How You have been Feeling in the past TWO WEEKS

Please tick the response that best describes the way you have been feeling in the past two weeks

1. **I feel tense or "wound up":**
   - ☐ *Most of the time*
   - ☐ *A lot of the time*
   - ☐ *From time to time, occasionally*
   - ☐ *Not at all*

2. **I still enjoy the things I used to enjoy:**
   - ☐ *Definitely as much*
   - ☐ *Not quite so much*
   - ☐ *Only a little*
   - ☐ *Hardly at all*

3. **I get a sort of frightened feeling as if something awful is about to happen:**
   - ☐ *Very definitely and quite badly*
   - ☐ *Yes, but not too badly*
   - ☐ *A little, but it doesn't worry me*
   - ☐ *Not at all*

4. **I can laugh and see the funny side of things:**
   - ☐ *As much as I always could*
   - ☐ *Not quite so much now*
   - ☐ *Definitely not so much now*
   - ☐ *Not at all*

5. **Worrying thoughts go through my mind:**
   - ☐ *A great deal of the time*
   - ☐ *A lot of the time*
   - ☐ *From time to time, but not too often*
   - ☐ *Only occasionally*

6. **I feel cheerful:**
   - ☐ *Not at all*
   - ☐ *Not often*
   - ☐ *Sometimes*
   - ☐ *Most of the time*

7. **I can sit at ease and feel relaxed:**
   - ☐ *Definitely*
   - ☐ *Usually*
   - ☐ *Not often*
   - ☐ *Not at all*

8. I feel as if I am slowed down:

- ☐ *Nearly all of the time*
- ☐ *Very often*
- ☐ *Sometimes*
- ☐ *Not at all*

9. I get a sort of frightened feeling like "butterflies" in the stomach:

- ☐ *Not at all*
- ☐ *Occasionally*
- ☐ *Quite often*
- ☐ *Very often*

10. I have lost interest in my appearance:

- ☐ *Definitely*
- ☐ *I don't take as much care as I should*
- ☐ *I may not take as much care*
- ☐ *I take just as much care as ever*

11. I feel restless as if I have to be on the move:

- ☐ *Very much indeed*
- ☐ *Quite a lot*
- ☐ *Not very much*
- ☐ *Not at all*

12. I look forward with enjoyment to things:

- ☐ *As much as I ever did*
- ☐ *Rather less than I used to*
- ☐ *Definitely less than I used to*
- ☐ *Hardly at all*

13. I get sudden feelings of panic:

- ☐ *Very often indeed*
- ☐ *Quite often*
- ☐ *Not very often*
- ☐ *Not at all*

14. I can enjoy a good book or radio or TV programme

- ☐ *Often*
- ☐ *Sometimes*
- ☐ *Not often*
- ☐ *Very seldom*

Section 11: How You deal with Unpleasant Situations

In this section I want to know how you think you might react in some unpleasant situations. Tick as many statements as you want, that apply to you.

1. Vividly imagine that you are **afraid** of the dentist and have to get some dental work done. Which of the following would you do? Place a tick against **all** of the statements that apply to you.

_____ I would ask the dentist exactly what he was going to do

_____ I would take a tranquilliser or have a drink before going

_____ I would try to think about pleasant memories

_____ I would want the dentist to tell me when I would feel pain

_____ I would try to sleep

_____ I would watch all the dentists movements and listen for the sound of the drill

_____ I would watch the flow of water from my mouth to see if it contained blood

_____ I would do mental puzzles in my mind

2. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Tick **all** the statements that might apply to you.

_____ I would sit by myself and have as many daydreams and fantasies as I could

_____ I would stay alert and try to keep myself from falling asleep

_____ I would exchange life stories with the other hostages

_____ If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing

_____ I would watch every movement of my captors and keep an eye on their weapons

_____ I would try to sleep as much as possible

_____ I would think about how nice it's going to be when I get home

_____ I would make sure I knew where every possible exit was

3. Vividly imagine that, due to a large drop in sales, it is rumoured that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about layoffs has been made and will be announced in several days. Tick **all** the statements that might apply to you.

_____ I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said

_____ I would review the list of duties for my present job and try to figure out if I had fulfilled them all

_____ I would go to the cinema to take my mind off things

_____ I would try to remember my arguments or disagreements I might have had with the supervisor that would have lowered his/her opinion of me.

_____ I would push all thoughts of being laid off out of my mind

_____ I would tell my partner that I'd rather not discuss my chances of being laid off

_____ I would try to think which employees in my department the supervisor might have thought had done the worst job

_____ I would continue doing my work as if nothing was happening

4. Vividly imagine that you are on an aeroplane, thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced all is well. Tick **all** of the statements that might apply to you.

_____ I would carefully read the information provided about the safety features in the plane and make sure I knew where the emergency exits were

_____ I would make small talk with the passenger beside me

_____ I would watch the end of the movie, even if I had seen it before

_____ I would call for the flight attendant and ask her exactly what the problem was

_____ I would order a drink or tranquilliser from the flight attendant

_____ I would listen carefully to the engines for unusual noises and would watch the crew to see if their behaviour was out of the ordinary

_____ I would talk to the passenger beside me about what might be wrong

_____ I would settle down and read a book or magazine or read a letter

Section 12: Coping with your IBS

This next section focuses upon the way you cope with your symptoms. Think about the times when your symptoms have been at their worst, and how you reacted to them. Now indicate the extent to which you did whatever each of the following statements says, using the key below.

1 = I usually don't do this at all.
2 = I usually do this a little bit.
3 = I usually do this a medium amount.
4 = I usually do this a lot.

1	I try to grow as a person as a result of the experience	
2	I turn to work or other substitute activities to take my mind off things	
3	I get upset and let my emotions out	
4	I try to get advice from someone about what to do	
5	I concentrate my efforts on doing something about it	
6	I say to myself "this isn't real"	
7	I put my trust in God	
8	I laugh about the situation	
9	I admit to myself that I can't deal with it, and give up trying	
10	I restrain myself from doing anything too quickly	
11	I discuss my feelings with someone	
12	I use alcohol or drugs to make myself feel better	
13	I get used to my symptoms	
14	I talk to someone to find out more about my symptoms	
15	I keep myself from getting distracted by other thoughts and activities	
16	I daydream about things	
17	I get upset and am really aware of it	
18	I seek God's help	
19	I make a plan of action	
20	I make jokes about it	
21	I accept my illness and that it can't be changed	
22	I hold off doing anything until the situation permits	

1 = I usually don't do this at all.
2 = I usually do this a little bit.
3 = I usually do this a medium amount.
4 = I usually do this a lot.

23	I try to get emotional support from friends and relatives	
24	I just give up trying to reach my goal	
25	I take additional action to try and get rid of the symptoms	
26	I try to lose myself for a while by drinking alcohol or taking drugs	
27	I refuse to believe it has happened	
28	I let my feelings out	
29	I try to see it in a different light, to make it seem more positive	
30	I talk to someone who can help	
31	I sleep more than usual	
32	I try to come up with a strategy about what to do	
33	I focus on dealing with this problem and, if necessary , let other things slide a little	
34	I get sympathy and understanding from someone	
35	I drink alcohol or take drugs, in order to think about it less	
36	I kid around about it	
37	I give up the attempt to get what I want	
38	I look for something good in what is happening	
39	I think about how I might best handle the problem	
40	I pretend that it hasn't really happened	
41	I make sure not to make matters worse by acting too soon	
42	I try hard to prevent other things from interfering with my efforts at dealing with this	
43	I go to the cinema or watch television to think about it less	
44	I accept the reality of the fact that I have this illness	
45	I ask people who have had similar experiences what they did	
46	I feel a lot of emotional distress and I find myself expressing those feelings a lot	
47	I take direct action to get around the illness	

1 = I usually don't do this at all.
2 = I usually do this a little bit.
3 = I usually do this a medium amount.
4 = I usually do this a lot.

48	I try to find comfort in my religion	
49	I force myself to wait for the right time to do something	
50	I make fun of the situation	
51	I reduce the amount of effort I'm putting into solving the problem of illness	
52	I talk to someone about how I feel	
53	I use alcohol or drugs to help me get through it	
54	I learn to live with it	
55	I put aside other activities in order to concentrate on this	
56	I think hard about what steps to take	
57	I act as though I don't have an illness	
58	I do what has to be done, one step at a time	
59	I learn something from the experience of illness	
60	I pray more than usual	

Section 13: How You see your Quality of Life with Illness

The last questionnaire I would like you to complete concerns how you feel about your quality of life, health and other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the ONE** that appears most appropriate. This can often be your first response.
Please keep in mind your standards, hopes, pleasures and concerns. I ask that you think about your life **in the LAST TWO WEEKS**. Circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither Poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things **in THE LAST TWO WEEKS.**

		Not at all	A little	A moderate amount	Very much	An extreme amount
3	How much do you feel that pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
6	To what extent do you feel life to be meaningful?	1	2	3	4	5
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experienced or were able to do certain things **in the LAST TWO WEEKS.**

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	To what extent do you have enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

The following questions ask you to say **how good or satisfied** you have felt about various aspects of your life **over the LAST TWO WEEKS.**

		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things **in the LAST TWO WEEKS.**

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

		Not at all	Not much	A moderate amount	Very much	An extreme amount
27	How fed up do you feel?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
28	How satisfied are you with your level of happiness?	1	2	3	4	5

Are you part of a self help group? Yes / No If Yes, which? ____________________

© Claire Rutter

Section 14: Anything Else

Now please tell me anything else you feel is relevant here. Have any treatments or medications worked for you? Have any treatments made you feel worse?

Please use the rest of this sheet to finish questions, or attach additional sheets if necessary.

How long did this questionnaire take to complete? ______________________

Thank you very much for completing this booklet. You have just completed part 1 of the study. I would like you to complete a similar booklet in 6 months time. If you would like to participate in the next stage, please give your name and address. If you do not want to continue then do not enter your details here, and I will not contact you again.

Name ______________________ Address ______________________

____

Now simply put this booklet into the pre-paid envelope and post it back to me.

Thank you once again for helping in my research.
Best wishes
Claire Rutter

© Claire Rutter

KENT
UNIVERSITY OF KENT
AT CANTERBURY

Living with Inflammatory Bowel Disease
Questionnaire Booklet

Miss Claire Rutter
Research Student
Centre for Research in Health Behaviour
Department of Psychology
University of Kent at Canterbury
Canterbury
Kent CT2 7NP

☎ (01227) 827147

This booklet contains several questionnaires from the health and illness field. Most require you to circle or tick your preferred choice (i.e. the one that best describes the way you feel). **There are no right or wrong answers.** Although you may choose not to answer some questions, all answers will be treated in the **strictest confidence.** No one other than myself will see your completed questionnaires.
There is a space at the back for you to add anything else you feel is relevant. Please write freely. Also there are a few sections which ask you to write in your own words, if you run out of space please use the sheet at the back to continue.
Try not to spend too long thinking about specific questions. Your initial choice for **each question should take only a few seconds.** It is hoped that the whole booklet should take no longer than 50 minutes to complete.

Thank you for taking the time to complete this for me.

Best wishes

Miss Claire Rutter

<u>Please Note:</u> All questionnaires are confidential. No one will see your responses apart from the researcher named above.

© Claire Rutter

Section 1: Information About You

This section asks you for information regarding your personal situation. Please try and answer all questions. Answers are for statistical purposes only.

Male / Female (please circle) Date of birth _____/_____/_____

Marital status (please circle)

Single Married Divorced Separated Widowed Co-habiting

No. of children (with ages)______________________________

Please state highest academic qualification achieved ____________________

Occupation ____________________ If no occupation, is this due to your symptoms? Yes / No

Part time / Full time (please circle) If part time, is this due to your symptoms? Yes / No

Please estimate how many days sick you have taken in the past year __________

I first experienced my bowel and related symptoms _______________(As near to the date as possible)

I was diagnosed with Crohn's Disease / Ulcerative Colitis __________(As near to the date as possible)

I have been to the GP about my irritable bowel and related symptoms (approximately) ____________ times, and saw (please circle)

same GP / two GP's / 3 or more GP's

Before I was diagnosed with IBD I had the following tests / examinations; (please tick)

- ☐ Barium meal
- ☐ Barium enema
- ☐ Colonoscopy
- ☐ Rectal examination
- ☐ Blood test
- ☐ Urine sample
- ☐ Stool sample
- ☐ Endoscopy
- ☐ Ultra sound scan
- ☐ Other (please state)____________________________________

____

Today's date _____/_____/______

© Claire Rutter

Section 2: Solving Problems

Please tick the response that best describes you

	Not at all True	Barely True	Moderately True	Exactly True
I can always manage to solve difficult problems if I try hard enough				
If someone opposes me, I can find means and ways to get what I want				
It is easy for me to stick to my aims and accomplish my goals				
I am confident that I could deal efficiently with unexpected events				
Thanks to my resourcefulness, I know how to handle unforeseen situations				
I can solve most problems if I invest the necessary effort				
I can remain calm when facing difficulties because I can rely on my coping abilities				
When I am confronted with a problem, I can usually find several solutions				
If I am in a bind, I can usually think of something to do				
No matter what comes my way, I'm usually able to handle it				

© Claire Rutter

Section 3: Emotional Feelings

Please read each of the 21 statements
and for each one tick the response that best describes you.

When I feel angry (very annoyed)…….	Almost Never	Sometimes	Often	Almost Always
I keep quiet				
I refuse to argue or say anything				
I bottle it up				
I say what I feel				
I avoid making a scene				
I smother (cover up) my feelings				
I hide my annoyance				

When I feel unhappy (miserable)…….	Almost Never	Sometimes	Often	Almost Always
I refuse to do anything about it				
I hide my unhappiness				
I put on a bold face				
I keep quiet				
I let others see how I feel				
I smother (cover up) my feelings				
I bottle it up				

When I feel afraid (worried)…….	Almost Never	Sometimes	Often	Almost Always
I let others see how I feel				
I keep quiet				
I refuse to say anything about it				
I tell others about it				
I say what I feel				
I bottle it up				
I smother (cover up) my feelings				

© Claire Rutter

Section 4: Your Outlook in General

The following table has a list of statements that may or may not be true for you. There are no "correct" or "incorrect" answers. Answer according to your **own** feelings, rather than how you think "most people" would answer. Please place a tick in the appropriate column.

	Strongly Disagree 0	Disagree 1	Neutral 2	Agree 3	Strongly Agree 4
1. In uncertain times, I usually expect the best.					
2. It's easy for me to relax					
3. If something can go wrong for me, it will					
4. I'm always optimistic about my future					
5. I enjoy my friends a lot					
6. It's important for me to keep busy					
7. I hardly ever expect things to go my way					
8. I don't get upset too easily					
9. I rarely count on good things happening to me					
10. Overall, I expect more good things to happen to me than bad					

© Claire Rutter

Section 5: How you rate your Feelings and Emotions

This scale consists of a number of words that describe different feelings and emotions. Read each item and then tick the best answer.

Please indicate to what extent you have felt this way during the past few weeks.

	1 Very Slightly	2 A Little	3 Moderately	4 Quite a Bit	5 Extremely
Interested					
Distressed					
Excited					
Upset					
Strong					
Guilty					
Scared					
Hostile					
Enthusiastic					
Proud					
Irritable					
Alert					
Ashamed					
Inspired					
Nervous					
Determined					
Attentive					
Jittery					
Active					
Afraid					

Section 6: Your Symptoms in the past TWO WEEKS

Below is a list of symptoms that you may, or may not have been suffering from in **THE PAST TWO WEEKS**. Please rate each one for your experience of the symptom by placing a tick in the appropriate box.

	I have never experienced this symptom	**I have suffered from this symptom very rarely**	**I have suffered from this symptom sometimes**	**I have suffered from this symptom frequently**	**I am constantly suffering from this symptom**
Abdominal Pain					
Diarrhoea					
Bloating					
General Muscle Pain					
Migraine					
Wind					
Tiredness					
Difficulty Concentrating					
Fatigue					
Constipation					
Memory loss					
Chest Pain					
Anxiety Attacks					
Loss of sex drive					
Headaches					
Incomplete evacuation of the bowel					
Joint pain					
Difficulty sleeping					
Reduced energy levels					
Toothache					
Severe Itching					
Indigestion					
Dizziness					

Now please rate each symptom again, this time for severity, once more by placing a tick in the appropriate box.

	No symptom	**This symptom is mild**	**This symptom is intrusive but manageable**	**This symptom is severe and unmanageable**
Abdominal pain				
Diarrhoea				
Bloating				
General Muscle Pain				
Migraine				
Wind				
Tiredness				
Difficulty Concentrating				
Fatigue				
Constipation				
Memory loss				
Chest pain				
Anxiety Attacks				
Loss of sex drive				
Headaches				
Incomplete evacuation of the bowel				
Joint pain				
Difficulty sleeping				
Reduced energy levels				
Toothache				
Severe Itching				
Indigestion				
Dizziness				

© Claire Rutter

Section 7: Your Views about Your Inflammatory Bowel Disease (IBD)

I am interested in your own personal views of how you see your IBD. Please indicate how much you agree or disagree with the following statements about your IBD

	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
A germ or virus caused my IBD					
My IBD was caused by poor medical care in the past					
There is little that can be done to improve my IBD					
My IBD is hereditary – it runs in my family					
My IBD will last a short time					
What I do can determine whether my IBD gets better or worse					
My IBD has strongly affected the way I see myself as a person					
Stress was a major factor in causing my IBD					
My IBD is a serious condition					
Pollution in the environment caused my IBD					
It was just by chance that I developed IBD					
My IBD has become easier to live with					
My IBD has serious economic and financial consequences					
My IBD has strongly affected the way others see me					
My state of mind played a major part in causing my IBD					
My treatments will be effective in curing my IBD					
Diet played a major role in causing my IBD					
My IBD is likely to be permanent rather than temporary					
My IBD will improve in time					
Recovery from my IBD is largely dependent on chance or fate					
My IBD has had major consequences on my life					
Other people played a large role in causing my IBD					
There is a lot I can do to control my symptoms					
My IBD will last for a long time					
My IBD is largely due to my own behaviour					
My IBD has not had much effect on my life					

Section 8: Your Illness Knowledge

This page is concerned with what you know about your illness, and where this information came from. Do not worry about whether your answers are right or wrong. It is how you think about them that is important. Please try to answer as fully as possible.

In your own words tell me about the illness you have been diagnosed with, focusing specifically upon:

(i) Why do you think you suffer from this illness? ______________________________

____

(ii) How serious is it? ______________________________

____

(iii) What can you do to help alleviate your symptoms? ______________________________

____

(iv) When some people are diagnosed with an illness like IBD, they actively seek out information about it. Please indicate (by circling) if you have gained information about your illness from the following sources;

Doctor	Yes / No	Television	Yes / No
Magazines	Yes / No	Radio	Yes / No
Self Help Book	Yes / No	Internet	Yes / No
Medical Journal	Yes / No	Friends/Family	Yes / No
Self Help Group	Yes / No		

Other (please state) ______________________________

____

(v) Are you satisfied that your doctor explained your diagnosis to you as fully as possible?

1	2	3	4	5
Very Satisfied	Satisfied	Neither Satisfied nor Dissatisfied	Dissatisfied	Very Dissatisfied

(vi) After answering the above how confident are you that you know enough about your illness?

1	2	3	4	5
Very Confident	Confident	Neither Confident nor Unconfident	Unconfident	Very Unconfident

Section 9: Your Attitudes Towards Doctors and Medicine

Please tick the appropriate box of each statement to show how strongly you agree or disagree with it. There are no right or wrong answers, I am interested just in your opinion.

		Strongly Disagree	Disagree	Tend to Disagree	Tend to Agree	Agree	Strongly Agree
1	All doctors are good doctors						
2	Medicine is based on scientific principles						
3	I only consult a doctor if I am at death's door						
4	Medicines can do as much harm as good						
5	I have absolute faith and confidence in all hospital doctors						
6	The improved health of the nation is due to effective medicine						
7	Doctors blame their patients if their treatment doesn't work						
8	The advice of doctors is mainly common sense						
9	No matter how long you have to wait and see a doctor, it's worth it						
10	Medicine has cures for most diseases						
11	Doctors are important in keeping us healthy						
12	No two doctors will agree on what is wrong with a person						
13	Many medicines are just placebos or sugar pills						
14	Doctors are too ready to solve patients' problems by prescribing tranquillisers						
15	Often the only purpose of tests is to make the doctor feel less anxious						
16	Doctors know what's best for you						
17	I don't like medical people						
18	Most tests and investigations are done routinely rather than for a particular purpose						
19	Medicine is the best profession a person can have						

© Claire Rutter

Section 10: How You have been feeling in the past TWO WEEKS.

Please tick the response that best describes the way you have been feeling in the past two weeks

1. **I feel tense or "wound up":**
   - ☐ *Most of the time*
   - ☐ *A lot of the time*
   - ☐ *From time to time, occasionally*
   - ☐ *Not at all*

2. **I still enjoy the things I used to enjoy:**
   - ☐ *Definitely as much*
   - ☐ *Not quite so much*
   - ☐ *Only a little*
   - ☐ *Hardly at all*

3. **I get a sort of frightened feeling as if something awful is about to happen:**
   - ☐ *Very definitely and quite badly*
   - ☐ *Yes, but not too badly*
   - ☐ *A little, but it doesn't worry me*
   - ☐ *Not at all*

4. **I can laugh and see the funny side of things:**
   - ☐ *As much as I always could*
   - ☐ *Not quite so much now*
   - ☐ *Definitely not so much now*
   - ☐ *Not at all*

5. **Worrying thoughts go through my mind:**
   - ☐ *A great deal of the time*
   - ☐ *A lot of the time*
   - ☐ *From time to time, but not too often*
   - ☐ *Only occasionally*

6. **I feel cheerful:**
   - ☐ *Not at all*
   - ☐ *Not often*
   - ☐ *Sometimes*
   - ☐ *Most of the time*

7. **I can sit at ease and feel relaxed:**
   - ☐ *Definitely*
   - ☐ *Usually*
   - ☐ *Not often*
   - ☐ *Not at all*

8. I feel as if I am slowed down:

- ☐ *Nearly all of the time*
- ☐ *Very often*
- ☐ *Sometimes*
- ☐ *Not at all*

9. I get a sort of frightened feeling like "butterflies" in the stomach:

- ☐ *Not at all*
- ☐ *Occasionally*
- ☐ *Quite often*
- ☐ *Very often*

10. I have lost interest in my appearance:

- ☐ *Definitely*
- ☐ *I don't take as much care as I should*
- ☐ *I may not take as much care*
- ☐ *I take just as much care as ever*

11. I feel restless as if I have to be on the move:

- ☐ *Very much indeed*
- ☐ *Quite a lot*
- ☐ *Not very much*
- ☐ *Not at all*

12. I look forward with enjoyment to things:

- ☐ *As much as I ever did*
- ☐ *Rather less than I used to*
- ☐ *Definitely less than I used to*
- ☐ *Hardly at all*

13. I get sudden feelings of panic:

- ☐ *Very often indeed*
- ☐ *Quite often*
- ☐ *Not very often*
- ☐ *Not at all*

14. I can enjoy a good book or radio or TV programme:

- ☐ *Often*
- ☐ *Sometimes*
- ☐ *Not often*
- ☐ *Very seldom*

© Claire Rutter

Section 11: How You deal with Unpleasant Situations

In this section I want to know how you think you might react in some unpleasant situations. Tick as many statements as you want, that apply to you.

1. Vividly imagine that you are **afraid** of the dentist and have to get some dental work done. Which of the following would you do? Place a tick against **all** of the statements that apply to you.

_____ I would ask the dentist exactly what he was going to do

_____ I would take a tranquilliser or have a drink before going

_____ I would try to think about pleasant memories

_____ I would want the dentist to tell me when I would feel pain

_____ I would try to sleep

_____ I would watch all the dentists movements and listen for the sound of the drill

_____ I would watch the flow of water from my mouth to see if it contained blood

_____ I would do mental puzzles in my mind

2. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Tick **all** the statements that might apply to you.

_____ I would sit by myself and have as many daydreams and fantasies as I could

_____ I would stay alert and try to keep myself from falling asleep

_____ I would exchange life stories with the other hostages

_____ If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing

_____ I would watch every movement of my captors and keep an eye on their weapons

_____ I would try to sleep as much as possible

_____ I would think about how nice it's going to be when I get home

_____ I would make sure I knew where every possible exit was

3. Vividly imagine that, due to a large drop in sales, it is rumoured that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about layoffs has been made and will be announced in several days. Tick **all** the statements that might apply to you.

_____ I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said

_____ I would review the list of duties for my present job and try to figure out if I had fulfilled them all

_____ I would go to the cinema to take my mind off things

_____ I would try to remember my arguments or disagreements I might have had with the supervisor that would have lowered his/her opinion of me.

_____ I would push all thoughts of being laid off out of my mind

_____ I would tell my partner that I'd rather not discuss my chances of being laid off

_____ I would try to think which employees in my department the supervisor might have thought had done the worst job

_____ I would continue doing my work as if nothing was happening

4. Vividly imagine that you are on an aeroplane, thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced all is well. Tick **all** of the statements that might apply to you.

_____ I would carefully read the information provided about the safety features in the plane and make sure I knew where the emergency exits were

_____ I would make small talk with the passenger beside me

_____ I would watch the end of the movie, even if I had seen it before

_____ I would call for the flight attendant and ask her exactly what the problem was

_____ I would order a drink or tranquilliser from the flight attendant

_____ I would listen carefully to the engines for unusual noises and would watch the crew to see if their behaviour was out of the ordinary

_____ I would talk to the passenger beside me about what might be wrong

_____ I would settle down and read a book or magazine or read a letter

Section 12: Coping with your IBD

This next section focuses upon the way you cope with your symptoms. Think about the times when your symptoms have been at their worst, and how you reacted to them. Now indicate the extent to which you did whatever each of the following statements says, using the key below.

1 = I usually don't do this at all.	2 = I usually do this a little bit.
3 = I usually do this a medium amount.	4 = I usually do this a lot.

1	I try to grow as a person as a result of the experience	
2	I turn to work or other substitute activities to take my mind off things	
3	I get upset and let my emotions out	
4	I try to get advice from someone about what to do	
5	I concentrate my efforts on doing something about it	
6	I say to myself "this isn't real"	
7	I put my trust in God	
8	I laugh about the situation	
9	I admit to myself that I can't deal with it, and give up trying	
10	I restrain myself from doing anything too quickly	
11	I discuss my feelings with someone	
12	I use alcohol or drugs to make myself feel better	
13	I get used to my symptoms	
14	I talk to someone to find out more about my symptoms	
15	I keep myself from getting distracted by other thoughts and activities	
16	I daydream about things	
17	I get upset and am really aware of it	
18	I seek God's help	
19	I make a plan of action	
20	I make jokes about it	
21	I accept my illness and that it can't be changed	
22	I hold off doing anything until the situation permits	

1 = I usually don't do this at all.	2 = I usually do this a little bit.
3 = I usually do this a medium amount.	4 = I usually do this a lot.

23	I try to get emotional support from friends and relatives	
24	I just give up trying to reach my goal	
25	I take additional action to try and get rid of the symptoms	
26	I try to lose myself for a while by drinking alcohol or taking drugs	
27	I refuse to believe it has happened	
28	I let my feelings out	
29	I try to see it in a different light, to make it seem more positive	
30	I talk to someone who can help	
31	I sleep more than usual	
32	I try to come up with a strategy about what to do	
33	I focus on dealing with this problem and, if necessary , let other things slide a little	
34	I get sympathy and understanding from someone	
35	I drink alcohol or take drugs, in order to think about it less	
36	I kid around about it	
37	I give up the attempt to get what I want	
38	I look for something good in what is happening	
39	I think about how I might best handle the problem	
40	I pretend that it hasn't really happened	
41	I make sure not to make matters worse by acting too soon	
42	I try hard to prevent other things from interfering with my efforts at dealing with this	
43	I go to the cinema or watch television to think about it less	
44	I accept the reality of the fact that I have this illness	
45	I ask people who have had similar experiences what they did	
46	I feel a lot of emotional distress and I find myself expressing those feelings a lot	
47	I take direct action to get around the illness	

1 = I usually don't do this at all.	2 = I usually do this a little bit.
3 = I usually do this a medium amount.	4 = I usually do this a lot.

48	I try to find comfort in my religion	
49	I force myself to wait for the right time to do something	
50	I make fun of the situation	
51	I reduce the amount of effort I'm putting into solving the problem of illness	
52	I talk to someone about how I feel	
53	I use alcohol or drugs to help me get through it	
54	I learn to live with it	
55	I put aside other activities in order to concentrate on this	
56	I think hard about what steps to take	
57	I act as though I don't have an illness	
58	I do what has to be done, one step at a time	
59	I learn something from the experience of illness	
60	I pray more than usual	

Section 13: How You see your Quality of Life with Illness

The last questionnaire I would like you to complete concerns how you feel about your quality of life, health and other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the ONE** that appears most appropriate. This can often be your first response.
Please keep in mind your standards, hopes, pleasures and concerns. I ask that you think about your life **in the LAST TWO WEEKS**. Circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither Poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things **in the LAST TWO WEEKS.**

		Not at all	A little	A moderate amount	Very much	An extreme amount
3	How much do you feel that pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
6	To what extent do you feel life to be meaningful?	1	2	3	4	5
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experienced or were able to do certain things **in the LAST TWO WEEKS.**

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	To what extent do you have enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

The following questions ask you to say **how good or satisfied** you have felt about various aspects of your life **over the LAST TWO WEEKS.**

		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things **in the LAST TWO WEEKS.**

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

		Not at all	Not much	A moderate amount	Very much	An extreme amount
27	How fed up do you feel?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
28	How satisfied are you with your level of happiness?	1	2	3	4	5

Are you part of a self help group Yes / No If Yes, which?__________________________

Section 14: Anything Else

Now please tell me anything else you feel is relevant here. Have any treatments, or medications worked for you? Have any treatments made you feel worse?

Please use the rest of this sheet to finish questions, or attach additional sheets.

How long did this booklet take to complete?______________________________

Thank you very much for completing this booklet. You have just completed part 1 of the study. I would like you to complete a similar booklet in 6 months time. If you would like to participate in the next stage, please enter your name and address. If you do not want to continue then do not enter your details here, and I will not contact you again.

Name ______________________ Address ______________________

____

Now simply put this booklet into the pre-paid envelope and post it back to me.

Thank you once again for helping in my research.
Best wishes
Claire Rutter

© Claire Rutter

1

KENT
UNIVERSITY OF KENT
AT CANTERBURY

Living with Chronic Fatigue Syndrome
Questionnaire Booklet

Miss Claire Rutter
Research Student
Centre for Research in Health Behaviour
Department of Psychology
University of Kent at Canterbury
Canterbury
Kent CT2 7NP

☎ (01227) 827147

This booklet contains several questionnaires from the health and illness field. Most require you to circle or tick your preferred choice (i.e. the one that best describes the way you feel). **There are no right or wrong answers.** Although you may choose not to answer some questions, all answers will be treated in the **strictest confidence**. No one other than myself will see your completed questionnaires.
There is space at the back for you to add anything else you feel is relevant. Please write freely. Also there are a few sections which ask you to write in your own words, if you run out of space please the sheet at the back to continue.
Try not to spend too long thinking about specific questions. Your initial choice for **each question should take only a few seconds**. The whole booklet should take no longer than 50 minutes to complete.

Thank you for taking the time to complete this for me.

Best wishes

Miss Claire Rutter

Please Note: *All questionnaires are confidential. No one will see your responses apart from the researcher named above.*

© Claire Rutter
CFS/GP/1

Section 1: Information About You

This section asks you for information regarding your personal situation. Please try to answer all questions. Answers are for statistical purposes only.

Male / Female (please circle) Date of birth _____/_____/_____

Marital status (please circle)

Single Married Divorced Separated Widowed Co-habiting

No. of children (with ages) ______________________________

Please state highest academic qualification achieved ____________________

Occupation ____________________ If no occupation, is this due to your symptoms? Yes / No

Part time / Full time (please circle) If part time, is this due to your symptoms? Yes / No

Please estimate how many days sick you have taken in the past year __________

I first experienced fatigue and related symptoms ________________(As near to the date as possible)

I was diagnosed with Chronic Fatigue Syndrome ________________(As near to the date as possible)

I have been to the GP about my chronic fatigue and related symptoms (approximately) ______________ times, and saw (please circle)

same GP / two GP's / 3 or more GP's

Before I was diagnosed with CFS I had the following tests / examinations; (please tick)

☐ MRI scan
☐ Blood test
☐ PET scan
☐ CT scan
☐ X-ray
☐ Urine test
☐ Stool test
☐ Liver function tests
☐ Ultra sound scan
☐ Other (please state)______________________________

____

Today's date _____/_____/_____

© Claire Rutter

Section 2: Solving Problems

Please tick the response that best describes you

	Not at all True	**Barely True**	**Moderately True**	**Exactly True**
I can always manage to solve difficult problems if I try hard enough				
If someone opposes me, I can find means and ways to get what I want				
It is easy for me to stick to my aims and accomplish my goals				
I am confident that I could deal efficiently with unexpected events				
Thanks to my resourcefulness, I know how to handle unforeseen situations				
I can solve most problems if I invest the necessary effort				
I can remain calm when facing difficulties because I can rely on my coping abilities				
When I am confronted with a problem, I can usually find several solutions				
If I am in a bind, I can usually think of something to do				
No matter what comes my way, I'm usually able to handle it				

Section 3: Emotional feelings

Please read each of the 21 statements
and for each one tick the response that best describes you.

When I feel angry (very annoyed).......	Almost Never	Sometimes	Often	Almost Always
I keep quiet				
I refuse to argue or say anything				
I bottle it up				
I say what I feel				
I avoid making a scene				
I smother (cover up) my feelings				
I hide my annoyance				

When I feel unhappy (miserable).......	Almost Never	Sometimes	Often	Almost Always
I refuse to do anything about it				
I hide my unhappiness				
I put on a bold face				
I keep quiet				
I let others see how I feel				
I smother (cover up) my feelings				
I bottle it up				

When I feel afraid (worried).......	Almost Never	Sometimes	Often	Almost Always
I let others see how I feel				
I keep quiet				
I refuse to say anything about it				
I tell others about it				
I say what I feel				
I bottle it up				
I smother (cover up) my feelings				

Section 4: Your Outlook in General

The following table has a list of statements that may or may not be true for you. There are no "correct" or "incorrect" answers. Answer according to your **own** feelings, rather than how you think "most people" would answer. Please place a tick in the appropriate column.

	Strongly Disagree 0	Disagree 1	Neutral 2	Agree 3	Strongly agree 4
1. In uncertain times, I usually expect the best.					
2. It's easy for me to relax					
3. If something can go wrong for me, it will					
4. I'm always optimistic about my future					
5. I enjoy my friends a lot					
6. It's important for me to keep busy					
7. I hardly ever expect things to go my way					
8. I don't get upset too easily					
9. I rarely count on good things happening to me					
10. Overall, I expect more good things to happen to me than bad					

© Claire Rutter

6

Section 5: How you rate your Feelings and Emotions

This scale consists of a number of words that describe different feelings and emotions. Read each item and then tick the best answer.

Please indicate to what extent you have felt this way during the past few weeks.

	1 Very Slightly	2 A little	3 Moderately	4 Quite a bit	5 Extremely
Interested					
Distressed					
Excited					
Upset					
Strong					
Guilty					
Scared					
Hostile					
Enthusiastic					
Proud					
Irritable					
Alert					
Ashamed					
Inspired					
Nervous					
Determined					
Attentive					
Jittery					
Active					
Afraid					

Section 6: Your Symptoms

Below is a list of Chronic Fatigue Related symptoms that you may, or may not have been suffering from. Please rate each one for your experience of the symptom by placing a tick in the appropriate box.

	I have never experienced this symptom	**Less than 3 or 4 times per year**	**Every month or so**	**Every week or so**	**More than once every week**
General Muscle Pain					
Tiredness					
Difficulty Concentrating					
Fatigue					
Memory loss					
Joint pain					
Difficulty sleeping					
Reduced energy levels					
Exhaustion					
Headache					

Below is a list of common symptoms or bodily sensations. Most people have experienced most of them at one time or another. I am interested in finding out how prevalent each symptom is. Using the scale below, write beside each symptom the letter which indicates how frequently you experience that symptom

A	**B**	**C**	**D**	**E**
Have never or almost never experienced the symptom	**Less than 3 or 4 times per year**	**Every month or so**	**Every week or so**	**More than once every week**

	Symptoms	Your Response
1	Eyes water	
2	Itching or painful eyes	
3	Ringing in ears	
4	Temporary deafness or hard of hearing	
5	Lump in throat	
6	Choking sensation	
7	Sneezing spells	
8	Running nose	
9	Congested nose	
10	Bleeding nose	
11	Asthma or wheezing	
12	Coughing	
13	Out of breath	

A **Have never or almost never experienced the symptom**	**B** **Less than 3 or 4 times per year**	**C** **Every month or so**	**D** **Every week or so**	**E** **More than once every week**

	Symptoms	Your Response
14	Swollen ankles	
15	Chest pains	
16	Racing heart	
17	Cold hands or feet even in hot weather	
18	Leg cramps	
19	Insomnia	
20	Toothaches	
21	Upset stomach	
22	Indigestion	
23	Heartburn	
24	Severe pains or cramps in stomach	
25	Diarrhoea	
26	Constipation	
27	Haemorrhoids	
28	Swollen joints	
29	Stiff muscles	
30	Back pains	
31	Sensitive or tender skin	
32	Face flushes	
33	Severe itching	
34	Skin breaks out in a rash	
35	Acne or pimples on face	
36	Acne or pimples other than on face	
37	Boils	
38	Sweat even in cold weather	
39	Strong reactions to insect bites	
40	Headaches	
41	Sensation of pressure in head	
42	Hot flushes	
43	Chills	
44	Dizziness	
45	Feel faint	
46	Numbness or tingling in any part of body	
47	Twitching of eyelid	
48	Twitching other than eyelid	
49	Hands tremble or shake	
50	Stiff joints	
51	Sore muscles	
52	Sore throat	
53	Sunburn	
54	Nausea	

Section 7: Your Views about Your Chronic Fatigue Syndrome (CFS)

I am interested in your own personal views of how you see your CFS. Please indicate how much you agree or disagree with the following statements about your CFS

	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
A germ or virus caused my CFS					
My CFS was caused by poor medical care in the past					
There is little that can be done to improve my CFS					
My CFS is hereditary – it runs in my family					
My CFS will last a short time					
What I do can determine whether my CFS gets better or worse					
My CFS has strongly affected the way I see myself as a person					
Stress was a major factor in causing my CFS					
My CFS is a serious condition					
Pollution in the environment caused my CFS					
It was just by chance that I developed CFS					
My CFS has become easier to live with					
My CFS has serious economic and financial consequences					
My CFS has strongly affected the way others see me					
My state of mind played a major part in causing my CFS					
My treatments will be effective in curing my CFS					
Diet played a major role in causing my CFS					
My CFS is likely to be permanent rather than temporary					
My CFS will improve in time					
Recovery from my CFS is largely dependent on chance or fate					
My CFS has had major consequences on my life					
Other people played a large role in causing my CFS					
There is a lot I can do to control my symptoms					
My CFS will last for a long time					
My CFS is largely due to my own behaviour					
My CFS has not had much effect on my life					

Section 8: Your Illness Knowledge

This page is concerned with what you know about your illness, and where this information came from. Do not worry about whether your answers are right or wrong. It is how you think about them that is important. Please try to answer as fully as possible.

In your own words tell me about the illness you have been diagnosed with, focusing specifically upon:

(i) Why do you think you suffer from this illness? ______________________________

____

(ii) How serious is it? ______________________________

____

(iii) What can you do to help alleviate your symptoms? ______________________________

____

(iv) When some people are diagnosed with an illness like CFS, they actively seek out information about it. Please indicate (by circling) if you have gained information about your illness from the following sources:

Doctor	Yes / No	Television	Yes / No
Magazines	Yes / No	Radio	Yes / No
Self Help Book	Yes / No	Internet	Yes / No
Medical Journal	Yes / No	Friends/Family	Yes / No
Self Help Group	Yes / No		

Other (please state) ______________________________

____

(v) Are you satisfied that your doctor explained your diagnosis to you as fully as possible?

1	2	3	4	5
Very Satisfied	Satisfied	Neither Satisfied nor Dissatisfied	Dissatisfied	Very Dissatisfied

(vi) After answering the above how confident are you that you know enough about your illness?

1	2	3	4	5
Very Confident	Confident	Neither Confident nor Unconfident	Unconfident	Very Unconfident

© Claire Rutter

Section 9: Your Attitudes Towards Doctors and Medicine

Please tick the appropriate box of each statement to show how strongly you agree or disagree with it. There are no right or wrong answers. I am interested just in your opinion.

		Strongly Disagree	Disagree	Tend to Disagree	Tend to Agree	Agree	Strongly Agree
1	All doctors are good doctors						
2	Medicine is based on scientific principles						
3	I only consult a doctor if I am at death's door						
4	Medicines can do as much harm as good						
5	I have absolute faith and confidence in all hospital doctors						
6	The improved health of the nation is due to effective medicine						
7	Doctors blame their patients if their treatment doesn't work						
8	The advice of doctors is mainly common sense						
9	No matter how long you have to wait and see a doctor, it's worth it						
10	Medicine has cures for most diseases						
11	Doctors are important in keeping us healthy						
12	No two doctors will agree on what is wrong with a person						
13	Many medicines are just placebos or sugar pills						
14	Doctors are too ready to solve patients' problems by prescribing tranquillisers						
15	Often the only purpose of tests is to make the doctor feel less anxious						
16	Doctors know what's best for you						
17	I don't like medical people						
18	Most tests and investigations are done routinely rather than for a particular purpose						
19	Medicine is the best profession a person can have						

© Claire Rutter

Section 10: How You have been Feeling in the past TWO WEEKS.

Please tick the response that best describes the way you have been feeling in the past two weeks

1. **I feel tense or "wound up":**
   - ☐ *Most of the time*
   - ☐ *A lot of the time*
   - ☐ *From time to time, occasionally*
   - ☐ *Not at all*
2. **I still enjoy the things I used to enjoy:**
   - ☐ *Definitely as much*
   - ☐ *Not quite so much*
   - ☐ *Only a little*
   - ☐ *Hardly at all*
3. **I get a sort of frightened feeling as if something awful is about to happen:**
   - ☐ *Very definitely and quite badly*
   - ☐ *Yes, but not too badly*
   - ☐ *A little, but it doesn't worry me*
   - ☐ *Not at all*
4. **I can laugh and see the funny side of things:**
   - ☐ *As much as I always could*
   - ☐ *Not quite so much now*
   - ☐ *Definitely not so much now*
   - ☐ *Not at all*
5. **Worrying thoughts go through my mind:**
   - ☐ *A great deal of the time*
   - ☐ *A lot of the time*
   - ☐ *From time to time, but not too often*
   - ☐ *Only occasionally*
6. **I feel cheerful:**
   - ☐ *Not at all*
   - ☐ *Not often*
   - ☐ *Sometimes*
   - ☐ *Most of the time*
7. **I can sit at ease and feel relaxed:**
   - ☐ *Definitely*
   - ☐ *Usually*
   - ☐ *Not often*
   - ☐ *Not at all*

8. I feel as if I am slowed down:

- ☐ *Nearly all of the time*
- ☐ *Very often*
- ☐ *Sometimes*
- ☐ *Not at all*

9. I get a sort of frightened feeling like "butterflies" in the stomach:

- ☐ *Not at all*
- ☐ *Occasionally*
- ☐ *Quite often*
- ☐ *Very often*

10. I have lost interest in my appearance:

- ☐ *Definitely*
- ☐ *I don't take as much care as I should*
- ☐ *I may not take as much care*
- ☐ *I take just as much care as ever*

11. I feel restless as if I have to be on the move:

- ☐ *Very much indeed*
- ☐ *Quite a lot*
- ☐ *Not very much*
- ☐ *Not at all*

12. I look forward with enjoyment to things:

- ☐ *As much as I ever did*
- ☐ *Rather less than I used to*
- ☐ *Definitely less than I used to*
- ☐ *Hardly at all*

13. I get sudden feelings of panic:

- ☐ *Very often indeed*
- ☐ *Quite often*
- ☐ *Not very often*
- ☐ *Not at all*

14. I can enjoy a good book or radio or TV programme

- ☐ *Often*
- ☐ *Sometimes*
- ☐ *Not often*
- ☐ *Very seldom*

© Claire Rutter

Section 11: How You deal with Unpleasant Situations

In this section I want to know how you think you might react in some unpleasant situations. Tick as many statements as you want, that apply to you.

1. Vividly imagine that you are **afraid** of the dentist and have to get some dental work done. Which of the following would you do? Place a tick against **all** of the statements that apply to you.

_____ I would ask the dentist exactly what he was going to do

_____ I would take a tranquilliser or have a drink before going

_____ I would try to think about pleasant memories

_____ I would want the dentist to tell me when I would feel pain

_____ I would try to sleep

_____ I would watch all the dentists movements and listen for the sound of the drill

_____ I would watch the flow of water from my mouth to see if it contained blood

_____ I would do mental puzzles in my mind

2. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Tick **all** the statements that might apply to you.

_____ I would sit by myself and have as many daydreams and fantasies as I could

_____ I would stay alert and try to keep myself from falling asleep

_____ I would exchange life stories with the other hostages

_____ If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing

_____ I would watch every movement of my captors and keep an eye on their weapons

_____ I would try to sleep as much as possible

_____ I would think about how nice it's going to be when I get home

_____ I would make sure I knew where every possible exit was

© Claire Rutter

3. Vividly imagine that, due to a large drop in sales, it is rumoured that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about layoffs has been made and will be announced in several days. Tick **all** the statements that might apply to you.

_____ I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said

_____ I would review the list of duties for my present job and try to figure out if I had fulfilled them all

_____ I would go to the cinema to take my mind off things

_____ I would try to remember my arguments or disagreements I might have had with the supervisor that would have lowered his/her opinion of me.

_____ I would push all thoughts of being laid off out of my mind

_____ I would tell my partner that I'd rather not discuss my chances of being laid off

_____ I would try to think which employees in my department the supervisor might have thought had done the worst job

_____ I would continue doing my work as if nothing was happening

4. Vividly imagine that you are on an aeroplane, thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced all is well. Tick **all** of the statements that might apply to you.

_____ I would carefully read the information provided about the safety features in the plane and make sure I knew where the emergency exits were

_____ I would make small talk with the passenger beside me

_____ I would watch the end of the movie, even if I had seen it before

_____ I would call for the flight attendant and ask her exactly what the problem was

_____ I would order a drink or tranquilliser from the flight attendant

_____ I would listen carefully to the engines for unusual noises and would watch the crew to see if their behaviour was out of the ordinary

_____ I would talk to the passenger beside me about what might be wrong

_____ I would settle down and read a book or magazine or read a letter

Section 12: Coping with your CFS

This next section focuses upon the way you cope with your symptoms. Think about the times when your symptoms have been at their worst, and how you reacted to them. Now indicate the extent to which you did whatever each of the following statements says, using the key below.

1 = I usually don't do this at all.
2 = I usually do this a little bit.
3 = I usually do this a medium amount.
4 = I usually do this a lot.

1	I try to grow as a person as a result of the experience	
2	I turn to work or other substitute activities to take my mind off things	
3	I get upset and let my emotions out	
4	I try to get advice from someone about what to do	
5	I concentrate my efforts on doing something about it	
6	I say to myself "this isn't real"	
7	I put my trust in God	
8	I laugh about the situation	
9	I admit to myself that I can't deal with it, and give up trying	
10	I restrain myself from doing anything too quickly	
11	I discuss my feelings with someone	
12	I use alcohol or drugs to make myself feel better	
13	I get used to my symptoms	
14	I talk to someone to find out more about my symptoms	
15	I keep myself from getting distracted by other thoughts and activities	
16	I daydream about things	
17	I get upset and am really aware of it	
18	I seek God's help	
19	I make a plan of action	
20	I make jokes about it	
21	I accept my illness and that it can't be changed	
22	I hold off doing anything until the situation permits	

1 = I usually don't do this at all.	2 = I usually do this a little bit.
3 = I usually do this a medium amount.	4 = I usually do this a lot.

23	I try to get emotional support from friends and relatives	
24	I just give up trying to reach my goal	
25	I take additional action to try and get rid of the symptoms	
26	I try to lose myself for a while by drinking alcohol or taking drugs	
27	I refuse to believe it has happened	
28	I let my feelings out	
29	I try to see it in a different light, to make it seem more positive	
30	I talk to someone who can help	
31	I sleep more than usual	
32	I try to come up with a strategy about what to do	
33	I focus on dealing with this problem and, if necessary , let other things slide a little	
34	I get sympathy and understanding from someone	
35	I drink alcohol or take drugs, in order to think about it less	
36	I kid around about it	
37	I give up the attempt to get what I want	
38	I look for something good in what is happening	
39	I think about how I might best handle the problem	
40	I pretend that it hasn't really happened	
41	I make sure not to make matters worse by acting too soon	
42	I try hard to prevent other things from interfering with my efforts at dealing with this	
43	I go to the cinema or watch television to think about it less	
44	I accept the reality of the fact that I have this illness	
45	I ask people who have had similar experiences what they did	
46	I feel a lot of emotional distress and I find myself expressing those feelings a lot	
47	I take direct action to get around the illness	

1 = I usually don't do this at all.	2 = I usually do this a little bit.
3 = I usually do this a medium amount.	4 = I usually do this a lot.

48	I try to find comfort in my religion	
49	I force myself to wait for the right time to do something	
50	I make fun of the situation	
51	I reduce the amount of effort I'm putting into solving the problem of illness	
52	I talk to someone about how I feel	
53	I use alcohol or drugs to help me get through it	
54	I learn to live with it	
55	I put aside other activities in order to concentrate on this	
56	I think hard about what steps to take	
57	I act as though I don't have an illness	
58	I do what has to be done, one step at a time	
59	I learn something from the experience of illness	
60	I pray more than usual	

Section 13: How you see your Quality of Life with Illness

The last questionnaire I would like you to complete concerns how you feel about your quality of life, health and other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the ONE** that appears most appropriate. This can often be your first response.
Please keep in mind your standards, hopes, pleasures and concerns. I ask that you think about your life **in the LAST TWO WEEKS**. Circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither Poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things **in the LAST TWO WEEKS.**

		Not at all	A little	A moderate amount	Very much	An extreme amount
3	How much do you feel that pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
6	To what extent do you feel life to be meaningful?	1	2	3	4	5
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experienced or were able to do certain things **in the LAST TWO WEEKS.**

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	To what extent do you have enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

The following questions ask you to say **how good or satisfied** you have felt about various aspects of your life **over the LAST TWO WEEKS.**

		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

20

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things **in the LAST TWO WEEKS.**

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

		Not at all	Not much	A moderate amount	Very much	An extreme amount
27	How fed up do you feel?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
28	How satisfied are you with your level of happiness?	1	2	3	4	5

Are you part of a self help group? Yes / No If Yes, Which? ____________________

Section 14: Anything Else

Now please tell me anything else you feel is relevant here. Have any treatments, or medications worked for you, have any treatments made you feel worse?

Please use the rest of this sheet to finish questions, or attach additional sheets.

How long did this booklet take to complete?________________________________

Thank you very much for completing this booklet. You have just completed part 1 of the study. I would like you to complete a similar booklet in 6 months time. If you would like to participate in the next stage, please give your name and address. If you do not want to continue then do not enter your details here, and I will not contact you again.

Name________________________ Address ________________________

____

Now simply put this booklet into the pre-paid envelope and post it back to me.

Thank you once again for helping in my research.
Best wishes
Claire Rutter

© Claire Rutter

Appendix D6

Time 2 letter to primary care patients

(On University Headed Notepaper)
Claire L Rutter
Research Student
Dialling code for Canterbury:
01227 (UK) or +44 1227
Tel: 827147 direct line
764000 switchboard (ext.7147)
Fax: 827030
Email: C.L.Rutter@ukc.ac.uk

(Participant Name)
(Participant Address)

(Date)

Dear (Participant Name)

Hello again. Thank you very much for taking part in part one of my study, I really appreciate your help with my research. It is now 6 months since I received your first questionnaire, and I am now hoping that you will help with part two.

You will soon realise that this questionnaire is very much like the first questionnaire, but please do not let this fact deter you from completing this one. My research hopes to be able to understand illness over time and to identify changes in your feelings towards your illness. The only way this is possible is to give the same measures at different time intervals and compare responses.

I am hoping that you will complete this questionnaire and one further questionnaire in 6 months time. You may notice that I have dropped the time 4 measurement, (i.e. a further booklet 12 months from now) due to constraints of time for both of us.

In completing this questionnaire please remember to include any treatments or medications you have found useful in the last 6 months. If you have noticed any improvement or worsening of your symptoms in these last 6 months please indicate this and try if possible, to explain why this may be the case, (e.g. a new GP, or a significant life event). Please feel free to write as little or as much as you want.

I would just like to state once more that you are free to drop out at any time, and to miss out any questions you feel uneasy about. The information you give will not be passed on to your GP, and your participation will not affect any future treatment you may have.

As I have stated, I would like to contact you again in 6 months from now, if there is to be a change of address during this time, I would really appreciate it if you would let me know this information.

All the information you can give helps us to understand the nature of illness and the way it impacts upon people's lives. I am looking forward to receiving your second questionnaire.

Thank you for your time.

Best wishes

Claire Rutter
Research Student

Appendix D7

Time 2 Questionnaire (IBS version only)

KENT
UNIVERSITY OF KENT
AT CANTERBURY ■■■■

Living with Irritable Bowel Syndrome
Questionnaire Booklet

Miss Claire Rutter
Research Student
Centre for Research in Health Behaviour
Department of Psychology
University of Kent at Canterbury
Canterbury
Kent CT2 7NP

☎ (01227) 827147

This booklet contains a lot of the same measures completed 6 months ago, however all the information you can give helps us to understand your illness better.
Most measures require you to circle or tick your preferred choice (i.e. the one that best describes the way you feel). **There are no right or wrong answers.** Although you may choose not to answer some questions, all answers will be treated in the **strictest confidence.** No one other than myself will see your completed questionnaires.
There is a space at the back for you to add anything else you feel is relevant. Please write freely. Also there are a few sections which ask you to write in your own words, if you run out of space please use the sheet at the back to continue.
Try not to spend too long thinking about specific questions. Your initial choice for **each question should take only a few seconds.** The whole booklet should take no longer than 50 minutes to complete.

Thank you for taking the time to complete this for me.

Best wishes

Miss Claire Rutter

Please Note: *All questionnaires are confidential. No one will see your responses apart from the researcher named above.*

© Claire Rutter
IBS/GP/2

Section 1: Information About You

This section asks you for information regarding your personal situation. Please try and answer all questions. Answers are for statistical purposes only.

Male / Female (please circle)   Date of birth ____/____/____

Marital status (please circle)

Single   Married   Divorced   Separated   Widowed   Co-habiting

Number of children (with ages) ____________________

Please state highest academic qualification achieved ____________________

Occupation ____________________ If no occupation, is this due to your symptoms? Yes / No

Part time / Full time (please circle)   If part time, is this due to your symptoms? Yes / No

Please estimate how many days sick you have taken in the past year ____________

I first experienced bowel and related symptoms ____________________ (As near to the date as possible)

I was diagnosed with Irritable Bowel Syndrome ____________________ (As near to the date as possible)

I have been to the GP about my irritable bowel and related symptoms (approximately) ____________ times, and saw (please circle)

same GP / two GP's / 3 or more GP's

Before I was diagnosed with IBS I had the following tests / examinations; (please tick)

- ☐ Barium meal
- ☐ Barium enema
- ☐ Colonoscopy
- ☐ Gynaecological examination (women only)
- ☐ Rectal examination
- ☐ Blood test
- ☐ Urine sample
- ☐ Stool sample
- ☐ Ultra sound scan
- ☐ Other (please state) ____________________

____

Today's date ____/____/____

© Claire Rutter

Section 2: Solving Problems

Please tick the response that best describes you

	Not at all True	**Barely True**	**Moderately True**	**Exactly True**
I can always manage to solve difficult problems if I try hard enough				
If someone opposes me, I can find means and ways to get what I want				
It is easy for me to stick to my aims and accomplish my goals				
I am confident that I could deal efficiently with unexpected events				
Thanks to my resourcefulness, I know how to handle unforeseen situations				
I can solve most problems if I invest the necessary effort				
I can remain calm when facing difficulties because I can rely on my coping abilities				
When I am confronted with a problem, I can usually find several solutions				
If I am in a bind, I can usually think of something to do				
No matter what comes my way, I'm usually able to handle it				

© Claire Rutter

Section 3: Emotional Feelings

Please read each of the 21 statements
and for each one tick the response that best describes you.

When I feel angry (very annoyed)…….	Almost Never	Sometimes	Often	Almost Always
I keep quiet				
I refuse to argue or say anything				
I bottle it up				
I say what I feel				
I avoid making a scene				
I smother (cover up) my feelings				
I hide my annoyance				

When I feel unhappy (miserable)…….	Almost Never	Sometimes	Often	Almost Always
I refuse to do anything about it				
I hide my unhappiness				
I put on a bold face				
I keep quiet				
I let others see how I feel				
I smother (cover up) my feelings				
I bottle it up				

When I feel afraid (worried)…….	Almost Never	Sometimes	Often	Almost Always
I let others see how I feel				
I keep quiet				
I refuse to say anything about it				
I tell others about it				
I say what I feel				
I bottle it up				
I smother (cover up) my feelings				

Section 4: Your Outlook in General

The following table has a list of statements that may or may not be true for you. There are no "correct" or "incorrect" answers. Answer according to your **own** feelings, rather than how you think "most people" would answer. Please place a tick in the appropriate column.

	Strongly Disagree 0	**Disagree 1**	**Neutral 2**	**Agree 3**	**Strongly Agree 4**
1. In uncertain times, I usually expect the best.					
2. It's easy for me to relax					
3. If something can go wrong for me, it will					
4. I'm always optimistic about my future					
5. I enjoy my friends a lot					
6. It's important for me to keep busy					
7. I hardly ever expect things to go my way					
8. I don't get upset too easily					
9. I rarely count on good things happening to me					
10. Overall, I expect more good things to happen to me than bad					

© Claire Rutter

Section 5: How you Rate your Feelings and Emotions

This scale consists of a number of words that describe different feelings and emotions. Read each item and then tick the best answer.

Please indicate to what extent you have felt this way during the past few weeks.

	1 Very Slightly	2 A Little	3 Moderately	4 Quite a Bit	5 Extremely
Interested					
Distressed					
Excited					
Upset					
Strong					
Guilty					
Scared					
Hostile					
Enthusiastic					
Proud					
Irritable					
Alert					
Ashamed					
Inspired					
Nervous					
Determined					
Attentive					
Jittery					
Active					
Afraid					

© Claire Rutter

Section 6: Your Symptoms

Below is a list of Irritable Bowel symptoms that you may, or may not have been suffering from. Please rate each one for your experience of the symptom by placing a tick in the appropriate box.

	I have never experienced this symptom	Less than 3 or 4 times per year	Every month or so	Every week or so	More than once every week
Abdominal Pain					
Diarrhoea					
Bloating					
Wind					
Constipation					
Blood in stools					
Incomplete evacuation of the bowel					
Passage of mucus					
Incontinence					
Rumbling and grumbling					

Below is a list of common symptoms or bodily sensations. Most people have experienced most of them at one time or another. I am interested in finding out how prevalent each symptom is. Using the scale below, write beside each symptom the letter, which indicates how frequently you experience that symptom.

A	B	C	D	E
Have never or almost never experienced the symptom	**Less than 3 or 4 times per year**	**Every month or so**	**Every week or so**	**More than once every week**

	Symptoms	Your Response
1	Eyes water	
2	Itching or painful eyes	
3	Ringing in ears	
4	Temporary deafness or hard of hearing	
5	Lump in throat	
6	Choking sensation	
7	Sneezing spells	
8	Running nose	
9	Congested nose	
10	Bleeding nose	
11	Asthma or wheezing	
12	Coughing	

A **Have never or almost never experienced the symptom**	**B** **Less than 3 or 4 times per year**	**C** **Every month or so**	**D** **Every week or so**	**E** **More than once every week**

	Symptoms	Your Response
13	Out of breath	
14	Swollen ankles	
15	Chest pains	
16	Racing heart	
17	Cold hands or feet even in hot weather	
18	Leg cramps	
19	Insomnia	
20	Toothaches	
21	Upset stomach	
22	Indigestion	
23	Heartburn	
24	Severe pains or cramps in stomach	
25	Diarrhoea	
26	Constipation	
27	Haemorrhoids	
28	Swollen joints	
29	Stiff muscles	
30	Back pains	
31	Sensitive or tender skin	
32	Face flushes	
33	Severe itching	
34	Skin breaks out in a rash	
35	Acne or pimples on face	
36	Acne or pimples other than on face	
37	Boils	
38	Sweat even in cold weather	
39	Strong reactions to insect bites	
40	Headaches	
41	Sensation of pressure in head	
42	Hot flushes	
43	Chills	
44	Dizziness	
45	Feel faint	
46	Numbness or tingling in any part of body	
47	Twitching of eyelid	
48	Twitching other than eyelid	
49	Hands tremble or shake	
50	Stiff joints	
51	Sore muscles	
52	Sore throat	
53	Sunburn	
54	Nausea	

Section 7: Your Views about Your Irritable Bowel Syndrome (IBS)

I am interested in your own personal views of how you see your IBS. Please indicate how much you agree or disagree with the following statements about your IBS

	Strongly Agree	**Agree**	**Neither Agree or Disagree**	**Disagree**	**Strongly Disagree**
A germ or virus caused my IBS					
My IBS was caused by poor medical care in the past					
There is little that can be done to improve my IBS					
My IBS is hereditary – it runs in my family					
My IBS will last a short time					
What I do can determine whether my IBS gets better or worse					
My IBS has strongly affected the way I see myself as a person					
Stress was a major factor in causing my IBS					
My IBS is a serious condition					
Pollution in the environment caused my IBS					
It was just by chance that I developed IBS					
My IBS has become easier to live with					
My IBS has serious economic and financial consequences					
My IBS has strongly affected the way others see me					
My state of mind played a major part in causing my IBS					
My treatments will be effective in curing my IBS					
Diet played a major role in causing my IBS					
My IBS is likely to be permanent rather than temporary					
My IBS will improve in time					
Recovery from my IBS is largely dependent on chance or fate					
My IBS has had major consequences on my life					
Other people played a large role in causing my IBS					
There is a lot I can do to control my symptoms					
My IBS will last for a long time					
My IBS is largely due to my own behaviour					
My IBS has not had much effect on my life					

Section 8: Your Illness Knowledge

This page is concerned with what you know about your illness, and where this information came from. Do not worry about whether your answers are right or wrong. It is how you think about them that are important. Please try to answer as fully as possible.

In your own words tell me about the illness you have been diagnosed with, focusing specifically upon:

(i) Why do you think you suffer from this illness? ________________________________

(ii) How serious is it? ________________________________

(iii) What can you do to help alleviate your symptoms? ________________________________

(iv) When some people are diagnosed with an illness like IBS, they actively seek out information about it. Please indicate (by circling) if you have gained information about your illness from the following sources:

Doctor	Yes / No	Television	Yes / No
Magazines	Yes / No	Radio	Yes / No
Self Help Book	Yes / No	Internet	Yes / No
Medical Journal	Yes / No	Friends/Family	Yes / No
Self Help Group	Yes / No		

Other (please state) ________________________________

(v) Are you satisfied that your doctor explained your diagnosis to you as fully as possible?

1	2	3	4	5
Very Satisfied	Satisfied	Neither Satisfied nor Dissatisfied	Dissatisfied	Very Dissatisfied

(vi) After answering the above how confident are you that you know enough about your illness?

1	2	3	4	5
Very Confident	Confident	Neither Confident nor Unconfident	Unconfident	Very Unconfident

© Claire Rutter

Section 9: Your Attitudes Towards Doctors and Medicine

Please tick the appropriate box of each statement to show how strongly you agree or disagree with it. There are no right or wrong answers. I am interested just in your opinion.

		Strongly Disagree	**Disagree**	**Tend to Disagree**	**Tend to Agree**	**Agree**	**Strongly Agree**
1	All doctors are good doctors						
2	Medicine is based on scientific principles						
3	I only consult a doctor if I am at death's door						
4	Medicines can do as much harm as good						
5	I have absolute faith and confidence in all hospital doctors						
6	The improved health of the nation is due to effective medicine						
7	Doctors blame their patients if their treatment doesn't work						
8	The advice of doctors is mainly common sense						
9	No matter how long you have to wait and see a doctor, it's worth it						
10	Medicine has cures for most diseases						
11	Doctors are important in keeping us healthy						
12	No two doctors will agree on what is wrong with a person						
13	Many medicines are just placebos or sugar pills						
14	Doctors are too ready to solve patients' problems by prescribing tranquillisers						
15	Often the only purpose of tests is to make the doctor feel less anxious						
16	Doctors know what's best for you						
17	I don't like medical people						
18	Most tests and investigations are done routinely rather than for a particular purpose						
19	Medicine is the best profession a person can have						

Section 10: How You have been Feeling in the past TWO WEEKS

Please tick the response that best describes the way you have been feeling in the past two weeks

1. I feel tense or "wound up":

☐ *Most of the time*
☐ *A lot of the time*
☐ *From time to time, occasionally*
☐ *Not at all*

2. I still enjoy the things I used to enjoy:

☐ *Definitely as much*
☐ *Not quite so much*
☐ *Only a little*
☐ *Hardly at all*

3. I get a sort of frightened feeling as if something awful is about to happen:

☐ *Very definitely and quite badly*
☐ *Yes, but not too badly*
☐ *A little, but it doesn't worry me*
☐ *Not at all*

4. I can laugh and see the funny side of things:

☐ *As much as I always could*
☐ *Not quite so much now*
☐ *Definitely not so much now*
☐ *Not at all*

5. Worrying thoughts go through my mind:

☐ *A great deal of the time*
☐ *A lot of the time*
☐ *From time to time, but not too often*
☐ *Only occasionally*

6. I feel cheerful:

☐ *Not at all*
☐ *Not often*
☐ *Sometimes*
☐ *Most of the time*

7. I can sit at ease and feel relaxed:

☐ *Definitely*
☐ *Usually*
☐ *Not often*
☐ *Not at all*

8. I feel as if I am slowed down:

☐ *Nearly all of the time*
☐ *Very often*
☐ *Sometimes*
☐ *Not at all*

9. I get a sort of frightened feeling like "butterflies" in the stomach:

☐ *Not at all*
☐ *Occasionally*
☐ *Quite often*
☐ *Very often*

10. I have lost interest in my appearance:

☐ *Definitely*
☐ *I don't take as much care as I should*
☐ *I may not take as much care*
☐ *I take just as much care as ever*

11. I feel restless as if I have to be on the move:

☐ *Very much indeed*
☐ *Quite a lot*
☐ *Not very much*
☐ *Not at all*

12. I look forward with enjoyment to things:

☐ *As much as I ever did*
☐ *Rather less than I used to*
☐ *Definitely less than I used to*
☐ *Hardly at all*

13. I get sudden feelings of panic:

☐ *Very often indeed*
☐ *Quite often*
☐ *Not very often*
☐ *Not at all*

14. I can enjoy a good book or radio or TV programme

☐ *Often*
☐ *Sometimes*
☐ *Not often*
☐ *Very seldom*

© Claire Rutter

Section 11: How You deal with Unpleasant Situations

In this section I want to know how you think you might react in some unpleasant situations. Tick as many statements as you want, that apply to you.

1. Vividly imagine that you are **afraid** of the dentist and have to get some dental work done. Which of the following would you do? Place a tick against **all** of the statements that apply to you.

_____ I would ask the dentist exactly what he was going to do

_____ I would take a tranquilliser or have a drink before going

_____ I would try to think about pleasant memories

_____ I would want the dentist to tell me when I would feel pain

_____ I would try to sleep

_____ I would watch all the dentists movements and listen for the sound of the drill

_____ I would watch the flow of water from my mouth to see if it contained blood

_____ I would do mental puzzles in my mind

2. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Tick **all** the statements that might apply to you.

_____ I would sit by myself and have as many daydreams and fantasies as I could

_____ I would stay alert and try to keep myself from falling asleep

_____ I would exchange life stories with the other hostages

_____ If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing

_____ I would watch every movement of my captors and keep an eye on their weapons

_____ I would try to sleep as much as possible

_____ I would think about how nice it's going to be when I get home

_____ I would make sure I knew where every possible exit was

3. Vividly imagine that, due to a large drop in sales, it is rumoured that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about layoffs has been made and will be announced in several days. Tick **all** the statements that might apply to you.

_____ I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said

_____ I would review the list of duties for my present job and try to figure out if I had fulfilled them all

_____ I would go to the cinema to take my mind off things

_____ I would try to remember my arguments or disagreements I might have had with the supervisor that would have lowered his/her opinion of me.

_____ I would push all thoughts of being laid off out of my mind

_____ I would tell my partner that I'd rather not discuss my chances of being laid off

_____ I would try to think which employees in my department the supervisor might have thought had done the worst job

_____ I would continue doing my work as if nothing was happening

4. Vividly imagine that you are on an aeroplane, thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced all is well. Tick **all** of the statements that might apply to you.

_____ I would carefully read the information provided about the safety features in the plane and make sure I knew where the emergency exits were

_____ I would make small talk with the passenger beside me

_____ I would watch the end of the movie, even if I had seen it before

_____ I would call for the flight attendant and ask her exactly what the problem was

_____ I would order a drink or tranquilliser from the flight attendant

_____ I would listen carefully to the engines for unusual noises and would watch the crew to see if their behaviour was out of the ordinary

_____ I would talk to the passenger beside me about what might be wrong

_____ I would settle down and read a book or magazine or read a letter

© Claire Rutter

Section 12: Coping with your IBS

This next section focuses upon the way you cope with your symptoms. Think about the times when your symptoms have been at their worst, and how you reacted to them. Now indicate the extent to which you did whatever each of the following statements says, using the key below.

1 = I usually don't do this at all.	2 = I usually do this a little bit.
3 = I usually do this a medium amount.	4 = I usually do this a lot.

1	I try to grow as a person as a result of the experience	
2	I turn to work or other substitute activities to take my mind off things	
3	I get upset and let my emotions out	
4	I try to get advice from someone about what to do	
5	I concentrate my efforts on doing something about it	
6	I say to myself "this isn't real"	
7	I put my trust in God	
8	I laugh about the situation	
9	I admit to myself that I can't deal with it, and give up trying	
10	I restrain myself from doing anything too quickly	
11	I discuss my feelings with someone	
12	I use alcohol or drugs to make myself feel better	
13	I get used to my symptoms	
14	I talk to someone to find out more about my symptoms	
15	I keep myself from getting distracted by other thoughts and activities	
16	I daydream about things	
17	I get upset and am really aware of it	
18	I seek God's help	
19	I make a plan of action	
20	I make jokes about it	
21	I accept my illness and that it can't be changed	
22	I hold off doing anything until the situation permits	

© Claire Rutter

1 = I usually don't do this at all. 2 = I usually do this a little bit.

3 = I usually do this a medium amount. 4 = I usually do this a lot.

23	I try to get emotional support from friends and relatives	
24	I just give up trying to reach my goal	
25	I take additional action to try and get rid of the symptoms	
26	I try to lose myself for a while by drinking alcohol or taking drugs	
27	I refuse to believe it has happened	
28	I let my feelings out	
29	I try to see it in a different light, to make it seem more positive	
30	I talk to someone who can help	
31	I sleep more than usual	
32	I try to come up with a strategy about what to do	
33	I focus on dealing with this problem and, if necessary , let other things slide a little	
34	I get sympathy and understanding from someone	
35	I drink alcohol or take drugs, in order to think about it less	
36	I kid around about it	
37	I give up the attempt to get what I want	
38	I look for something good in what is happening	
39	I think about how I might best handle the problem	
40	I pretend that it hasn't really happened	
41	I make sure not to make matters worse by acting too soon	
42	I try hard to prevent other things from interfering with my efforts at dealing with this	
43	I go to the cinema or watch television to think about it less	
44	I accept the reality of the fact that I have this illness	
45	I ask people who have had similar experiences what they did	
46	I feel a lot of emotional distress and I find myself expressing those feelings a lot	
47	I take direct action to get around the illness	

1 = I usually don't do this at all.	2 = I usually do this a little bit.
3 = I usually do this a medium amount.	4 = I usually do this a lot.

48	I try to find comfort in my religion	
49	I force myself to wait for the right time to do something	
50	I make fun of the situation	
51	I reduce the amount of effort I'm putting into solving the problem of illness	
52	I talk to someone about how I feel	
53	I use alcohol or drugs to help me get through it	
54	I learn to live with it	
55	I put aside other activities in order to concentrate on this	
56	I think hard about what steps to take	
57	I act as though I don't have an illness	
58	I do what has to be done, one step at a time	
59	I learn something from the experience of illness	
60	I pray more than usual	

Section 13: How You see your Quality of Life with Illness

The last questionnaire I would like you to complete concerns how you feel about your quality of life, health and other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the ONE** that appears most appropriate. This can often be your first response.
Please keep in mind your standards, hopes, pleasures and concerns. I ask that you think about your life **in the LAST TWO WEEKS**. Circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither Poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things **in THE LAST TWO WEEKS.**

		Not at all	A little	A moderate amount	Very much	An extreme amount
3	How much do you feel that pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
6	To what extent do you feel life to be meaningful?	1	2	3	4	5
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experienced or were able to do certain things **in the LAST TWO WEEKS.**

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	To what extent do you have enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

The following questions ask you to say **how good or satisfied** you have felt about various aspects of your life **over the LAST TWO WEEKS.**

		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things **in the LAST TWO WEEKS.**

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

		Not at all	Not much	A moderate amount	Very much	An extreme amount
27	How fed up do you feel?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
28	How satisfied are you with your level of happiness?	1	2	3	4	5

Are you part of a self help group? Yes / No If Yes, which? ______________________

© Claire Rutter

Section 14: Anything Else

Now please tell me anything else you feel is relevant here. Have any treatments or medications worked for you? Have any treatments made you feel worse?

Please use the rest of this sheet to finish questions, or attach additional sheets if necessary.

How long did this questionnaire take to complete? ____________________

Thank you very much for completing this booklet. You have just completed part 1 of the study. I would like you to complete a similar booklet in 6 months time. If you would like to participate in the next stage, please give your name and address. If you do not want to continue then do not enter your details here, and I will not contact you again.

Name ____________________ Address ____________________

____

Now simply put this booklet into the pre-paid envelope and post it back to me.

Thank you once again for helping in my research.
Best wishes
Claire Rutter

© Claire Rutter
IBS/GP/2

Appendix D8

Time 3 letter to primary care patients

(on University Headed Notepaper)
Claire L Rutter
Research Student
Dialling code for Canterbury:
01227 (UK) or +44 1227
Tel: 827147 direct line
764000 switchboard (ext.7147)
Fax: 827030
Email: C.L.Rutter@ukc.ac.uk

(Participant Name)
(Participant Address)

(Date)

Dear (Participant Name)

Hello there, me again! It has now been 6 months since I received your part two questionnaire and a year since I received the first from you. Thank you very much for participating, I really appreciate your time and effort.

I am pleased to inform you that this is the final questionnaire that I would like you to complete for me. This one is slightly shorter than the previous two that you have completed, but contains many of the measures that you are now familiar with. This questionnaire will be matched with the previous two so that your data can be analysed over the three time points.

I have recently started analysing this data. I expect to submit my thesis in July this year, I will write to you with my findings as soon after the submission date as possible. At that point I should be able to give you details about where this research is likely to be published and when. If you have a change of address between now and this summer then drop me a line so that I can let you have this information.

Once again this questionnaire includes space at the end for you to write anything you wish. All your comments are useful, so please feel free to write as little or as much as you want.

Thank you once again for participating, without your help this research could not be carried out.

Thank you for your time.

Best wishes

Claire Rutter
Research Student

Appendix D9

Time 3 Questionnaire (IBS version only)

KENT
UNIVERSITY OF KENT
AT CANTERBURY

Living with Irritable Bowel Syndrome
Questionnaire Booklet

Miss Claire Rutter
Research Student
Centre for Research in Health Behaviour
Department of Psychology
University of Kent at Canterbury
Canterbury
Kent CT2 7NP

☎ (01227) 827147

This booklet contains a lot of the same measures you have completed previously, however all the information you can give helps us to understand your illness better.
Most measures require you to circle or tick your preferred choice (i.e. the one that best describes the way you feel). **There are no right or wrong answers.** Although you may choose not to answer some questions, all answers will be treated in the **strictest confidence**. No one other than myself will see your completed questionnaires.
There is a space at the back for you to add anything else you feel is relevant. Please write freely. Also there are a few sections which ask you to write in your own words, if you run out of space please use the sheet at the back to continue.
Try not to spend too long thinking about specific questions. Your initial choice for **each question should take only a few seconds**. It is hoped that the whole booklet should take no longer than 30 minutes to complete.

Thank you for taking the time to complete this for me.

Best wishes

Miss Claire Rutter

<u>Please Note:</u> All questionnaires are confidential. No one will see your responses apart from the researcher named above.

Section 1: Information About You

Please enter your name and address here so the details of this study can be passed on to you.

Name ____

Address ____

____

Please state any investigations you have undergone in the past six months

____

Section 2: Your Symptoms

Over the last six months do you believe your symptoms have?

☐ Stayed the same
☐ Worsened
☐ Got better

Below is a list of common symptoms or bodily sensations. Most people have experienced most of them at one time or another. I am interested in finding out how prevalent each symptom is. Using the scale below, write beside each symptom the letter, which indicates how frequently you experience that symptom.

A	B	C	D	E
Have never or almost never experienced the symptom	**Less than 3 or 4 times per year**	**Every month or so**	**Every week or so**	**More than once every week**

	Symptoms	Your Response
1	Eyes water	
2	Itching or painful eyes	
3	Ringing in ears	
4	Temporary deafness or hard of hearing	
5	Lump in throat	
6	Choking sensation	
7	Sneezing spells	
8	Running nose	
9	Congested nose	
10	Bleeding nose	
11	Asthma or wheezing	
12	Coughing	

A	B	C	D	E
Have never or almost never experienced the symptom	**Less than 3 or 4 times per year**	**Every month or so**	**Every week or so**	**More than once every week**

	Symptoms	Your Response
13	Out of breath	
14	Swollen ankles	
15	Chest pains	
16	Racing heart	
17	Cold hands or feet even in hot weather	
18	Leg cramps	
19	Insomnia	
20	Toothaches	
21	Upset stomach	
22	Indigestion	
23	Heartburn	
24	Severe pains or cramps in stomach	
25	Diarrhoea	
26	Constipation	
27	Haemorrhoids	
28	Swollen joints	
29	Stiff muscles	
30	Back pains	
31	Sensitive or tender skin	
32	Face flushes	
33	Severe itching	
34	Skin breaks out in a rash	
35	Acne or pimples on face	
36	Acne or pimples other than on face	
37	Boils	
38	Sweat even in cold weather	
39	Strong reactions to insect bites	
40	Headaches	
41	Sensation of pressure in head	
42	Hot flushes	
43	Chills	
44	Dizziness	
45	Feel faint	
46	Numbness or tingling in any part of body	
47	Twitching of eyelid	
48	Twitching other than eyelid	
49	Hands tremble or shake	
50	Stiff joints	
51	Sore muscles	
52	Sore throat	
53	Sunburn	
54	Nausea	

Below is a list of Irritable Bowel symptoms that you may, or may not have been suffering from. Please rate each one for your experience of the symptom by placing a tick in the appropriate box.

	I have never experienced this symptom	**Less than 3 or 4 times per year**	**Every month or so**	**Every week or so**	**More than once every week**
Abdominal Pain					
Diarrhoea					
Bloating					
Wind					
Constipation					
Blood in stools					
Incomplete evacuation of the bowel					
Passage of mucus					
Incontinence					
Rumbling and grumbling					

© Claire Rutter

Section 3: Your Views about Your Irritable Bowel Syndrome (IBS)

I am interested in your own personal views of how you see your IBS. Please indicate how much you agree or disagree with the following statements about your IBS

	Strongly Agree	Agree	Neither Agree or Disagree	Disagree	Strongly Disagree
A germ or virus caused my IBS					
My IBS was caused by poor medical care in the past					
There is little that can be done to improve my IBS					
My IBS is hereditary – it runs in my family					
My IBS will last a short time					
What I do can determine whether my IBS gets better or worse					
My IBS has strongly affected the way I see myself as a person					
Stress was a major factor in causing my IBS					
My IBS is a serious condition					
Pollution in the environment caused my IBS					
It was just by chance that I developed IBS					
My IBS has become easier to live with					
My IBS has serious economic and financial consequences					
My IBS has strongly affected the way others see me					
My state of mind played a major part in causing my IBS					
My treatments will be effective in curing my IBS					
Diet played a major role in causing my IBS					
My IBS is likely to be permanent rather than temporary					
My IBS will improve in time					
Recovery from my IBS is largely dependent on chance or fate					
My IBS has had major consequences on my life					
Other people played a large role in causing my IBS					
There is a lot I can do to control my symptoms					
My IBS will last for a long time					
My IBS is largely due to my own behaviour					
My IBS has not had much effect on my life					

Section 4: Your Illness Knowledge

This page is concerned with what you know about your illness, and where this information came from. Do not worry about whether your answers are right or wrong. It is how you think about them that is important. Please try to answer as fully as possible.
In your own words tell me about the illness you have been diagnosed with, focusing specifically upon:

(i) Why do you think you suffer from this illness? ________________________________

____

(ii) How serious is it? ________________________________

____

(iii) What can you do to help alleviate your symptoms? ________________________________

____

(iv) When some people are diagnosed with an illness like IBS, they actively seek out information about it. Please indicate (by circling) if you have gained information about your illness from the following sources;

Doctor	Yes / No	Television	Yes / No
Magazines	Yes / No	Radio	Yes / No
Self Help Book	Yes / No	Internet	Yes / No
Medical Journal	Yes / No	Friends/Family	Yes / No
Self Help Group	Yes / No		

Other (please state) ________________________________

____

(v) Are you satisfied that your doctor explained your diagnosis to you as fully as possible?

1	2	3	4	5
Very Satisfied	Satisfied	Neither Satisfied nor Dissatisfied	Dissatisfied	Very Dissatisfied

(vi) After answering the above how confident are you that you know enough about your illness?

1	2	3	4	5
Very Confident	Confident	Neither Confident nor Unconfident	Unconfident	Very Unconfident

Section 5: Your Attitudes Towards Doctors and Medicine

Please tick the appropriate box of each statement to show how strongly you agree or disagree with it. There are no right or wrong answers, I am interested just in your opinion.

		Strongly Disagree	Disagree	Tend to Disagree	Tend to Agree	Agree	Strongly Agree
1	All doctors are good doctors						
2	Medicine is based on scientific principles						
3	I only consult a doctor if I am at death's door						
4	Medicines can do as much harm as good						
5	I have absolute faith and confidence in all hospital doctors						
6	The improved health of the nation is due to effective medicine						
7	Doctors blame their patients if their treatment doesn't work						
8	The advice of doctors is mainly common sense						
9	No matter how long you have to wait and see a doctor, it's worth it						
10	Medicine has cures for most diseases						
11	Doctors are important in keeping us healthy						
12	No two doctors will agree on what is wrong with a person						
13	Many medicines are just placebos or sugar pills						
14	Doctors are too ready to solve patients' problems by prescribing tranquillisers						
15	Often the only purpose of tests is to make the doctor feel less anxious						
16	Doctors know what's best for you						
17	I don't like medical people						
18	Most tests and investigations are done routinely rather than for a particular purpose						
19	Medicine is the best profession a person can have						

© Claire Rutter

Section 6: How You have been feeling in the past TWO WEEKS.

Please tick the response that best describes the way you have been feeling in the past two weeks

1. **I feel tense or "wound up":**
   - ☐ *Most of the time*
   - ☐ *A lot of the time*
   - ☐ *From time to time, occasionally*
   - ☐ *Not at all*
2. **I still enjoy the things I used to enjoy:**
   - ☐ *Definitely as much*
   - ☐ *Not quite so much*
   - ☐ *Only a little*
   - ☐ *Hardly at all*
3. **I get a sort of frightened feeling as if something awful is about to happen:**
   - ☐ *Very definitely and quite badly*
   - ☐ *Yes, but not too badly*
   - ☐ *A little, but it doesn't worry me*
   - ☐ *Not at all*
4. **I can laugh and see the funny side of things:**
   - ☐ *As much as I always could*
   - ☐ *Not quite so much now*
   - ☐ *Definitely not so much now*
   - ☐ *Not at all*
5. **Worrying thoughts go through my mind:**
   - ☐ *A great deal of the time*
   - ☐ *A lot of the time*
   - ☐ *From time to time, but not too often*
   - ☐ *Only occasionally*
6. **I feel cheerful:**
   - ☐ *Not at all*
   - ☐ *Not often*
   - ☐ *Sometimes*
   - ☐ *Most of the time*
7. **I can sit at ease and feel relaxed:**
   - ☐ *Definitely*
   - ☐ *Usually*
   - ☐ *Not often*
   - ☐ *Not at all*

8. I feel as if I am slowed down:

- ☐ *Nearly all of the time*
- ☐ *Very often*
- ☐ *Sometimes*
- ☐ *Not at all*

9. I get a sort of frightened feeling like "butterflies" in the stomach:

- ☐ *Not at all*
- ☐ *Occasionally*
- ☐ *Quite often*
- ☐ *Very often*

10. I have lost interest in my appearance:

- ☐ *Definitely*
- ☐ *I don't take as much care as I should*
- ☐ *I may not take as much care*
- ☐ *I take just as much care as ever*

11. I feel restless as if I have to be on the move:

- ☐ *Very much indeed*
- ☐ *Quite a lot*
- ☐ *Not very much*
- ☐ *Not at all*

12. I look forward with enjoyment to things:

- ☐ *As much as I ever did*
- ☐ *Rather less than I used to*
- ☐ *Definitely less than I used to*
- ☐ *Hardly at all*

13. I get sudden feelings of panic:

- ☐ *Very often indeed*
- ☐ *Quite often*
- ☐ *Not very often*
- ☐ *Not at all*

14. I can enjoy a good book or radio or TV programme:

- ☐ *Often*
- ☐ *Sometimes*
- ☐ *Not often*
- ☐ *Very seldom*

© Claire Rutter

Section 7: How You deal with Unpleasant Situations

In this section I want to know how you think you might react in some unpleasant situations. Tick as many statements as you want, that apply to you.

1. Vividly imagine that you are **afraid** of the dentist and have to get some dental work done. Which of the following would you do? Place a tick against **all** of the statements that apply to you.

_____ I would ask the dentist exactly what he was going to do

_____ I would take a tranquilliser or have a drink before going

_____ I would try to think about pleasant memories

_____ I would want the dentist to tell me when I would feel pain

_____ I would try to sleep

_____ I would watch all the dentists movements and listen for the sound of the drill

_____ I would watch the flow of water from my mouth to see if it contained blood

_____ I would do mental puzzles in my mind

2. Vividly imagine that you are being held hostage by a group of armed terrorists in a public building. Which of the following would you do? Tick **all** the statements that might apply to you.

_____ I would sit by myself and have as many daydreams and fantasies as I could

_____ I would stay alert and try to keep myself from falling asleep

_____ I would exchange life stories with the other hostages

_____ If there was a radio present, I would stay near it and listen to the bulletins about what the police were doing

_____ I would watch every movement of my captors and keep an eye on their weapons

_____ I would try to sleep as much as possible

_____ I would think about how nice it's going to be when I get home

_____ I would make sure I knew where every possible exit was

3. Vividly imagine that, due to a large drop in sales, it is rumoured that several people in your department at work will be laid off. Your supervisor has turned in an evaluation of your work for the past year. The decision about layoffs has been made and will be announced in several days. Tick **all** the statements that might apply to you.

_____ I would talk to my fellow workers to see if they knew anything about what the supervisor's evaluation of me said

_____ I would review the list of duties for my present job and try to figure out if I had fulfilled them all

_____ I would go to the cinema to take my mind off things

_____ I would try to remember my arguments or disagreements I might have had with the supervisor that would have lowered his/her opinion of me.

_____ I would push all thoughts of being laid off out of my mind

_____ I would tell my partner that I'd rather not discuss my chances of being laid off

_____ I would try to think which employees in my department the supervisor might have thought had done the worst job

_____ I would continue doing my work as if nothing was happening

4. Vividly imagine that you are on an aeroplane, thirty minutes from your destination, when the plane unexpectedly goes into a deep dive and then suddenly levels off. After a short time, the pilot announces that nothing is wrong, although the rest of the ride may be rough. You, however, are not convinced all is well. Tick **all** of the statements that might apply to you.

_____ I would carefully read the information provided about the safety features in the plane and make sure I knew where the emergency exits were

_____ I would make small talk with the passenger beside me

_____ I would watch the end of the movie, even if I had seen it before

_____ I would call for the flight attendant and ask her exactly what the problem was

_____ I would order a drink or tranquilliser from the flight attendant

_____ I would listen carefully to the engines for unusual noises and would watch the crew to see if their behaviour was out of the ordinary

_____ I would talk to the passenger beside me about what might be wrong

_____ I would settle down and read a book or magazine or read a letter

© Claire Rutter

Section 8: Coping with your IBS

This next section focuses upon the way you cope with your symptoms. Think about the times when your symptoms have been at their worst, and how you reacted to them. Now indicate the extent to which you did whatever each of the following statements says, using the key below.

1 = I usually don't do this at all.
2 = I usually do this a little bit.
3 = I usually do this a medium amount.
4 = I usually do this a lot.

1	I try to grow as a person as a result of the experience	
2	I turn to work or other substitute activities to take my mind off things	
3	I get upset and let my emotions out	
4	I try to get advice from someone about what to do	
5	I concentrate my efforts on doing something about it	
6	I say to myself "this isn't real"	
7	I put my trust in God	
8	I laugh about the situation	
9	I admit to myself that I can't deal with it, and give up trying	
10	I restrain myself from doing anything too quickly	
11	I discuss my feelings with someone	
12	I use alcohol or drugs to make myself feel better	
13	I get used to my symptoms	
14	I talk to someone to find out more about my symptoms	
15	I keep myself from getting distracted by other thoughts and activities	
16	I daydream about things	
17	I get upset and am really aware of it	
18	I seek God's help	
19	I make a plan of action	
20	I make jokes about it	
21	I accept my illness and that it can't be changed	
22	I hold off doing anything until the situation permits	

1 = I usually don't do this at all.
2 = I usually do this a little bit.
3 = I usually do this a medium amount.
4 = I usually do this a lot.

23	I try to get emotional support from friends and relatives	
24	I just give up trying to reach my goal	
25	I take additional action to try and get rid of the symptoms	
26	I try to lose myself for a while by drinking alcohol or taking drugs	
27	I refuse to believe it has happened	
28	I let my feelings out	
29	I try to see it in a different light, to make it seem more positive	
30	I talk to someone who can help	
31	I sleep more than usual	
32	I try to come up with a strategy about what to do	
33	I focus on dealing with this problem and, if necessary , let other things slide a little	
34	I get sympathy and understanding from someone	
35	I drink alcohol or take drugs, in order to think about it less	
36	I kid around about it	
37	I give up the attempt to get what I want	
38	I look for something good in what is happening	
39	I think about how I might best handle the problem	
40	I pretend that it hasn't really happened	
41	I make sure not to make matters worse by acting too soon	
42	I try hard to prevent other things from interfering with my efforts at dealing with this	
43	I go to the cinema or watch television to think about it less	
44	I accept the reality of the fact that I have this illness	
45	I ask people who have had similar experiences what they did	
46	I feel a lot of emotional distress and I find myself expressing those feelings a lot	

1 = I usually don't do this at all. 2 = I usually do this a little bit.

3 = I usually do this a medium amount. 4 = I usually do this a lot.

47	I take direct action to get around the illness	
48	I try to find comfort in my religion	
49	I force myself to wait for the right time to do something	
50	I make fun of the situation	
51	I reduce the amount of effort I'm putting into solving the problem of illness	
52	I talk to someone about how I feel	
53	I use alcohol or drugs to help me get through it	
54	I learn to live with it	
55	I put aside other activities in order to concentrate on this	
56	I think hard about what steps to take	
57	I act as though I don't have an illness	
58	I do what has to be done, one step at a time	
59	I learn something from the experience of illness	
60	I pray more than usual	

Section 9: How You see your Quality of Life with Illness

The last questionnaire I would like you to complete concerns how you feel about your quality of life, health and other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the ONE** that appears most appropriate. This can often be your first response.
Please keep in mind your standards, hopes, pleasures and concerns. I ask that you think about your life **in the LAST TWO WEEKS**. Circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither Poor nor good	Good	Very good
1	How would you rate your quality of life?	1	2	3	4	5

© Claire Rutter

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
2	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things **in the LAST TWO WEEKS.**

		Not at all	A little	A moderate amount	Very much	An extreme amount
3	How much do you feel that pain prevents you from doing what you need to do?	1	2	3	4	5
4	How much do you need medical treatment to function in your daily life?	1	2	3	4	5
5	How much do you enjoy life?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
6	To what extent do you feel life to be meaningful?	1	2	3	4	5
7	How well are you able to concentrate?	1	2	3	4	5
8	How safe do you feel in your daily life?	1	2	3	4	5
9	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experienced or were able to do certain things **in the LAST TWO WEEKS.**

		Not at all	A little	Moderately	Mostly	Completely
10	Do you have enough energy for everyday life?	1	2	3	4	5
11	Are you able to accept your bodily appearance?	1	2	3	4	5
12	To what extent do you have enough money to meet your needs?	1	2	3	4	5
13	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

© Claire Rutter

The following questions ask you to say **how good or satisfied** you have felt about various aspects of your life **over the LAST TWO WEEKS.**

		Very poor	Poor	Neither poor nor good	Good	Very good
15	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied or dissatisfied	Satisfied	Very satisfied
16	How satisfied are you with your sleep?	1	2	3	4	5
17	How satisfied are you with your ability to perform daily living activities?	1	2	3	4	5
18	How satisfied are you with your capacity for work?	1	2	3	4	5
19	How satisfied are you with yourself?	1	2	3	4	5
20	How satisfied are you with your personal relationships?	1	2	3	4	5
21	How satisfied are you with your sex life?	1	2	3	4	5
22	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24	How satisfied are you with your access to health services?	1	2	3	4	5
25	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things **in the LAST TWO WEEKS.**

		Never	Seldom	Quite often	Very often	Always
26	How often do you have negative feelings, such as blue mood, despair, anxiety, depression?	1	2	3	4	5

		Not at all	Not much	A moderate amount	Very much	An extreme amount
27	How fed up do you feel?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
28	How satisfied are you with your level of happiness?	1	2	3	4	5

© Claire Rutter

Section 10: Anything Else

Now please tell me anything else you feel is relevant here. Have any treatments, or medications worked for you? Have any treatments made you feel worse?

Please use the rest of this sheet to finish questions, or attach additional sheets.

How long did this booklet take to complete?____

You have now completed your participation in my research. Your help has been invaluable to me and I cannot thank you enough for your participation. Please place this final booklet into the pre-paid envelope and post it back to me.

I will write to you with the findings of my research in the summer of 2001.

Thank you once again for helping in my research.
Best wishes
Claire Rutter

Appendix D10

Letter to GPs in second phase of recruitment

(On University Headed Notepaper)
Claire L Rutter
Research Student
Dialling code for Canterbury:
01227 (UK) or +44 1227
Tel: 827147 direct line
Fax: 827030
Email:C.L.Rutter@ukc.ac.uk

(Doctor Name)
(Doctor Address)

(Date)

Dear Dr (Name)

I am a PhD student conducting research into **Irritable Bowel Syndrome (IBS), Inflammatory Bowel Disease (IBD), and Chronic Fatigue Syndrome (CFS).** I am desperately trying to recruit patients with one of the above illnesses. I am hoping that you may be able to help with this.

I am interested in how patients with **IBS, IBD and CFS** compare in the way they think and feel about their diagnoses, and to see if these factors have any bearing on future reported symptoms, and other outcome measures. It is hoped that this research may help in the planning of therapy for these patients.

All I require of you is to hand out information envelopes. Included with this letter are 4 such information envelopes that I am hoping that you can distribute to suitable patients. Each envelope contains: an information sheet, which includes a reply slip; a consent form; and a prepaid envelope.

Patients who agree to participate will simply be asked to complete a questionnaire booklet on three occasions (if you are interested in seeing a copy of this questionnaire I would be happy to send you one).

I submitted by research protocol and questionnaire measures to the South Thames Multi-Centre Research Ethics Committee. My study was approved by this MREC on 7th January 1999. I have since applied and have been approved by 24 Local Research Ethics Committees around the country including your local health authority.

I hope the information in this letter has gone some way in persuading you to help me in my research. I realise the time pressures on GPs, which is why I am keeping this letter as short as possible, so if you require any more information about this study, please do not hesitate to get in touch. **Your help is crucial to my research.** Please help if you can.

My inclusion criteria are:
- IBD sufferers who have a positive diagnosis of Crohn's disease or colitis after investigative techniques
- IBS sufferers who have been diagnosed with the **Rome criteria**
- CFS sufferers who have been diagnosed with the **Oxford criteria**
- Only patients who can give their informed consent
- Either recently diagnosed or up to 5 years after diagnosis

On distributing these envelopes, I am trying to keep instructions similar, so I hope that you can say something along the lines of *"Here is an envelope containing information about a study that a PhD student wanted me to hand out to patients with IBS / CFS / IBD. I am only giving out these envelopes, it's up to you whether you want to participate or not."*

This longitudinal study will run until summer 2001, so if you require more information envelopes please do not hesitate to contact me, I would be delighted to send you more envelopes. Also, please feel free to contact me if you have any questions about this study, I will be pleased to talk to you.

I would be very grateful for your help in this task.

Thank you for your time.

Yours sincerely,
Claire Rutter