AN EXPLORATORY STUDY OF COPING, PSYCHOLOGICAL DISTRESS, SELF-ESTEEM AND PERCEIVED STRESS IN PATIENTS WITH CHRONIC BOWEL DISORDERS

By

GEORGINA CRATCHLEY

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ABSTRACT

AN EXPLORATORY STUDY OF COPING, PSYCHOLOGICAL DISTRESS, SELF-ESTEEM AND PERCEIVED STRESS IN PATIENTS WITH CHRONIC BOWEL DISORDERS

By

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This study had 4 aims. The first aim was to explore the relationships between personal control and coping responses in patients with the chronic bowel disorders of irritable bowel syndrome (IBS) and inflammatory bowel disease (IBD). The second aim examined coping in IBS and IBD patients as a process, by focusing on a specific episode of their primary symptoms. The coping profiles of the IBS and IBD patients were compared to establish whether differences in coping between the 2 groups were present. The third aim examined differences between groups and tested for linear trends across IBS, IBD patients and Non-patient controls in relation to anxiety, depression and self-esteem. A supplementary aim was to evaluate whether anxiety in the 3 groups was considered to be clinically significant (i.e. fell above the threshold for "caseness"). The fourth aim tested differences between the 3 groups in perceived stress, as previous findings have been inconclusive.

Fifteen IBS patients and 15 IBD patients who attended a Gastroenterology (G.I.) Clinic were interviewed and completed a battery of self-report measures. Fifteen Non-patient controls completed a battery of self-report measures.

The data was analysed using Pearson's product moment correlation coefficients for aim 1; profile analysis using MANOVA for aim 2, and one-way between subjects ANOVA's for aims 3 and 4.

The research hypotheses were not met, as the results were not statistically significant. However, two post-hoc findings revealed that patients with bowel disorders used equal proportions of problem and emotion-focused coping and these types of coping were significantly positively correlated. The test of flatness within profile analysis was statistically significant which indicated that patients with bowel disorders do not use a "blanket" approach to coping with an episode of their primary symptoms. A percentage of people in each group met the criterion for "caseness" of clinically significant anxiety.

The results were evaluated in relation to the research literature and directions for future research were outlined.

It was suggested that there might be a subset of patients with bowel disorders who experience clinical anxiety and/or depression and screening in G.I. clinics was recommended.

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AUTHOR'S DECLARATION

At no time during the registration for the degree of Doctor of Clinical Psychology has the author been registered for any other University award.

The contents of this volume are identical to the volume submitted for examination in temporary binding except for the amendments requested at the examination.

This study was conducted while the author was a Trainee Clinical Psychologist in the South & West Region based in Avalon Somerset NHS Trust and the research was conducted in collaboration with Southmead Health Services (NHS) Trust and the general public.

Signed Cratchley Date 26/7/99

CHAPTER 1: INTRODUCTION

1.1 WHY THIS IS AN IMPORTANT AREA TO STUDY (Facts and Figures)

Irritable Bowel Syndrome (IBS) is a benign, chronic and common illness prevalent in approximately 20% of the Western population. IBS has considerable cost (i.e. time, financial) implications reflected in utilization of health services and absenteeism from work. In the United States more than two million prescriptions per year are given out for people with IBS (Sandler, 1990). This chronic illness is often associated with unnecessary and often harmful tests, procedures and surgery (Thompson, Dotevall, Drossman, Weaton & Kruis, 1989). For example, a study carried out in the U.S. by Whitehead, Cheskin, Heller, Robinson, Crowell, Benjamin & Schuster, (1990) found that 21% of their IBS sample had undergone hysterectomies without benefit. The U.S. national average is 5.5%! People with IBS who are referred to Gastroenterology Clinics account for over 50% of the referrals. (Kumar & Clark, 1994; Francis & Whorwell, 1997). IBS has been ranked as the second most common cause of industrial absenteeism due to illness (Young, Alpers, Norland & Woodruff, 1976).

In a prospective study of a community sample of 383 women, Whitehead, Crowell, Robinson, Heller, & Schuster, (1992), found that psychological stress (as a consequence of stressful life events) was significantly related to the self-reported number of disability days and medical clinic visits for bowel symptoms.

People with IBS who seek treatment have higher levels of psychological distress compared to those who do not seek treatment (i.e. IBS non-patients), (Lynn &

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Friedman, 1995). IBS patients are more anxious and depressed than control patients and tend to overuse medical services (Camilleri & Neri, 1989).

The economic impact of this chronic illness is substantial. This warrants research endeavours to elicit more information about the impact of the illness on the patient. Although many studies have explored and identified the psychological distress associated with IBS, there is limited research about how these patients cope with their illness and no research about how these patients cope with the primary symptoms of their illness. Studies addressing this neglected area begin to tackle the issues of reducing costs, benefiting not only the health care services but also the patients themselves.

1.2 STRESS (how this relates to distress and coping)

Walter Cannon (1935) was among the first to use the term stress in a non-engineering context. He regarded stress as a disturbing force, which upsets the person's equilibrium or homeostasis. From this perspective, stress refers to those events or situations that challenge a person's psychological and/or physiological homeostasis.

According to Lazarus (1966), for us to experience an event or situation as stressful we have to perceive or appraise it as such. Some appraisals can ameliorate the impact of a potentially stressful event. There are psychological mechanisms that may combat stress. Freud referred to these as defence mechanisms; today these are generally called coping strategies.

For example, Pearlin and Schooler (1978) examined stress and coping in four role areas (i.e. marriage, parenting, household economics and occupation) in an adult community

sample. They found a clear order in the efficacy of people's psychological resources in vitiating stress; freedom from negative attitudes towards self, the possession of a sense that one is in control of the forces impinging on one, and the presence of favourable attitudes towards one's self. They also found that the greater the scope and variety of the individual's coping repertoire, the more protection coping affords.

Glass and Singer (1972) provided evidence that the perception that one is in control of potentially stressful events reduces their impact.

A widely used measure of perceived control in relation to personal health is the Multidimensional Health Locus of Control Scales (MHLC), (Wallston, Wallston, & DeVellis, 1978). Health locus of control refers to a person's beliefs regarding the source of control over his/her health. If the person believes that his/her own behaviour influences his/her health status, the person is said to possess an internal locus of control orientation with regard to his/her health. If, however, the person believes that his/her health is influenced by the actions of other people or is due to fate, luck or chance, the person is said to have an external health locus of control orientation. According to Wallston's (1984, 1992) modification of Rotter's (1954) social learning theory, a person's health locus of control orientation is one of several factors that determine which health-related behaviours a person will perform. The MHLC (Forms A & B) measure beliefs about peoples general health status. As it is possible that people with a given health condition may hold different locus of control beliefs about that condition than about their general health status Wallston, Stein & Smith, (1994) developed a disease-specific version of the MHLC (Form C), which can be adapted to any medical condition.

The studies by Pearlin & Schooler (1978) and Glass and Singer (1972), support Lazarus and Folkman's (1984) cognitive-phenomenological theory of stress which states that adaptation to a stressor is mediated by two factors; 1) the personal **appraisal** of the stressor and of one's resources for dealing with it and 2) the thoughts and behaviours used to manage the demands of the stressors (i.e. coping responses).

Appraisal is the cognitive process through which an event is evaluated with respect to what is at stake (primary appraisal) and what coping resources and options are available (secondary appraisal). Appraisals of stress are of three types: harm/loss (referring to damage that has already occurred); threat (referring to anticipated or future harm and challenge (in which the focus is placed positively on potential gain, growth or mastery rather than negatively on the possible risks). The degree to which a person experiences psychological stress (i.e. feels harmed, threatened or challenged) is determined by the relationship between the person and the environment in that specific encounter (Folkman and Lazarus, 1980).

Lazarus (1993) states that, "An appraisal-centered approach to stress directs our attention not merely to environmental stressors but to how these stressors are construed by the person. I am confident that personal meanings are the most important aspects of psychological stress with which the person must cope, and they direct the choice of coping strategy".

1.3 WHAT IS COPING?

Lazarus and Folkman (1984) defined coping as "the person's constantly changing cognitive and behavioural efforts to manage specific external/internal demands that are

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appraised as taxing or exceeding the person's resources". This definition emphasises the process, i.e. what people do when they are faced with psychological stress. Lazarus outlined two main types of coping responses (i.e. what people do), problem-focused (PF) and emotion-focused (EF).

Problem-focused coping consists of efforts to change the actual circumstances of an adaptational encounter, e.g. by changing the environment or oneself. This includes confrontive coping, self control, seeking social support, accepting responsibility and planful problem solving. Emotion-focused coping involves purely cognitive activities that do not directly alter the actual relationship with the environment but do alter how this relationship is cognized. This includes, distancing, escape-avoidance (e.g. wished the situation would go away or somehow be over with) and positive reappraisal. Changing the relational meaning of what is happening can be very powerful and widely employed for regulating stress and emotion. (Lazarus, 1992).

1.4 COPING AND CHRONIC ILLNESS

Folkman and Lazarus (1980) studied the appraisal and coping responses to stressful events experienced by a middle-aged community sample during one year. They found the context of the stressful situation (e.g. work related/health related) and the individual's appraisal of its amenability to personal control to be important predictors of modes of coping.

Health-related stressors were associated with increased emotion-focused coping whereas work-related stressors were associated with higher levels of problem-focused coping.

This finding was consonant with situation-oriented studies of coping with physical illness and disabilities (e.g. Cohen & Lazarus, 1979; Lipowski, 1970 & Moos, 1977).

In terms of appraisal, they found that situations in which something could be done and in which more information was needed generated higher levels of problem-focused coping than situations that had to be accepted. Situations that had to be accepted and in which the person had to hold back from acting, generated higher levels of emotion-focused coping than in those in which something constructive could be done.

This finding supported Pearlin & Schooler's study (1978) which found that emotion-focused strategies were most effective in situations which were not amenable to individual control. More recently, Andrew Steptoe at the Conference of the European Health Psychology Society (1997), focused on the mounting evidence of the importance of feeling in control of stressors.

Lazarus (1993) commented on the importance of the context in which illness occurs (i.e. at what stage, what threats are perceived etc.) in order to determine peoples' coping responses. "When studying how the patient copes with illness, it is necessary to specify the particular threats of immediate concern to the patient and to treat them separately, rather than broadening the focus of attention to the **overall illness**".

There are numerous studies of coping based on normal populations, but there are only a few studies of the coping strategies used by people with chronic illnesses. These can be broadly divided in to two categories, 1) studies which have examined the coping strategies of people with the same illness and 2) studies which have examined the coping strategies of people with a variety of chronic illnesses.

In the first category, Holm, Holroyd, Hursey & Penzien (1986), carried out a study comparing the coping strategies used by recurrent headache sufferers and headache-free controls. They found that recurrent headache sufferers used more emotion-focused strategies (avoidance and self-blame) and appraised ambiguous stressors as more negative and less controllable than the headache-free controls. Another study (Newman, Fitzpatrick, Lamb & Shipley, 1990) analysed 158 rheumatoid arthritis patients' responses to a measure of coping specifically designed for this population, using hierarchical cluster analysis. This produced a four group solution, i.e. four groups who coped using different strategies. A high proportion of R.A. patients (n = 105) formed group 2 which did not show a distinctive coping strategy. These R.A. patients tended to use a large range of coping strategies to a moderate extent.

In the second category of studies, Bombardier, D'Amico & Jordan (1990), assessed the coping strategies used by 101 patients with a wide range of medical and psychiatric conditions which had been refractory to conventional medical or surgical treatment. The coping measure used was The Ways of Coping Checklist - Revised (WCCL-R) which asked patients to indicate which thoughts and behaviours they used to cope with their medical conditions. The WCCL-R has 5 subscales, problem-focused; seeks social support; wishful thinking; blames self and avoidance. Qualitatively the sample was characterised by relatively high utilisation of seeking social support (problem-focused coping strategy) and relatively little self-blame (emotion-focused coping strategy). When Bombardier et al, analysed the relative scores of coping (rather than the raw scores) to provide a means of comparing the proportion of coping effort attributable to each of the coping factors, they found that this heterogeneous sample used an equal amount of problem-focused (49%) and emotion-focused (51%) coping.

Bombardier et al's study did not support Folkman and Lazarus's (1980) finding that when faced with health-related stressors more emotion-focused strategies are used. The study is limited, because the findings can not be generalised to any single illness or condition.

Another study which examined the coping strategies used by a sample of people with a variety of chronic illnesses was carried out by Felton, Revenson & Hinrichsen, (1984). However, they went one step further to make comparisons in terms of coping strategies between the different illness groups, to address whether people with chronic illnesses cope differently. The sample consisted of 170 adults with the chronic illnesses of hypertension, diabetes, cancer and rheumatoid arthritis. Most of the coping strategies were drawn from the Ways of Coping Scale.

When the sample was taken as a whole, Felton et al found that people with chronic illnesses used a moderate amount of each coping strategy, with self blame being used the least often and threat minimization being used most often. In terms of the division of problem-focused and emotion-focused coping strategies, comparisons were not possible as unfortunately the measure used only had one problem-focused subscale and five emotion-focused subscales.

When comparisons were made between different illness groups, they found that there were no significant differences in the types of coping between the groups; with the exception of people with rheumatoid arthritis, who used significantly more wish fulfilling fantasy. These results suggest that particular diseases are not exclusively linked with particular coping styles. However, differences among illnesses may have been partially

obscured by the use of the coping measure which asked about reactions to the illness in general rather than to specific kinds of stress.

The above studies are very difficult to compare, as comparison is fraught with methodological problems, such as the use of very different types of sample and a variety of coping measures.

What the coping literature about chronic illnesses does tell us is that it is important to address perceptions of stress, appraisal and feelings of personal control when assessing peoples coping responses to chronic illness. It also highlights the importance of assessing a wide range of coping responses to identify if any specific strategies are used. Additionally, if a process-centered approach to coping is being examined, then there needs to be clarity/specificity about what aspect of the illness is being addressed.

1.5 IBS AND IBD AS CHRONIC ILLNESSES

Irritable Bowel Syndrome (IBS) is a gastrointestinal disorder characterised by the most common symptoms of abdominal pain or discomfort; abnormal bowel habits; abdominal distension; feelings of incomplete evacuation and mucus per rectum (Francis & Whorwell, 1997).

IBS is a recently recognised chronic illness prevalent in 15-20% of the Western population. Recent reports suggest that this prevalence is similar in third world countries (e.g. Olubutide et al, 1995). People are usually given the diagnoses of IBS in primary care settings, where the female to male ratio is 2.5:1 and up to 50% of these people

attend Gastroenterology (G.I.) Clinics (Francis & Whorwell, 1997). IBS is restricted to adults, it is uncommon in children and in people over the age of 60 years (Desai, 1982).

Inflammatory Bowel Disease (IBD) is an umbrella term for Crohn's Disease (C.D.) and Ulcerative Colitis (U.C.) which are chronic gastrointestinal diseases. C.D. is characterised by the most common symptoms of diarrhoea, abdominal pain and weight loss and U.C. by the symptoms of diarrhoea with blood and mucus which is sometimes accompanied by lower abdominal pain or discomfort. (Kumar & Clark, 1994).

IBD has a worldwide distribution, but is more common in Western countries. IBD can occur at any age but has a peak incidence between the ages of 20-40 years old. C.D. is equally distributed between the sexes, but U.C. is more common in women than men.

IBS and IBD are chronic illnesses which share primary symptoms of abdominal pain and abnormal bowel habits which occur episodically, vary in their severity and typically affect patients for years. (Schwarz, Blanchard, Berreman, Scharff, Taylor, Greene, Suls & Malamood, 1993). Both illnesses have unknown aetiology and are generally considered to be multifactorial in origin. Psychological factors are considered to have an important role in the exacerbation and perpetuation of both illnesses.

1.6 PSYCHOLOGICAL MORBIDITY IN IBS AND IBD

Living with a chronic illness is generally considered to be taxing and stressful. When people with IBS have been directly asked about stress more than half of them have reported that stressful events exacerbate their symptoms (Ford, Miller, Eastwood & Eastwood, 1987). Clouse (1988) found that experimentally induced emotional stress affects gastrointestinal motility. However, studies which have examined stressful life events or daily stress in IBS sufferers have produced inconsistent results. For example, Suls. Wan, & Blanchard, (1994) did not find any consistent relationship between daily stressors and gastrointestinal (GI) symptoms in 44 patients with IBS and Schwarz et al. (1993) found no significant correlations between Life Events Scores and GI symptoms in 109 IBS patients. The latter study may have been limited because it measured life events per se as being indicative of stress rather than examining the perceived stress aroused by life events. A study by Arun, Kanwai, Vyas, & Sushil, (1993) found that IBS patients perceived significantly more stressful life events compared to controls. A study by Whitehead et al. (1992) clarified that when perceived levels of stress were measured in relation to stressful life events then people with IBS perceived significantly more of these when compared to controls. They also found that these levels of stress (in the IBS group) were significantly correlated with the amount of subsequent bowel symptoms. However, the correlations were relatively low and indicated that approximately 11% of the variance in bowel symptom reports were attributable to life event stress. Whitehead et al (1992) examined several different approaches to the measurement of stress and bowel symptomatology and concluded that the correlation between stress and bowel symptoms was relatively low.

In a review of the research examining the influence of distressing life events on IBD, the results were inconsistent (Faller & Kraus, 1996). Schwarz et al, (1993) compared Life Events Scores between IBS patients, IBD patients and a control group and found no significant differences between the groups but an ordering of IBS<IBD<Controls. As mentioned above, this study provides limited information, as it did not examine the perceived amount of stress aroused by the life events. All of the studies examined the

effects of stress on illness without accounting for the effects of coping responses which may have moderated these effects.

Coping responses to perceived stress, such as living with the chronic illnesses of IBS and IBD are likely to affect symptomatology of the illness and any accompanying psychological distress.

When examining the effects of perceived stress and coping in relation to chronic illnesses, it is important also to examine the amount of psychological distress, e.g. levels of anxiety and depression. Lazarus (1993) stated that, "the emotions are a much richer source of information about how people are faring in adaptational encounters,... than the unidimensional concept of stress".

As mentioned earlier, IBS and IBD are considered multifactorial in origin with psychological factors affecting how illness is experienced and acted on by patients. It is well documented in the literature that amongst the IBS population, those who seek treatment are noticeably psychologically distressed, whereas the non-treatment seekers are not more psychologically distressed than the normal population. (Blanchard & Malamood, 1996; Drossman, McKee, Sandler, Mitchell, Cramer, Lowman & Burger, 1988; Lynn & Friedman, 1995 & Whitehead, Bosmajian, Zonderman, Costa & Schuster, 1988).

Several studies have shown that IBS patients score significantly higher on a variety of psychological measures compared to non-patient controls. For example, IBS patients scored significantly higher than normals on the Beck Depression Inventory (BDI), and on both subscales of the State-Trait Anxiety Inventory (STAI). (Blanchard, Radnitz, Evans,

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Schwarz, Neff & Gerardi, 1986 & Latimer, Sarna, Campbell, Latimer, Waterfall & Daniel, 1981). The psychological profiles of IBS patients have been compared with other illnesses (e.g. Tension Headache, Migraine) and controls on 17 different psychological measures. On almost all of these it was found that the means were ordered IBS>Tension Headache>Migraine>Normal Controls and the scores on the BDI were significantly higher for the IBS group. (Blanchard et al, 1986).

The research evidence for psychological distress in IBD patients is mixed. A study by Gazzard, Price, Libby & Dawson, (1978) found a depression rate of 32-38% in 85 outpatients with Crohn's Disease. When IBD patients were assessed using the BDI, the mean score indicated that these patients were on the borderline for clinical depression. When the IBD patients were separated into two groups, those with Crohn's Disease (C.D.) and those with Ulcerative Colitis (U.C.), it was found that the C.D. group had a mean score indicating mild depression and the U.C. group fell within the normal range (i.e. were not depressed). (Kinash, Fischer, Lukie & Carr, (1993a). These studies suggest that only some IBD patients experience depression at a mild level.

Tartar, Switala, Carra & Edwards, (1987) studied 53 IBD patients (before and after disease onset) and compared them to normal controls. Tartar et al found that IBD patients had increased prevalence of depression, anxiety and panic disorder in comparison to the controls at any time in their life.

A study which helps to clarify the experience of depression and anxiety in IBD patients was carried out by Porcelli, Leoci & Guerra (1996). They assessed anxiety and depression using the Hospital Anxiety and Depression Scale (HADS) in 104 IBD outpatients in conjunction with a measure of Disease Activity. Both the measures were used at baseline and at 6 months. The patients were grouped according to whether the

-21-

disease activity had remained unchanged, improved or worsened from baseline to follow up. Anxiety and depression were analysed separately using two-way repeated measures anova's, ie. both between groups and within group factors were examined as well as any interaction effects. Porcelli et al. found that for anxiety there were significant main effects of group, time and interaction. For depression there were significant main effects of time and interaction. These results showed that patients whose disease activity improved over time also had decreased levels of anxiety and depression over time. The patients whose disease activity had got worse over time showed the opposite effect in terms of anxiety and depression, (i.e. both anxiety and depression had increased over time). Porcelli et al. concluded that symptoms of psychological distress occur concurrently with the exacerbation of IBD and recover with improvement in the clinical activity of the disease.

There are four studies which have compared psychological distress between IBS and IBD patients and controls. These studies have produced inconsistent results in terms of finding significant differences between the two groups. The first study (Esler & Goulston, 1973) compared 2 IBS groups (those with predominantly diarrhoea and those with predominantly pain) with an Ulcerative Colitis group and a Patient Control group. The 4 groups were compared on the Eysenck Personality Inventory (EPI) and the IPAT Anxiety Scale. They found that the IBS group (with predominantly diarrhoea) were significantly more anxious and neurotic than the other 3 groups (i.e. IBS with pain; U.C. and Patient Control). There were no other significant differences between the four groups.

The second study (Fava & Pavan, 1976/77) compared IBS patients with U.C. patients and an Appendicitis Control group. They found a 70% prevalence of psychopathology in the IBS patients, which were predominantly depression and hysteria, in comparison to 25% in U.C. patients and 15% in the appendicitis controls.

The third study (Gomborone, Dewsnap, Libby & Farthing, 1995) compared three groups on the Beck Depression Inventory (BDI). They found that IBS patients scored higher on the BDI compared to patients with an organic gastrointestinal disease and healthy controls.

The fourth study (Schwarz et al, 1993) compared IBS and IBD patients and non-patient controls on a variety of psychological measures. These measures were as follows: BDI; State-Trait Anxiety Inventory; Rathus Assertiveness Scale (RAS); Psychosomatic Symptom Checklist (PSC); Social Readjustment Scale which yielded a single Life Events Score (LES) for the previous year and the MMPI. They found that with the exception of the RAS and MMPI scale 9., every psychological measure was ordered IBS>IBD>Controls. The IBS and IBD groups scored significantly higher than the controls on the BDI, the STAI and MMPI scales 0-3. However, the only significant difference which was found between the IBS and IBD patients was for anxiety. IBS patients were significantly more anxious than IBD patients. A finding that was supported by Walker, Roy-Byrne, Katon, Li, Amos, & Jiranek, (1990) where the SCL-90 was used to measure anxiety.

Schwarz et al's study confirms the findings in the literature that IBS patients' scores are higher than non-patient controls on psychological measures and that this holds true for IBD patients. However, an interesting and important finding was that although the elevations in the scores were significant relative to controls, the scores **did not reach** clinically pathological levels. This may explain the variable results found in the studies on psychological distress in IBD patients.

All four studies suggest that IBS patients are more psychologically distressed than IBD patients. However, the only **consistent** finding of **significant differences** between these two groups was that IBS patients are more anxious than IBD patients. This is supported by a 5 year follow up study of IBS patients where anxiety was considered important in the maintenance of the disease (Fowlie, Eastwood, & Ford, 1992).

1.7 RATIONALE AND HYPOTHESES (1)

The coping literature emphasises the importance of control in determining people's feelings of personal control when examining their coping responses, as control is an important predictor of the type of coping response used (i.e. problem-focused or emotion-focused). When people feel they have personal control over stressful situations, problem-focused coping predominates. When people perceive stressful situations as refractory to change, then emotion- focused coping predominates.

It is therefore hypothesised that:

1a) There will be a positive correlation between internal health locus of control beliefs (IHLC) and the proportion of problem focused coping strategies across both patient groups.

1b) There will be a negative correlation between IHLC beliefs and the proportion of emotion focused coping strategies across both patient groups.

1c) There will be a negative correlation between health locus of control beliefs due to chance (CHLC) and the proportion of problem focused coping strategies across both patient groups.

1d) There will be a positive correlation between CHLC beliefs and the proportion of emotion focused coping strategies across both patient groups.

1.8 <u>COPING AND IBS AND IBD</u>

There is very little research about the coping strategies of people with the chronic illnesses of IBS and IBD, a point that has been made by, Baer, Gagnon, Musgrove & Winston, (1982); Feifel, Strack & Nagy, (1987); Grace & Priest, (1982) & Meyer, Wolfish, Sachar, Greenstein, Hill & Janowitz, (1980). There is no study that has compared how these two patient groups cope with their illness.

There are only two studies which have examined coping responses in IBD patients. The first study (Turnbull & Vallis, 1995) used the Rosenbaum Self Control Schedule (SCS) which has been shown to predict coping and health care behaviours in a number of clinical samples. The SCS was used in conjunction with other measures assessing quality of life in IBD patients. Turnbull and Vallis found that coping was significantly negatively correlated with psychological distress (SCL-90R). When they split subjects into extreme groups on the coping scale, with 8 "good" copers and 8 "poor" copers they found that the "good" copers were significantly less distressed (SCL-90R) and less impaired (SIP Psychosocial Scale) than "poor" copers. Unfortunately, Turnbull and Vallis did not report the total mean score on the coping scale, nor how they discriminated between "good" and "poor" copers. The results are limited in providing information about how IBD patients cope.

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The second study (Kinash, Fischer, Lukie, & Carr, 1993b) involved assessing the coping behaviours of 150 IBD patients (Crohn's Disease, N=88; Ulcerative Colitis, N=62) who had been diagnosed for at least one year. They used the Jalowiec Coping Scale (JCS) which consists of 40 coping behaviours, 15 problem-oriented and 25 affective-oriented. They found no significant differences between the coping patterns of the 2 IBD groups. Both groups used significantly more problem-oriented coping strategies than affective-oriented strategies.

There is only one study which has examined coping responses in IBS patients. Lewis et al (1994) used the Ways of Coping Checklist retrospectively to assess coping strategies pre-to-post-illness in 47 IBS patients. They found that IBS patients used significantly more distancing, self controlling and seeking social support (post illness). These patients had expanded their coping repertoire to include more emotion-focused (33%) and problem- focused (67%) coping responses (post illness).

These studies do not support the community sample of Folkman & Lazarus, (1980) who, when faced with health-related stressors, tended to use more emotion-focused coping strategies. This may reflect a difference in coping between a normative sample and patient samples.

A criticism of these studies is that they attempted to explain how people with IBS and IBD cope with their illness generally, using process-oriented coping measures. When coping is defined as a process rather than a trait concept it is important to examine the specific threats (or stressors) to the individuals concerned. A useful question to ask would be, "How do people with IBS and IBD cope with an episode of their primary

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symptoms of abdominal pain and/or abnormal bowel movements". This is one of the aims of this study.

1.9 RATIONALE AND HYPOTHESES (2)

Taking in to account the differences found between these two chronic illnesses in terms of their psychological distress (as outlined in section 1.6), it is possible that they also differ in terms of the coping strategies they endorse when faced with an episode of abdominal pain and/or abnormal bowel movements.

It is therefore hypothesised that:

2) There will be a significant difference in the profile of coping strategies endorsed between IBS and IBD patient groups when coping with their most recent episode of abdominal pain and/or abnormal bowel movements.

The research literature has shown that IBS patients' scores and IBD patients' scores are higher than non-patient controls on a variety of psychological measures. When IBS patients have been compared to IBD patients on measures of psychological distress (e.g. anxiety, depression, life events and MMPI) there has been a consistent ordering of IBS>IBD>Controls. One consistent significant difference that has been found between these two chronic illness groups is that IBS patients are significantly more anxious than IBD patients. A further finding was that elevations in anxiety scores did not reach clinically pathological levels for both IBS and IBD patients. It is therefore hypothesised that:

3) There will be significant differences in the anxiety scores between the 3 groups with the ordering of IBS>IBD>Non-patient controls.

4) The anxiety scores in each group (i.e. IBD, IBS and Non-patient controls) will not reach clinically significant levels.

5) There will be a significant difference in the depression scores between the 3 groups with the ordering of IBS>IBD>Non-patient controls.

6) There will be a significant difference in the self esteem scores between the 3 groups with the ordering of IBS<IBD<Non-patient controls.

Perceived stress is another important variable to examine when studying peoples' coping responses to chronic illness. There is some evidence which indicates that IBS patients perceive more stressful life events than controls. The results from research with IBD patients are inconsistent.

It is hypothesised that:

7) There will be a significant difference in perceived stress scores between the IBS, IBD and non-patient control groups.

1.10 SUMMARY

This study has several aims. The first aim focuses on the issue of personal control in relation to coping responses, to establish whether the relationships found in previous studies can also be applied to people with the chronic illnesses of IBS and IBD.

The second aim is to examine coping in people with IBS and IBD as a process, by focusing on a specific episode of primary symptoms rather than focusing on the overall illness. Also, to assess a wide range of coping responses to identify if these two patient groups use any specific strategies and to compare their coping profiles to establish differences in coping. There are no studies that have compared how these two patient groups cope with the primary symptoms of their illness.

The third aim focuses on psychological distress between patients with IBS, IBD and Non-patient controls in an attempt to replicate previous studies, especially Schwarz et al's (1993) findings that these groups are ordered IBS>IBD>Non-patient controls in terms of their anxiety and depression. Also to replicate the finding that anxiety does not reach clinically significant levels in these 3 groups and to establish whether a similar ordering is present in terms of self esteem, (i.e. IBS<IBD<Non-patient controls).

The fourth and final aim focuses on perceived stress, as previous research has been inconclusive about the differences found in perceived stress between IBS patients and Non-patient controls and IBD patients and Non-patient controls. There has been no study that has compared all 3 groups.

Answers to the aims (as outlined above) have an important bearing on, 1) Clinical management/advice and 2) Future research examining the most effective coping strategies in dealing with these and possibly other chronic illnesses.

CHAPTER 2: METHOD

2.1 PARTICIPANTS

There were 3 groups of participants. Group 1 = 15 patients with irritable bowel syndrome (IBS); Group 2 = 15 patients with inflammatory bowel disease (IBD) and Group 3 = 15 non-patient controls, (total n = 45). Groups 1 and 2 were diagnosed by a Consultant Gastroenterologist to ensure that they met the criteria for their diagnoses. (See Appendix 1). In order to obtain patient groups that were matched as closely as possible on their primary symptoms and age, the following exclusion criteria were applied: IBS patients with mainly diarrhoea; IBS patients with mainly constipation; under the age of 18 years old and over the age of 45 years old. Exclusion criteria for all 3 groups were as follows: other major illness and reading difficulties in the English language. All 3 groups of participants were volunteers. There were 6 potential volunteers who were not included in the study; three of these decided they did not want to take part in the study; one was very difficult to contact and two were not eligible for the study as they met one or more of the exclusion criteria.

2.1.1 Group 1 - IBS patients

This group consisted of 12 females and 3 males, whose ages ranged from 20 to 58 years (mean = 34.2, s.d. = 9.9). The group was predominantly Caucasian in origin (86%) and the mean Standard Occupational Classification (SOC) = 4. The mean duration of diagnosis was 1 year and 8 months with a mean duration of symptoms of 8 years and 6 months. Three patients, (20%) were taking painkillers ; no patients were taking steroids and 8 patients (53%) were taking medication specifically prescribed for bowel disorders

at the time the study was conducted. Twelve patients (80%) had previously been treated with medication; none had previously had surgery and 1 patient (7%) had received both medication and surgery prior to taking part in the study. Ten out of the 15 IBS patients (i.e. 67%) stated that living with their illness was stressful.

2.1.2 Group 2 - IBD patients

This group consisted of 9 patients with Crohn's disease and 6 patients with Ulcerative Colitis. There were 12 females and 3 males, whose ages ranged from 19 years to 49 years (mean = 34.8, standard deviation = 7.8). The group was 100% Caucasian in origin and the mean SOC = 4. The mean duration of diagnosis was 3 years with a mean duration of symptoms of 7 years and 4 months. Two patients (13%) were taking painkillers ; 5 patients (33%) were taking steroids and 10 patients (67%) were taking medication specifically prescribed for bowel disorders at the time the study was conducted. Ten patients (67%) had previously been treated with medication; 2 patients (13%) had previously had surgery and 2 patients (13%) had received both medication and surgery prior to taking part in the study. Ten out of 14 IBD patients (i.e. 71%) stated that living with their illness was stressful. One patient was unable to state whether this was the case or not.

2.1.3 Group 3 = Non-patient controls

This group consisted of 9 females and 6 males, whose ages ranged from 23 years to 56 years (mean = 36.3, s.d. = 9.7). The group was 100% Caucasian in origin and the mean SOC = 4. This group did not have a bowel disorder, nor any other major health problem.

2.1.4 Demographic Group Comparisons

There were significantly more females than males in the IBS group, (Chi-square = 5.4, p<0.05) and in the IBD group, (Chi-square = 5.4, p<0.05). There were no significant differences in gender in the Non-patient control group, (Chi-square = 0.6, p>0.05), but this group did consist of a female to male ratio of 3:2. There were no significant differences in age between the 3 groups, (one-way independent analysis of variance, F (2, 42) = 0.494, p>0.05). There were also no significant differences in Standard Occupational Classification (SOC) between the 3 groups, (Kruskal-Wallis Test: Chi-square = 0.633, p>0.05). (For more detailed information about SOC, see Appendix 2). Independent Samples T-Tests found no significant differences between the IBS and IBD groups in terms of the duration of their diagnosis, (t = 0.41, df = 28, p>0.05, two-tailed test) and the duration of their symptoms, (t = 0.41, df = 28, p>0.05, two-tailed test).

2.2 <u>SAMPLING</u>

The patient groups were purposeful samples, in the sense that those who were asked to volunteer met all the inclusion criteria (e.g. diagnostic criteria; between the ages of 18-45 years old; no other major illness and being able to read the English language) and therefore formed homogeneous groups on this basis. Two patients in each group were over the age limit but included in the study due to the restraints of time.

The non-patient control group was a convenience volunteer sample asked to participate on the basis that they matched the patient samples as closely as possible on age; that they did not have a bowel disorder or any other major health problem and were able to read the English language.

The size of the samples would determine the robustness of the findings. When examining the experimental effects of any study, two types of error can occur, called Type 1 (Alpha) and Type II (Beta) errors. A Type 1 error is the probability of falsely rejecting the null hypothesis, (i.e. saying there is an effect when this is not present). The level of Alpha (type 1 error) needs to be specified before research begins. The scientific community generally agrees that 0.05 is the minimum level of significance required. A Type II error is the probability of falsely accepting the null hypothesis, (i.e. saying there is not an effect when there is one present). Power is defined as the probability of correctly rejecting a false null hypothesis (i.e. 1-Beta). The Power of statistical tests to be able to detect real experimental effects in samples needs to be calculated before research is conducted, in order to estimate the sample sizes required to establish these effects. For example, if a sample size is too small then the results will not have sufficient power to ensure confidence in the results.

2.2.1 Initial calculation of Power

Before the study was conducted, a test of Power was calculated to determine the sample size for each group. As the majority of the group comparisons would involve the statistical analysis of variance (ANOVA), tables produced by Bratcher, Moran & Zimmer (1970) were used to estimate the sample size required to achieve a given power in the ANOVA.

To establish the estimated sample size using these tables, values of C, Alpha, 1-Beta and p needed to be specified, where C = the ratio of differences between means to the square root of error variance (i.e. the effect size); Alpha = the level of significance; 1-Beta = the level of power and p = the number of treatment means being compared.

Taking a small estimate of effect size, (i.e. C = 1.00) with a level of significance at 0.05 (Alpha) and the level of power at 0.8 and p = 3 then the estimated sample size per group is 21.

My initial aim was to obtain a sample size of 21 participants in each group which would meet the estimated sample size for a power of 0.8. (i.e. the study has an 80% chance of recording an accurate result or alternatively a 20% chance of a Type Π error).

Due to limited time and the slow attrition of participants this was not met. The actual number of participants obtained in each group was 15. If the level of power is maintained at 0.8, then 15 participants in each group at the 0.05 level of significance has a consequence for C, i.e. effect size. The consequence is that C is increased to 1.25, which means that slightly larger differences between the groups will be detected.

2.3 DESIGN

As it is impossible to randomly allocate bowel disorders, this study was based on a quasi-experimental, independent groups design, and measures of associations between psychological processes and outcome measures.

2.4 SETTINGS

Fifty percent of the patient groups (9 IBD; 6 IBS) were seen in a quiet room within an outpatient psychology department based in a general hospital. The remaining 50% of patients (5 IBD; 10 IBS), were seen within their own homes.

The Non-patient control group participated in their own homes but did not have face-to-face contact with the researcher.

2.5 MEASURES

2.5.1 <u>Measures used with IBS and IBD patients</u> (see Appendix 3)

A Semi-Structured Interview designed to engage the participants and obtain factual information about themselves and their chronic illness. This includes discussion of a Symptom Checklist which the patients were given prior to the interview and brought with them, and priming the patients about their most recent episode of primary symptoms.

A questionnaire battery consisting of 5 measures as follows:

1. <u>The COPE</u> (Carver, C.S.; Scheier, M.F. & Weintraub, J.K, 1989), is a multidimensional coping inventory consisting of 60 self-report items which represent 15 conceptually distinct scales of coping. These are as follows:

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1. Active Coping: taking action, and exerting efforts, to remove or circumvent the stressor.

2. **Planning:** thinking about how to confront the stressor, planning one's active coping efforts.

3. Seeking Instrumental Social Support: seeking assistance, information, or advice about what to do.

4. Seeking Emotional Social Support: getting sympathy or emotional support from someone.

5. Suppression of Competing Activities: suppressing one's attention to other activities in which one might engage, in order to concentrate more completely on dealing with the stressor.

6. Turning to Religion: increased engagement in religious activities.

7. Positive Reinterpretation and Growth: making the best of the situation by growing from it, or viewing it in a more favourable light.

8. **Restraint Coping:** coping passively by holding back one's coping attempts until they can be of use.

9. Acceptance: accepting the fact that the stressful event has occurred and is real.

10. Focus on and Venting of Emotions: an increased awareness of one's emotional distress, and a concomitant tendency to discharge those feelings.

11. Denial: an attempt to reject the reality of the stressful event.

12. Mental Disengagement: psychological disengagement from the goal with which the stressor is interfering, through day-dreaming, sleep or self-distraction.

13. Behavioural Disengagement: giving up, or withdrawing effort from, the attempt to attain the goal with which the stressor is interfering.

14. Alcohol/Drug Use: increased engagement in alcohol or drug use.

15. Humour: the use of humour directed at the situation.

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The situational format of the Cope was used which focuses on responses to a specific stressful situation, (i.e. the most recently experienced episode of abdominal pain and/or abnormal bowel movements). Separate scores for each of the coping scales are computed by adding the scores of the four items that make up each scale. As the scores for each item range from, 1 ='I did not do this at all' to 4 ='I did this a lot', the scores for each coping scale range from 4 to 16. (i.e. the higher the score the more this type of coping was used).

Carver et al. (1989) found that the COPE scales have high internal consistency (Cronbach's alpha > 0.6) with the exception of mental disengagement. Test-retest reliabilities ranged from 0.42 to 0.89 for the different scales (dispositional version). Construct validity was tested by correlating selected scales with measures of personality dimensions. Selected scales (i.e. 1, 2 & 7) were found to correlate positively with measures of dispositional optimism and self-esteem, and negatively with trait anxiety. Selected scales (i.e. 11 & 13), displayed the opposite pattern of associations.

2. <u>A disease-specific version (i.e. MHLC Form C) of the Multidimensional Health</u> <u>Locus of Control Scale (MHLC)</u>, (Wallston, K ; Stein, M.J. & Smith, C.A., 1994). This is an 18 item self-report measure of beliefs about control over illness. There are four subscales - internal, chance, external which includes doctors and other (powerful) people. There are 6 items for each of the internal and chance subscales and 3 items each for the two external subscales. The scores for each item range from 1 = 'Strongly Disagree' to 6 = 'Strongly Agree'. Scores for each subscale range from 6 to 36 for the internal and chance subscales and 3 to 18 for the two external subscales. (i.e. the higher the score, the stronger the belief about control over illness). The subscales are orthogonal and therefore represent uni-dimensional factors. The MHLC-Form C subscales have good internal consistency, alphas > or = 0.7 (range 0.7-0.87). Test-retest reliability has shown stability coefficients ranging from 0.4 to 0.8 for the subscales. To test the concurrent validity of Form C, Wallston et al. (1994) correlated it with Form B, and found that the subscales in Form C significantly correlated with their appropriate counterparts on Form B, (p<0.001).

3. <u>Rosenberg's Self Esteem Scale (1965)</u> is a 10 item Guttman scale designed to evaluate individuals' overall sense of being capable, worthwhile and competent. Five of the items are worded positively (1,2,4,6, & 7) and 5 negatively (3,5,8,9, & 10) in order to reduce response bias. The scores for each item range from, 1 = 'Strongly Disagree' to 4 = 'Strongly Agree'. The negatively worded items require reverse scoring. The total score ranges from 10 to 40, (i.e. the higher the score, the higher the self-esteem).

4. <u>The Hospital Anxiety and Depression Scale (HADS)</u> designed by Zigmond & Snaith (1983) is a 14 item self-report measure of anxiety (7 items) and depression (7 items) over a one week period. Each item is scored from 0 to 3. The total scores range from 0 to 21 for each subscale. (i.e. the higher the scores the greater the anxiety or depression). Scores from 8 to 10 on each subscale indicate possible clinical disorder and scores from 11 to 21 indicate probable clinical disorder.

The HADS has good internal consistency, Cronbach's alpha = 0.93 for anxiety; 0.90 for depression, (Moorey, Greer, Watson, Gorman, Rowden, Tunmore, Robertson & Bliss, 1991). The concurrent validity was assessed by comparison with 5-point psychiatric rating scales of anxiety and depression for 100 medical out-patients. The HADS subscales significantly correlated with these ratings; r = 0.54 for anxiety and r = 0.79 for depression. (Zigmond & Snaith, 1983). Moorey et al. (1991) confirmed the construct

validity of the HADS as a measure of two factors, in a factor analysis of the responses of 568 cancer patients.

5. The Perceived Stress Scale (PSS-10) designed by Cohen et al (1983) is a 10 item self-report measure of the 'degree to which situations in one's life are appraised as stressful'. The 10 items refer to subjective appraisals of events occurring within a one-month time frame. Items 1,2,3,6,9 & 10 are negatively worded and items 4,5,7 & 8 are positively worded. The scores for each item range from 0 = 'Never' to 4 = 'Very Often'. The positively worded items require reverse scoring. The total score ranges from 0 to 40, (i.e. the higher the score the higher the perceived stress).

The PSS-10 has good internal consistency, Cronbach's alpha was 0.84, 0.85 and 0.86 in three samples tested by Cohen et al. (1983) and 0.78 in a general population of 2,387 people, (Cohen and Williamson, 1988). Test-retest reliability should only be high over short time intervals, since perceived stress is affected by both daily hassles and the availability of coping resources. Over two days, test-retest reliability assessed in college students was 0.85, and over six weeks it was 0.55. Concurrent validity was tested in several studies of college students by correlating the PSS with measures of number of life events, (r, ranging from 0.17 to 0.39) and impact of life events, (r, ranging from 0.24 to 0.49). (Cohen et al., 1983). The PSS-10 was validated using factor analysis which indicated two factors representing positively and negatively worded items, which explained 49% of the variance. (Cohen and Williamson, 1988).

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2.5.2 <u>Measures used with Non-Patient Controls</u> (see Appendix 4)

Demographic information was obtained and a questionnaire battery consisting of 3 measures as follows:

1. Rosenberg's Self Esteem Scale (1965) : as detailed above.

2. <u>The Hospital Anxiety and Depression Scale (HADS)</u> (Zigmond & Snaith, 1983): as detailed above.

3. The Perceived Stress Scale (PSS-10) (Cohen et al, 1983): as detailed above.

2.6 PROCEDURE

Before this study was conducted it was approved by the Medical Research Ethics Committee, Southmead Health Services NHS Trust, Bristol, on 10th June 1998. (See Appendix 5).

2.6.1. Recruitment of IBS and IBD patient groups

Initially, all potential participants (i.e. those who met the inclusion criteria) were given an introductory leaflet by the Consultant when they attended appointments at the Gastroenterology Clinic. The introductory leaflet provided information about the study and the opportunity for patients to volunteer and consent to participation in the study. (See Appendix 6). In response to the low volunteer rate, (24% out of all potential participants approached) and the time limitation of the study, the consultant asked all potential participants to make a decision about volunteering at the time of their visit to the GI Clinic. (See Flowchart, pg. 42).

The volunteer participants' consent and personal details (i.e. name, address, telephone number and diagnosis) were posted to the researcher who contacted them by telephone to arrange an appointment. This was followed up with an appointment letter and the Symptom Checklist which participants were asked to complete prior to their appointment. (See Appendix 7).

2.6.2. IBS and IBD patient groups participation

The semi-structured interview was administered to each patient. The latter part of this interview asked the patient to describe the last time they had experienced an episode of primary symptoms. The purpose of this description was to prime the patient before responding to the first questionnaire in the battery to ensure that they were focusing on a specific episode of symptoms rather than responding generally to their illness. Each patient was given the questionnaire battery in the following order: the Cope; MHLC-Form C; Rosenberg's Self Perception; HADS and PSS-10. The instructions for each questionnaire were included in the battery.

Each patient was given a brief synopsis about the aims of the study, (i.e. expanded on the information given in the leaflet) and were asked if they wanted to receive details about the outcome of the study.

Each patient was reminded about the confidentiality and anonymity of participating in the study and were thanked for taking part. Questions which arose from patients were answered by the researcher and/or were advised to direct these towards the consultant.

FLOWCHART TO SHOW THE PROCESS OF RECRUITING VOLUNTEER PATIENT PARTICIPANTS

July 1998 - 50 Introductory leaflets delivered to GI Clinic

August'98 = 1 IBD

September'98 = no volunteers

October'98 = no volunteers

November'98 = 3 IBD; 1 IBS

December'98 = 4 IBD; 3 IBS

TOTAL = 12 volunteers (8 IBD; 4 IBS)

12 out of 50 leaflets distributed = 24% volunteer rate

All participated in hospital setting

Consultant changed recruitment strategy

Supplied more Introductory leaflets

January'99 = 5 IBD; 2 IBS

3 participated in hospital setting

4 participated in their own homes

No room availability in hospital setting as slow attrition rate led to running over time course of study, therefore had to see remaining volunteers in their own homes

February'99 = 2 IBD; 5 IBS

March'99 = 4 IBS

TOTAL NUMBER OF VOLUNTEERS ELIGIBLE FOR STUDY = 30 (15 IBD; 15 IBS)

2.6.3 <u>Recruitment and participation of Non-patient control group</u>

Initially, potential control participants were recruited via the appointment letter to the patient, (i.e. volunteer patients were asked to bring a volunteer participant, e.g. friend or relative with them if possible). However, due to the fact that there was such a low response rate and that it was difficult to control for age using this strategy it was changed. Volunteer control participants who met the inclusion criteria formed this convenience sample, (i.e. were obtained by, "word of mouth").

The Non-patient control participants were sent the questionnaire battery with a covering letter which outlined the aims of the study; instructions for completing the battery; information about anonymity and thanks for their participation. (See Appendix 8). Before completing the battery they were asked to provide demographic information about themselves, (i.e. age, sex and occupation). The questionnaire battery was set out in the following order: Rosenberg's Self Perception; HADS and PSS-10. The instructions for completing each questionnaire were included in the battery. These were returned in the envelope provided to the researcher by hand or post.

<u>CHAPTER 3: RESULTS</u>

3.1 <u>HYPOTHESES 18-1d - PERSONAL CONTROL IN RELATION TO</u> COPING RESPONSES

Before these hypotheses could be tested, certain computations from the raw coping data needed to be carried out in order to find the proportions of problem-focused and emotion-focused coping. These were as follows:

1. The 5 problem-focused coping scales, (i.e. active coping, planning, seeking instrumental social support, suppression of competing activities and restraint coping) were summed, to establish the, "Total Amount of Problem-Focused Coping Score" for each patient.

2. The 5 emotion-focused coping scales, (i.e. seeking emotional social support, religion, positive reinterpretation and growth, acceptance and denial) were summed, to establish the, "Total Amount of Emotion-Focused Coping Score" for each patient.

3. The two totals were summed to obtain the, "Total Amount of Coping Score" for each patient.

4. To obtain the PROPORTION of Problem-Focused Coping for each patient, the total problem-focused coping score was divided by the total amount of coping score.

5. To obtain the PROPORTION of Emotion-Focused Coping for each patient, the total emotion-focused coping score was divided by the total amount of coping score.

The means and standard deviations for each type of coping are displayed in Table 1.

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	Total Amount	Total Amount	Total Amount	Proportion of	Proportion of
	of Problem-	of Emotion-	of Coping	Problem-	Emotion-
	Focused	Focused		Focused	Focused
	Coping	Coping		Coping	Coping
	(min.=20,	(min.=20,			
	max.=80)	max.=80)			
Mean	46.38	41.69	88.07	0.52	0.48
Standard	13.03	8.77	19.64	0.05	0.05
Deviation			·		
N *	29	29	29	29	29

* one patient was excluded from the computations due to missing data

Means and Standard Deviations for Problem and Emotion-Focused Coping for IBS and IBD Groups.

To test Hypotheses 1a-1d, a statistical test of association was required. Before this was applied, consideration was given to the assumptions for the use of correlational data. These assumptions are as follows; that the sample must be representative; the variables being correlated must approximate a normal distribution; for every value of X, the distribution of Y scores must have approximately equal variability (this is called the assumption of homoscedasticity), and the relationship between X and Y should be linear. (Munro & Page, 1993). However, extreme outliers can severely affect the value of the correlation.

These assumptions were taken in to account. Box-plots (see Appendix 9, Fig. 1.) revealed that there was one extreme outlier in the data. To avoid violating the assumption of normality this case was excluded from the analyses. The data met the requirements for a parametric test of association. Pearson's Product Moment Correlation Coefficients were performed on the data, using SPSS 7.5.

Hypothesis 1a: There will be a positive correlation between internal health locus of control beliefs (IHLC) and the proportion of problem-focused coping strategies across both patient groups.

There was no significant correlation between IHLC and the proportion of problem-focused coping strategies across patient groups, (r = -0.195, n = 28, p>0.05, one-tailed test).

Hypothesis 1b: There will be a negative correlation between IHLC beliefs and the proportion of emotion-focused coping strategies across both patient groups.

There was no significant correlation between IHLC and the proportion of emotion-focused coping strategies across patient groups, (r = 0.195, n = 28, p>0.05, one-tailed test).

Hypothesis 1c: There will be a negative correlation between health locus of control beliefs due to chance (CHLC) and the proportion of problem-focused coping strategies across both patient groups.

There was no significant correlation between CHLC and the proportion of problem-focused coping strategies across patient groups, (r = 0.237, n = 28, p>0.05, one-tailed test).

Hypothesis 1d: There will be a positive correlation between CHLC beliefs and the proportion of emotion -focused coping strategies across both patient groups.

There was no significant correlation between CHLC beliefs and the proportion of emotion-focused coping strategies across patient groups, (r = -0.237, n = 28, p>0.05, one-tailed test).

Hypotheses 1a-1d were all rejected and the null hypotheses were accepted, i.e. that there were no associations between internal and chance health locus of control beliefs and type of coping strategies. Any associations were due to chance factors.

Post-hoc results: There were two interesting post-hoc findings; 1) Visual inspection of the mean proportions of each type of coping strategies, indicated that the patients' used **equal** proportions of problem-focused and emotion-focused coping strategies (see Table 1 above). This result was confirmed in a paired samples t-test, where the differences between the mean proportion of problem-focused coping and the mean proportion of emotion-focused coping was not significant, (t = -1.90, df = 28, p>0.05, two-tailed test).

2) There was a significant positive correlation between the total amount of problem-focused coping scores and the total amount of emotion-focused coping scores, (r = 0.608, n = 29, p < 0.001, two-tailed test). (See Appendix 10, Fig. 2. for scatterplot).

3.2 HYPOTHESIS 2: COPING PROFILES

Profile analysis is a special application of multivariate analysis of variance (MANOVA) in which several dependent variables are measured and compared between two or more groups. (Stevens, 1986; Tabachnick & Fidell, 1996). Before applying profile analysis, certain assumptions about the data needed to be addressed.

3.2.1 Assumptions of Data for Profile Analysis

Multivariate normality: profile analysis is as robust to violation of normality as other forms of MANOVA. However, as the sample sizes were slightly unequal and the IBS sample had one less case than the number of dependent variables (i.e. 14 patients and 15 D.V.'s) the distributions of the D.V.'s were examined for each group. Each patient group had 2 significant, positively skewed dependent variables, one of the D.V.'s was the same for each group. As only 3 out of the 15 D.V.'s across both groups were significantly skewed, normalising transformations were not performed on the data.

Outliers: profile analysis is extremely sensitive to outliers. These were examined and several extreme outliers were found for 3 of the D.V.'s (i.e. Alcohol/Drug Use; Behavioural Disengagement & Religion). The outliers were retained in the analysis as they were considered to be clinically meaningful.

Homogeneity of variance-covariance matrices: as the sample sizes were not highly divergent and there was no evidence of strong heterogeneity, this assumption was not violated.

Linearity: of the relationships among D.V.'s is assumed for 2 of the tests within profile analysis (i.e. parallelism and flatness). This assumption was evaluated by examining scatterplots between all pairs of the D.V.'s and was not violated.

Scaling: the measures used are assumed to have similar scaling or that they are commensurable. This is necessary as 2 of the tests in profile analysis use numbers which are the difference scores between the D.V.'s measured on adjacent occasions. The difference scores are called segments in the analysis. This assumption was not violated as the coping scales have the same range of possible scores, with the same value having the same meaning on all the measures (i.e. how much coping was endorsed).

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3.2.2 Profile Analysis

In profile analysis, 3 questions are tested on the data in the following order:

1) 'Are the profiles parallel? If the answer to this were yes for two groups, it would imply that one group scored uniformly better than the other on all the variables'.

2) 'If the profiles are parallel, then are they coincident? In other words, did the groups score the same on each variable?'.

3) 'If the profiles are coincident, then are the profiles flat? In other words, are the means on all variables equal to the same constant'.

(Stevens, 1986)

Profile analysis was applied to the data (using SPSS 7.5), to answer the questions outlined above in order to test *Hypothesis 2: There will be a significant difference in the profile of coping strategies endorsed between IBS and IBD patient groups when coping with their most recent episode of abdominal pain and/or abnormal bowel movements.*

The profiles of the IBS and IBD groups are shown in Fig. 3.

The results are shown in Tables 2, 3 & 4.



Fig. 3: Profile Plots of the Mean Coping Responses for the 2 Patient Groups

	Value	F	Hypothesis df	Error df	Significance of F
IBS vs IBD	0.54	1.18	14	14	0.383

 Table 2: Profile Analysis: The test for Parallelism using a Multivariate test of

 significance - Pillai's Trace.

Table 2 shows that there was no significant group by variable interaction for the IBS and IBD groups, (Pillai's Trace Test, F (14, 14) = 1.18, p>0.05). The exact probability of 0.383 is greater than 0.05, therefore the profiles of the 2 groups did not deviate significantly from parallelism, i.e. the results were consistent with the IBS and IBD groups having parallel coping profiles over all the coping strategies. It was therefore meaningful to proceed to test the second question in profile analysis, i.e. were the 2 groups profiles coincident?

Source of	Sum of	df	Mean	F	Significance
vanation	Squares		Square		OIF
Group (i.e. IBS & IBD	54.98	1	54.98	1.17	0.28
Within Cells	1,265.1	27	46.86		

 Table 3:
 Profile Analysis:
 The test for Coincidence using a Repeated Measures

 Multivariate Test of Between-Subjects Effects.

Table 3 shows that there was no significant difference between the IBS and IBD groups profiles in terms of coincidence, (F (1, 27) = 1.17, p>0.05). The exact probability of 0.28 is greater than 0.05, therefore the profiles of the 2 groups did not deviate significantly from coincidence, i.e. the results were consistent with the IBS and IBD groups scoring the same on each coping strategy. It was therefore meaningful to proceed to test the third and final question in profile analysis, i.e. were the 2 groups profiles flat?

	Value	F	Hypothesis df	Error df	Significance of F
Coping	0.94	16.74	14	14	0.000

 Table 4: Profile Analysis: The test for Flatness using a Multivariate test of significance

 Pillai's Trace.

Table 4 shows that there was a significant difference between the coping variables within the IBS and IBD groups, (Pillai's Trace Test, F (14, 14) = 16.74, p<0.001). The exact probability of 0.000 is less than 0.001, therefore the profiles of the 2 groups were not flat, i.e. the means of the coping strategies were significantly different.

The results from the Profile Analysis found that the profiles of IBS and IBD patients were consistent with the absence of significant deviations from parallelism and coincidence. This means that the coping profiles of the coping strategies endorsed by the 2 groups were not significantly different. Therefore, Hypothesis 2 was rejected and the null hypothesis was accepted.

The test of flatness within Profile Analysis found a significant difference between the fifteen coping strategies endorsed within each patient group.

It can be seen from Fig. 3., that the most frequently endorsed coping strategies in both patient groups were; Active Coping; Seeking Emotional Social Support and Acceptance. The least frequently endorsed coping strategies in both patient groups were; Turning to Religion; Denial; Behavioural Disengagement and Alcohol/Drug Use.

3.3 <u>HYPOTHESES 3,4,5,6, & 7: ANXIETY, DEPRESSION, SELF-ESTEEM</u> <u>AND PERCEIVED STRESS IN ALL 3 GROUPS</u>

All these hypotheses, with the exception of hypothesis 4, required the statistical test of one-way independent analysis of variance (ANOVA). Before applying this test to the data, certain assumptions about the data needed to be considered.

3.3.1 Assumptions of Data for One-Way Independent ANOVA

The assumptions for ANOVA are as follows: the dependent variable (D.V.) should be measured at the interval or ratio level; the groups should be mutually exclusive (i.e. independent of each other); the D.V. should be normally distributed and the groups should have equal variances, (i.e. the assumption of homogeneity of variance).

ANOVA is considered to be fairly "robust" to departures from normality. To test the assumption of homogeneity of variance, Levene's homogeneity of variance test was applied to the data for each D.V. The results found no significant differences between the 3 groups for each D.V., (p>0.05). Therefore the 3 groups had equal variances for each D.V. The data met the assumptions as outlined above.

ANOVA tests the differences between the means of the groups. The means and standard deviations of the 3 groups on the D.V.'s are shown in Table 5.

Dependent Variables	IBS Means & (S.D.)	IBD Means & (S.D.)	CONTROL Means & (S.D.)
ANXIETY	7.87 (3.80)	8.13 (3.42)	6.60 (3.54)
DEPRESSION	4.40 (3.58)	4.07 (3.71)	3.00 (2.10)
SELF ESTEEM	33.87 (4.69)	32.67 (3.98)	31.33 (3.13)
PERCEIVED STRESS	18.27 (6.47)	14.53 (6.32)	14.93 (4.18)

 Table 5: Means and Standard Deviations of the 3 Groups for Anxiety, Depression,

 Self-Esteem and Perceived Stress.

ANOVA was performed on the data using SPSS 7.5, the results are shown in Tables 6,7,8 & 9.

Source of Variation	Sum of Squares	df	Mean Square	F	Significance of F
BETWEEN GROUPS Linear Term Contrast	20.13 12.03	2	10.07 12.03	0.78 0.93	0.464 0.339
WITHIN GROUPS	541.07	42	12.88		

Table 6: One-Way Independent ANOVA for HADS - Anxiety.

Hypothesis 3: There will be significant differences in the anxiety scores between the

3 groups with the ordering of IBS>IBD>Non-patient controls.

There were no significant differences in anxiety between the 3 groups, (ANOVA, F (2. 42) = 0.78, p>0.05). There was no significant linear trend in scores of the 3 groups, (Polynomial Linear Trend Test, F (1, 42) = 0.93, p>0.05).

Hypothesis 4: The anxiety scores in each group (i.e. IBS, IBD and Non-patient controls) will not reach clinically significant levels.

It can be seen from Table 5, that on average the 3 groups fell below the cut-off, of 11, for probable clinical disorder on the HADS-Anxiety Scale. However, frequency data indicated that there were some people in each group that fell above the cut-off. The percentage of people that met the criteria for probable clinical anxiety in each group were as follows: 27% of IBS patients (n = 4); 20% of IBD patients (n = 3) and 7% of Non-Patient Controls (n = 1).

Source of Variation	Sum of Squares	df	Mean Square	F	Significance of F
BETWEEN GROUPS Linear Term Contrast	16.04 14.70	2 1	8.02 14.70	0.76 1.42	0.467 0.240
WITHIN GROUPS	434.53	42	10.35		

Table 7: One-Way Independent ANOVA for HADS - Depression.

Hypothesis 5: There will be a significant difference in the depression scores between the 3 groups with the ordering of IBS>IBD>Non-patient controls.

There were no significant differences in depression between the 3 groups, (ANOVA, F (2, 42) = 0.78, p>0.05). There was no significant linear trend in scores of the 3 groups, (Polynomial Linear Trend Test, F (1, 42) = 1.42, p>0.05).

Source of Variation	Sum of Squares	df	Mean Square	F	Significance of F
BETWEEN GROUPS Linear Term Contrast	48.18 48.13	2 1	24.09 48.13	1.52 3.03	0.231 0.089
WITHIN GROUPS	666.4	42	15.87		

Table 8: One-Way Independent ANOVA for Self-Esteem.

Hypothesis 6: There will be a significant difference in the self esteem scores between the 3 groups with the ordering of IBS<IBD<Non-patient controls.

There were no significant differences in self-esteem between the 3 groups, (ANOVA, F (2, 42) = 1.52, p>0.05). There was no significant linear trend in scores of the 3 groups, (Polynomial Linear Trend Test, F (1, 42) = 3.03, p>0.05).

Source of Variation	Sum of Squares	df	Mean Square	F	Significance of F
BETWEEN GROUPS Linear Term Contrast	126.04 83.33	2	63.02 83.33	1.90 2.52	0.162 0.120
WITHIN GROUPS	1,391.6	42	33.13		

Table 9: One-Way Independent ANOVA for Perceived Stress.

Hypothesis 7: There will be a significant difference in perceived stress scores between the IBS, IBD and non-patient control groups.

There were no significant differences in perceived stress between the 3 groups, (ANOVA, F (2, 42) = 1.90, p>0.05). A post-hoc contrast test showed that there was no significant linear trend of scores in the 3 groups, (Polynomial Linear Trend Test, F((1, 42) = 2.52, p>0.05)

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Hypotheses 3,5,6 & 7 which were analysed using ANOVA were all rejected and the null hypotheses were accepted, i.e. that there were no significant differences between the 3 groups in terms of their anxiety, depression, self-esteem and perceived stress. Any differences were due to chance factors.

CHAPTER 4: DISCUSSION

4.1 RESULTS IN RELATION TO AIMS AND HYPOTHESES

The first aim of this study focused on the issue of personal control in relation to coping responses. Previous studies of normative samples established that control is an important predictor of the type of coping response endorsed in stressful situations. (e.g. Folkman & Lazarus, 1980; Pearlin & Schooler, 1978). These studies found that when people feel they have personal control over stressful situations, problem-focused coping predominates and when people perceive stressful situations as refractory to change, then emotion-focused coping predominates.

Hypotheses 1a - 1d tested whether these relationships could be found in people with the chronic illnesses of IBS and IBD. These patients were asked about their internal beliefs of control over their bowel disorders and beliefs about chance being in control over their bowel disorders. The relationships between these beliefs about control over their illness and the proportion of coping strategies (i.e. problem-focused and emotion-focused) endorsed were tested. The results found no associations between these variables; i.e. no significant relationships were found between internal and chance health locus of control beliefs about bowel disorders and type of coping strategies endorsed. These results suggest that the relationships between personal control and type of coping are not present in people with bowel disorders. Alternatively, these relationships may be present in people with bowel disorders but were not found in this study due to certain methodological and statistical limitations discussed in detail in the critique (Section 4.2.1).

Two post-hoc results revealed interesting findings about coping in IBS and IBD patients. The first result found that when coping with a specific episode of their primary symptoms, IBS and IBD patients used equal proportions of problem-focused and emotion-focused coping. This finding does not tend to support the work of Folkman & Lazarus (1980) who found that when faced with health-related stressors people use more emotion-focused coping, nor does it support situation-oriented studies of coping with physical illness and disabilities whose findings were consonant with Folkman & Lazarus (1980), e.g. Cohen & Lazarus, (1979); Lipowski, (1970) & Moos, (1977). However, this finding does support Bombardier et al's (1990) results of a heterogeneous sample of patients with a wide range of medical and psychiatric conditions that also used equal proportions of problem and emotion-focused coping.

The findings (outlined above) suggest that patient samples vary from normative ones in their utilisation of coping and, that different illnesses may lead to different types of coping strategy utilisation. However, the discrepancy in findings between certain types of coping strategy utilisation may reflect differences between the coping measures used and the interpretation of those measures. This is a common difficulty when making comparisons between studies and means that general conclusions need to be made with caution.

The second result found that, when IBS and IBD patients coped with a specific episode of their primary symptoms, there was a significant positive correlation between the total amount of problem-focused coping and the total amount of emotion-focused coping. Therefore the more these patients endorsed problem-focused coping; the more they endorsed emotion-focused coping and vice versa. This finding suggests that the 2 types

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of coping are not independent and therefore both types contribute to the management of dealing with a stressful episode of abdominal symptoms.

The second aim of this study was to examine coping in people with IBS and IBD as a process, to explore whether these patients differed in terms of their coping profiles when coping with their most recent episode of primary symptoms. There are no previous studies comparing these two patient groups in relation to coping. On the basis of prior research, which found differences between these 2 groups in terms of their psychological distress, it was hypothesised that there would be differences between these 2 groups in terms of their coping strategies, (i.e. Hypothesis 2).

The results from the Profile Analysis found no significant differences between the 2 groups on tests of parallelism and coincidence. This result suggests that IBS and IBD patients have similar coping profiles when coping with their most recent episode of primary symptoms. However, significant differences between the 2 groups may exist but were not found in this study due to the relatively small sample sizes in relation to the number of different coping strategies which were analysed.

The test of flatness within Profile Analysis found a significant difference between the 15 coping strategies endorsed by the IBS and IBD patients combined. This result indicates that IBS and IBD patients do not use a "blanket" approach to coping with an episode of their primary symptoms, but utilise particular coping strategies more than others. The most frequently endorsed strategies were, Active Coping, Seeking Emotional Social Support and Acceptance. The least frequently endorsed strategies were, Turning to Religion, Denial, Behavioural Disengagement and Alcohol/Drug Use. With the exception of Denial these latter strategies were the ones which produced extreme outliers

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in the data. The outliers represented people who overall used these strategies a moderate amount in comparison to the remainder of the sample who on average did not use these strategies at all. Implications about the frequencies of particular coping strategies will be discussed in the critique, (Section 4.2.2).

The third aim of this study focused on differences in psychological distress between patients with IBS, IBD and Non-patient controls to replicate previous findings (e.g. Schwarz et al, 1993) about, a) significant differences between these 3 groups and b) significant trend toward ordering of IBS>IBD>Non-patient controls in terms of their anxiety and depression. Also to explore whether these findings are similar with regard to self-esteem between the 3 groups. Finally, to replicate the finding in Schwarz et al's study that anxiety does not reach clinically significant levels in these 3 groups.

Hypotheses 3,5 & 6 tested the differences and the ordering between the 3 groups in terms of their anxiety, depression and self-esteem. The results found no significant difference in these variables between the 3 groups, nor any significant trend across the 3 groups. The findings for anxiety and depression are surprising, given that they do not support a substantial number of previous studies which have found that IBS patients scores are higher than Non-patient controls and, when all 3 groups have been compared, both IBS and IBD patients' scores are higher than Non-patient controls. The results did not replicate the findings of Schwarz et al (1993) that these groups were ordered IBS>IBD>Non-patient controls. In light of the findings for anxiety and depression, it does not seem surprising that no significant results were found for self-esteem between the groups, nor was there an ordering of IBS<IBD<Non-patient controls. An interesting observation is that the self-esteem scores in all the groups were reasonably high, i.e. the means were all over 30, (maximum score = 40).

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Hypothesis 4 aimed to replicate the findings of Schwarz et al (1993) that the anxiety scores in each group would not reach clinically significant levels, i.e. the scores would fall below the threshold for "caseness". Initially the mean values indicated that this held true for the 3 groups as the means fell below the cut-off for probable clinical anxiety disorder (i.e. "caseness"). However, frequency data indicated that there was a percentage of people who did fall above the cut-off for probable clinical anxiety in all 3 groups, (i.e. 27% IBS, 20% IBD and 7% Non-patient controls). Therefore, this finding did not support Schwarz et al's (1993) study in relation to "caseness". The implications of these findings will be discussed in more detail in the critique, (Section 4.2.2).

The fourth and final aim of this study focused on perceived stress, as previous studies have been inconclusive about the differences found in perceived stress between IBS patients and Non-patient controls, and IBD patients and Non-patient controls, and no previous studies have compared all 3 groups.

Hypothesis 7 tested the differences between the 3 groups in terms of their perceived stress and found that there were no significant differences between the groups. A post-hoc linear contrast test also found no significant ordering effect over the 3 groups. This finding suggests that when people are asked about their perceptions of stress rather than the number of stressful life events they have experienced per se, people with the chronic illnesses of IBS and IBD do not differ from Non-patient controls. However, differences between the groups may exist in terms of perceived stress but were not found in this study due to methodological and statistical limitations (discussed below). The research evidence to date remains inconclusive about any differences that may exist between groups in terms of perceived stress.

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4.2 <u>CRITIQUE</u>

4.2.1 Methodological & Statistical Implications

The null hypotheses were accepted and the research hypotheses were rejected in this study, as all the results were greater than an alpha of 0.05. Although the most obvious conclusion is that the expected differences between groups and associations between variables, do not exist in IBS, IBD and Non-patient populations, it is possible that they went undetected in this sample for several reasons.

Firstly, the samples for each group consisted of volunteers. The characteristics of people who volunteer their participation in studies can differ from the rest of the sample they represent (Silverman, 1985). This means that interpretations of the findings need to be evaluated with caution, in terms of the ability to generalise to the rest of the population they represent, (i.e. in this study the IBS, IBD and Non-patient control populations).

Secondly, due to the actual sample size obtained, the power of the statistical tests could only detect relatively large differences between groups (i.e. C = 1.25) in terms of effect size. Therefore it is possible that a larger sample may have produced significant results. However, C = 1.25 represents a reasonable estimate of an effect size corresponding to a difference in therapeutic or clinical effectiveness, and it is questionable whether the statistically significant (but therapeutically small) differences detectable in a large sample would have practical implications for treatment.

Thirdly, a confounding variable may have been present in the IBD group. As IBS is so common it can coexist with other disorders, such as IBD. For example, a study by Isgar,

Harmen, Kaye & Whorwell (1983), found a high prevalence of IBS symptoms in a group of patients with Ulcerative Colitis in remission. As patients with Ulcerative Colitis were included in the IBD category in this study, it is possible that some of the IBD patients also have IBS. This would have introduced a confounding variable in the study, which may account for the lack of significant differences between the IBS and IBD groups.

Due to time constraints a single measurement of coping with a specific episode of primary symptoms was obtained in the IBS and IBD groups. Repeated measurements of specific episodes which were then aggregated for each person would have provided a more reliable (i.e. stable) measure of how people with IBS and IBD cope with a specific episode of their primary symptoms.

The validity of the coping strategies endorsed by IBS and IBD patients may have been inaccurate, as they responded retrospectively about their last episode of primary symptoms. Although the most common episode was within a week, the range of episodes varied from a few days ago to 2 years and 2 months ago. Therefore, some of the patients' memories of what they actually did may have been inaccurate, despite the priming technique in the interview, which attempted to overcome this problem.

Taking the above comments into account, the findings from this study cannot be generalised to the general IBS and IBD populations that attend G.I. Clinics.

Two issues emerged from the findings that are interesting from a clinical viewpoint. One of these relates to anxiety and the other relates to the coping strategies endorsed by IBS and IBD patients.

The research literature about psychological distress in IBS patients who seek treatment has found that these patients have higher levels of psychological distress than non-treatment seekers and non-patient controls. This has been shown on a multitude of variables including anxiety and has led to the claim that treatment seekers are vulnerable to and have a higher prevalence of psychiatric disorders. Over the last 10 years, several authors have attempted to counteract this claim, arguing that psychiatric disorders in this population are not as high as previous studies have claimed (e.g. Thornton, McIntyre, Murray-Lyon & Gruzelier, 1990), and taking this one step further, that elevations in psychological measures of distress in this population do not reach clinically significant levels, (e.g. Schwarz et al, 1993).

In Thornton et al's (1990) study of 25 patients with IBS, only 4 met the criteria for psychiatric disorder. What is of greater interest in relation to the present study are the findings for the remaining 21 non-psychiatric cases of IBS. Scores on the STAI were below average for general medical and surgical patients (this measure was the same one used by Schwarz et al, 1993) and this supports their argument that elevations did not reach clinically significant levels. However, scores on the HADS revealed that 4 of the IBS patients had clinically significant levels of anxiety and none of the IBS patients had clinically significant levels of anxiety and none of the IBS patients had clinically significant levels of depression.

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This latter finding is similar to the present study where 4 out of the 15 IBS patients met the criterion for clinically significant anxiety, and 1 IBS patient met the criterion for clinically significant depression on the HADS. In the IBD group, 3 out of the 15 patients met the criterion for clinically significant anxiety, and 2 IBD patients met the criterion for clinically significant depression on the HADS. An interesting anecdotal finding was that 33.3% of patients with bowel disorders had felt anxious/concerned about the possibility of having bowel cancer. When these patients had been reassured that this was not the case (usually by having a colonoscopy), they reported that their anxiety had dissipated. These findings suggest that anxiety may be elevated at certain points in time, depending on the duration of the illness and bowel symptom activity. These may account for the varying results in previous studies. It also suggests that there may be a subset of patients with bowel disorders that experience clinically significant levels of anxiety and depression throughout their illness experience.

Several issues are raised in relation to the findings about the coping strategies the IBS and IBD patients endorsed. The study by Bombardier et al. (1990) found equal proportions of problem and emotion-focused coping in a heterogeneous sample. These findings were limited, as they could not be generalised to any single illness or condition. The findings in the present study add support to the equal proportions claim and when analysed separately (as well as together) suggest that IBS and IBD patients' use equal proportions of both types of coping strategies.

The coping strategies endorsed by patients with bowel disorders when coping specifically with an episode of primary symptoms are worth attending to, despite the methodological limitations. The frequency of particular coping strategies indicates that this sample of patients were using potentially adaptive coping strategies to manage their episode of primary symptoms. This observation is based on results from Carver et al's (1989) paper, where they found significant correlations between some of the scales on the COPE and certain personality dimensions. The personality dimensions of interest to the present study are self-esteem and anxiety. The most frequently used coping strategy in the present study was Active Coping. Carver et al., (1989) found that Active Coping was correlated positively with self-esteem and negatively with anxiety. Two of the least frequently used coping strategies in the present study were Denial and Behavioural Disengagement. Carver et al., (1989) found that both these strategies were negatively correlated with self-esteem and positively correlated with anxiety. These correlations suggest that Active Coping is adaptive and Denial and Behavioural Disengagement are maladaptive. The patients in this study, on average had high levels of self-esteem and low levels of anxiety. These findings indicate the possibility that this sample used adaptive coping strategies, but is not in any way conclusive, due to methodological limitations, (e.g. the time between last episode of primary symptoms varying; intervening variables between last episode and measurement of anxiety and self-esteem were not assessed; only one measurement of coping with a specific episode was taken; duration of illness since diagnosis varied, etc.). Therefore, it can only be tentatively implied that this sample of patients, who had been diagnosed on average over 1.5 years ago, coped positively with a specific episode of their primary symptoms.

4.3 DIRECTIONS FOR FUTURE RESEARCH

This study was explorative in nature, as it was the first attempt to assess the coping process in patients with IBS and IBD. A strength of this study was that it assessed a wide range of coping strategies. The conclusions that can be drawn from this study were limited, primarily due to constraints of time, which led to a relatively small sample size, single measurements and design limitations. Future research needs to direct attention to the following:

Coping with chronic illnesses often changes over time (Lazarus, 1992; 1993; Weinman, 1987). A cross-sectional design targeted at varying durations of the chronic illnesses of IBS and IBD would address this issue. Ideally this cross-section of patients would then be assessed longitudinally, to allow for repeated measurements of psychological distress, self-esteem and coping with specific episodes of their primary symptoms. Preferably, there would also be a measure to indicate how the episode was construed and appraised, (as it was interesting to note that not all the patients in the present studied viewed their illness as stressful). To reduce inaccuracies in memory, patients would be asked to complete the coping measure at the time the episode was experienced.

A cross-sectional, longitudinal design as outlined above would lead to a better understanding of the coping process in patients with IBS and IBD and identify both consistencies and inconsistencies in the coping profiles they endorse. It would also aid our understanding about how the coping process relates to psychological distress and self-esteem. This may lead on to further research, which could address the relationships between coping and adaptational outcomes and identify the efficacy of particular coping strategies for positive psychological health. It is worth noting that adaptational outcome requires a measure of health status. For these patients it would be meaningful to assess their quality of social functioning, as anecdotal data indicated that this was an area that could be greatly affected by an episode of primary symptoms.

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4.4 IMPLICATIONS FOR PRACTICE

The research about coping in IBS and IBD patients is just beginning and it would be premature to draw any conclusions about the implications for clinical/medical practice.

An issue which at present does have implications for clinical/medical practice, is the psychological distress experienced by patients with IBS and IBD that was discussed in Section 4.2.2. The conclusions that were drawn from the findings suggested that there might be a subset of patients with bowel disorders who experience clinically significant levels of anxiety and depression throughout their illness experience. The implications of this finding advocate for the use of a measure of anxiety and depression to be implemented in all Gastroenterology Clinics to screen for this subset of patients. Once identified, these patients should be offered a psychological referral for assessment and intervention. The intervention offered would be dependent on the resources and protocols established and available in each locality. For example, this could vary from patients being referred on to mainstream psychology services or health psychologists available within the hospital setting. The intervention may be individual or group based depending on the current practices of the providers for mental health support services.

APPENDICES

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APPENDIX 1 DEPARTMENT OF GASTROENTEROLOGY

Our Ref: SH/rec

NHS No:

Southmead Hospital Westbury-on-Trym Bristol BS10 5NB Direct Line: 0117 959 5286 Fax Number : 0117 959 5366

29 April 1999

Mrs G Cratchely 54 Wades Road Filton Bristol

Dear Gina

Please find enclosed some information on how I make the diagnosis of irritable bowel syndrome. I hope this is satisfactory, but if not, please get back to me.

Best wishes with the dissertation.

Yours sincerely

.

Dr S Hughes Consultant Physician and Gastroenterologist

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Diagnosis of Irritable bowel Syndrome

- 1 A positive diagnosis should be made from symptoms rather than by exclusion.
- 2 Symptoms vary between patients and not all patients have all recognized symptoms.
- 3 The main symptoms identified are recognized in the manning criteria. Many of them are minor features, however, are recognised by gastroenterologists.
- 4 Symptoms include abdominal pain relieved by defaecation, the passage of mucus in the stool, disordered bowel habit, including constipation and diarrhoea, an association between the abdominal pain and the bowel disturbance, a sensation of incomplete evacuation and bloating.
- 5 Less frequently identified symptoms are psuedo constipation, pseudo diarrhoea, an exaggerated gastro colic reflex and even frequency of micturition.
- 6 Patients over the age of 45 are not diagnosed with irritable bowel syndrome without a barium enema to exclude colon cancer and inflammatory bowel disease.
- 7 A diagnosis of irritable bowel syndrome is not accepted if the patient has any alarm symptoms such as rectal bleeding, weight loss or extra intestinal manifestations suggesting inflammatory bowel disease.
- 8 Using the above criteria it is rare to miss diagnose colon cancer, but occasional cases of inflammatory bowel disease, especially Crohn's disease are missed.
- 9 The diagnosis is made in my patients by clinical history, examination and rigid sigmoidoscopy with supplementary tests as necessary.
Diagnosis of Inflammatory bowel disease

- 1 The diagnosis is based on appropriate symptoms, physical signs and investigation results.
- 2 The symptoms suffered by patients with inflammatory bowel disease vary on the type of inflammatory bowel disease and the site of the problem.
- 3 Patients with Crohn's disease present with diarrhoea, abdominal pain and sometimes rectal bleeding.
- 4 Patients with ulcerative colitis present with diarrhoea and rectal bleeding, but rarely have significant pain. Weight loss may be a feature of both Crohn's disease and ulcerative colitis. Blood tests may show signs of inflammation and sigmoidoscopy will show inflammation if the rectum is involved. If disease is confirmed to the small bowel it may show on contrast studies.

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General Nature of Qualifications, Training and Experience for Occupations in SOC Major Groups

No	Major Group	General Nature of Qualifications Training &
110.		Function of for Occupations in the Major Crown
		Experience for Occupations in the Major Oroup
	Administration	A significant amount of knowledge and experience of the
	Auministrators	production processes, automistrative procedures of service
		organisations and husinesses
		organisations and ousinesses.
	Buofessional	A degree of equivalent qualification, with some ecourations
2	Cocupations	A degree of equivalent qualifications and/or a formal period of
	Occupations	experience-related training
2	Associate Professional	An associated high-level vocational qualification often involving a
3	& Technical	substantial period of full-time training or further study. Some
	Occupations	additional task-related training is usually provided through a
		formal period of induction.
4	Clerical & Secretarial	A good standard of general education. Certain occupations will
-	Occupations	require further additional vocational training to a well defined
	•	standard (e.g. typing or shorthand).
5	Craft & Related	A substantial period of training, often provided by means of a
	Occupations	work-based training programme.
6	Personal & Protective	A good standard of general education. Certain occupations will
	Service Occupations	require further additional vocational training, often provided by
	-	means of a work-based training programme.
		-
7	Sales Occupations	A general education and a programme of work-based training
		related to sales procedures. Some occupations require additional
		specific technical knowledge but are included in this major group
		because the primary task involves selling.
8	Plant & Machine	The knowledge and experience necessary to operate vehicles and
	Operatives	other mobile and stationary machinery, to operate and monitor
[industrial plant and equipment, to assemble products from
		component parts according to strict rules and procedures and
		major group will gravify a minimum standard of competence that
1		must be attained for satisfactory performance of the associated
		tasks and will have an associated period of formal
!		experience-related training.
[
9	Other Occupations	The knowledge and experience necessary to perform mostly simple
_		and routine tasks involving the use of hand-held tools and in some
1		cases, requiring a degree of physical effort. Most occupations in
		the major group require no formal educational qualifications but
ļ		will usually have an associated short period of formal
l		experience-related training. All non-managerial agricultural
		occupations are also included in this major group, primarily
		because of the difficulty of distinguishing between those
		occupations which require only a limited knowledge of agricultural
		techniques, animal husbandry, etc. from those which require
]]	specific training and experience in these areas. These occupations
		are defined in a separate minor group.

SEMI-STRUCTURED INTERVIEW

NAME:

1 1 1

(1, 2, 2)

PARTICIPANT NO:

AGE: SEX: OCCUPATION: **GROUP: IBS/IBD**

ETHNIC ORIGIN:

For patient groups only:

DURATION OF ILLNESS:

MEDICATION:

PREVIOUS TREATMENTS:

Check completed the Symptom Checklist, then ask the questions below:

What do you find helps make these symptoms better?

What do you find makes these symptoms worse?

Do you find living with your illness stressful? YES/NO-

What concerns you the most about your illness?

When did you last experience an episode of abdominal pain and/or abnormal bowel movements? (ask person to describe this experience).

Give patient descriptor card:

<u>.</u> М. . -

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....

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ANSWER: 1 2 3 4 (Circle the answer the patient gives)

RESEARCH QUESTIONNAIRE BATTERY

NAME:

DATE:.....

GROUP: IBS/IBD PARTICIPANT NO:

<u>COPE</u>

Please think about the last time you experienced an episode of abdominal pain and/or abnormal bowel movements and how you reacted to this. Then indicate the extent to which you did whatever each of the following statements says by circling one number for each, using the rating scale shown in the box.

Please try to respond to each statement separately in your mind. Choose your answers thoughtfully, and make your answers as true FOR YOU as you can. Please answer every statement. There are no 'right' or 'wrong' answers, so choose the most accurate answer for YOU.

RATING SCALE	
1= I did not do this at all	

2= I did this a little bit

3= I did this a medium amount

4= I did this a lot

1. I tried to grow as a person as a result of the experience.	1	2	3	4	
2. I turned to work or other substitute activities to take my mind off things.	1	2	3	4	
3. I got upset and let my emotions out.	1	2	3	4	
4. I tried to get advice from someone about what to do.	1	2	3	4	
5. I concentrated my efforts on doing something about it.	1	2	3	4	
6. I said to myself "this isn't real".	1	2	3	4	
7. I put my trust in God.	1	2	3	4	
8. I laughed about the situation.	1	2	3	4	
9. I admitted to myself that I couldn't deal with it, and gave up trying.	l	2	3	4	
10. I restrained myself from doing anything too quickly.	1	2	3	4	
11. I discussed my feelings with someone.	1	2	3	4	
12. I used alcohol.	1	2	3	4	
13. I got used to the idea that it happend.	1	2	3	4	
14. I talked to someone to find out more about the situation.	1	2	3	4	
15. I kept myself from getting distracted by other thoughts or activities.	1	2	3	4	
16. I daydreamed about things other than this.	1	2	3	4	
17. I got upset, and was really aware of it.	I	2	3	4	
18. I sought God's help.	I	2	3	4	
19. 1 made a plan of action.	l	2	3	4	
20. I made jokes about it.	l	2	3	4	
21. I accepted that this had happened and that it couldn't be changed.	1	2	3	4	
22. I held off doing anything about it until the situation permitted.	1	2	3	4	
23. I tried to get emotional support from friends and relatives.	1	2	3	4	
24. I just gave up trying to reach my goal.	1	2	3	4	

F 1 2 3 4	LATING SCALI = I did not do t = I did this a lin = I did this a m = I did this a la	E his ttle edit	at a bit um	ill am	ount
25. I took additional action to try to get rid of the problem.		1	2	3	4
26. I tried to lose myself for a while by drinking alcohol or taking dri	ıgs.	1	2	3	4
27. I refused to believe that it had happened.		1	2	3	4
28. I let my feelings out.		1	2	3	4
29. I tried to see it in a different light, to make it seem more positive.		1	2	3	4
30. I talked to someone who could do something concrete about the p	roblem.	1	2	3	4
31. I slept more than usual.		1	2	3	4
32. I tried to come up with a strategy about what to do.		1	2	3	4
33. I focused on dealing with this problem and, if necessary, let other a little.	things slide	1	2	3	4
34. I got sympathy and understanding from someone.		1	2	3	4
35. I drank alcohol or took drugs, in order to think about it less.		1	2	3	4
36. I kidded around about it.		1	2	3	4
37. I gave up the attempt to get what I wanted.		1	2	3	4
38. I looked for something good in what was happening.		1	2	3	4
39. I thought about how I might best handle the problem.		1	2	3	4
40. I pretended that it hadn't really happened.		1	2	3	4
41. I made sure not to make matters worse by acting too soon.		1	2	3	4
42. I tried hard to prevent other things from interfering with my effordealing with this.	rts at	1	2	3	4
43. I went to the cinema or watched television, to think about it less.		ł	2	3	4
44. I accepted the reality of the fact that it had happened.		l	2	3	4
45. I asked people who had had similar experiences what they did.		1	2	3	4
46. I felt a lot of emotional distress and I found myself expressing the	ose feelings a lot.	1	2	3	4
47. I took direct action to get around the problem.		1	2	3	4
48. I tried to find comfort in my religion.		1	2	3	4
49. I forced myself to wait for the right time to do something.		1	2	3	4
50. I made fun of the situation.		1	2	3	4
51. I reduced the amount of effort I put into solving the problem.		1	2	3	4
52. I talked to someone about how I felt.		1	2	3	4
53. I used alcohol or drugs to help me get through it.		1	2	3	4
54. I learnt to live with it.		1	2	3	4
55. I put aside other activities in order to concentrate on this.		1	2	3	4
56. I thought hard about what steps to take.		1	2	3	4
57. I acted as though it hadn't happened.		1	2	3	4
58. I did what had to be done, one step at a time.		1	2	3	4
59. 1 learnt something from the experience.		1	2	3	4
60. I prayed more than usual.		l	2	3	4

MULTIDIMENSIONAL HEALTH LOCUS OF CONTROL SCALE (FORM C)

This is a questionnaire designed to determine the way in which different people view their Irritable Bowel Disease or Inflammatory Bowel Disease. Each item is a belief statement with which you may agree or disagree. Beside each statement is a scale which ranges from strongly disagree (1) to strongly agree (6). For each item we would like you to circle the number that represents the extent to which you disagree or agree with the statement. The more strongly you agree with a statement, then the higher will be the number you circle. The more strongly you disagree with a statement, then the lower will be the number you circle. Please make sure that you answer every item and that you circle only one number per item. This is a measure of your personal beliefs: obviously, there are no right or wrong answers.

Please answer these items carefully, but do not spend too much time on any one item. As much as you can, try to respond to each item independently. When making your choice, do not be influenced by your previous choices. It is important that you respond according to your actual beliefs and not according to how you feel you should believe or how you think we want you to believe.

		Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
1.	If my bowel disease worsens, it is my own behaviour which determines how soon I feel better again.	1	2	3	4	5	6
2.	As to my bowel disease, what will be will be.	l	2	3	4	5	6
3.	If I see my doctor regularly, I am less likely to have problems with my bowel disease.	I	2	3	4	5	6
4.	Most things that affect my bowel disease happen to me by chance.	1	2	3	4	5	6
5.	Whenever my bowel disease worsens, I should consult a medically trained professional.	1	2	3	4	5	6
6.	I am directly responsible for my bowel disease getting better or worse.	1	2	3	4	5	6
7.	In order for my bowel disease to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
8.	Whatever goes wrong with my bowel disease is my own fault.	1	2	3	4	5	6
9.	Luck plays a big part in determining how my bowel disease improves.	1	2	3	4	5	6
10.	Other people play a big role in whether my bowel disease improves, stays the same, or gets worse.	I	2	3	4	5	6
11	Whatever improvement occurs with my bowel disease is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing which affects my bowel disease is what I myself do.	e 1	2	3	4	5	6

	Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strong <u>ly</u> Agree
 If my bowel disease takes a turn for the worse, it is because I have not been taking proper care of myself. 	I	2	3	4	5	6
 The type of help I receive from other people determines how soon my bowel disease improves. 	1	2	3	4	5	6
15. If my bowel disease worsens, it's a matter of fate.	1	2	3	4	5	6
16. If I am lucky, my bowel disease will get better.	1	2	3	4	5	6
17. I deserve the credit when my bowel disease improves and the blame when it gets worse.	1	2	3	4	5	6
 Following doctor's orders to the letter is the best way to keep my bowel disease from getting worse. 	1	2	3	4	5	6

ROSENBERG'S SELF-PERCEPTION

Here are some statements that people have used to describe themselves. Please read each statement carefully and decide whether you agree with it or not. Please circle the number below (from 1 to 4)which best describes how much in agreement or disagreement you are with it.			RATING SCALE 1 = Strongly Disagree 2 = Disagree 3 = Agree 4 = Strongly Agree				
 I feel that I am a person of worth, at least on an equal plane with others. 	1	2	3	4			
2. I feel that I have a number of good qualities.	1	2	3	4			
3. All in all, I am inclined to feel that I am a failure.	1	2	3	4			
4. I am able to do things as well as most other people.	1	2	3	4			
5. I feel I do not have much to be proud of.	1	2	3	4			
6. I take a positive attitude towards myself.	1	2	3	4			
7. On the whole, I am satisfied with myself.	1	2	3	4			
8. I wish I could have more respect for myself.	1	2	3	4			
9. I certainly feel useless at times.	1	2	3	4			
10. At times I think I am no good at all.	1	2	3	4			

HOSPITAL ANXIETY AND DEPRESSION SCALE

Health Professionals are aware that emotions play an important part in most illnesses. This questionnaire is designed to let us know how you feel. Please read each item and underline the reply which comes closest to how you have been feeling in the past week.

Don't take too long over your replies; your immediate reaction to each item will probably be more accurate than a long thought-out response.

1. I feel tense or 'wound up':	8. I feel as if 1 am slowed down:
Most of the time	Nearly all the time
A lot of the time	Very often
From time to time, occasionally	Sometimes
Not at all	Not at all
2. I still enjoy the things I used to enjoy:	9. I get a sort of frightened feeling like 'hutterflies' in
Definitely as much	in the stomach:
Not quite so much	Not at all
Only a little	Occasionally
Hardly at all	Quite often
3. I get a sort of frightened feeling as if something	Very often
awful is about to happen:	10. I have lost interest in my appearance:
Very definitely and quite badly	Definitely
Yes, but not too badly	I don't take as much care as I should
A little, but it doesn't worry me	I may not take quite as much care
Not at all	I take just as much care as ever
4. I can laugh and see the funny side of things:	11. I feel restless as if I have to be on the move:
As much as 1 always could	Very much indeed
Not quite as much now	Quite a lot
Definitely not so much now	Not very much
Not at all	Not at all
5. Worrying thoughts go through my mind:	12. I look forward with enjoyment to things:
A great deal of the time	As much as ever I did
A lot of the time	Rather less than I used to
From time to time but not too often	Definitely less than I used to
Only occasionally	Hardly at all
6, 1 feel cheerful:	13. I get sudden feelings of panic:
Not at all	Very often indeed
Not often	Quite often
Sometimes	Not very often
Most of the time	Not at all
7. I can sit at ease and feel relaxed:	14. I can enjoy a good book or radio or TV
Definitely	programme:
Usually	Often
Not often	Sometimes
Not at all	Not often
	Very soldom

PERCEIVED STRESS SCALE

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each |0| = Neverquestion fairly quickly. That is, don't try to count up the number of 1 =Almost Never times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate.

For each question choose from the following alternatives:

- 2 = Sometimes
- 3 = Fairly Often
- 4 = Very Often

1.	In the last month, how often have you been upset because of something that happened unexpectedly?	0	1	2	3	4
2 .	In the last month, how often have you felt that you were unable to control the important things in your life?	0	1	2	3	4
3.	In the last month, how often have you felt nervous and stressed?	0	1	2	3	4
4.	In the last month, how often have you felt confident about your ability to handle your personal problems?	0	1	2	3	4
5.	In the last month, how often have you felt that things were going your way?	0	1	2	3	4
6.	In the last month, how often have you found that you could not cope with all the things you had to do?	0	1	2	3	4
7.	In the last month, how often have you been able to control irritations in your life?	0	1	2	3	4
8.	In the last month, how often have you felt that you were on top of things?	0	1	2	3	4
9.	In the last month, how often have you been angered because of things that happened that were outside of your control?	0	1	2	3	4
10	In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	0	1	2	3	4

THANK YOU FOR YOUR CO-OPERATION IN COMPLETING THIS RESEARCH **QUESTIONNAIRE BATTERY.**

RESEARCH QUESTIONNAIRE BATTERY

OCCUPATION:.....AGE:....

DATE:.....SEX: M/F

CONTROL GROUP PARTICIPANT NO:

r-----

ROSENBERG'S SELF-PERCEPTION

Here are some statements that people have used to describe themselves. Please read each statement carefully and decide whether you agree with it or not. Please circle the number below (from 1 to 4) which best describes how much in agreement or disagreement you are with it.

	RATING SCALE 1 = Strongly Disagree 2 = Disagree 3 = Agree 4 = Strongly Agree					
1. I feel that I am a person of worth, at least on an equal plane with others.	1	2	3	4		
2. I feel that I have a number of good qualities.	1	2	3	4		
3. All in all, I am inclined to feel that I am a failure.	1	2	3	4		
4. I am able to do things as well as most other people.	1	2	3	4		
5. I feel I do not have much to be proud of.	1	2	3	4		
6. I take a positive attitude towards myself.	1	2	3	4		
7. On the whole, I am satisfied with myself.	1	2	3	4		
8. I wish I could have more respect for myself.	1	2	3	4		
9. I certainly feel useless at times.	1	2	3	4		
10. At times I think I am no good at all.	I	2	3	4		

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This questionnaire is designed to let us know how you feel. Please read each item and underline the reply which comes closest to how you have been feeling in the past week.

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Most of the time	Nearly all the time
A lot of the time	Very often
From time to time, occasionally	Sometimes
Not at all	Not at all
2. I still enjoy the things I used to enjoy:	9. I get a sort of frightened feeling like 'butterflies' in
Definitely as much	in the stomach:
Not quite so much	Not at all
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Hardly at all	Quite often
3. I get a sort of frightened feeling as if something	Very often
awful is about to happen:	10. I have lost interest in my appearance:
Very definitely and quite badly	Definitely
Yes, but not too badly	I don't take as much care as I should
A little, but it doesn't worry me	I may not take quite as much care
Not at all	I take just as much care as ever
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Not at all	Not at all
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6. I feel cheerful:	13. I get sudden feelings of panic:
Not at all	Very often indeed
Not often	Quite often
Sometimes	Not very often
Most of the time	Not at all
7. I can sit at ease and feel relaxed:	14. I can enjoy a good book or radio or TV
Definitely	programme:
Usually	Often
Not often	Sometimes
Not at all	A_ Not often
-0-	Very seldom

PERCEIVED STRESS SCALE

The questions in this scale ask you about your feelings and thoughts during the last month. In each case, you will be asked to indicate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each question fairly quickly. That is, don't try to count up the number of times you felt a particular way, but rather indicate the alternative that seems like a reasonable estimate.

For each question choose from the following alternatives:

- 0 = Never
- 1 = Almost Never
- 2 = Sometimes
- 3 = Fairly Often
- 4 = Very Often

1.	In the last month, how often have you been upset because of something that happened unexpectedly?	0	1	2	3	4
2.	In the last month, how often have you felt that you were unable to control the important things in your life?	0	1	2	3	4
3.	In the last month, how often have you felt nervous and stressed?	0	1	2	3	4
4.	In the last month, how often have you felt confident about your ability to handle your personal problems?	0	1	2	3	4
5.	In the last month, how often have you felt that things were going your way?	0	1	2	3	4
6.	In the last month, how often have you found that you could not cope with all the things you had to do?	0	1	2	3	4
7.	In the last month, how often have you been able to control irritations in your life?	0	1	2	3	4
8.	In the last month, how often have you felt that you were on top of things?	0	l	2	3	4
9.	In the last month, how often have you been angered because of things that happened that were outside of your control?	0	1	2	3	4
10	D. In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	0	1	2	3	4

THANK YOU FOR YOUR CO-OPERATION IN COMPLETING THIS RESEARCH QUESTIONNAIRE BATTERY.



A NATIONAL HEALTH SPRVICE TRUST

Administration Department Trust Headquarters Southmead Hospital Bristol BS10 5NB

Tel: (0117) 959 5207 (direct line) Fax: (0117) 959 0902

Mrs G Cratchley 54 Wades Road Filton Bristol BS12 7ED

Dear Mrs Cratchley

PROJECT No. 45/98: HOW DO PEOPLE WITH IRRITABLE BOWEL SYNDROME AND INFLAMMATORY BOWEL DISEASE COPE WITH THEIR CHRONIC ILLNESS? A STUDY WHICH EXAMINES THE DIFFERENCES IN COPING STRATEGIES BETWEEN THESE TWO GROUPS

I am pleased to inform you that at its meeting on 10 June 1998, the Medical Research Ethics Committee approved your application in respect of the above project.

Approval is given on the understanding that:-

- a) Any ethical problems arising in the course of the project will be reported to the Ethics Committee;
- b) Any change in protocol will be reported to the Ethics Committee;
- c) An annual progress report will be submitted and a brief final report on completion.

Yours sincerely

rownan me E

Mrs S B Bowman Secretary Southmead Medical Research Ethics Committee

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A University of Bristol Associated Teaching Trust

19 June 1998

COPING WITH BOWEL DISORDERS

Many people with a bowel disorder find it makes their lives more difficult and stressful than people who do not have to live with a bowel disorder.

There is a lot of research about the distress living with a bowel disorder can create. However, I have found that there is **hardly any** <u>research</u> which asks people with a bowel disorder how they COPE.

e.g. How living with a bowel disorder makes people feel, think and behave.

I am therefore carrying out a study to ask people like yourself how YOU COPE with a bowel disorder.

What will happen with the information collected?

The information you give will remain anonymous. It will be used to help people in the future when they find out they have a bowel disorder.

What would taking part in this study involve?

If you would like to take part in this study it will involve a brief conversation and answering some questionnaires with the researcher (i.e. myself).

It will take about 1 hour.

If you are willing to take part in this study, please fill in your details in the last section of this leaflet, tear this section off and return it to Dr. Steve Hughes.

If you do not wish to take part this will **not** affect your treatment.

THANK YOU FOR READING THIS LEAFLET

I WOULD LIKE TO TAKE PART IN THE
STUDY ABOUT HOW PEOPLE COPE
WITH BOWEL DISORDERS
(Please sign your name on the dotted line)
Please fill out the details below in CAPITAL
LETTERS.
NAME:
ADDRESS:
TELEPHONE NO
These details will be given to Gina Cratchley
(Researcher) who will contact you to arrange
an appointment.

Dept: Clinical Psychology GLOUCESTER HOUSE

0117 9595808 Fax:

February 1999

Dear,

Re: Participation in Research about Coping with a Bowel Disorder

Thank you for agreeing to take part in the above study.

I am writing to confirm your appointment on This meeting will be held at your home address. at

I have enclosed a Symptom Checklist. Please could you fill this in prior to your appointment.

I would be grateful if you could telephone the above number if you need to re-arrange this appointment.

I look forward to meeting you.

Yours sincerely,

Gina Cratchley Researcher

Enc.

Southmead Hospital, Westbury-on-Trym Bristol BS10 5NB

Switchboard: 0117 950 5050

SYMPTOM CHECKLIST

NAME:.....

GROUP: IBS/IBD

DATE:....

Below are a list of 11 symptoms that you may or may not experience. Please read each symptom and circle the answer that is true for you.

Example: I experience diarrhoea

NO MILDLY MODERATELY STRONGLY SEVERELY

This person experiences diarrhoea mildly.

1.	l experience diarrhoea	NO	MILDLY	MODERATELY	STRONGLY	SEVERELY
2 .	l experience constipation	NO	MILDLY	MODERATELY	STRONGLY	SEVERELY
3.	l experience abdominal pain	NO	MILDLY	MODERATELY	STRONGLY	SEVERELY
4.	l experience rectal bleeding	NO	MILDLY	MODERATELY	STRONGLY	SEVERELY
5 .	l experience passing mucus	NO	MILDLY	MODERATELY	STRONGLY	SEVERELY
6 .	l experience abdominal bloating	NO	MILDLY	MODERATELY	STRONGLY	SEVERELY
7.	l experience incomplete evacuation of my bowel	NO	MILDLY	MODERATELY	STRONGLY	SEVERELY
8.	I experience tiredness	NO	MILDLY	MODERATELY	STRONGLY	SEVERELY
9 .	I experience nausea	NO	MILDLY	MODERATELY	STRONGLY	SEVERELY
10.	I experience difficulty in swallowing	NO	MILDLY	MODERATELY	STRONGLY	SEVERELY
11.	I experience the need to urinate frequently	NO	MILDLY	MODERATELY	STRONGLY	SEVERELY

Please write down below any other symptoms you experience which are not on the list.

SOUTHMEAD HEALTH _____ServiceA—

Dept: Clinical Psychology GLOUCESTER HOUSE (0117) 9595808 Fax:

VOLUNTEERS FOR THE HEALTH STUDY

Dear Volunteer,

Thank you for agreeing to take part in this study. This study aims to help research in to how people cope with bowel disorders, such as Irritable Bowel Syndrome, Crohn's Disease, Ulcerative Colitis etc.

Please make sure that you do **NOT** have any of these disorders, nor any other major health problems as they will disqualify you from taking part.

Please fill in the enclosed questionnaire battery, 4 questionnaires in total. There are instructions at the top of each questionnaire which will help you to fill it in.

Your participation should take between 15 - 30 minutes.

The information you provide will remain anonymous and on completion of the study (around June 1999) will be destroyed.

Please return in the envelope provided.

MANY THANKS FOR YOUR HELP.

Yours sincerely,

Gina Cratchley Researcher

Encs.

Southmead Hospital, Westbury-on-Trym Bristol BS10 5NB

Switchboard: 0117 950 5050

A University of Bristol Associated NHS Teaching Trust



Triangle = extreme outlier; Circle = minor outlier

Fig. 1: Boxplots of the Proportion of Problem-Focused and the Proportion of Emotion-Focused Coping.



Fig. 2: <u>Scatterplot of the Positive Correlation between the Total Amount of</u> <u>Problem-Focused Coping and the Total Amount of Emotion-Focused Coping.</u>

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