The Common Sense Model, Quality of Life and Symptom Frequency in Irritable Bowel Syndrome (IBS)

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Thesis submitted for the degree of Doctor of Philosophy

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2007

ABSTRACT

In this thesis the application of the Common Sense Model (CSM) of illness representations (Leventhal et al., 1890; 1984) to Irritable Bowel Syndrome (IBS) was investigated. A systematic literature review and three empirical studies were conducted to investigate the factors that influence the illness representations, explore the relationship between illness representations and illness outcomes (health related quality of life (HRQOL) and symptom frequency) and to potentially alter illness representations and illness outcomes.

Study 1 was an exploratory cross sectional study with 116 participants (n = 58 doctors, n = 58 IBS sufferers). Patients reported significantly more negative perceptions of the consultations than doctors; however patients perceived communication was not predictive of illness representations, or illness outcomes. Independently of perceived communication an internal locus of control was found to be predictive of illness outcomes.

Study 2 was a cross sectional study with 301 participants (n = 239 general population, n = 62 IBS sufferers). IBS sufferers' perceptions of the general populations' attitudes were significantly more negative than reported attitudes. Perceived attitudes towards witnessing symptoms were predictive of HRQOL. Independently of perceived attitudes, emotional representations were predictive of HRQOL, and illness identity was predictive of diarrhoea.

Study 3 was a longitudinal intervention study with 62 IBS sufferers. Significant findings were as follows: reductions in symptom frequency from pre intervention to immediately post, and two months post intervention; improvements in HRQOL from pre intervention to two months post intervention; improvements in perceived social support immediately post intervention; improvements in illness representations from pre intervention to immediately post, and two months post intervention. There were no significant predictors of change in total symptoms or HRQOL post the intervention.

Overall these studies demonstrate the utility of CSM in IBS research. Further investigation of the CSM in IBS is recommended.

ACKNOWLEDGEMENTS

The last few years have seen some of the most rewarding and some of the most stressful moments of my life so far. Although the process of studying for a PhD can be a solitary experience I would not have been able to write this thesis without the help of some very special people. In some respects this is the hardest part of the thesis to write as there are so many people to thank that I am worried that I am going to miss someone out. If you helped me in anyway then please know how grateful I am and if you are not on this list than please accept the oversight, it is most probably caused by sleep deprivation, and it by no means indicates a lack of gratitude. Therefore I would like to say a general thank you to all my friends and family for any help they have given me, and also for just 'putting' up' with me when I have been too stressed or too busy to give them the time they deserve. Special thanks go to:

My supervisor Professor Richard Shepherd. Dick you have been an excellent supervisor to me over the last few years, with your gentle guidance sowing the seeds helping me to develop my ideas. I am grateful to you for allowing this thesis to be truly mine from the initial stages through to the final write up. Thank you providing support whenever needed, in particular thank you for responding so quickly to e-mails and drafts of chapters over the last few years, and especially in the final week! I know that it is your efficiency and indeed your care that has allowed me to submit at this time. Thank you for making me feel capable even when I doubted myself and for ensuring that my time was never wasted. You are a wonderful supervisor.

My stage two supervisor Dr Marie Clarke. Marie, although you were not directly involved with the thesis I still wanted to say a few words of thanks, partly for the help regarding the systematic literature review (chapter 3) and also in general for your time throughout the last few years. Your motherly approach complemented Dick perfectly, and I always felt that you cared how I was achieving as a friend rather than just a supervisor. You always made me feel that I was handing in work above your

expectations, and where criticisms were necessary they were always broached in the nicest way. So thank you.

To my participants. I am extremely grateful to all of my participants, to my friends and family who filled in the questionnaires on my attitude study and to all the kind people I approached, who had no reason to help me but filled in the questionnaire any way. A big thank you to all the medical professionals who took the time out of their busy schedules to take part in the doctor-patient communication study, I am extremely grateful as many people told me I would never get any doctor's to fill in the forms, but with your help I managed to conduct the study, so thank you. And of course the biggest thank you to my IBS participants, to whom I owe such a debt of gratitude I do not quite know how to put it into words. I hope the success of the intervention goes someway towards repaying your kindness. Thank you so much for having the same commitment to understanding and improving this condition as I do.

To the IBS Network. There is simply no way that I could have conducted the research in this thesis without your support, from allowing me to advertise at reduced rates, to talking at support groups. I am extremely grateful, and I hope that I will be able to repay your kindness in the future, in the advancement of IBS research for a long time to come.

To the MREC and University Ethics committees. Thank you for allowing me to conduct the research, and for helping me in the initial stages to clarify my aims and hypothesis.

To all the people who helped me collect data through snowballing, although there are too many to list special thanks go to:

My mum. Thank you for putting you loquacious nature to good use and finding me many participants for each of my studies, and for providing useful comments at each stage over the last few years. Talking to you over the last few years have been some of the only times I have managed to stop thinking about the PhD and for that I am grateful, thank you.

To Jody and Aimée for helping me recruit participants, particularly for the attitude study. To Jody for actually being interested in my research and for taking time to read it and discuss it with me. To Aimee thank you for always making me feel that I am the smartest person in the world, despite the fact that you are clearly the cleaver sister, you just don't realise it yet!

To Papa Alan, for pretty much dedicating himself to my every request over the last few years, and asking any body and everybody to fill in my questionnaire, in particular for your help in getting doctors to participate. And of course to nana too, for making sure Papa did as I requested. Thank you both for your faith in me, the way you look at me with such pride helped me to keep on going when I was getting disheartened.

To Rosemary for her support and her interest to David for the lap top which has helped me considerably. To Tracy for her networking skills, and her laptop in Thailand, and to the rest of my family thank you.To all my friends who I have neglected for reminding my to find time to relax, special thanks go to Matt, Stuart, Shash, Martin, Tushna, Helen Shumona, Ryan and Ed.

To the University of Surrey for funding my PhD there is no way I could have studied over the last few years without your support so special thanks to Marc Cropley for believing in my abilities, offering me a PhD place and for suggesting me for funding. To Evanthia Lyons for deciding to give me funding, and any body else involved in the decision to fund me I am so very grateful. A final work of thanks to everyone who helps behind the scene in the department, for being organised at times when I haven't been! I am especially grateful to Carole, Nigel and Andrew for always going that extra mile.

My special thanks go to men who have been most important in my life over the last few years to my best friend David and my ever so supportive loving father, Earl. There is no way I can put into words how grateful I am to you both, hopefully my gratitude will be in some way shown by the fact this thesis is jointly dedicated to you.

DEDICATIONS

The first dedication is to my father: thank you for always making me feel special, for having an unwavering belief in my ability to succeed, and for being proud of everything I have achieved no matter how insignificant. Without your support, both financially and emotionally I would never have been able to undertake this PhD and for that I will always be grateful. Thank you for always making my wishes come true, no matter what cost to yourself. You may not know this but without your faith in my abilities from a child I would never have even considered that I was capable to doing a PhD.

The second dedication is to my wonderful David, although listing the ways you have supported me would constitute a second thesis I think everything I need to say is summed up best by saying thank you for always keeping your promises. You are my inspiration, and my hero. There is no way I would have got to this point without your support, which was always exactly what I needed, even though I may not have realised it at the time. I may not have said it enough throughout the last few years but I am so grateful to you. No matter what happens in life I will always remember how selfless you were when I needed help. Thank you.

In loving memory of Clifford Irons, it was your inspirational teaching and faith in my ability as an A level student which set the wheels in motion for this thesis long before I even knew what a psychologist was. Thank you.

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CHAPTER 1

IRRITABLE BOWEL SYNDROME: AN OVERVIEW

Aim

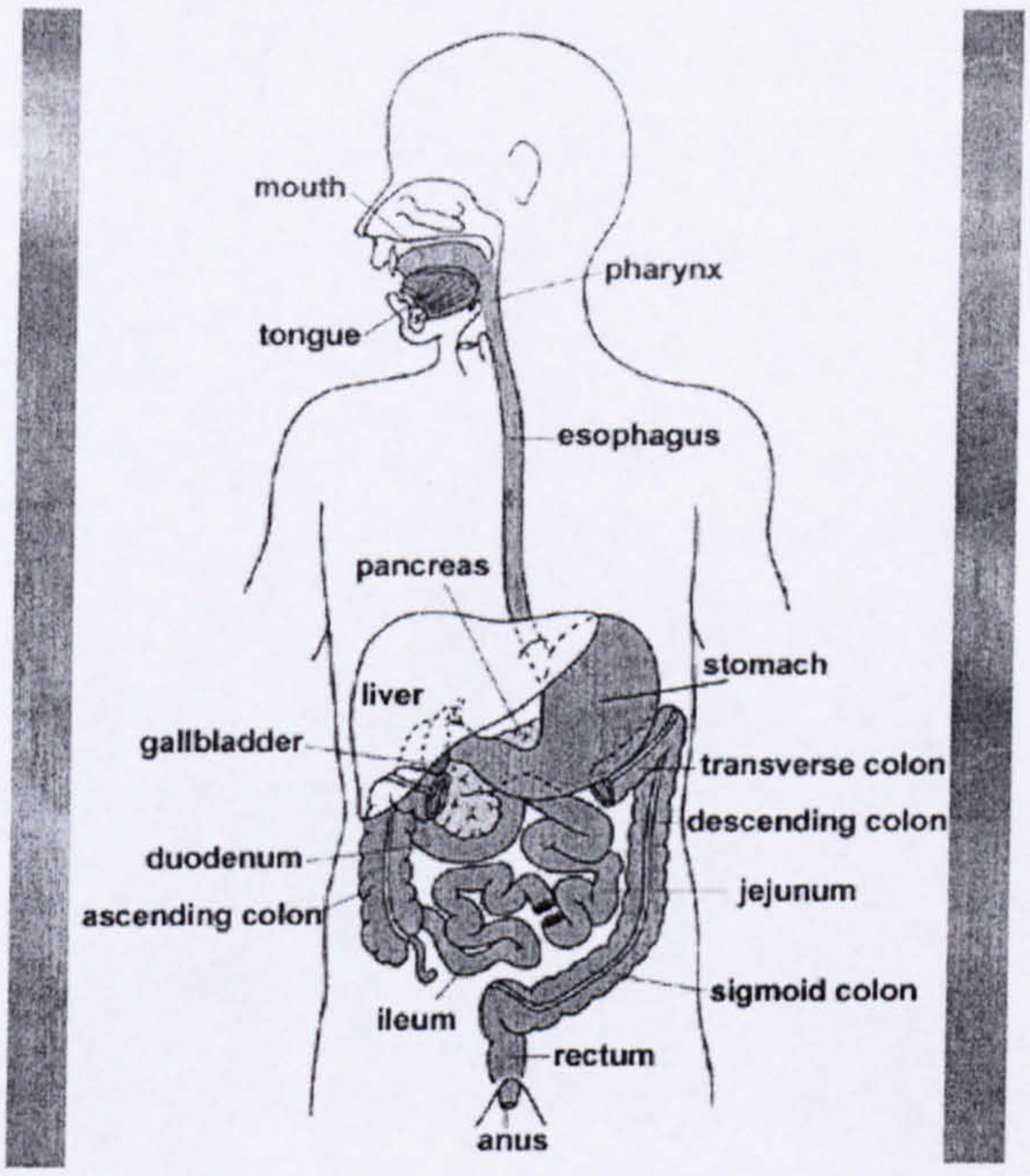
The aim of chapter one is to demonstrate the suitability of psychological approaches in irritable bowel syndrome (IBS). In order to provide a background to IBS a brief overview of the normal digestive system will be provided, followed by the current definition of IBS and the diagnostic criteria used. The rest of the chapter will detail proposed aetiological factors, epidemiology, co-morbidity and treatment options. In each of these areas the suitability of psychologically based approaches will be demonstrated. By the end of this chapter the utility of psychological methods to the study and treatment of IBS should be clear.

NORMAL DIGESTIVE PROCESSES AND BOWEL FUNCTION

OVERVIEW OF THE DIGESTIVE SYSTEM

The information presented in this section is extrapolated from Silk (1997) and Case (1979). The purpose of the digestive system is to convert food and drink into nutrients that can be used to enable functioning of bodily systems. The digestive system comprises both the gastrointestinal tract (gut) and other supportive organs (tongue, salivary glands, pancreas, liver and gall bladder, nerves and blood). The gastrointestinal tract runs from the mouth to the anus and is essentially a long twisting muscular tube connecting a series of hollow organs (mouth, oesophagus, stomach, small intestine, large intestine, rectum and anus). This tube is approximately 7-8 meters long (in adults) and its function is to process the food and fluids consumed. Essentially the process involves ingestion, digestion, absorption and elimination. Various organs contribute to each stage of the process and these are labelled in figure 1.

Figure 1 - The human digestive system



From http://www.umm.edu/digest/howworks.htm

In the context of irritable bowel syndrome (IBS) the areas of the normal digestive system of greatest relevance are the large intestine (bowel / colon) and the enteric nervous system (ENS).

LARGE INTESTINE / BOWEL (Colon)

This is the final section of the digestive tract. At this stage the breaking down of nutrients is considered to be complete and the indigestible food and fluid pass from the small intestine to the large intestine (approximately 4ft) where the process of re-absorption of water and excretion of ions (calcium, magnesium and iron) occurs. This is one of the most important processes involved in digestion. In normal digestion the excess water passes through the wall of the large intestine and into the blood stream. This means that as material passes though the large intestine it becomes progressively more solid allowing for the formation of waste matter in the form of faeces.

ENTERIC NERVOUS SYSTEM (ENS)

The ENS is the intrinsic nervous system of the gut (Saffrey, 2006) and therefore influences all digestive processes. Without it the digestive organs would be unable to

function, a rather crude example could be of a machine without electricity. ENS dysregulation will therefore unsurprisingly have an impact on digestive processes; this is suggested to be through alterations in smooth muscle contractibility (Saffrey, 2006). Current conceptions suggest that the ENS is essentially an extensive network of millions of neurons, which are dispersed throughout the gut. There are many different types of neurons (e.g. sensory, motor, inter) and it is the coordination of these neurons that regulate the gastrointestinal processes (McMillin et al., 1999). The central nervous system (CNS) influences the ENS and in turn the ENS influences the CNS; this is through both nerve reflexes and neuropeptides (McMillin et al., 1999). However, if the CNS-ENS interaction is suspended the ENS is capable of functioning autonomously, it is the only peripheral system capable of this and is most likely a result of anatomical similarity to the autonomic nervous system (ANS). A quotation that gives a clear indication of the current conceptualisations of the ENS is provided by Wood (1994):

"A minibrain placed in close proximity to the effector systems it controls. Rather than crowding the hundred million neurons required for control over the gut into the cranial cavity as part of the cephalic brain, and transmitting signals over long, unreliable pathways, natural selection placed the integrative microcircuits at the site of the effectors"

Although, the ENS is capable of functioning autonomously, normal digestion generally requires effective communication between the ENS and CNS, with potentially negative effects on the functioning of either system if the synergy is disrupted (see Brain-gut axis, Drossman et al.,1999). Communication is via parasympathetic and sympathetic fibres; these can either connect the CNS and ENS or even the CNS directly with the digestive tract. A basic example of this would be the stimulation of secretion in the stomach as a result of the CNS receiving sensory messages about the presence of food (Bowen, 2004).

IRRITABLE BOWEL SYNDROME

DEFINITION

The broad definition of Irritable Bowel Syndrome (IBS) is that it is a 'chronic functional digestive disorder' (Corazziari, 2004), affecting approximately 20% of western populations (Dancey et al., 1999) which is characterised by abdominal pain and altered bowel functioning. However when defining IBS it is important to recognise the limitations in current levels of understanding (Simrèn, 2006). As Simrèn (2006) notes "current conceptualisations about every aspect of the illness are controversial and as new research emerges our conceptions of IBS may alter". In fact recent research by Holtmann (2004) suggests that future conceptualisations of IBS may actually divide its many components into different disorders. It is therefore not possible to provide a standard outline of the illness; instead the most widely accepted definitions will be presented along with justification and discussion of alternatives where appropriate.

The definition of IBS as a "chronic functional gastrointestinal disorder" (FGID, Corazziari, 2004) is generally considered as the gold standard in terms of its medical categorisation. This label describes a number of characteristics of the illness that are important to consider. The first factor is that the label of a FGID is not unique to IBS, in fact the Rome II criteria (Drossman et al., 2000) list 47 different kinds of FGIDs. The categorisation of a patient as being an IBS sufferer, or suffering from another FGID is dependent on the combination of gastrointestinal symptoms (GI) the patient presents.

The second facet of this definition that is of importance is the labelling of IBS as 'chronic' (as opposed to either terminal or acute). A broad definition of a chronic illness would be that in contrast to an acute illness, it is a permanent state of ill health, but one that does not (usually) result in mortality as a direct consequence. Although the illness itself is permanent the specific symptoms or degree of severity may be may be either permanent or *cyclic* (whereby the periods of symptom presentation and remission alternate). This is one of the facets common to IBS (Camilleri, 2004). Regardless of whether the symptoms are permanent or cyclic the

main distinction between chronic and acute illnesses is that rather than adopting the 'sick role' (Suchman, 1965) for an extended period of time the effects of the illness must be incorporated into everyday functioning in order to maintain health related quality of life (e.g. Gralnek et al., 2000). Therefore the long-term management of any chronic illness becomes a central part of the patient's life. The categorisation of IBS as a chronic illness therefore implies an acceptance by the medical community that alterations to both cognitions and behaviours are likely to play a role in the everyday functioning of the IBS sufferer (Drossman et al., 2000). Therefore research with IBS sufferers should take into account cognitive and emotional factors rather than adopting a merely symptomatic approach.

DIAGNOSIS

The classification of IBS as a functional disorder affects the nature of the processes that need to be employed in initial diagnostic investigations (Olden, 2002). If an illness has an established organic cause diagnostic tests can be relatively simple and standardised, such as blood tests, X-rays etc. In Irritable Bowel Syndrome (and the other functional illnesses) the absence of an objective marker results in a diagnosis based on both *symptom presentation* and *exclusion criteria* (Corazziari, 2004). It is not sufficient to define IBS purely on its symptomatic presentation as many other illnesses (both functional and organic) have similar features (Camilleri, 2001). It has been suggested that the illnesses most likely to be misdiagnosed in a purely symptom based examination are celiac disease, Crohn's disease, bowel cancer, food intolerance, disaccharide intolerance, ulcerative colitis, infection, bacterial overgrowth, diverticular disease of the colon and bile acid induced diarrhoea (Gilkin, 2005; Hatlebakk & Hatlebakk, 2004). For this reason a diagnosis of IBS is not given until all other possibilities have been excluded.

SYMPTOM MANIFESTATIONS

As the name Irritable Bowel *Syndrome* suggests factor analytic studies of reported symptoms can be used to categorise patients into either IBS or one of the other FGIDs. One problem with factor analytic studies is that different researchers report different symptoms as comprising IBS (this can be for both overall symptom presentation for subcategories within IBS e.g. Silk, 1997). An additional problem

with using factor analytic studies is that unlike objective medical procedures many doctors are reluctant to use these procedures, and in fact many may still report being unaware of their existence (Drossman et al., 1999). However, there are two main classification systems that are used to elucidate diagnosis of IBS, these are the 'Manning Criteria' (Manning et al., 1978) and the 'Rome Criteria' (Drossman et al., 2000). Although both of these criteria are used in the literature, it should be noted that the most recent revision of the Rome criteria, the Rome II criteria (Drossman et al., 2000) is generally regarded as being superior (Camilleri, 2001). This is somewhat unsurprising as the Rome criteria are actually a revision to the Manning criteria and were specifically designed and reformulated for clinical use (Hatlebakk & Hatlebakk, 2004). This is in contrast to the Manning criteria where the main purpose was to define differences between IBS and potentially organic bowel disorder. Table 1 lists the criteria defined by Manning et al. (1978).

Table 1 - Manning criteria

Abdominal pain relieved by defecation
More frequent stools at the onset of pain
Looser stools at the onset of pain
Visible abdominal distension
Passage of mucus
Sensation of incomplete evacuation

The current version of the Rome criteria, Rome II (Drossman et al., 2000), is therefore essentially the classification system used to diagnose IBS. Because this is a factor analytic approach in addition to diagnosing IBS this classification system necessarily defines our current conceptualisation of IBS. It is only when full consideration of these criteria is given that it is possible to move away from the broad definition of IBS as a 'functional gastrointestinal disorder, with abdominal pain and altered bowel habit' and move towards a structured definition of the illness. Broadly the Rome II criteria state that there is a cluster of eight primary symptoms comprising irritable bowel syndrome. These are: abdominal pain or discomfort plus altered defecation; abdominal pain or discomfort relieved by defecation; abdominal pain associated with a change in the frequency or consistency of stool; altered stool frequency, altered stool form, altered stool passage, passage of mucus and bloating

and visible distension (Rome Diagnostic Criteria II, Drossman et al., 2000). Presentation of symptoms within the syndrome manifests in three distinct subtypes.

The subtypes are diarrhoea predominant (IBS-D), constipation predominant (IBS-C) and alternating. As the categories suggest sufferers are classified according to their symptom profile. The particular category a sufferer is classified into is related to their *primary* symptom, though the other seven symptoms will generally be experienced to a lesser extent. One of the key facets in the definition of this illness is that even within these defined subcategories idiosyncratic differences are prevalent. More detail on these criteria is given in the following sections.

THE ROME II DIAGNOSTIC CRITERIA

The Rome classification system is based on the rationale that for each functional disorder there are a number of symptoms that tend to cluster together, as factor analytic studies have shown (Drossman et al., 2000). Although there can be exceptions to this rule the criterion is robust enough to provide the framework for identification of research participants. The commitment to development and improvements by the Rome group ensures that the criteria are updated as new scientific data emerges, accordingly the current criteria are the Rome II, published in the Rome II book (Drossman et al., 2000) and the Gut supplement (Drossman et al., 1999).

The diagnostic criteria

At least twelve weeks, which need not be consecutive, in the preceding 12 months of abdominal discomfort or pain that has two of three features:

1) Relieved with defecation
2) Onset associated with a change in frequency of stool
3) Onset associated with a change in form (appearance) of stool

Supportive Symptoms

A) **Abnormal bowel frequency:** for research purposes is classified as having fewer than three bowel movements per week (1)*, or greater than three bowel movements per day (2).

B) **Abnormal stool form:** hard / lumpy stools (3) or loose (mushy) / watery stools (4)

C) **Abnormal stool passage:** straining during a bowel movement (5), urgency i.e. rush to have a bowel movement (6), feelings of incomplete evacuation (7).

D) **Passing mucus** (white material) during a bowel movement (8)

E) **Abdominal fullness,** bloating or swelling, actual or perceived abnormal distension (9).

*numbers in brackets refer to the symptoms that make up the IBS-subtypes.

Sub-Types of IBS

According to the Rome II criteria, the symptom patterns of the different subgroups for a typical week are as follows:

IBS-D (Diarrhoea) one or more of 2, 4, 6, and none of 1, 3, 5.

IBS-C (Constipation) one or more of 1, 3, 5, and none of 2, 4, 6.

If the symptom presentation does not fit into either category the person is considered to have IBS-A (Alternating).

This subgroup classification guideline is a useful tool for research purposes, both because it stipulates a minimum requirement of experiencing at least one symptom per week to be considered to be suffering from IBS, and also because it provides a framework for checking the accuracy of self-reported subgroup if a 7-day dairy is used to assess symptom frequency. It is important, however, to reiterate that symptom presentation is idiosyncratic (Naliboff et al., 1999), ranging from mild to intense both within and between sufferers and ranging from continuous, to infrequent and cyclical, in particular in women, due to the menstrual cycle (Heitkemper et al., 2003).

CRITIQUE OF THE ROME II CRITERIA

Although the Rome II are recognised to be the gold standard for identification of symptoms in IBS, it should be noted that they are not without their limitations. The limitations of the criteria are obviously noted by the research group as the revisions to the criteria show (Drossman et al., 2000). However, the fact that a superior version

may emerge in the future does not negate the criticisms at this current time. The first criticism is that the accuracy of any symptom led approach can never by established, a problem that is exemplified by the amount of 'IBS sufferers' who are categorised incorrectly (Olden, 2002). In addition if an objective biological marker is discovered then these criteria will be largely rendered unnecessary (Hatlebakk & Hatlebakk, 2004). Other criticisms have been suggested by Camilleri (2001) who comments that although the criteria are fairly robust they are still not comprehensive enough to encompass the range of idiosyncrasies in IBS seen in a clinical population. This is a view that is shared by Silk (1997), who adopts his own categorisation system of IBS for his work with the IBS research appeal. Although one could argue that allowing for all of these idiosyncrasies would make the model unmanageable in a clinical sense, it is of importance when considering that the benefits of differing treatment options might be a function of specific aspects of different types of IBS (Camilleri, 2001). Alongside this one of the major criticisms suggested by Camilleri (2001) is that the necessity for abdominal pain in the diagnosis of IBS precludes those patients for whom bowel dysfunction is predominant. The Rome II criteria have also been criticised by those researchers investigating postprandial exacerbation of symptoms (e.g. Delvaux, 2004) for not considering that this might be a subgroup of IBS. It therefore seems likely that further revisions of the criteria will address these issues, however they are currently the best available option for research studies as they are considered to be robust and despite some limitations largely comprehensive (Drossman et al., 2000).

IMPLICATIONS OF THE DIAGNOSTIC PROCESSES

In addition to the specific critique of the Rome II criteria there are a number of issues that need to be considered regarding the diagnostic procedures for IBS.

The first is that the lengthy procedures employed in this style of diagnosis in particular the embarrassing nature of many of the procedures, coupled with the potential of them exacerbating the symptoms (particularly for diarrhoea predominant patients having to take laxatives) means that many sufferers are likely to suffer from increased stress and anxiety. As these emotions have been shown to exacerbate symptoms (Dancey et al., 1998) it is likely that the diagnostic process itself will, at least in the short term, increase the frequency and severity of the symptoms for some sufferers. Secondly if doctor-patient communication is poor and patients feel

frustrated with their medical consultation this may also have a negative impact on both the prognosis of the illness and the associated quality of life (Bertram et al., 2001). The use of exclusion processes in diagnosis also has its own problems with many patients being frustrated at being told there is not an organic cause due to potential worries over being considered hypochondriacs (Bertram et al., 2001), or due to the mere frustration of not being able to comprehend the aetiological factors (Brennan et al., 2005). The final point of consideration, as briefly mentioned earlier, is that neither exclusion criteria nor symptom presentation is sufficient to ensure accuracy of diagnosis, and even when diagnosis is accurate concerns are still prevalent. This is especially concerning when diagnoses are given by doctors based on their own assessment with very little attempt to refer the patient to colleagues or consultants (Drossman et al., 1999). In fact Hatlebakk & Hatlebakk (2004) report that only 3% of IBS sufferers are referred to secondary care. Franklin (2006) suggests that the low percentage of sufferers being referred to gastroenterologists is because referrals are generally only made if the GP is concerned over the possibility of the patient actually having "cancer, ulcerative colitis or Crohn's disease".

AETIOLOGY

There is currently no unifying consensus on the aetiology of IBS. However the majority of hypothesised causes can be sub categorised into three main perspectives. These are: persistent organic, non-persistent organic, and psychological. Proponents of an organic aetiology suggest that our current knowledge of the bowel is insufficient and therefore organic causes cannot be discounted until every part of the digestive system has been explored (Corazziari, 2004). According to this argument the suggestion of an organic cause cannot be dismissed, however at this current time all research aimed at identifying a structural defect or pathogenic cause have not yielded significant findings (e.g. Franklin, 2006; Mättö et al., 2004; D'anchino et al., 2002).

Slightly more support has been provided for a non-persistent aetiology (that is where bowel disruption was initially caused organically, but that that this is no longer present at the time of IBS diagnosis). A non-persistent aetiology is plausible as there is often a delay (in some cases for a very long time) from the initial experiencing of

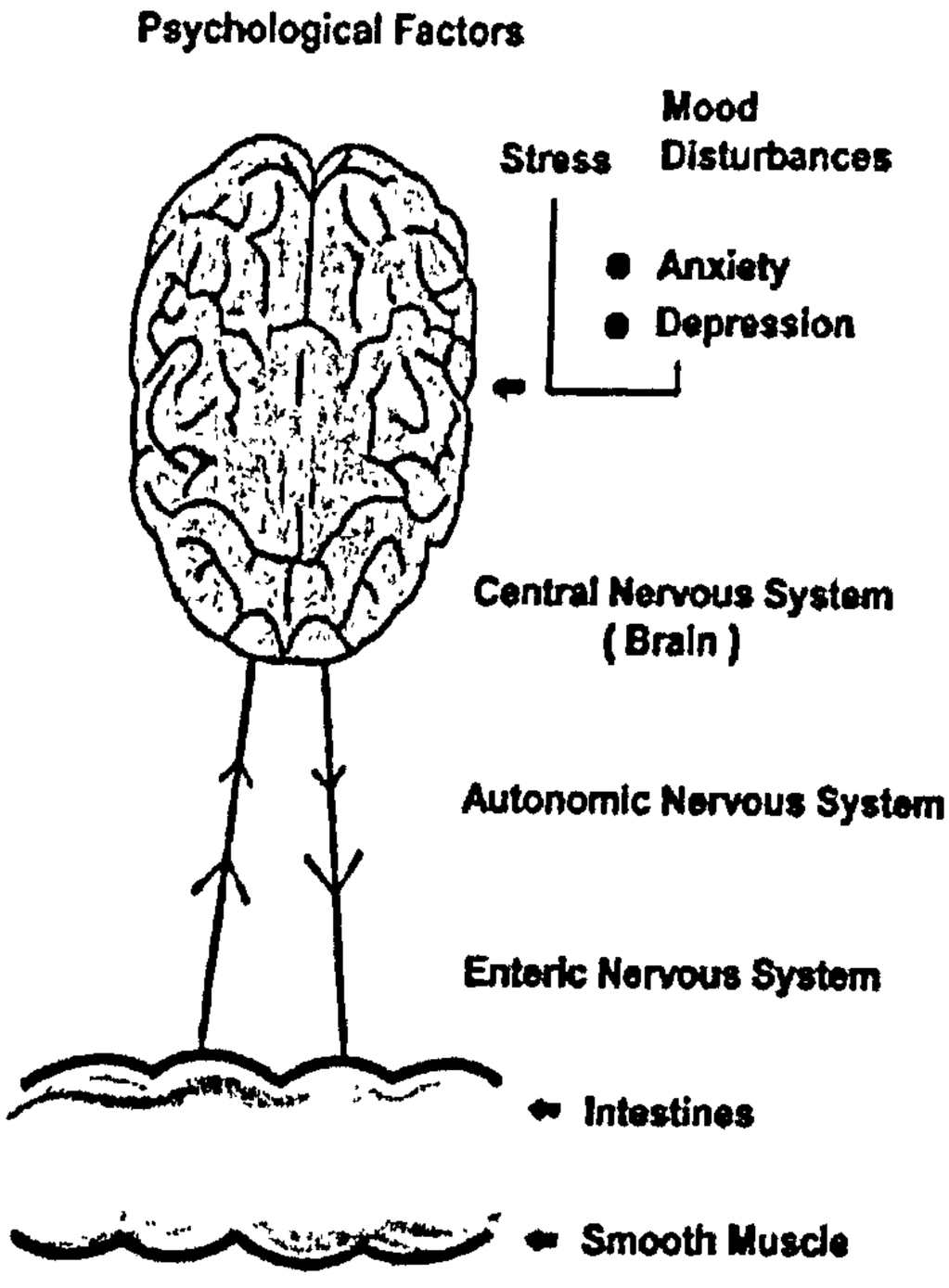
bowel disruption to the diagnosis of IBS. There are two suggested non-persistent organic causes for which support is emerging; these are changes in gut physiology due to hormone replacement therapy (HRT, Ruigómez et al., 2003) and inflammation caused by gastrointestinal infections (e.g. Spiller, 2004; Camilleri, 2001; Thompson, 2005; Hunt & Tougus, 2002; Gwee, 2001). It may therefore be the cause that a non-persistent organic aetiology is responsible for the development of IBS in some sufferers. Prevelance estimates for inflammation range from one in ten (Spiller, 2004) to as many as one third (Drossman et al., 1999). In conclusion whilst it does therefore seem likely that inflammation is a cause of IBS in some patients it is by no means the only cause. It therefore seems necessary to move away from a rigid biomedical view if the aetiology of IBS is to be identified, therefore the next section will detail suggested psychological causes.

PSYCHOLOGICAL CAUSES

There are many single psychological causes that have been suggested, however, it is only relatively recently that theoretical developments have suggested a common mechanism underpinning all of the psychological triggers. This 'mechanism', suggested by proponents of the biopsychosocial approach (e.g. Silk, 1997; Drossman et al., 1999) does seem to provide a plausible route to explain how experience of psychological 'trauma' can result in the symptoms required for classification of IBS. The model is termed the brain-gut axis (Drossman et al., 1999).

The brain-gut axis (figure 2) is theoretically derived from current levels of understanding of the interaction between the ENS and the CNS. It is a multifactorial approach that can encompass idiosyncratic differences. The model is therefore robust and allows for the gaps in current understanding of these processes at a physiological level.

Figure 2 - The brain-gut axis



Reproduced from Silk (1997)

Broadly the model proposes, as pictorially represented on figure 2, that there is a reciprocal relationship between psychological factors and gut functioning. This model forms the basis of the justification for studying biopsychosocial approaches to IBS (discussed later). Essentially the model proposes that psychological factors, such as anxiety and stress are processed by the central nervous system (CNS) as expected, but from this system a reaction to the ENS is initiated. In addition the model also suggests that this process can be reversed, that is that gut processes in the ENS can evoke psychological reactions in the CNS. In normal brain-gut processing as described by Delvaux (2004) the CNS is continuously receiving information from the gut and has the responsibility of integrating this information with that received from other organs. It should be noted however that in physiological conditions most of the information relating to digestion is processed by the hypothalamus below the level of conscious perception. However, sensations, which serve to initiate a particular behaviour, such as hunger, gastric distension and the need to defecate will be consciously perceived. In the context of IBS this has important implications for the processing of food; in normal digestion this occurs autonomously, governed by the ENS, but as the 'brain' and the 'gut' are connected then CNS moderation of an

otherwise autonomic process may be an important aetiologic factor in the pathophysiology of IBS. If this is indeed found to be the case then it provides logical explanations to many of the main areas of controversy regarding IBS. Briefly it provides a model to explain disordered bowel functioning without the need for a structural defect, but does not preclude it. Secondly it explains why aetiologic factors may differ between sufferers and why symptoms and food tolerances are idiosyncratic and dynamic. Finally it provides a plausible explanation for the role of psychological factors in both the aetiology and daily experience of IBS, and suggests the need to use a psychological model which takes these aspects into account. The evidence for the main psychological factors will be detailed in the following sections.

PERSONALITY TYPE

Presence of a personality type, or types that predisposes development of IBS has been suggested by Dancey et al. (1995). As with many other disorders, such as schizophrenia, the conception of a personality predisposition does not necessarily mean that all people of a personality type will develop IBS or that people without the personality type will not develop it. However it does suggest an increased likelihood of developing the illness. The personality types that are most often found in people presenting with IBS are anxiety disorders: such as panic and generalised anxiety disorders, mood disorders: such as major depression and dysthmic disorders, and somatoform disorders: such as hypochondriasis and somatizaton disorders. They are present in 42-61% of patients seen in gastroenterology clinics compared with 25% in the control groups (Drossman et al., 1999). Whilst this figure does seem persuasive it is important to consider that there is no guarantee that it is trait rather than state personalities that cause the high scores on these dimensions. In this respect it is therefore possible that these personality characteristics develop as a function of the illness rather than *prior* to it. In order to assess this properly epidemiological research is needed. In addition it is common for many medical disorder patients to have higher trait anxiety and neuroticism scores than people without health problems, taking this into account it seems currently unlikely that there is a specific personality profile unique to IBS.

STRESS

Stress is the most often cited contributing factor to the aetiology of IBS (e.g. Dancey et al., 1995). Although stress caused by a single traumatic event has been suggested (Drossman et al., 1999) as an etiologic factor stress is generally considered to be persistent in the form a series of severe life stressors, within this abuse is also included but is distinct from general stress. Support for severe life stress in the aetiology of IBS comes from studies that report severe life stress prior to the onset of IBS (e.g. Craig & Brown, 1984). In particular high social stress is an important contributory factor to the exacerbation of symptoms and subsequent treatment seeking (Drossman et al., 1999). Although stress has been shown to play a role in symptom presentation (Dancey et al., 1998) there is currently no research that has recorded occurrence of stressful life events from reliable historical data, that is to say it is only the subjective experience of stress rather then specific factors that have been investigated. Therefore, sufferers of IBS may in fact have enhanced perception of stressors (possibly as a result of personality trait, or as a result of their IBS), rather than a history of events. Further epidemiological research is needed to clarify this issue.

ABUSE

Related to the high stressor hypothesis is the possible aetiologic factor of abuse (either sexual or physical). Frequency rates of abuse range from 30-56% of people with functional gastrointestinal disorders (including IBS). Although some researchers (e.g. Drossman et al., 1999) suggest this figure to be high it should be noted that even at the top end of this range only 50% of the sample report abuse, whilst this figure is considerably higher than the percentage of the general population who report abuse, it would not be sufficient to be considered a single source explanation for developing IBS (as psychodynamic therapists posit) as it leaves the aetiology of 44-70% of the sample unexplained. In addition, whilst not discounting the possibility of abuse as a contributing factor in some patients it should also be considered that all studies to date have relied on self-reports to elicit this information. It is therefore difficult to confirm whether prior history of abuse has actually occurred, or whether the information received is due to dishonesty, or false memory syndrome, this is of particular relevance for patients with co-morbid psychosocial difficulties (Blanchard et al., 2004). Even if the highest percentage of abuse can be accepted as accurate this

does still not necessarily mean that abuse history is an IBS specific aetiological factor. It has often been reported as being associated with poorer health status, and in particular with other chronic pain disorders, and it would therefore seem more likely that sufferers of abuse who go on to develop IBS do so as one of a number of ways that psychological distress is communicated through physical symptoms (Baccini et al., 2003).

DOMESTIC VIOLENCE

Perona et al. (2005) investigated the presence of functional gastrointestinal disorders (including IBS, diagnosed by Rome II) in a sample of 70 women who had reported domestic violence to the police. They discovered that 71% of their sample had a FGID and of these 47% had irritable bowel syndrome. An interesting finding is that in two thirds of the cases the FGID either occurred simultaneously with the reported abuse, or within a short enough time period to make the suggestion of causation, rather then mere correlation seem plausible. When comparing the characteristics of the groups with and without a FGID the authors did not find any significant difference in the women's ages, nor in type or duration of the abuse. A significant finding was however observed in the levels of reported psychological distress, with higher distress being associated with presence of a FGID. This study therefore suggests that women who suffer from physical abuse are more likely to suffer from IBS (or another FGID) and importantly that the mediator of this relationship is the level of psychological distress experienced. This study therefore provides support for the plausibility of the brain-gut axis.

Unfortunately the research on the aetiology of IBS does not easily fit into one of the psychological categories either, and although the brain-gut axis model is plausible the difficulty in producing accurate research means that it has largely focussed on either the daily exacerbation of psychological factors in IBS, or correlating factors (both organic and psychological) rather than directly as aetiologic factors. For this reason any further discussion on aetiological factors would be circular without resolution and in this respect it is important to focus on the issues that can be identified despite problems in identifying a causal factor.

EPIDEMIOLOGY

There is a very small amount of epidemiological data available for IBS, as is unfortunately the case for all the FGIDs. The lack of established epidemiological data is due to the fact that study in this area is still in its infancy (Corazziari, 2004). Accordingly the epidemiological data that does exist shows a wide range in estimates of incidence and prevalence (Saito et al., 2002: Sanders et al., 2001). There are a number of contributing factors to the differential reporting including: delay in help seeking; the embarrassment of admitting suffering from IBS in general population surveys, especially those which are telephone based; the bias towards treatment seeking amongst females; and the different types of diagnostic criteria used (Boekema et al., 2001). On the balance of the current evidence it would appear that prevalence of IBS in western countries is around 15-22% (Dancey et al., 1999).

Drossman et al. (1999) show support for the similar prevalence rates in western countries by showing that reported rates of the United States, England and France are nearly identical (Drossman et al., 1999). However, Boekema et al. (2001) elicited a much lower prevalence rate of 5.8% with his Dutch population based research. Methodological considerations in this research, primarily due to its telephone based nature, mean that it is plausible that the low prevalence was due to embarrassment concerning discussing bowel habits on the phone, and accordingly further research is needed to establish if prevalence rates are actually much lower in Holland.

Although Dancey et al. (1999) state that prevalence rates are considerably higher in non-western populations, (Dancey et al., 1999), this does not mean that all non-western populations show this. Drossman et al. (1999) also note that the prevalence rates for the eastern countries Japan, China, Nigeria and in the Indian subcontinent are similar to western countries, with the only distinction being Thailand, where it is less. Prevalence rates in the Middle East may also be lower with Babak et al. (2006) reporting prevalence rates of 7.1% with their community sample of 4762 Middle Eastern participants. The prevalence rates are also suggested to be lower for black ethnic groupings compared with whites (Wigington et al., 2005), but increased prevalence has been observed amongst Hispanics and some Asian groups (Drossman et al., 1999).

It is often reported that there is a gender bias with females being more likely to have IBS than males but this issue is contentious. It is a reasonable observation that the proportion of females in primary care in western countries is greater than males (Drossman et al., 1999) but it is still unclear whether this represents an actual gender bias, or merely differential help seeking. This is of particular note when you consider that the proportion of people who seek help for their symptoms is considerably less than those who would fulfil the diagnostic criteria (Boekema et al., 2001). Taking this controversy into account it is unsurprising that no common consensus has yet been reached. Some studies e.g. Heaton et al. (1992), report a ratio of 2:1 (women: men) whereas others report no difference (e.g. Saito et al., 2002). On the balance of the evidence it seems plausible to conclude that IBS does have a majority of female sufferers (Dancey et al., 1999), but that this gender bias is overestimated. In addition Drossman et al. (1999) suggest that in Sri Lanka and India males are predominant with females only representing 20-30% of the IBS population.

The final epidemiological factor is age: there is a widespread belief amongst and the general population that IBS is an illness of ageing. Whilst older adults do seem more likely to participate in research, this is most likely due to a sampling bias, perhaps because older adults have more time to participate in research, rather than a true representation of the population. To clarify this issue Saito et al. (2002) conducted a systematic review on all the available research. The results showed age related difference in prevalence to be minimal. This view is supported by Drossman et al. (1999) and Dancey et al. (1995) who state that IBS generally develops in early adulthood.

CO-MORBIDITY (AND EXTRA INTESTINAL SYMPTOMS)

The high frequency of IBS assures that at least a proportion of sufferers will have at least one other illness. In terms of co-occuring conditions theoretically the full range of illnesses are possible, however, there are some conditions which show a greater than chance association in this illness group and these can be considered to be co-morbid.

OTHER FUNCTIONAL GASTROINTESTINAL DISORDERS

The first area of co-morbidity is between IBS and other FGIDs, in some cases the boundary between a diagnosis of constipation-predominant IBS and functional-constipation is very difficult to establish, and theoretically due to the cyclical nature of IBS a dual diagnosis could be made. The FGID that is most frequently co-morbid with IBS is dyspepsia, with a reported range of 23–50% of sufferers satisfying criteria for both conditions (Corazziari, 2004).

ORGANIC DISORDERS

The second area of co morbidity is between IBS and organic disorders. In fact this occurs so frequently that is has been suggested by one of the members of the Rome team (Corazziari, 2004) that the categorisation of IBS as a functional disorder is misleading. Corazziari (2001) argues that although the 'functional' definition is technically accurate due to the lack of (identification of) *IBS specific* structural or biochemical abnormalities as was seen earlier, it is misleading as it implies that no other organic abnormalities will affect the presentation of the IBS symptoms. The most frequently recorded organic co-morbid 'illnesses' in research reports are gastric reflex disease, and prolapsed rectum. However, although a general search will provide commentary on the co-occurrence of these illnesses there has been to date no scientific evidence for specific co-morbidity. The two main illnesses that have been researched are coeliac disease (Sanders, 2001) and asthma (e.g. Roussos et al., 2003, Ekici et al., 2005 and Babak et al., 2006)

PSYCHOLOGICAL CO-MORBIDITY

In addition to the physical co-morbidity, IBS is also considered to show co-morbidity with psychological conditions. However, this relationship is potentially more complex than for physical co-morbidity as many of the co-morbid psychological conditions proposed are conditions that were implicated in the aetiology of IBS. This is indicative of an inability to show cause and effect with cross-sectional research and points to the need for prospective epidemiological research. In our current state of understanding it does, however, appear that whilst these may be aetiologic factors for some sufferers, for others, especially in the case of depression, they are likely to

occur following the disorder. Regardless as research on the brain-gut axis suggests, they are likely to interact with digestive functioning on a daily basis.

STRESS AND RELAXATION

Stress is one of the primary psychological factors that has been researched in IBS. It is unsurprising that high levels of stress are found in IBS populations, because in most instances where health related quality of life are affected there is likely to be an increase in levels of stress and depression (Wong et al., 2001). In IBS the experience of stress has been found to correlate with symptom presentation. In fact research by Stam et al. (1999) shows objective biological evidence that stress and psychoneurogastroenterology are inherently linked. Although their research is not heavily generalisable to humans their discovery that *stress can actually induce colonic motility* in animals is highly relevant. Interestingly in their discussion they also note how their research does not disprove the concept of coping strategies (e.g. Rutter & Rutter, 2002), but merely gives additional information. They concluded, that the colonic response to stress is related to both basal motility status and individual coping strategies. The directionality of this research suggests that stress exerts an influence on gastrointestinal functioning, and although the style of the research cannot prove that a serial dependency is present, their comments regarding coping strategies suggests that certainly in humans rather than a unidirectional route from stress to symptoms there is actually a complex interaction between the two factors. Research by Dancey one of the most influential researchers in this field, certainly suggests this to be the most likely (Dancey et al., 1993; 1995). Support for the role of stress in IBS is also offered by Gwee (2001) and Drossman et al. (1982).

The most informative research so far which suggests stress to be not just a predictor of symptoms but also that symptom can influence stress levels was conducted by Dancey et al. (1998). They used time series procedures to investigate the relationship between daily stress and symptoms. Their cohort was recruited via the IBS Network, on the rationale that it is particularly important to study non-clinical samples of IBS (Phillips et al., 1992). Although their sample was somewhat small at N=31 the participants were required to answer lengthy questionnaires every evening for a month. Therefore due to the extremely rich level of data that this design yields it is not only understandable to have a low cohort but arguably acceptable. The

methodology utilized two questionnaires, both of which were designed for the study, and no reliability estimates were given. It is therefore possible that the questionnaires are not valid psychometric instruments; however, their simple structure means that they probably did yield reliable data.

The first questionnaire, entitled the 'Daily Symptom Questionnaire' involved a seven point Likert scale (0 – do not suffer from this symptom at all, to 7 – most troublesome this symptom has been) of the seven most experienced symptoms: diarrhoea, constipation, pain, wind, an urgent need to defecate, feelings of incomplete evacuation and bloating. The ratings for symptoms on each day were summed to give a total symptom score. This was based on the findings of Dancey et al. (1995) that it is the *cumulative* effect of symptoms that correlates with stress, rather than any individual symptom. Dancey et al. (1998) claim that rather than stress solely influencing symptoms a serial dependence exists between stress and 'symptomlogy' for a statistically significant proportion of sufferers. In fact multiple regression analysis carried out on same day and lagged relationships up to and including four days revealed the best regression model was one in which symptoms were a function of hassles and symptoms on the previous 2 days and hassles on the same day. Multiple regression analyses on each participant individually revealed that stress was a predictor for 67% of participants. As an exploratory study this research is a springboard for disentangling the relationship between stress and symptoms.

The main criticism with this research is that although the within-subjects design is good for establishing idiosyncratic factors, it would have been more prudent to conduct a between subjects analysis with type of IBS as a grouping variable. Although this is not necessary in the context of this research because they used the summed symptom score rather than individual symptoms, it is plausible that it might not be just the cumulative affect of symptoms that shows an effect as they assert (Dancey et al., 1995; Dancey et al 1998), but rather individual symptoms do show the same relationship between stress, and that this has merely been obscured due to IBS being analysed as a homogonous population, which it is not. Future research should take this into consideration. Although the results of this study cannot be considered as conclusive it does seem likely that stress levels and symptom presentation are inherently connected.

Further support for the notion of stress affecting symptoms is provided by the success of relaxation intervention programmes (see systematic review). An example of this is the study by Heymann-Mönnikes et al. (2000). Support for stress influencing symptoms is demonstrated by intervention experiments because a decrease in symptoms after a decrease in stress shows the reduction in symptoms to come directly from the reduction in stress. It is clear that it is this reduction in stress, which has directly caused the improvement in symptoms because it is the effect of stress as the independent variable that the relaxation programmes target. Relaxation programmes are therefore able to isolate this causation in the way that simple correlations are not. The main research into relaxation strategies is that produced by Keefer & Blanchard (2001; 2002). They conducted two experiments into the efficacy of relaxation interventions, using, Herbert Benson's (1975) Relaxation Response Meditation (cited in Keefer & Blanchard, 2001; 2002). One of the key features of their research is the use of high quality psychometric instruments and daily symptom diaries (considered the gold standard, Meissner et al., 1997). One tailed independent samples t-tests revealed the reduction of symptoms in the meditation group to be significantly greater than in the control group for flatulence, and belching at initial post treatment assessment. A three-month follow up was also conducted, which revealed sustained improvements on these symptoms and also an improvement in bloating and diarrhoea, with constipation approaching significance, with ten of the original participants and concluded that symptom reduction was maintained in the long term. They concluded that relaxation response meditation appears to be an effective and viable treatment option. An interesting feature of their research was that they paired their sample on the basis of axis one disorders, providing support for the notion that they are common in this population (Blanchard et al., 2001). On the basis that one of the most common axis one disorders observed in this population is depression (Swiatkowski & Rybakowski, 1993) it seems plausible that depression might exert the same impact on IBS symptoms as stress.

DEPRESSION

Another psychological candidate, much less researched then stress, is depression. Unfortunately due to current controversy regarding the efficacy of specific diagnostic tools for measuring the co-morbidity of depression in IBS it is not possible to ascertain exactly what percentage of sufferers also have clinically significant levels

of depression. Blanchard et al. (2001) suggest this is particularly problematic when researching possible gender differences in depression. Their research utilised 341 IBS patients, 223 females, and 83 males, a very high number of respondents. In addition they held structured psychiatric interviews on 250 of their sample. According to the diagnostic interviews (which are considered the gold standard) they found 65.5% of sufferers to be classifiable under axis one of psychiatric disorders. Most importantly they did not find any gender difference. However, when classified according to the Beck Depression Inventory (BDI), the Trait Anxiety scale of the State-Trait anxiety inventory (STAI) and scales 2 and 3 of the MMPI significantly higher scores were found for females (compared with males). The differential findings relative to the measuring tool used means that it is currently not possible to ascertain gender differences in regard to depression and this research is useful in alerting the researcher not to use these measures in research with IBS until more validation studies have been performed. It is however clear that depression remains an important facet of the psychological aspects of IBS and as such should be included in any analysis. As the relationship between stress and depression may well be based around the subjective experience of depression affecting symptoms it would seem practical, until further clarifications have been made to the existing diagnostic instruments to use a simple Likert scale method of assessing self-perceived level of depression.

Further support for the role of depression as a significant predictor of symptom severity has also been provided by Drossman et al. (1999). His paper looks at the impact of psychosocial factors from a number of angles and concludes that psychological difficulties, such as depression, impact on severity of experienced symptoms. As with stress one method for establishing whether a factor has an effect on symptoms is by assessing symptoms after an intervention has occurred, if there is a reduction in the factor, and a consequent reduction in the symptoms then we can fairly safely conclude that the level of the factor affected the level of the symptoms. This method has been employed in the context of depression by Lydiard & Falsetti (1999) with their systematic review. Though limited to three primary articles their research suggests that treatment of depression shows a subsequent marked reduction in symptoms and as such should be treated in addition to the symptoms, rather than

merely treating the symptoms alone (Clouse et al., 1994; Heffner et al.,1978, Lydiard et al.,1986).

Two main areas supported by research are enhanced perception of pain amongst IBS sufferers (Verne et al., 2003; Lembo et al., 2000) and the role of serotonin in the enhancement of bowel motility, the peristaltic reflex and facilitating intraluminal secretions (Crowell., 2001). This has important implications for the co-morbidity of depression, as this suggests that depressive state will necessarily increase abdominal pain, and tendency towards diarrhoea, creating a vicious cycle making it difficult for the person it elevate their current mood. It should be noted that the relationship between psychological factors and symptoms exists even when the psychological factors are not severe enough to meet DSM classification.

CURRENT TREATMENT OPTIONS IN IBS

There are four primary (non-psychological) categories of treatment in IBS, these are medical management, complementary and alternative medicine, dietary interventions and exercise interventions. However, as this section will demonstrate, none of these treatments are effective.

MEDICAL MANAGEMENT

Treatment traditionally takes place within primary care following diagnosis. IBS sufferers are the highest proportion of those seen by gastroenterologists and one of the more common illnesses seen by GPs (Camilleri, 2001). The main medications used in IBS are Antispasmodics, Antidiarrhoeals, Fibre supplements and Antidepressants. Despite their widespread use (Tally, 2001) many researchers remain sceptical of their usefulness (e.g. Heitkemper et al., 2002; Parsons & Whittle, 2004). The first criticism is that the medications focus on symptoms rather than aetiological factors, and therefore they merely mask the intensity of the symptoms rather then preventing them from occurring (Hussain & Quigley, 2006). The second criticism is that medical management is restricted to the specific times when the symptoms are experienced. This is highly unsuitable as IBS is characterised by alternating periods of symptoms and remissions, with potentially distinct triggers for symptom occurrences (Camilleri, 2001). It is therefore unsurprising that some psychologists'

view the current pharmacological treatments as simply not capable of alleviating the idiosyncratic, multiple, and often alternating symptoms associated with IBS (Talley, 2001; Tougas, 2001). The third, and most worrying criticism of medical management in IBS is that the side effects of many of the main medications are at least as bad (often opposing IBS symptoms) if not drastically worse than the symptoms the patient experienced in the first place (e.g. Farthing, 2004; 1999). This is exemplified most strongly by controversial debate surrounding the licensing of Alosetron.

COMPLEMENTARY AND ALTERNATIVE MEDICINE (CAM)

Unsurprisingly the failure of traditional medicines in many cases leads sufferers to look for non-traditional therapies, although this is usually in conjunction with traditional medication (*complementary*), rather than instead of it (*alternative*) (Hussain & Quigley, 2006). Koloski et al. (2001) suggest use of CAM is more prevalent amongst those sufferers who report a greater frequency of abdominal pain, and perhaps unsurprisingly by those who report dissatisfaction with medical professionals. Preliminary research for traditional Chinese medicine (TCM, Bensoussan et al., 1998), and peppermint essential oil (e.g. Pittler & Ernst, 1998; Grigoleit & Grigoleit, 2004) suggest that CAM methods may be useful for some sufferers, however further (high quality) research is needed before any firm conclusions can be drawn (Makk et al., 1995).

DIETARY INTERVENTIONS

As IBS patients commonly report postprandial precipitation of their symptoms dietary interventions (inclusions and exclusions) are common. The success of elimination diets have varied markedly from 6% to 58% (Zar et al., 2005; Niec et al., 1998; Atkinson et al., 2004) as a consequence no general recommendations can be made. Various inclusions have been suggested; however the main suggestions are to increase 'healthy bacteria' and fibre. Although both have been found to be important for normal digestion (e.g. Thompson, 2001) their efficacy in IBS is unfounded. In fact Bosaeus (2004) suggests that increasing fibre can be damaging to sufferers of diarrhoea predominant IBS. Whilst there are no reported adverse effects of probiotics the evidence for their utility in IBS is inconclusive with some studies reporting beneficial effects (e.g. Nobeak et al., 2000), and others finding no significant

difference from placebo (e.g. Franklin, 2006; Bausserman & Michial, 2005; Niv et al., 2005).

EXERCISE INTERVENTIONS

Although exercise is undoubtedly beneficial to general health (e.g. Bull et al., 1999) and therefore advising IBS sufferers to exercise is likely to improve their symptoms there is currently only one study investigating its efficacy in IBS (Levy et al., 2005). Although this study offers preliminary support for the efficacy their cohort was restricted to an obese population and therefore more research is needed before the results can generalised.

THE NEED FOR DEVELOPMENT OF TREATMENTS IN IBS

From the previous review it is clear that none of the treatment options are currently effective at providing lasting cure or even controlling the multiple and fluctuating symptoms of IBS (Talley, 1995),

If effective treatments are going to be devised there is a clear need for a perspective which takes a holistic approach to the patient, rather that a merely symptomatic approach. In fact some researchers have suggested that the only way to successfully treat patients is to "identify which particular cause or causes are applicable to each individual patient" (Franklin, 2006). Although this method is undoubtedly superior to a general pharmacological intervention (e.g. Talley, 2001) there are obviously serious practical limitations, such as time, money and resources. Therefore one of the major challenges in the future of IBS treatment is to devise interventions that can encompass its idiosyncratic and potentially multifaceted aetiology without being impractical. There are many reasons why effective treatments in IBS should be developed. Firstly "IBS is associated with a substantial burden on individual patients, health care systems and society as a whole" (Gilkin, 2005). This view is echoed by Sandler et al. (2002) with their statement "considering the burden to the patients due to the sometimes disabling symptoms and the burden to society due to the economic impact, the reward to accomplish these goals [providing effective treatments for IBS] is enormous". Although these are evocative statements and may initially appear to be over emotive, it can be seen throughout the literature and correspondence on this area

that much support is shown for these statements (e.g. Talley et al., 1995; Gralnek, 2000; Bellini et al., 2005; Quigley et al., 2006; WHO, 1992; Silk, 2001; Stam et al., 1999; Heymann-Mönnikes et al., 2002; Bertram et al., 2001; Munir et al., 2005).

In this thesis the main area where the need for treatments is demonstrated is in the impact on individual sufferers, the term used to describe this impact is Health Related Quality of Life (HRQOL). The concept of HRQOL is a necessarily subjective one, as it aims to assess patients' perceptions of the aspects of their lives that are affected by their having a chronic illness. It is most coherently described by Frank et al. (2002) as a multidimensional concept "comprising physical, social and psychological functioning and well being". People without an understanding of IBS often comment that it is not a serious disorder which does not affect quality of life. Whilst this may be true for a small proportion of sufferers for many this statement is both inaccurate and insulting. As the studies by Bertram et al. (2001) and Dalton et al. (2004) demonstrate this is particularly problematic when it is the medical professional that does not consider HRQOL to be affected. The article by McCarthy (2002) in the context of the Alosetron debate is littered with evocative statements which clearly shows sufferers' HRQOL being affected. In addition IBS Network's quarterly publication and internet message boards are filled with comments from sufferers complaining about the impact IBS has on their quality of life.

A recent paper by Simrén et al (2006) investigating HRQOL compared organic and functional bowel disorders (including IBS). Their study used a large sample of patients (n=399) as they attended a GI outpatient clinic. Participants completed both the SF-36 and the Psychological General Well Being Index to assess quality of life, and also a gastrointestinal symptom rating scale. Although the analyses only compared functional (n=112) to organic (n=287) GI disorders and not IBS specifically the finding that patients with FGIDs report a lower HRQOL is of importance and the conclusion reached by the authors that the impact is 'profound' cannot be overlooked. This study is also important as it shows that just because an illness does not have an identified organic cause does not mean impairment is any less real.

Gralnek et al. (2000) performed a large study utilizing IBS patients (n=877) and compared their HRQOL scores (on SF-36) with data from the American normal population, and with sufferers of a number of other chronic illnesses. The findings revealed that on all eight of the SF-36 scales IBS sufferers reported significantly worse quality of life than the general population ($p < 0.001$). When comparing the IBS group to the other illnesses similar levels of HRQOL were found. The only significant differences were for diabetes gastroesophageal reflux disease (GERD), where lower HRQOL was reported for IBS sufferers on selected scales, $p < 0.001$. The overall conclusions drawn from this research suggest that HRQOL is indeed impaired in IBS sufferers and that beyond the basic symptoms, "what matters most is how they are able to function in their day to day lives". This research clearly suggests that the goal for research into treatments should focus on improving HRQOL rather than just symptoms, although they are inherently interrelated. This is a useful study as it compares IBS to the general population and also to other illnesses; type 2 errors are avoided by the use of large samples and adjustments for multiple comparisons. In addition strict inclusion criteria for the IBS participants of Rome II plus 3 Manning criteria ensured that the HRQOL reported here is likely to be generalisable to sufferers outside of the United States. The results of this study are supported by Frank et al. (2002).

Taking the concept of HRQOL one stage further Miller (2004) investigated suicidal ideation in patients with IBS, one hundred tertiary care patients were compared with 100 secondary care and 100 primary care. Patients were asked if they had either seriously contemplated or attempted suicide as a result specifically of their bowel problems. The results were recorded using the Hospital Anxiety and Depression Scale (HADS) and other clinical details were collected by the researchers. It was discovered that a proportion of patients in all groups had seriously considered suicide but this was statistically much higher in those patients who were in tertiary care ($p = 0.002$ compared to secondary, $p = 0.001$ compared to primary). Of the 100 tertiary care patients 5% had actually attempted suicide. This figure may appear quite low but is of importance as it shows the negative impact suffering from IBS can have, and interestingly that it seems to be much higher in those sufferers who are not getting as much medical attention. It is also important to note that this study cannot account for people who were actually successful in their suicide attempts, and

therefore it is possible that actual suicidal ideation may be higher. A closer interpretation of the reasons for this suicidal ideation revealed the main causes were feelings of hopelessness due to symptom severity, the interference suffering from IBS caused with general life, and perhaps unsurprisingly as the highest ideation was seen in the tertiary group, inadequacy of treatment were highlighted as crucial issues for all IBS patients. The authors concluded that IBS has the potential for a fatal outcome from suicide, and that despite previous claims, general depression does not account for all the variance in this relationship. This research therefore emphasises the level of hopelessness felt by some sufferers of IBS and the need for improvement in services.

THE NEED FOR BIOPSYCHOSOCIAL BASED TREATMENTS IN IBS

The research therefore strongly suggests that treatments are needed in IBS and that an integrated model is the way forward in designing effective management techniques for sufferers. As Camilleri (2001) suggests "understanding the brain-gut axis is the key to the development of effective therapies for IBS". This stance is logical as the section on aetiology demonstrated. In addition if IBS is truly a functional illness, or at least has a psychological component which many researchers agree is the case (e.g. Dancy et al., 1995; Drossman et al., 1999), then interventions from a psychological stance are highly suited.

THE BIOPSYCHOSOCIAL MODEL

It is clear that one reason why standard interventions meet with limited success is that the biomedical model underpinning their design is theoretically weak in comparison with the biopsychosocial model. Although there may be some reluctance to this theoretical shift amongst the medical community, there is clearly a need to explain and treat illnesses that do not seem to conform to traditional expectations of illnesses. The biopsychosocial approach, although rooted in the philosophical concept of dualism (e.g. Plato) has since its re-emergence in the late 1970s proved itself to be a highly scientific approach. The re-emergence of this model (table 5) is largely credited to Engel (1977). His contention that "health, illness and disease are

an interaction of biologic, psychological and social subsystems operating at multiple levels" has had a profound effect on medical advancement over the last thirty years.

Table 2 – The Biopsychosocial view of health and illness

BIO	PSYCHO	SOCIAL
Viruses	Behaviour	Class
Bacteria	Beliefs	Employment
Lesions	Coping	Ethnicity
	Stress	
	Pain	

The key consideration with this model is, unlike some other alternative theories, it does not negate the success of the biomedical approach, it merely suggests that it is too rigid. Although different illnesses may vary in the degree to which psychological and social factors affect onset and progression it would be very naive to suggest they do not play a role as issues such as social inequalities in health (e.g. Hernández-Quevedo, 2006), personality traits (e.g. Grant & Langham-Fox, 2006), pre-disposition (e.g. Shore & Johnson, 2006) and many other factors (e.g. Maguire, 1999) have all been shown to play a role not just in health and illness, but in the specific nature of the illness developed. It is perhaps somewhat unsurprising that the biomedical approach is too rigid for IBS as this seems to be a general finding across all chronic illnesses (Munir et al., 2005). The complexity of the psychological, social and physiological factors in IBS makes this illness highly exemplary of the superiority of this approach in explaining its progression (Camilleri, 2001).

BIOPSYCHOSOCIAL CONCEPTUALISATIONS OF IBS

There are a number of justifications for the suitability of the biopsychosocial model for IBS (and indeed other FGIDS) which will be described below. Firstly there is a general reluctance for doctors to treat chronic conditions, especially functional ones. This is partly because functional illnesses may not be considered to be legitimate medical problems, and partly due to a general feeling of insecurity when pharmacological approaches to treatment fail (e.g. Bertram et al, 2001; Talley, 2001; Tougas, 2001). The biopsychosocial model therefore legitimises IBS as an illness by

suggesting a model to explain its aetiology, prognosis, and by increasing scientific research.

The next justification for the suitability for the biopsychosocial model for this illness, is that it is far less rigid than the biomedical model allowing for both aetiology and symptom progression to be understood as multifaceted and multi-determined. Previously symptoms were considered to be purely physiological but this model allows for psychological, biological and social factors to contribute to symptom experience.

Research into co-morbidity suggests interplay with psychology and physiology through hormones, neurotransmitters and perception. The two main areas supported by research are enhanced perception of pain amongst IBS sufferers (Verne et al., 2003; Lembo et al., 2000) and the role of serotonin in the enhancement of bowel motility, the peristaltic reflex and facilitating intraluminal secretions (Crowell, 2001). This has important implications for the co-morbidity of depression, as this suggests that depressive state will necessarily increase abdominal pain, and tendency towards diarrhoea, creating a vicious cycle making it difficult for the person it elevate their current mood. It should be noted that the relationship between psychological factors and symptoms exists even when the psychological factors are not severe enough to meet DSM classification. Indeed the change in explanation from co-morbidity to bi-directionality also means that treatment programmes can be implemented which combine approaches rather than taking them as separate entities.

The biopsychosocial approach therefore legitimises the so-called brain-gut axis, and the role of the central nervous system (CNS) in the aetiology of this illness (Drossman et al., 2000). This approach can therefore explain vast differences in aetiological suggestions from gastroenteritis to sexual abuse, and furthermore it also explains why IBS can, but does not necessarily result from these life events.

In a similar vein the model can explain the illness prognosis, for instance the idiosyncrasies that exist between different sufferers, and also why symptom presentation is varied in the same person at different times. This is because the model

allows for psychological factors such as daily stresses, personality traits, and coping styles.

In summary therefore chapter 1 has introduced the background to IBS. The information presented shows that IBS is a chronic, functional, gastrointestinal illness. Its aetiology and prognosis involve a complex interaction of physiological, psychological and social factors. It is therefore clear that in order to further understanding of IBS and to develop effective treatments for sufferers a biopsychosocial approach should be adopted. This is not merely a justifiable alternative approach to the study and treatment of IBS but is, as the previous chapter has shown highly suited to IBS. This has the potential to explain the main areas of previously unanswered questions, including brain-gut axis relationships, illness representations, illness behaviour, and coping styles. It should be noted that biopsychosocial approaches cover a broad spectrum of many theoretical models and it is therefore important to establish which specific biopsychosocial model is the most efficacious for IBS research. The aim of the systematic review (presented in the following chapter, chapter 2) was to investigate whether a successful model already existed or if an alternative model was in need of exploration. The systematic review revealed that whilst psychologically based approaches are no doubt efficacious in IBS treatment there is no model which dominates. Therefore an alternative model which was felt to have a number of useful components was used for this thesis, this is Leventhal et al's (1980; 1984) common sense model of illness representations (CSM). The description of the model and its justification are presented in chapter 3 (following the systematic review in chapter 2). The three empirical chapters in this thesis, commencing with chapter 4, present a number of results based around the exploration of the different features of the CSM.

Chapter 4 reports the results of study 1. This was an exploratory study which investigated the role of doctor-patient communication in irritable bowel syndrome. There were a number of different research questions but they grouped into three main areas of interest. The first area was a comparison of patients' and doctors' perceptions of doctor-patient communication. The second area was an assessment of the potential impact of patients' perceptions of doctor-patient communication on their illness representations and their illness outcomes (perceived health related

quality of life and symptom frequency). The third and final area of investigation was an exploration of the relationship between illness representations and illness outcomes independently from perceptions of doctor-patient communication. The rationale for this study is based on the need to identify which factors impact on the illness representations sufferers develop as without a clear understanding of these factors it will not be possible to devise effective interventions.

Chapter 5 reports the results of study 2. This was an exploratory study which investigated the role of perceived social support in irritable bowel syndrome. There were a number of different research questions but they are grouped into four main areas of interest. The first area was an investigation of the attitudes that the general population held towards sufferers of IBS (in comparison with other illnesses). The second was a comparison of the general populations' attitudes towards IBS sufferers, with IBS sufferers' perceptions of the general populations' attitudes towards them. The third area of investigation was an assessment of the potential impact of IBS sufferers' perceptions of the general populations' attitudes, on their illness representations and illness outcomes. The fourth and final area of investigation was an exploration of the relationship of illness representations and illness outcomes independently from perceived attitudes to IBS. The rationale for this study stems from reports by sufferers of perceived lack of social support, as social support may be an important moderating factor in illness outcomes it is important to ascertain whether this perception is justified as this will affect the design of interventions for sufferers of IBS.

Chapter 6 reports the results of study 3 the final study in this thesis. This study is entitled "a self-help booklet intervention study for irritable bowel syndrome (IBS) based on the common sense model (CSM)". This study is the culmination of the research preceding it, which serves to identify those factors which impact on the illness representations sufferers hold, and where appropriate to ascertain its impact on illness outcomes. Through the previous research conducted in this thesis, and the available literature this evidence-based intervention was designed. The rationale for this study was to produce an intervention which would improve both symptom frequency and quality of life for sufferers of IBS. Importantly the intervention should be superior to previous research on key dimensions, such as cost effectiveness (in

time and money), adaptive to the idiosyncratic nature of IBS and easily administrated to sufferers.

Chapter 7 is the final chapter in the thesis. This provides a general discussion of the results found in the thesis, implications for treatment of IBS and any methodological issues raised.

CHAPTER 2

PSYCHOLOGICALLY BASED ILLNESS INTERVENTIONS IN IRRITABLE BOWEL SYNDROME (IBS): A SYSTEMATIC REVIEW

Aim

The current review summarises interventions in IBS (conducted since the 1980s) that include a psychological component. The aims of the review were to gain an overview of a) the viability of a psychologically based intervention in IBS and b) to assess if any of the theoretical models used in the interventions are dominant in the field. In order to assess the efficacy of psychologically based treatments both psychological correlates of IBS and gastrointestinal symptoms were to be evaluated. The review therefore provides an overview of research in this area; clearly showing how the research presented in this thesis is contextualised with previous research, and also will provide a summary of the weaknesses in previous research which will serve to justify the need for alternative styles of intervention research. As Mulrow (1994) states:

"The hundreds of hours spent conducting a scientific study ultimately contribute only a piece of an enormous puzzle. The value of any single study is derived from how it fits with and expands previous work, as well as from the study's intrinsic properties. Through systematic review the puzzle's intricacies may be disentangled".

The systematic review is therefore considered to provide essential background information to the development of IBS interventions. The assessment of the literature in a systematic way allows for a clear depiction of current states of knowledge and allows for an assessment of how future research should be directed.

INTRODUCTION

All available research that included a psychological component to the intervention was included, as this was a qualitative systematic review (as opposed to a meta-

analysis) it was not considered justifiable to restrict the literature to randomised control trials (RCTs). If a large number of studies had been conducted such as to render total inclusion unmanageable this would have been considered, but as less than 50 studies have been produced to date restricting the review to RCTs would have undoubtedly led to biased results due to the small number of studies eligible for inclusion. The review therefore covered all types of studies. The primary inclusion criterion was that the intervention itself had to include a psychological component and therefore studies, which measured psychological factors as an outcome variable but not as a factor in the intervention, were excluded. Full details of the inclusion criteria are given below. The efficacy of these interventions for both IBS symptoms and psychological outcomes (e.g. stress, depression, anxiety) was examined.

A systematic search of the literature was performed on Medline, Embase, Science direct, Psych lit, Psych info and the Cochrane library. Reference lists and paper journals were also screened for studies that met inclusion / exclusion criteria. Studies were classified by their primary intervention stance and the different components of the intervention were determined. A total of 42 papers met the inclusion criteria.

METHOD

SEARCH TERMS

Studies to be included in the review were identified using the following search terms:

1. IBS / irritable bowel syndrome review
2. IBS / Irritable bowel syndrome intervention
3. IBS / Irritable bowel syndrome psychological
4. IBS / Irritable bowel syndrome treatment
5. IBS / Irritable bowel treatment trial
6. IBS / Irritable bowel syndrome RCT
7. IBS / Irritable bowel syndrome prospective
8. IBS / Irritable bowel syndrome hypnotherapy
9. IBS / Irritable bowel syndrome CBT
10. IBS / Irritable bowel syndrome cognitive therapy

Systematic literature review

The internet search covered years 1980-2006 inclusive. In addition studies were identified by manually searching reference lists of reviews and retrieved papers. The studies listed in the review are from 1983 (when the first IBS intervention study was published) to studies published until July 2006.

INCLUSION CRITERIA

Inclusion criteria were: studies with (i) a psychological component to the intervention (as previously stated). In addition studies to be included were those that (ii) investigated an adult (> 18 years of age) IBS population (all subtypes), (iii) assessed a dependent measure of either physical (symptoms) or psychosocial outcomes, e.g. quality of life, stress, depression and anxiety, (iv) were published in peer reviewed English language journals. (The decision was taken not to include studies which had not been translated into English as resources were limited and the internet ensured that a majority of high quality research is available in English). In addition unpublished studies were also not included as their scientific validity is weaker and therefore their inclusion was unjustified in a review of this type, (v) were published from 1980 onwards (there are no published studies before this point).

Intervention studies that did not involve a psychological intervention component were not included, as this was not felt to have any relevance to the devising of psychologically based interventions. In addition a number of recent reviews have focussed on medical management of IBS (e.g. Brandt et al., 2002).

INTERVENTION TYPES

Intervention type varied across studies, and as the majority contained a number of different intervention components each component was coded separately and listed accordingly. This was felt to be superior to simply including a small number of global categories, which would have overshadowed the multifaceted nature of the interventions. The coding of the intervention components is presented in table 3.

Table 3 - Coding of intervention components

Code	Component description
BF	Bowel sound biofeedback: by learning to control bowel sounds through increasing and decreasing the amount of activity with the aim of learning to regulate bowel activity and thus get symptom relief.
BT	Behaviour therapy: use of behavioural techniques such as goal setting, reinforcement, modelling, reward systems, alteration of environmental cues.
CBT	Cognitive behaviour therapy: use of both behavioural and cognitive techniques.
CT	Cognitive therapy: teaching or use of cognitive techniques to influence cognitions, e.g. challenging beliefs, considering role of thought and emotions, counselling and psychotherapy. When the term coping skills was used and did not adhere to the definition of problem solving it was coded as cognitive therapy.
D	Diet: participants prescribed a specific nutrition plan as part of the intervention.
E	Exercise: specific exercise sessions as part of the intervention.
GISM	Gastro intestinal symptom monitoring.
HT	Hypnotherapy: use of hypnotic techniques.
IE	Illness education: basic provision of information, commonly using didactic techniques, can include clarification of misconceptions.
P	Placebo
PS	Problem solving: identification of problems or barriers to behaviour and strategies to overcome them. Includes both practical and psychosocial problems. Focus should be on patient problem solving rather than by health care professionals.
R	Relaxation: actual practice of relaxation may include imagery or distraction techniques.
SM	Stress management: techniques for identifying and dealing with stressors.
SMT	Use / continuation of standard medical treatment.
SS	Social support: teaching techniques to specifically help participants to improve social support, e.g. where to go for extra support, communication skills.
ST	Skills training: teaching of practical aspects, such as meal planning.

STUDY CATEGORISATION

There were four categories of study design: Randomised controlled trial (RCT); Prospective longitudinal design (PLD); Case Study and Meta-analysis.

RESULTS

Table 4 presents the summary of the 42 studies which satisfied the inclusion criteria and were therefore included in the review. The mean number of participants in the studies was 76 (s.d. 102), and participant numbers ranged from 1 to 431. It is worth noting that the mean number may not be the most representative average to take as

the standard deviation demonstrates, in fact only 10 (out of 42) studies had over 75 participants, therefore although a handful of studies involved large samples the majority did not. The median number of participants in the studies was therefore calculated, and at 35 is considered to be a more representative average.
Further detail on participant numbers is given in table 9, following the systematic review summary (table 4) and the coding for measures table (table 5). The 'coding for measures' table explains the abbreviations given to the questionnaires in the systematic review (table 4).

As this was a systematic review a number of key criteria were used to assess the quality of each of the studies. The assessment of study quality was based on the areas of importance proposed by Mulrow (1994). There are five criteria upon which each study was assessed. For each criterion the study received a 'grade' of poor, fair, good or very good. There was not felt to be any justification for weighting any of the criteria more heavily than others, as all were felt to be important components to overall study quality. Therefore each category is equally weighted and the final grade reflects the overall quality of the study. The five areas are as follows:

1) Study design: This assessment criterion is based on the quality of the study. In most cases it would be expected that an RCT would achieve the highest grading, however in determining the quality of the overall studies the appropriateness of the design is also considered. Therefore in order to receive a 'grading' of very good the RCT would be expected to be double-blind and with an appropriate placebo control group.

2) Number of participants: 'grading' in this category primarily refers to the total number of participants in the study (as the name suggests). However, it was felt that limiting this category to total number would not be sufficient to take into account the number of participants in each group. This is important as although two studies may have 50 participants a study which has two conditions (n=25 per condition) would score more highly that a study with five conditions (n=10 per condition). This is a legitimate distinction as the two main reasons for securing a large cohort are sample distribution and power to detect significant findings.

3) Generalisability of participants: In addition to the amount of participants the generalisability is also important. In this category a study which includes all subtypes of IBS would receive a higher grading than a study which only used diarrhoea predominant sufferers. Another example would be a study with a large sample size, but one that only used female participants would be graded lower than a study with both males and females. This category also allows for an assessment where group may be highly selected (either by the researchers or self-selected), an example of this would be hypnosis.

4) Adherence to the theoretical model: This is an important category as simply stating that research is based on a theoretical model does not mean that this was actualised in the methodology. In this respect two studies using the same theoretical model (for example CBT) might appear to show inconsistent findings. However, if a close appraisal reveals that one study actually used a methodology closer to cognitive therapy then it would be clear that the two studies were not congruent and this needs to be taken into consideration. As the name suggests studies that adhere strictly to their defined model will be graded higher than those that do not.

5) Likelihood that the observed finding is a true finding: This category is of importance because it is not sufficient for a study merely to report a significant finding there needs to be an assessment as to whether the significant finding can be attributed to the success of the intervention as claimed. This category takes into account the possibility of placebo effects and other factors which may have been responsible for the finding. This category also takes into account possible reasons for when a good study does not yield a significant result, for example insufficient power.

A summary of the quality of each of the areas (poor, fair, good and very good) is provided following each study listed in the systematic review table (table 4). In addition the overall quality of the study is reiterated in table 7.

Table 4 - Systematic review of psychologically based interventions in IBS: summary table

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
1	Bennet & Wilkinson	1985	UK	33	Outpatient (newly diagnosed)	RCT	Pychotherapy	IBSQ RQ STAI	1.SMT (Movitol 2/day and fybogel 1/day) 2.PSY (Stress management training and progressive muscle relaxation). Prior to the intervention participants underwent a six week control period where all treatment was suspended. Both interventions lasted for eight weeks. Measures were taken in week five (T1) and week six (T2) of the control period and following the intervention (T3)	SMT SM R	ANOVA revealed significant reduction in levels of anxiety between T2 and T3 for PSY No significance for SMT. No difference in conditions for reductions in symptoms. Although symptoms did reduce from T1, this most probably reflects a bias due to the withholding of treatments initially. No other significant differences were found between conditions. In conclusion psychological treatment was superior in reducing anxiety, did result in symptom decreases but was not superior to SMT.	YES

study design = fair; number of participants = fair; generalisability of participants = poor;
adherence to theoretical model = good; likelihood that the observed finding is a true finding = fair; overall quality = FAIR

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
2	Bengtsson et al	2005	Sweeden	29	Outpatient	PLD	Self management instruction	GSRS PGWB index	1. N=29 women participated in an instructional programme on medical care, physical activity, stress management, diet and health insurance. The programme consisted of four lectures of two hour duration with a break for informal discussions. The measures completed were the GSRS and PGWB (time 1). N=23 women completed the questionnaires twelve months after the course (time 2).	IE ST SM E D R SS	No significant change were observed immediately following the course, however, when comparing the post scores to those at baseline significant improvements were observed in abdominal pain, vitality, visits to physicians and dieticians. The authors conclude that these changes were related to the course, but with no theory underlying the changes and no control group it cannot be assumed that the course was a causal factor as longer duration since diagnosis medication or other reasons could be equally plausible.	INCONL

study design = fair; number of participants = fair; generalisability of participants = poor; adherence to theoretical model = poor; likelihood that the observed finding is a true finding = poor; overall quality = POOR

3	Blanchard & Schwarz	1987	USA	19	Outpatient	RCT	Albany multicompent behaviour therapy program	CI DSD	1. Multicomponent CBT sessions over eight weeks (n=10). 2. Symptom Monitoring	CBT GISM	Treatment was effective in reducing abdominal pain/tenderness, constipation, diarrhoea, nausea, and flatulence in six out of the ten patients in the intervention group, there was no change in the symptom monitoring group post treatment.	INCONL

study design = good; number of participants = poor; generalisability of participants = fair; adherence to theoretical model = good; likelihood that the observed finding is a true finding = good; overall quality = GOOD

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
4	Blanchard et al	1988	USA	14	Outpatient	RCT follow up to 1987 (a)	Albany multicomp. behaviour therapy program	CI DSD	1. Multicomponent CBT twelve sessions over eight weeks (n=14) 2. Waitlist control	CBT	Eight out of the fourteen (57%) met criteria for clinical improvement, that is a 50% reduction in symptoms. Significant (one-tailed) reductions were obtained on abdominal pain/tenderness, constipation, diarrhoea, nausea, and flatulence; the means on all measures at follow-up were better than those obtained prior to treatment.	YES

study design = good; number of participants = poor; generalisability of participants = fair;
adherence to theoretical model = good; likelihood that the observed finding is a true finding = good; overall quality = GOOD

5	Blanchard et al	1988	USA	41	Outpatient	Meta-analysis of five RCTs (b)	Albany multicomp. behaviour therapy program	MMPI BDI STAI PSC RAS SRRS DSD	1.CBT n=20 successfully treated patients 2. CBT n= 12 unsuccessfully treated patients 3. N=9 symptom monitoring	R CBT IE	Successfully treated patients had significantly more reductions on all measures, including trait anxiety compared with the unsucessfully treated group and the symptom monitoring group. The 'unsuccessfully treated' group showed a significant reduction in trait anxiety, compared with symptom monitoring group	YES

study design = v. good; number of participants = good; generalisability of participants = v. good;
adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = good; overall quality = V. GOOD

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
6	Blanchard et al	1992	USA	study 1 n=30 study 2 n=92	Outpatients	RCT	Albany multicom. behaviour therapy program	DSD CPSR STAI BDI PSC	1. Mulicomponent CBT, relaxation, thermal feedback,cognitive therapy. (study 1 n=10, study 2 n=31) 2. Attention-plaebo control (pseudo-meditation and EEG alpha suppression, study 1 n=10, study 2 n=30). 3. Symptom monitoring control (study 1 n=10 study 2 n=31). For both intervention groups there were twelve sessions over eight weeks.	CBT R GISM	Neither study showed superiority of CBT over the attention-placebo condition, although subjects in both conditions showed significant reductions in GI symptoms, and significant reductions in trait anxiety and depression, this held after a six month follow up.	INCONL

study design = v. good; number of participants = good; generalisability of participants = good; adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = fair; overall quality = GOOD

7	Blanchard et al	1993	USA	16	Outpatients	RCT	Relaxation training	DSD CI CPSR	1. Progressive muscle relation n=8. Ten sessions over eight weeks, with regular home practice. 2. Symptom monitoring n=8. Both groups filled in symptom diaries for four weeks before and after the intervention stage	R GISM	The relaxation condition showed significantly more improvement on composite measures of primary GI symptom reduction than the symptom monitoring condition.	YES

study design = fair; number of participants = poor; generalisability of participants = poor; adherence to theoretical model = good; likelihood that the observed finding is a true finding = good; overall quality = FAIR

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
8	Blanchard et al	2006	USA	127	IBS screening from general population sample	PLD	Cognitive therapy	GGR DSD BDI SF-36 DAS ATQ	1. CT applied in small groups (3-6 participants)	CT	Immediate post treatment scores for quality of life are significantly related to a reduction in GI distress, immediately post treatment and at three month follow up, but this was not found to be related to bowel regularity	INCONL

study design = fair; number of participants = good; generalisability of participants = poor;
adherence to theoretical model = poor; likelihood that the observed finding is a true finding = poor; overall quality = POOR

9	Boyce et al	2000	Australia	8	Outpatient	PLD	CBT	BSSS BDI STAI SF-36	1. CBT. Following a two week baseline period participants began a structured psychological treatment comprising eight sessions of CBT (n=8)	CBT	After treatment five of the eight patients no longer met the diagnostic criteria for IBS, however there was no significant reduction in symptom frequency. There were, however, significant improvements in distress, disability, anxiety and depression.	INCONL

study design = fair; number of participants = poor; generalisability of participants = poor;
adherence to theoretical model = good; likelihood that the observed finding is a true finding = poor; overall quality = POOR

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
10	Boyce et al	2003	AUS	105	Outpatient (54) Advertisements (51)	RCT	CBT	BSSS MOSSF	1. SMT 2. PSMT (relaxation) 3. PSMT (CBT) 8 week treatment period with one year follow up	SMT IE R	All of the treatment conditions resulted in significant improvements to symptom severity, overall however, there were no significant differences found between treatment conditions with respect to symptom improvements. Significant improvements overall were observed for general physical functioning, pain, general health, vitality, and social functioning. Again there were no significant differences between conditions. Results suggest that whilst treatment in itself is effective, CBT and relaxation therapy may not be superior to SMT.	INCONL

study design = v. good; number of participants = good; generalisability of participants = good;
adherence to theoretical model = good; likelihood that the observed finding is a true finding = fair; overall quality = GOOD

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
11	Colwell et al	1998	USA	52	Outpatient	PLD	Pender's (1982) Health Promotion Model	BDQ (selected items) HPLP Pain Manning Score	1.EDUC (3 hour structured class teaching health promoting behaviours) Completion of questionnaires at start of class and at 1 month and 6 months post intervention	IE	Sig. 1 and 6 months improvements in pain and Manning symptoms. Sig. increased exercise at 1 month. Sig. increased stress management at 6 month Conclusions suggest that EDUC is effective, but no comparison group.	INCONL

study design = fair; number of participants = good; generalisability of participants = fair; adherence to theoretical model = fair; likelihood that the observed finding is a true finding = fair; overall quality = FAIR

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
12	Corney et al	1991	UK	42	Outpatient attenders	RCT PLD	Psychotherapy	Structured demographic interview CIS GHQ-30 SPQ Three rating scales to measure frequency, severity and duration of pain. Rating scales to measure avoidance on particular activities. Visual analogue scales to record symptom severity over previous 7-days.	1.SMT (n= 20) Patients received between one and four appointments and were treated by explanation, reassurance and a variety of medications depending on IBS-type. 2.BPT (n= 22) (behavioural psychotherapy).Were mostly seen at weekly intervals for between six and fifteen one hourly sessions, and followed up at four months and nine months post commencing of treatment	PT BT SMT	There was a general improvement over nine months on a number of physical and psychological symptoms. However, no differences were found between treatment groups except for changes in avoidance of specific foods and domestic tasks. A significant correlation was found between improvement in abdominal pain and diarrhoea with psychological symptoms. Although they defined it as BPT a close reading of the article suggests that it was closer to EDUC or BT than psychotherapy.	INCONL

study design = good; number of participants = good; generalisability of participants = good;
adherence to theoretical model = fair; likelihood that the observed finding is a true finding = fair; overall quality = GOOD

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
13	Creed et al	2003	UK	257	Outpatients	RCT	Psychotherapy	Abdominal pain health costs SF-36	1. PT - 8 sessions of individual psychotherapy. 2. SSRI (antidepressants) 3.SMT	PT SMT	Both psychotherapy and anti-depressants were superior to SMT improving physical aspects of HRQL but there was no difference in the psychological component. PT associated with a significant reduction in health care costs	YES

study design = v. good; number of participants = v. good; generalisability of participants = v. good; adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = good; overall quality = V. GOOD

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
14	Drossman et al	2003	USA	431	Outpatients	RCT	CBT	BDI FBDSI IBS-QOL	1.CBT 2. EDUC 3.Antidepressant 4 Placebo Treatment period was for 12 weeks.	CBT IE	CBT was significantly more effective than EDUC for both main effects and all subgroups (except depression) Antidepressants were not found to be significantly better than the placebo condition for severe symptoms but were for moderate symptoms. They were also beneficial for diarrhoea-predominant symptoms and, patients who had been abused, and they were superior even for patients who were not depressed. In conclusion CBT is an effective treatment, and antidepressants drugs may be beneficial is some cases.	YES

study design = v. good; number of participants = v. good; generalisability of participants = good;
adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = v. good; overall quality = V. GOOD

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
15	Galovski and Blanchard	1998	USA	12	Outpatient	RCT matched pairs	Gut directed hypnotherapy	DSD STAI BDI CIS	1. Gut directed hypnotherapy n= 6, between 30min to 1h session per week for 12 weeks 2. Wait list control n=6	HT	Results indicated that HT was superior to symptom monitoring, especially for abdominal pain, constipation, and flactulance. State and trait anxiety scores also improved significantly. At two months follow up improvements persisted.	YES

study design = good; number of participants = poor; generalisability of participants = fair;
adherence to theoretical model = v.good; likelihood that the observed finding is a true finding = good; overall quality = GOOD

16	Galovski and Blanchard	2002	USA	1	Outpatient	case study	Gut directed hypnotherapy	DSD STAI BDI	1. Gut directed hypotherapy n= 1	HT	Results indicated that after 6 sessions his IBS symptoms had improved.At six month follow up there was continued improvement, which continued at a two year follow up depression and anxiety levels also decreased	YES

study design = poor; number of participants = poor; generalisability of participants = poor;
adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = good; overall quality = FAIR

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
17	Green & Blanchard	1994	USA	20	Outpatient	RCT	Cognitive therapy	BDI STAI DAS ATQ DSD	1.CT (10 sessions over 8 weeks for the first two weeks there were two one hour sessions per week, this reduced to one session in week three, n=10) 2.GISM (8 weeks of daily symptom monitoring n=10)	CT GISM	Significant improvements post treatment for CT (80% showed improvement) group on all measures, compared to GISM (10%) . Results held at three month follow up. Cognitive therapy is superior but arguably the control group is flawed in that it brings attention to symptoms	YES

study design = good; number of participants = fair; generalisability of participants = fair;
adherence to theoretical model = fairr; likelihood that the observed finding is a true finding = good; overall quality = FAIR

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
18	Gonsalkorale et al	2002	UK	250	Outpatient	PLD	Hypnotherapy	symptom scoring questionnaire HADS CSFBDS	1. 12 sessions of hypnotherapy over a 3 month period	HT	Marked improvements were seen in all symptom scores, as well as quality of life, anxiety and depression There was no significant difference between sub-types of IBS with the exception of males with diarrhoea responding significantly higher.	YES

study design = good; number of participants = v. good; generalisability of participants = good; adherence to theoretical model = good; likelihood that the observed finding is a true finding = good; overall quality = GOOD

19	Gonsalkorale et al	2004	UK	78	Outpatients	PLD	Hypnotherapy	symptom scoring questionnaire HADS CSFBDS	1. 12 sessions of gut directed hypnotherapy over a three month period, sessions were usually at weekly intervals. Patients were asked to practise the hypnotic skills on a daily basis, and were each given an audio-tape.	HT	Significant improvements in symptoms, quality of life and anxiety and depression. IBS-related cognitions also improved, with a reduction in the total cognitive score and also in all component themes relating to bowel function A reduction in symptom score following treatment was significantly correlated with an improvement in the cognitive score.	YES

study design = good; number of participants = good; generalisability of participants = good; adherence to theoretical model = good; likelihood that the observed finding is a true finding = good; overall quality = GOOD

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
20	Guthrie et al	1991	UK	102	Outpatients	RCT	CBT	DSD Gastro reports. CAS HRSD	1 CBT + SMT (7 sessions over twelve weeks, n=53) 2. SMT (n=49)	PT R SMT	At three months the treatment group showed significantly greater improvement over controls on both gastroenterologists and self-ratings of diarrhoea and adominal pain	YES

study design = v. good; number of participants = v. good; generalisability of participants = good; adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = v. good; overall quality = V. GOOD

21	Harvey et al	1989	UK	36	Outpatient – all of which had been refractory to SMT.	PLD	Hypnotherapy, with a technique similar to that used by Whorewell	GHQ DSD - completed daily from two weeks before, all through the treatment, and for two weeks before the follow up visit.	1.HT - individual 2.HT group (four 40 minute sessions over a 7 week period at 0,1,3,7 weeks). Patients were seen three months after the fourth session for assessment and a treatment.	HT IE STR SS	20 out of 33 sufferers reported an improvement in their symptoms. Of the 20, 11 were virtually symptom free by the end of the study. It should noted that these tended to be patients with moderate symptoms Success of treatment was largely maintained at follow-up Patients whose GHQ scores suggested psychological illness were less likely to respond to treatment, but there were no differences between genders, condition, or different hypnotherapists.	YES

study design = good; number of participants = fair; generalisability of participants = fair; adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = good; overall quality = GOOD

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
22	Heyman-Mönnikes et al	2000	GER	24	Outpatient	RCT	Multi- component behavioural therapy	DSD Rectal Perception Thresholds PDQ Overall well being questionnaire Illness related coping abilities questionnaire IBS-QOL BDI STAI IBQ HRLCQ	1. CSMT(standardised symptom orientated medical treatment plus gastroenterologists visits every other week, n=12) 2. PSMT (CSMT plus, IBS information and education, progressive muscle relaxation, training in illness related cognitive coping strategies, problem solving and assertiveness, n=12)(10 one hour sessions over 10 weeks)	IE RC ST SMT	Sig. IBS symptom reduction in the SMBT group as compared with CSMT group No change in rectovisceral perception in either group Overall well being post intervention sig. Higher post intervention in SMBT group, CSMT no change. Sig. Increases in perceptions of control in the SMBT group post intervention, no change in the CSMT group. Quality of Life significantly improved post intervention in SMBT group, CMST no change. Overall sig. Superiority of SMBT over CMST.	YES

study design = v. good; number of participants = fair; generalisability of participants = good;
adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = v. good; overall quality = V. GOOD

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
23	Houghton et al	1996	UK	50	Outpatient	RCT	Hypnotherapy	Validated quality of life measure, which included questions on symptoms, employment and health seeking behaviours	1. Control group (n=25) 2. Hypnotherapy (n=25) 12 thirty minute sessions	HT	Patients treated with hypnotherapy reported less severe abdominal pain, bowel habit, bloating, nausea, flatculance, backache. dyspaeunia, urinary symptoms, lethargy as compared with controls, as well as improved quality of life, improved mood and locus of control, also significantly improves work adherence in HT as opposed to controls.	YES

study design = v. good; number of participants = good; generalisability of participants = good; adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = v. good; overall quality = V. GOOD

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
24	Ilyckyj et al	2003	Canada	70	Outpatient	PLD	Gastroenterology consultation	an admin database and morbidity scales	1. Emphasis is placed on the physicians role promoting the physician as the therapeutic modality, health care utilization was monitored for two years prior to the intervention, morbidity was measured at baseline and a one and two years post intervention	SMT IE CT	Health care utilization decreased immediately after intervention and remained unchanged for 4 years Pain was reduced, but all other symptoms persisted This suggests that a meaningful consultation is in itself associated with a decrease in health care use, and therefore doctor-patient communication is an important predictor of subsequent visits, but the persistence of the symptoms remains unclear.	INCONL

study design = poor; number of participants = fair; generalisability of participants = fair; adherence to theoretical model = poor; likelihood that the observed finding is a true finding = poor; overall quality = POOR

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
25	Keefer & Blanchard	2001	USA	13	Outpatient	RCT	Herbert Benson's (1975) Relaxation Response Meditation Program (RRM)	CPSR DSD SCID	1. Relaxation training (6 sessions over 6 week, n=6) 2.Wait list control (n=7)	R GISM	Meditation was superior to control. Significant improvements were found in flactulance and belching immediately post-treatment. At three month follow up significant improvements were sustained and additional significant improvements in bloating and diarrhoea were also found. Constipation was also approaching significance.	YES

study design = fair; number of participants = poor; generalisability of participants = poor; adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = good; overall quality = FAIR

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
26	Keefer & Blanchard	2002	USA	10	Outpatient	RCT one year follow up	Herbert Benson's (1975) Relaxation Response Meditation Program (RRM)	Postal based follow up. Participants were asked to monitor their GI symptoms for one week and complete a brief follow-up questionnaire asking if they were still meditating, life events and perceived symptom severity	1. PSMT at this stage all participants had received PSMT as this was a one year follow up of the intervention.	SMT IE R	From pre-treatment to one year follow-up significant reductions were noted for symptoms of abdominal pain, diarrhoea, flatulence and bloating. From 3 month follow-up to one year follow-up there were significant additional reductions in pain and bloating. Therefore appears that continued use of meditation is particularly effective in reducing pain and bloating with both short and long-term benefits.	YES

study design = fair; number of participants = poor; generalisability of participants = poor;
adherence to theoretical model = fair; likelihood that the observed finding is a true finding = poor; overall quality = POOR

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
27	Kennedy et al	2005	UK	249	Outpatients	RCT	Lang's three systems model (CBT)	Irritable bowel syndrome severity scale WSAS HADS	1. SMT (6 weeks f mebeverine, n= 77) 2. CBT plus SMT (6 weekly sessions of face to face contact lasting 50 minutes, n=72. As a control prior to the study all participants received SMT for one month.	CBT SMT	CBT plus SMT was significantly superior to SMT alone at reducing symptom severity. This was upheld at six months post therapy. CBT plus SMT was significantly superior to SMT alone. This was upheld at one year post therapy. No significant findings for the HADS.	YES

study design = v. good; number of participants = v. good; generalisability of participants = v. good; adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = v. good; overall quality = V. GOOD

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
28	Lackner et al	2006	USA	11	Outpatients Healthy controls all female	RCT	CT	Rectal balloon distention PET BSI PSWQ ASI SF-36 CI	1. IBS (n=6) underwent 10 weekly sessions of CT, the CT consisted of small group sessions (3-6) with four overlapping phases, education of the illness, cognitive training, challenging maladaptive beliefs and formal problem solving. Home work assignments were also given 2. Controls (n=5)	CT IE SS SM	Differences were observed between groups at baseline for worry, pain intensity, pain unpleasantness and anxiety following rectal distention Due to the sample size post treatment changes were not significant but clinical significance (20% change) was obtained for multiple measures of somatic complaints and psychological distress. In addition in vivo ratings of anxiety were significantly reduced. Importantly this study shows that improvement in symptoms after CT corresponds with baseline brain neural activity, specifically improvement was associated with reduced neural activity in parts of the limbic system which have been identified as underlying pain perception and self regulation	YES

study design = good; number of participants = poor; generalisability of participants = poor; adherence to theoretical model = fair; likelihood that the observed finding is a true finding = good; overall quality = FAIR

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
29	Lynch & Zamble	1989	UK	21	Outpatients	RCT	CBT	CI DSD BDI STAI EPI LES RAS PSC QSI	1. CBT (n=11) one two hour session per week over eight weeks 2. Waitlist (n=10)	CBT GISM	CBT showed significant improvements over wait list for abdominal pain, discomfort, constipation and STAI-Trait. Also improvements in questionnaire measures of mood and self-perceptions Therapeutic gains were maintained over a follow-up period of five months after the end of treatment.	YES

study design = good; number of participants = fair; generalisability of participants = fairr; adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = v. good; overall quality = GOOD

30	Neff &Banchard	1987	USA	23	Outpatients	RCT	Albany multicomp. behaviour therapy program	CI DSD	1. CBT 2. SM (symptom monitoring) 3. SM + CBT Intervention comprisd twelve sessions over eight weeks. It was conducted as two studies but as the same methodology was used it is reported as one.	CBT GISM R IE	Treatment was clinically effective in over half of participants in the intervention groups, this was also echoed by participants self-reports.	INCONL

study design = fair; number of participants = poor; generalisability of participants = poor; adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = fair; overall quality = FAIR

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
31	Payne & Blanchard	1995	USA	34	Self-help group Outpatients	RCT	CT	BDI STAI DAS ATQ-N ATQ-P Hassles scale GI symptom scale CPRS	1. CT (cognitive therapy n=12) 2. SG (support group n=12) 3. WL (wait list n=10) Each condition lasted for eight weeks, 2 x one hour session for first two weeks, 1 x one hour session from week three.	CT SS	Significantly greater reductions in symptoms in CT group as compared with the others. Significant greater reduction for CT on measures of depression, and anxiety Was maintained at three-month follow up. Suggests superiority of psychological interventions but arguably over two control groups, rather than SMT.	INCONL

study design = good; number of participants = fair; generalisability of participants = fair;
adherence to theoretical model = good; likelihood that the observed finding is a true finding = fair; overall quality = FAIR

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
32	Robinson et al	2006	UK	420	Self-help group Outpatients	RCT	Self-help booklet	Global impression scale. Hospital consultation rates. IBS-QOL GHQ-28 SF-36 costs to health service and visual analogue scales	1. SMT plus self-help booklet. 2. SMT plus self-help booklet plus a group meeting (8-12 per meeting). 3. SMT	IE PS	Post assessment data was recorded at one year post intervention, so there are no immediate effects of the treatment available, and it is difficult to ascertain if the results are due to the self-help booklet or other factors However, the reported results were that patients in the guidebook group had a 60% reduction in primary care consultations, a reduction in perceived symptom severity, average costs per person were reduced by 40% per year, but there were no actual reductions in symptom scores. There were no differences observed between the two intervention groups either.	INCONL

study design = poor; number of participants = v. good; generalisability of participants = fair;
adherence to theoretical model = poor; likelihood that the observed finding is a true finding = poor; overall quality = POOR

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
33	Radnitz & Blanchard	1988	USA	5	Outpatients	PLD	Biofeedback	CI DSD	1.bowel sound biofeedback. This involved listening to bowel sounds then self-control phases, initial treatment condition two sessions per week for five weeks then assessed at two weeks, one month, three months, six months and one year post follow up	BF	Participants reported the therapy was logical non-aversive and practiced at least once a day. All reported satisfaction with treatment but this was not related to improvements in symptoms Three patients reported clinically significant improvements in diarrhoea and this improvement was maintained through one year and in some cases two year follow up. Improvement in symptoms was found to be related to significant improvements in bowel sound control and related to this the two cases who did not show a reduction in symptoms were also shown not to grasp bowel sound control therefore suggesting the efficacy of this treatment	YES

study design = fair; number of participants = poor; generalisability of participants = poor;
adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = good; overall quality = GOOD

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
34	Rumsey	1991	UK	37	Outpatients	RCT	CBT	DSD HADS IBS-QOL Subjecive stress	1. CBT 1.5 hour session for 6 weeks 2. SMT	CBT SMT SM	CBT was significantly more effective at anxiety and depression. It was also effective at alleviating gastrointestinal symptoms but was not more effective than SMT for gastrointestinal symptoms.	INCONL

study design = good; number of participants = fair; generalisability of participants = good;
adherence to theoretical model = good; likelihood that the observed finding is a true finding = good; overall quality = GOOD

35	Saito et al	2002	USA	211	Outpatient	PLD	Education	HPLP BDQ GSI PSC SF-36 symptom checklist	1. One time group education program on patient-based outcomes in IBS	IE SS	Class attendance was associated with an improvement in symptoms, HPLP scores but not with pain, QOL, satisfaction or health care use. Authors conclude that a one time multi-disciplinary class is beneficial	YES

study design = poor; number of participants = good; generalisability of participants = good;
adherence to theoretical model = poor; likelihood that the observed finding is a true finding = poor; overall quality = POOR

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
36	Schwarz et al	1990	USA	19	Outpatient	RCT	CBT	DSD CI	Assessment of multicomponent CBT in which group 1. Had eight weeks of treatment 2. Had 12 twelve weeks of symptom monitoring followed by eight weeks of treatment .	CBT IE R	Following intervention half of the participants met criteria for clinical improvement, and significant improvements were obtained for abdominal pain, diarrhoea, nausea and flactulance. Significant changes from pre to post treatment were maintained	YES

study design = v. good; number of participants = poor; generalisability of participants = fair;
adherence to theoretical model = v. god; likelihood that the observed finding is a true finding = good; overall quality = GOOD

37	Shaw et al	1991	UK	35	Outpatient	RCT	Stress management	GI symptoms Questionaire responses	1. Stress management six forty minute sessions over six month (relaxation n=18) 2. Drug (colpermin peppermint oil n=17)	R SMT SM	Two thirds of those in the stress management programme found the programme effective in relieving symptoms and experienced fewer attacks of less severity. This meant that the stress management group showed significantly more improvement compared to drug group. This benefit was maintained for 12 months. Therefore the stress management programme would appear to be of value for patients with irritable bowel syndrome.	YES

study design = good; number of participants = fair; generalisability of participants = fair;
adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = v. good; overall quality = GOOD

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
38	Svedlund et al	1983	Sweeden	101	Outpatient	RCT	Psychotherapy	Semi-structured interview to assess symptom severity. CPRS 18 item somatic symptom scale	1.SMT (n=51), bulk forming agents and when appropriate anticholinergics, anacids and minor tranquilisers. 2. SMT plus PT, ten, hour long sessions over a three month period (n=50) of dynamically orientated short-term inividual PT.	PT SMT IE PS	At three months significantly greater improvement in the psychotherapy group for somatic symptoms as compared with the SMT group. This difference was more pronounced a year later, with the PT Patients showing more improvement and the SMT showing deterioration. There was also significant improvement in self reported ability to cope in the PT group as opposed to SMT.	YES

study design = v. good; number of participants = v. good; generalisability of participants = v. good; adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = v. good; overall quality = V GOOD

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
39	Van Dulmen et al	1996	Netherlands	45	Outpatients	RCT	CBT	DSD CI daily abdominal complaint score daily avoidance behaviour psychological well-being Inventory severity score Successful coping strategies	1. CBT (n=25) eight two hour sessions over three months 2. Wait list (n=20)	CBT	Significant improvement in the CBT group as compared with wait list controls. Improvements were found in the reported daily intensity, less avoidance and better coping behaviour was also reported in the CBT group. There were also assessments taken as follow up at 6, 12, 24, 36 and 48 months, changes were maintained at all follow up points.	YES

study design = v. good; number of participants = good; generalisability of participants = good; adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = v. good; overall quality = V. GOOD

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
40	Vollmer & Blanchard	1998	USA	32	Outpatients	RCT	Albany multicomp. behaviour therapy program	CI GI symptom monitoring CPSR patient global ratings.	1. CBT(individual n=10) 2. CBT (group n=11) 3. SM (n=11) Intervention groups attended ten sessions over ten weeks. Each individual session was 1h and each group session was 1h30	CBT GISM SS	Significantly greater post treatment reductions in symptoms for CBT groups compared to the symptom monitoring group. There were no significant differences between individual or group administration of CBT. Data at three months was obtained on twelve of the CBT participants and symptom improvements were withheld	YES

study design = v. good; number of participants = fair; generalisability of participants = fair; adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = good; overall quality = GOOD

41	Whorewell et al	1984	UK	30	Outpatient	RCT	Hypnotherapy psychotherapy	GHQ DSD	1. HT = 7 half hour sessions of decreasing frequeny over the three month period (n=15) 2. PT and Placebo (n=15)	HT PT P R	The overall changes in abdominal pain, bowel habit, abdominal distension and well-being were significantly greater in the hypnotherapy group than the control group. The control group showed a small but significant improvement except for bowel habit from pre and post treatment.	YES

study design = good; number of participants = fair; generalisability of participants = fair; adherence to theoretical model = v. good; likelihood that the observed finding is a true finding = good; overall quality = GOOD

	Author	Year	Country	N	Study population	Design	Theoretical Framework	Measures	Group allocation and intervention type description	Intervention Components	Findings	Sig
42	Whorewell et al	1987	USA	50	Outpatient	PLD	Hypnotherapy	CI GI symptom monitoring DSD GHQ	1. 30 minute sessions of decreasing frequency over three months.	HT	Patients over the age of 50 years responded very poorly (25%) whereas those below the age of 50 with classical irritable bowel syndrome exhibited a 100% response rate. This study confirms the successful effect of hypnotherapy in a larger series of patients with irritable bowel syndrome and defines some subgroup variations. This was maintained at 18 months post intervention	INCONL

study design = fair; number of participants = fair; generalisability of participants = fair; adherence to theoretical model = good; likelihood that the observed finding is a true finding = good; overall quality = FAIR

Table 5 - Coding for measures used in the systematic review

ATQ-N	Automatic thoughts questionnaire - negative (Holland & Kendall, 1980, cited in Blanchard et al., 2006)
ATQ-P	Automatic thoughts questionnaire – positive (Ingram & Wisnicki, 1988, cited in Blanchard et al., 2006)
ASI	Anxiety sensitivity index (Peterson & Reis 1993, cited in Lackner et al 2006)
BDI	Beck depression inventory (Beck et al., 1961, cited in Blanchard et al 1987)
BDQ	Bowel Disease Questionnaire (Tally et al., 1989, cited in Colwell et al 1998)
BSI	Brief symptom inventory (Derogatis 1993, cited in Lackner et al., 2006)
BSSS	Bowel symptom severity scale (Boyce et al., 2000)
CAS	Clinical anxiety scale (Snaith et al., 1982, cited in Guthrie et al., 1991)
CI / CPSR	Clinical improvement or composite primary symptom reduction score (Blanchard et al, 1988), essentially refers to a 50% reduction in symptom scores post treatment
CIS	Clinical Interview Schedule (DSM III criteria, cited in Corney et al., 1991)
CSFBDS	The cognitive scale for functional bowel disorders (Toner et al., 1998, cited in Gonsalkorale et al., 2004)
CPRS	Comprehensive Psychopathological Rating Scale (Asberg et al., 1978, cited in Payne & Blanchard, 1995)
DAS	Dysfunction Attitudes Scale (Weissman & Beck 1978, cited in Blanchard et al, 1988)
DSD	Daily symptom diaries designed for individual studies
EPS	Eysenck Personality Inventory (Eysenck & Eysenck 1968, cited in Lynch and Zamble, 1989)
GHQ	General health questionnaire (Goldberg, 1972, cited in Corney et al, 1991)
GSI	General severity index of the SCL-90R (Rosen et al., 2000, cited in Saito et al., 2002)
GSRS	Gastrointestinal symptom rating scale (Svetlund et al., 1988, cited in Bengtsson et al., 2005)
HRSD	Hamilton's rating scale for depression (Hamilton 1960, cited in Guthrie et al., 1991)
HADS	Hospital anxiety and depression scale (Zigmond & Snaith 1993, cited in Gonsalkorale et al., 2004)
HPLP	Health Promoting Lifestyle Profile (Walker et al., 1987, cited in Colwell et al., 1998)
HRLCQ	Health and illness related locus of control questionnaire (Lohan & Schmidt, cited in Heyman-Mönnikes et al., 2000)
FBDSI	Functional bowel disorder severity index (Drossman et al., 2003, cited in Drossman et al., 2003)
IBSQ	IBS questionnaire, a self rating symptoms scale, Bennet & Wilkinson, 1985)
IBS-QOL	IBS quality of life (Patrick et al., 1889, cited in Drossman et al., 2003)
IBQ	Irrational beliefs questionnaire (Klages, 1989, cited in Heyman-

	Mönnikes et al., 2000)
LES	Life events survey (Sarason et al 1978, cited in Lynch and Zamble, 1989)
MMPI	Minnesota multiphasic personality inventory (Stark et al., 1942, cited in Blanchard et al., 1988)
MOSSF	Medical outcomes study short form (Ware & Sherbourne, 1992, cited in Boyce et al., 2000)
PDQ	Psychological distress questionnaire (Zersen, 1976, cited in Heyman-Mönnikes et al., 2000)
PET	Positron emission topology – assessment of gamma rays after 'ingestion' of a biological substance such as food.
PGWB index	Psychological general well being index (Dupy, 1984, cited in Bengtssom et al., 1985)
PSC	Psychosomatic symptom checklist (Attanasio et al., 1984, cited in Blanchard et al., 1988)
PSQW	Penn State worry questionnaire (Meyer et al., cited in Lackner et al., 2006)
QSI	Queens stress inventory (Malton, 1982, cited in Lynch and Zamble, 1989)
RAS	Rathus Assertiveness Scale (Rathus, 1973, cited in Blanchard et al., 1988)
RQ	Relatives questionnaire for recording the daily number of IBS related behaviours (Hellawell et al., 1984, cited in Bennet and Wilkinson, 1985)
SCID	Structured clinical interview for DSM-IV (First et al., 1996 cited in Keefer and Blanchard, 2001)
SF-36	SF-36 Health Survey (Ware, 1993, cited in Blanchard et al., 2006)
SRRS	Social Readjustment Rating Scale (Holmes and Rahe, 1967, cited in Blanchard et al., 1988)
STAI	Stait - trait anxiety inventory (Spielberger et al., 1970, cited in Blanchard et al.,1988)
WSAS	Work and social adjustment scale (Marks, 1986, cited in Kennedy et al., 2005)

Table 6 – Further details on participant numbers

Number of IBS participants	Number of studies	Case numbers
n = 1 – 10	**4**	9, 16, 26, 33
n = 11 – 20	**8**	3, 4, 7, 15, 17, 25, 28, 36
n = 21 – 30	**5**	2, 22, 29, 30, 41
n = 31 – 40	**7**	1, 6(a), 21, 31, 34, 37, 40
n = 41=50	**5**	5, 12, 23, 39, 42
n = 51-60	**1**	11
n = 61-70	**1**	24
n = 71-100	**2**	6(b), 19
n = 100+	**10**	10, 13, 14, 18, 20, 27, 32, 35, 38

Table 7 – Assessment of retrieved papers

Study number and design	Significant improvement in IBS symptoms	Significant improvement in psychosocial factors	Theoretical model used	Overall quality
1 (RCT)	No	Yes	PT	Fair
2 (PLD)	Yes	Yes	IE	Poor
3 (RCT)	Yes	No	CBT	Good
4 (RCT)	Yes	No	CBT	Good
5 (Meta)	Yes	Yes	CBT	Very good
6 (RCT)	Yes	Yes	CBT	Good
7 (RCT)	Yes	No	R	Fair
8 (PLD)	Yes	No	CT	Poor
9 (PLD)	No	Yes	CBT	Poor
10 (RCT)	Yes	Yes	CBT	Good
11 (PLD)	Yes	Yes	HP	Fair
12 (RCT)	Yes	Yes	PT	Good
13 (RCT)	Yes	No	PT	Very good
14 (RCT)	Yes	Yes	CBT	Very good
15 (RCT)	Yes	Yes	HT	Good
16 (Case)	Yes	Yes	HT	Fair
17 (RCT)	Yes	Yes	CT	Fair
18 (PLD)	Yes	Yes	HT	Good
19 (PLD)	Yes	Yes	HT	Good
20 (RCT)	Yes	No	HT	Very good
21 (PLD)	Yes	No	HT	Good
22 (RCT)	Yes	No	CBT	Very good
23 (RCT)	Yes	No	HT	Very good
24 (PLD)	No	No	MC	Poor
25 (RCT)	Yes	No	R	Fair
26 (RCT)	Yes	No	R	Poor
27 (RCT)	Yes	No	CBT	Very good
28 (RCT)	Yes	No	CT	Fair
29 (RCT)	Yes	No	CBT	Good
30 (RCT)	Yes	No	CBT	Fair
31 (RCT)	Yes	Yes	CT	Fair
32 (RCT)	No	No	IE	Poor
33 (PLD)	Yes	No	BF	Good
34 (RCT)	Yes	Yes	CBT	Good
35 (PLD)	Yes	No	IE	Poor
36 (RCT)	Yes	No	CBT	Good
37 (RCT)	Yes	Yes	SM	Good
38 (RCT)	Yes	Yes	PT	Very good
39 (RCT)	Yes	Yes	CBT	Very good
40 (RCT)	Yes	No	CBT	Good
41 (RCT)	Yes	No	HT	Good
42 (PLD)	Yes	No	HT	Fair

As can be seen in table 7 some of the studies report significant results, whereas others do not. In addition the quality of papers is not consistent. A summary of the main findings for both symptom reductions and psychological factors are presented in table 8.

Table 8 – Summary of main findings for symptoms and psychosocial factors

Number of studies reporting significant reductions in IBS symptoms	38	Number of studies reporting significant reductions in psychological symptoms	19
Number of studies where symptom reduction is not attributed to the placebo effect	25	Number of studies where psychological reduction is not attributed to the placebo effect	12
Number of studies where symptom reduction is not attributed to the placebo effect, that are rated as reliable	9	Number of studies where psychological reduction is not attributed to the placebo effect, that are rated as reliable	4

The first aim of this review was to assess the overall efficacy of psychologically based interventions in IBS. As table 8 demonstrates of the 42 studies only 25 provided reasonable support for the efficacy of psychologically based interventions for symptom reduction. An even smaller number of studies, 12, provide support for the efficacy of psychologically based interventions for an improvement in psychological factors. As is also seen in table 8 when considering the assessment of the overall quality of the studies the number of studies which reliably report symptom reductions reduces to 9, and only 4 provide reliable support for psychological improvements. Further information and a consideration of the implications of these findings is given in the discussion.

The second aim of this review was to assess which psychological models have been used in previous research and to establish the relative efficacy of each of the models.

A total of ten different theoretical models were identified, these were: psychotherapy (PT), illness education (IE), cognitive behavioural therapy (CBT), relaxation (R), cognitive therapy (CT), health promotion (HP), Hypnotherapy (HT), medical consultation (MC), bowel sound feedback (BF) and stress management (SM). A summary of this is provided in table 9.

Table 9 – Summary of psychological models identified from the review

Model	Number of studies	Case numbers	Scientific quality of identified papers
PT	4	1[a], 12*[a], 13*, 38*[a]	1 = fair, 12 = good, 13 = reliable, 38 = reliable
IE	3	2*[a], 32, 35*	2 = weak, 32 = fair, 35 = good
CBT	15	3*, 4*, 5*[a], 6*[a], 9[a], 10*[a], 14*[a], 22*, 27*, 29*, 30*, 34*[a], 36*, 39*[a], 40*	3 = good, 4 = good, 5 = reliable, 6 = good, 9 = weak, 10 = good, 14 = reliable, 22 = reliable, 27 = reliable, 29 = good, 30 = fair, 34 = good, 36 = good, 40 = good.
R	3	7*, 25*, 26*	7 = fair, 25 = fair, 26 = weak
CT	4	8*, 17*[a], 28*, 31*[a]	8 = weak, 17 = fair, 28 = fair, 31 = fair
HP	1	11*[a]	11 = fair
HT	9	15*[a], 16*[a], 18*[a], 19*[a], 20*, 21*, 23*, 41*, 42*	15 = good, 16 = fair, 18 = good, 19 = good, 20 = reliable, 21 = good, 23 = reliable, 41 = good, 42 = fair
MC	1	24	24 = weak
BF	1	33*	33 = good
SM	1	37*[a]	37 = good

* indicates a significant decrease in symptoms, [a] indicates a significant improvement in psychological factors.

As table 12 demonstrates although there are ten theoretical models, only six have multiple papers. Of the six models with multiple papers the majority of research has been conducted using CBT (15 studies), with PT coming second (9 studies). For each

of the other theoretical models less than five studies have been published. Further information and a consideration of the implications of these findings is given in the discussion.

DISCUSSION

As detailed in the introduction there were two aims for this systematic review. The first aim was to gain an overview of the viability of psychologically based interventions for research into IBS. The second aim was to assess if any of the theoretical models emerged as dominant. For both of these several areas of the results need to be considered, the findings relating to the first aim, will be discussed now.

As table 4 demonstrates a total of 42 published studies were identified. Although this is a relatively small number of papers, it should be noted research of this type in IBS has only been conducted since the 1980s. In the last few years interest in conducting intervention research in IBS has increased, with some specialised groups, such as the IBS Research Foundation, and the IBS Network emerging in the UK. It is therefore likely that future research will clarify the efficacy of psychologically based interventions, and provide detail on those specific interventions which yield the greatest successes. However, the aim of this review was simply to assess the viability of psychologically based interventions, and in this respect, the review demonstrates that psychological interventions are definitely efficacious. Although there is a possibility of a publication bias, it should be noted that the vast majority of studies showed significant results for either or both symptom reductions and psychological improvements, and importantly that no study showed the opposite effect. Although as tables 7 and 8 show in many cases there are methodological issues with the studies conducted so far, there are still a sufficient number of studies that beyond simply suggesting the viability of psychologically based interventions, actually show a superiority over standard medical care. This obviously has important implications for the future of IBS treatment, as has previously been addressed in chapter 1.

The second aim of the review was to assess if any of the psychological models emerged as dominant. This is arguably more important than simply assessing the viability of psychological models. Firstly if one model is dominant to the extent to

which its results are largely consistent and conclusive, then the justification for conducting research on one of the alternative models is weaker. Secondly, if all psychological models are shown to be highly successful regardless to the theoretical model used, then there is a likelihood of an underlying factor (such as the placebo effect), and as such trying to design a complex model may prove an unnecessary waste of resources. Finally and most importantly by assessing the strengths and weaknesses of the models and study designs it will be possible to design an intervention that complements and extends the research already conducted, which is undoubtedly the aim of a systematic review (Mulrow, 1994).

The first theoretical model is psychotherapy (PT). Four studies were identified, and all report significant findings. Two of these studies yielded significant results for both symptom reductions and psychological improvements. The other two studies both showed significant findings but only for either symptoms or psychological factors. Overall the quality of this research was high, and there would therefore appear to be preliminary support for psychotherapy in the treatment if IBS. There would therefore be justification for conducting research based on PT principles, however, the specific components of PT that bring about change should be easier to identify.

The second theoretical model is that of illness education (IE). Here three studies were identified, of which two report significant findings. One study yielded significant results for both symptom reductions and psychological improvements, whilst the other one only reported significant reduction in symptoms. Unfortunately only one of these papers was regarded as of suitable scientific quality. It would therefore appear that there is preliminary evidence for illness education, but that further research is needed to identify the specific components of illness education that elicit change. There are two issues that need to be addressed in future research using illness education. The first aspect is to ensure that the education is given in a psychological way. Although these pieces of research claim to address these by actually ensuring both understanding, and cognitive alterations based on the new information, care should be taken to ensure this is actually the case for all participants. Secondly, and partially related is to ensure that the cohort selected is matched in both their levels of understanding and length of time suffering from IBS,

as the potential benefit of illness education may be somewhat minimised if the participants already were aware of the information being provided. In none of these papers was an assessment of current levels of understanding given. Therefore in summary, although illness education has the potential to have a tremendous impact in terms of reducing anxiety, and encouraging sufferers to make informed self management choices there is a need to ensure that the interventions are implemented in a structured way which will actually alter patient's cognitions. Therefore future research using illness education should ensure that sufferers actively assimilate the information, and that this actually changes their illness cognitions. In addition whilst further research is needed to clarify this issue, at the moment it would appear that illness education is best as part of a multi-component intervention.

The third psychologically based intervention is cognitive behavioural therapy (CBT), which with fifteen studies identified is by far the largest category of research. In addition to the number of papers with the exception of two studies they were deemed to be of good quality. Together they provide a high level of support for the efficacy of this model as all papers report significant findings. 6 studies yielded significant results for both symptom reductions and psychological improvements, a further 8 only reported significant reduction in symptoms, and a further 1 reported significant improvement in psychological factors. It would therefore appear that there is a large amount of support for CBT in irritable bowel syndrome; this is consistent with CBT being the primary therapy offered in IBS clinics (such as the Cardinal Clinic in Windsor which hosted a conference in 2004 to inform general practitioners about their use of CBT in IBS). However, although there is a disproportionate amount of papers compared to the other models, it is not fair to say that the efficacy of CBT has been established beyond doubt, as several biases may have affected the results. Firstly, it is possible that a publication bias exists, and therefore studies showing no support for the model may have been produced but are not available to include in the review. Secondly, there is a dominant research group (Albany multi-component CBT), and it could be case that this specific type of CBT, which includes additional components might be the crucial element, and in this respect it could be a factor other than CBT which is responsible for the underlying change, or for that matter a location bias. As none of the studies provide a way of assessing the specific elements of the intervention which bring about change it is difficult to conclude that the

efficacy of CBT has been established beyond reasonable doubt. On balance however, CBT does appear to be an effective treatment option, and with a number of researchers championing its cause, one that does not seem necessary to research in this thesis. However, a model which shares similar principles of challenging maladaptive thoughts and altering behaviour would seem likely to meet with success.

The fourth theoretical model is relaxation (R), interestingly whilst all three papers identified showed a significant reduction in symptoms, none showed a reduction in psychological factors. As none of the studies are of high quality it is difficult to assess if it is the model that is flawed, or if the methodological issues obscure this relationship. Despite the observed symptom reduction, there is currently no evidence for the superiority of relaxation over placebo effects, and in two of the three studies this is clearly the case. It is possible that relaxation is of benefit to sufferers, as research into stress strongly suggests an increase in symptoms following stressful events. (e.g. Dancey et al., 1995). However, in order to assess the potential benefits of relaxation high quality research is needed, and it is likely that achieving true relaxation in patients is going to be difficult with a short, group based intervention. It does not appear therefore that there is much justification for conducting simple relaxation research, however, if research is conducted measures must be included to assess if relaxation has occurred, and if so which how this affects illness outcomes. Simply showing a correlation will not be sufficient.

The fifth theoretical model is cognitive therapy (CT). Of the four studies identified all show reductions in symptoms, and two additionally show an improvement in psychological factors. It would therefore seem that there is preliminary support for CT, however, all of the papers are of poor quality, and with this in mind there is no firm evidence. Therefore although this model seems plausible its efficacy has not been currently established. It would however, be interesting to compare its efficacy directly with CBT, as it may be the case that although some improvements are observed with CT greater changes may be found by adding the behavioural component.

The sixth theoretical model is health promotion (HP). Although there is only one study, and it is not of particularly high quality, it did yield significant results for both

psychological and symptom factors. Although more research is clearly needed it is possible that this approach could be potentially useful to sufferers, and its initial support certainly suggests there may be some benefit (and at the very least no disbenefit) for incorporating general health promotion issues, such as exercise, and other positive health behaviours into an intervention.

The seventh theoretical model is hypnotherapy (HP), which along with CBT is the second area where a majority of research has been conducted, and is again consistent with the use of hypnotherapy in clinical IBS populations, or through self-help tapes. Of the nine studies identified, only two are of poor quality, and therefore the results yielded can be considered to be largely reliable. The research suggests that HT is an effective treatment with all studies showing a significant reduction in symptoms, and four additionally showing an improvement in psychological factors. In addition in eight of these studies it seems highly unlikely that results are due to placebo effects. It would therefore appear that HT is an efficacious treatment. However, there are many people who would not be prepared to visit a hypnotherapist, and others who are not susceptible to hypnosis. With this in mind although the therapy was undoubtedly effective in these studies, it is possible that the samples used were specifically selected for these trials, and it may therefore not be a therapy that is suitable for many sufferers. It is also expensive, and may therefore not be a viable option for some sufferers. In addition although self-help hypnosis materials are available none of these papers investigate their efficacy, and until this is established the widespread utility of HT is unclear.

The eighth theoretical model is a medical consultation (MC). Although this was designed to assess if the consultation itself provided a positive psychological environment and was therefore included in the review, it is perhaps unsurprising that it was found to be unsuccessful. Although Illyckyj et al's., (2003) aim was to alter the standard medically consultation in a psychologically beneficial way is an interesting idea, it is one that is difficult to put into practice and is one which is unlikely to be revealed by a short intervention study. It is however, possible that doctor-patient communication does contribute to IBS illness outcomes, and as every RCT uses SMT as a comparison group it is important to assess that relative impact of the consultation itself as differential consultation styles may skew the results in the

supposed control group. This therefore represents an important area of research and one that is worthy of future research. However, at present it does not appear to be the case that an intervention based on medical consultations will be useful, as even for those studies where psychologically based interventions are not superior to SMT, they have so far never been found to produce worse results.

The ninth theoretical model is bowel sound feedback (BF). There is only one study specifically investigating this, and this study did provide significant reductions in symptoms, but not for psychological aspects, and therefore its usefulness appears to be rather limited. There are no real conclusions that can be drawn at this point.
The tenth and final theoretical model is stress management (SM). Although only one study was identified it did provide significant results for both symptoms and psychological factors. Therefore stress management techniques may be beneficial. Although more research is needed in this area, the rationale for stress management research is supported by previous research on the relationship between stress and symptom severity in IBS (e.g. Dancey et al., 1995). It therefore seems likely that stress management programmes will be beneficial and that future research will support the findings of this study. On this basis providing advice for stress reductions would appear sensible; this is consistent with the research on general health promotion previously mentioned.

Overall the previous summary provides evidence for the efficacy of psychologically based interventions in IBS research; however, there is currently no conclusive evidence for any of the models. Although some models meet with success neither the level of improvement nor the consistency justifies a cessation of the search for alternative models in this area. One of the useful features of a systematic review is that it allows for an assessment of the 'active' components of the interventions. Based on the review it is clear that the theoretical models that are particularly weak are those where the psychological component is limited, e.g. MC and HP, and conversely those that tend to produce significant results are those where the psychological components are clearly defined, such as CBT and HT. Based on these characteristics it seems likely that a model that may meet with success in psychologically based IBS interventions is the common sense model (Leventhal et al, 1980; 1984). Although this model has not previously been considered in IBS

interventions research is emerging that suggests it to be a viable model for use in IBS research (e.g. Rutter and Rutter, 2002) and it therefore worthy of study. A full description and justification for this model will be provided in the following chapter.

In terms of the development of interventions for IBS this systematic review also points to the necessity to assess not just that changes have occurred, but why this is the case. The difficulty is establishing the active components of the intervention is something that is particularly noticeable for less clearly defined interventions such as stress management. Therefore a measure should be used to establish if particular dimensions of the model are altered by the intervention, until this is assessed it is difficult to conclude with any degree of certainty that it is the specific nature of the intervention, rather than a 'halo' or 'placebo' effect that is responsible for the results. Although using a control group does minimise the likelihood of the placebo effect it should be noted that with the possible exception of SMT control groups used are not appropriate. This is due to their potential to inflate symptoms of IBS prior to study commencement, in particular in the case of waitlist controls, especially those in which SMT is suspended, and in the case of symptom monitoring, where participants may be resentful that they have to focus on their illness without being in the active intervention part of the trial. In addition it is important to ensure that the measures used for assessing change are accurate as this may explain the discrepancy of some of the research findings reported here.

One final point is regarding the limitations of this review, although care was taken to search all the databases, and reference lists in order to compile the studies in this review it should be noted that there was no dual searching of references from an independent collaborator, therefore it is possible, although unlikely that references may have been omitted. If this is the case, I do not feel that this would in any way alter the results presented here. In conclusion, based on the findings elicited from the systematic review, chapter 3 considers the common sense model as a useful theory in the design of future interventions in IBS research.

CHAPTER 3

THE COMMON SENSE MODEL OF ILLNESS REPRESENTATIONS (CSM) AND ITS APPLICATION TO IRRITABLE BOWEL SYNDROME (IBS)

Aim

The thesis so far has demonstrated that psychologically based approaches to studying IBS are not only appropriate based on the characteristics of the illness (chapter 1), but that interventions based on psychological principles may prove efficacious in the advancement of treatments in this area (chapter 2). However, as yet it is unclear which theoretical model these psychologically based treatments should adhere to. Based on the results of the systematic review in the previous chapter the information presented clearly shows that no one treatment dominates (Kennedy et al., 2005). However, as was proposed at the end of the review a theoretical model which takes account of the 'active' components of the other models is likely to meet with success. As such Leventhal et al.'s (1980; 1984) common sense model of illness representations was proposed (CSM). This chapter seeks to explain this model, justify its choice for the studies conducted in this thesis, and briefly discuss why it was considered to be superior to other dominant models in this field.

COMMON SENSE MODEL OF ILLNESS REPRESENTATIONS - OVERVIEW

The common sense model of illness representations (CSM) was designed by Leventhal et al., (1980; 1984). It is a social cognitive model which proposes that health and illness behaviour are directed by two interrelated aspects regarding beliefs about a disease. The CSM states that people learn to think and feel about somatic and illness sensations from prior symptom episodes and ongoing visceral experiences. The CSM states that illness beliefs are structured and that coping reactions are dependent on the outcome of initial processing. Unlike other models the CSM posits the influence of emotional variables (such as stress, depression, anxiety) on health

and illness behaviours and incorporates a symptomatology component, defining its outcomes in terms of reactions to a health threat. It is worth noting that although it was recommended in personal communication that the CSM / common sense model of illness representations was chosen as the name for the model in this thesis (Leventhal, 2006) it is also commonly referred to as the common sense model of illness perceptions and the self regulatory model (SRM). Although the CSM will be the name used throughout this thesis it should be noted that the measure used to obtain scores on the illness representation dimensions is termed the illness perception questionnaire (revised version, Moss-Morris et al., 2002). The self regulatory model (SRM) is a useful alternative name for this approach as it reinforces a key aspect of the model: that it is the goal of the sufferer to re-establish a health state, a process which is affected by the different factors in the model. The CSM consists of three stages, these are outlined below.

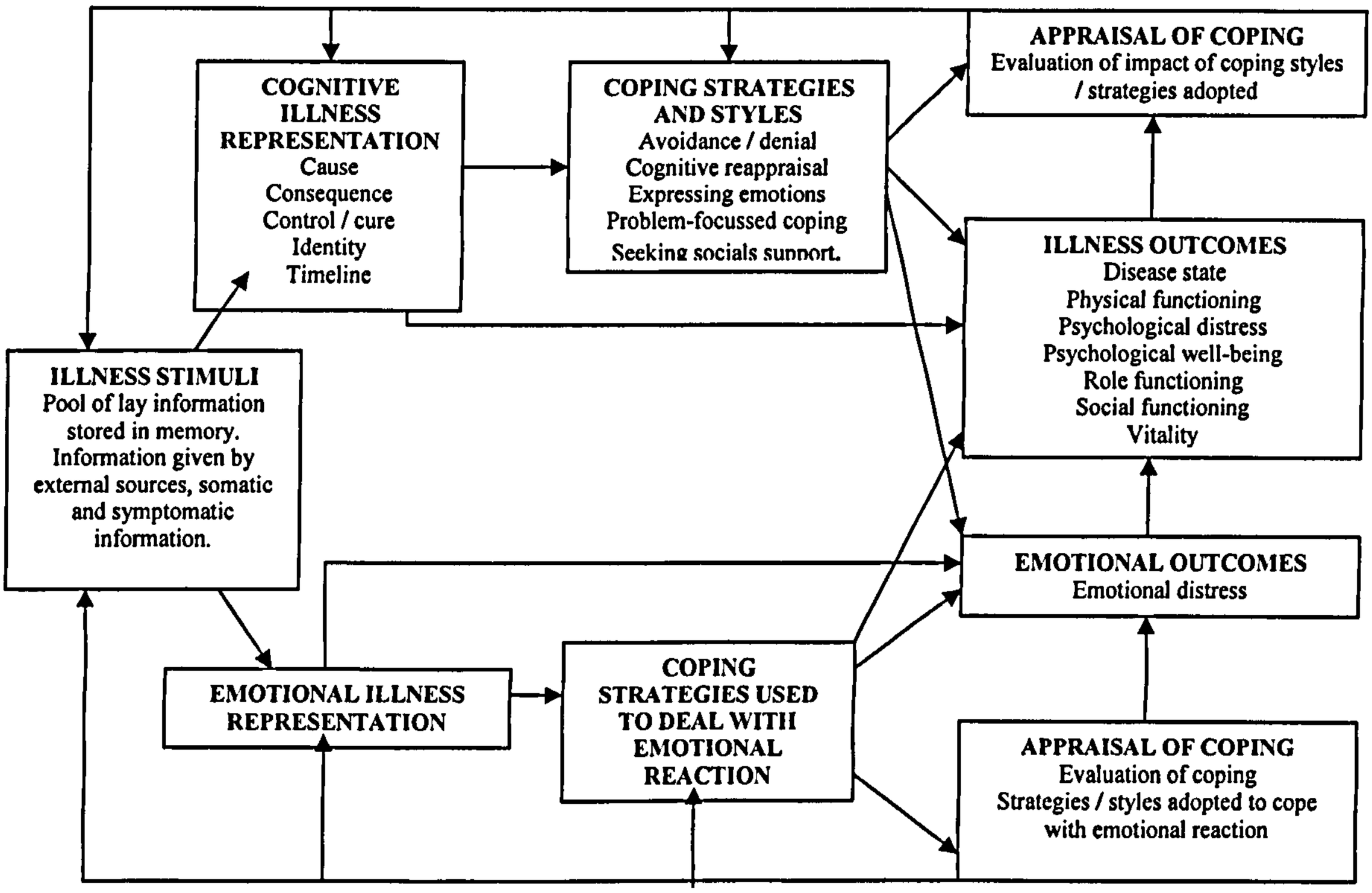
The first stage is the *interpretation* stage, whereby cognitive and emotional representations of a health threat are used by the patient to identify the meaning of the threat, also known as illness perceptions / representations. Earlier studies have identified five domains; these are emotional representations, identity, time line, consequences, cause and control beliefs.

The second stage of the model is the *coping stage*, this stage constitutes avoidance or approach techniques, such as "action plans". Action plans relate to both action intentions (the planning of a response) and "actions" (executing a response by implementation of actions into one's daily routines (such as adhering to medical prescriptions), also including perceived self-efficiency to act upon intentions.

The third stage of the model is termed *appraisal*. This is where the patient reflects on the outcome of the action plan. Although the definition of the three stages appear linear it is important to note that according to Leventhal et al. (1980) interaction between stages occurs in both directions. This means that the CSM is a parallel processing model in which illness stimuli simultaneously trigger cognitive and emotional feedback loops comprising illness representations, coping strategies, appraisal and outcomes. A cognitive representation may result in a particular action plan, which may lead to certain appraisal, but equally the perceived outcome of the

action plan may feedback to influence illness representations. A pictorial representation of this model is given in figure 3.

Figure 3 – The common sense model of illness representations*



*From Hagger & Orbell (2003)

As the pictorial representation demonstrates the parallel processing nature of this model means that an illness intervention aiming at only one stage should influence the entire CSM.

COMMON SENSE MODEL – STAGE 1 INTERPRETATION

The first stage of the CSM (Leventhal et al., 1980), termed illness representations, refers to the combination of the cognitive and emotional perceptions of the illness. The information, which contributes to the illness representation, comes from a number of different areas, but these are broadly divided into symptom experiences and social messages (e.g. from doctors or general public). Current conceptualisations of illness representations have identified five factors, these are:

1) Illness identity

2) Cause

3) Timeline

4) Consequences

5) Cure / controllability

Illness Identity refers to the meaning ascribed to the illness label, the knowledge that the sufferer possesses, and the specific feelings experienced.

Cause does not refer to what actually caused the illness but rather to the beliefs the sufferer has about what they view to be possible for causing their illness. In addition to medical factors, such as gastroenteritis or food poisoning the cause component also incorporates the patient's beliefs about their personal responsibility in causing the illness.

Timeline refers to the individual's belief about the course of their illness. Based once again on available medical and idiosyncratic information the sufferer makes a judgement as to whether the illness timeline is acute, chronic and or cyclical.

Consequences refers to both the severity of the symptoms experienced and also to any illness related consequences such as reductions in quality of life and impact on psychological, social, physical, sexual and economic dimensions.

Cure / Control is the final component of this model. Broadly cure is considered an outcome for an acute illness and control in chronic illnesses, although theoretically a cure can be found for chronic illnesses too. A sufferer's belief about this component can have a profound impact on the illness progression, such as illness related loci of control and beliefs about the necessity of taking medications or upholding advised self-management behaviours. The first four components of this model are credited to Leventhal et al. (1980), and the fifth to Lau and Hartman (1983).

COMMON SENSE MODEL – STAGE 2 COPING / ACTION PLANS

Stage two involves the development of coping strategies, broadly categorised into approach / avoidance strategies. Coping can refer to the individual's attempt to a) come to terms with the diagnosis itself, b) deal with the crisis of an illness, or c) adjust to the illness through a process of cognitive adaptation often termed action plans. Action plans provide a framework for the influence of the representation on illness behaviours and related outcomes. Action plans incorporate both 'action intentions', such as the planning of a response to a particular aspect, and also to 'actions' themselves, which is the direct implementation of the plan into daily behaviours. In this respect actions incorporate such aspects as adhering to medications or dietary interventions, which may be influenced by the perceived controllability part of the representations formed (e.g. Edwards et al., 2001). As this is a highly psychological model it is somewhat unsurprising that perceived efficacy at performing particular actions have an impact upon the operationalisation of action intentions into actions. This is part of the conceptualisation of the CSM as a dynamic parallel processing model whereby the stages are continually interacting with each other. Therefore a specific illness representation may result in the devising of a particular action plan, but the outcome of enacting the action (actual or appraised) may lead to a modification of the illness representation. Although actions can be clearly specified they are often influenced by subconscious or unstructured processes. The dynamic nature of the model is crucial in the context of designing illness intervention studies as it suggests that an intervention at any stage of the model will have an impact on the other stages. However, an intervention incorporating both illness representations and actions would arguably give sufferers a more structured way of maintaining self-management behaviours.

COMMON SENSE MODEL – STAGE 3 APPRAISAL

Stage three involves appraisal, the evaluation of the strategies utilized so far and the decision of whether to proceed in the same way or use an alternative course of action. As this is a dynamic parallel processing model this stage does not require

much detail because the outcome of the appraisal process will necessarily link into other stages.

COMMON SENSE MODEL – JUSTIFICATION FOR USE IN IBS RESEARCH

Although there is limited research on the CSM in IBS specifically there is justification for the theoretical utility of this model from the other chronic illnesses that have been researched such as Addison's disease (Heijmans, 1999), epilepsy (Kemp et al., 1999) and chronic fatigue syndrome (CFS, Edwards et al., 2001). Importantly from the context of the idiosyncratic nature of IBS this model is suitable for heterogeneous illnesses. The recent meta-analysis by Hagger & Orbell (2003) suggests that the illness cognition dimensions are robust across illness types, and that the CSM is therefore a useful model for studying chronic illnesses. In addition the CSM with its focus on action planning and interaction of stages is a practical model, which allows for a degree of flexibility in the designing of interventions based on its principles.

To date there is only one published paper investigating the CSM in IBS (Rutter & Rutter, 2002). Although a conference paper by Boddington et al. (2001, cited in Hagger & Orbell, 2003) is considered to be of sufficient quality to be included in the aforementioned meta-analysis, this only offers weak support and therefore will not be described here.

The justification for the theoretical utility of the CSM in IBS is therefore largely based on one paper. Although it is generally considered weak evidence to provide justification on one paper, in this case an exception should be made. There are a number of reasons for this exception. Firstly the application of the CSM to other illnesses, particularly those with similar illness components, such as chronic fatigue syndrome (Edwards et al., 2001) suggest that its application to irritable bowel syndrome will meet with similar success. Secondly as evidenced by the systematic review, even from a purely exploratory stance it is of importance to understand the theoretical constructs behind IBS symptoms if effective scientific interventions are going to be designed. Thirdly the current definition of IBS as a functional illness,

coupled with its embarrassing symptoms and the mixed messages patients receive (e.g. Bertram et al., 2001) strongly suggest the illness representations play a role in illness outcomes. Finally it is arguably the case that one good quality research paper is worth a great deal more than a large number of poor pieces of research, and with this in mind the study elicited is useful as it not only suggests the application of the CSM to the study of irritable bowel syndrome but suggests and implies a number of suggestions for further research based on this model. As this is the only published paper specifically addressing the role of the CSM in IBS it will be described in some detail here.

The research by Rutter & Rutter (2002) investigated the relationship between illness representations, coping and symptom based outcome. Their research was conducted on 209 members of the IBS NETWORK (a common cohort for research in this area). As the systematic review demonstrated this is an uncharacteristically large number of participants for IBS research, and is therefore likely to be more representative of IBS sufferers than some other studies. A number of psychometric instruments were used, including the illness perception questionnaire (IPQ, Weinman et al., 1996), the COPE (Carver et al., 1999) and the Hospital Anxiety and Depression Scale (HADS, Zigmond & Snaith, 1983). Participants rated their self perceived quality of life and their satisfaction with their health. Symptoms were measured using a questionnaire devised by the authors, it comprised ten frequently experienced symptoms on a five point Likert scale, ranging from "no experience of this symptom" to "experience the symptom once a week", the Cronbach's alpha coefficient for this scale was 0.61. Finally in order to assess patients' perceived quality of life two items were taken from the WHOQOL-BREF (WHOQOL Group, 1998). These items were "how would you rate your quality of life" (1. very poor – 5. very good); and "How satisfied are you with your health" (1. very dissatisfied – 5. very satisfied).

The results from the study show the reporting of serious perceived consequences of IBS were associated with lower scores on both of the quality of life scales, but only the satisfaction with health scale correlated with reported symptoms. Weaker control beliefs showed this same pattern (but was not associated to symptoms) but was also found to be associated with higher depression scores. Finally psychological causal attribution was positively correlated with both anxiety and depression. In summary

the reporting of serious consequences independently predicted symptoms and quality of life, coping strategies independently predicted depression, and finally coping mediated between representation and outcome.

It is clear therefore that there are a number of key outcomes of this study, and in particular the relationship of illness representations to illness outcomes is of importance because it shows that it should be possible to alter symptom frequency and associated psychological factors by encouraging positive representations of illness and their related productive coping strategies. This ability to change physical symptoms based on psychological factors is essential to the core of health psychology and is especially relevant in the context of IBS due to the ineffectiveness of pharmacological 'solutions'.

Although this research does not provide a conclusive account of the role of the CSM in IBS, it clearly provides justification of the utility of this model for IBS specifically, which adds to the justification for its utility in general illness research. In addition there are a number of methodological aspects of the study, which suggests ways in which this area of research should be conducted.

The first methodological aspect is the use of psychometric instruments. Symptom-based questionnaires are often criticised as validity of retrospective recall of symptoms can be affected by poor memory, or perceptual biases. However, they are also essential in some areas of research where a formal assessment of symptoms is not viable. For IBS research specifically this poses a special problem. In some medical research analysis of stool samples is used, but in a psychological study this would be considered invasive, and indeed the likely anxiety it would cause to participants would ensure that the results were not accurate. Equally open ended questions about general symptoms are not going to yield usable data. In this research although a symptom questionnaire is used care is obviously taken to ensure its validity by the use of clearly defined Likert scale questions. The questionnaire designed is therefore a cohesive scientific instrument with an alpha coefficient of 0.61, which considering the considerable heterogeneity of IBS symptoms does appear to be fairly reliable. By using questionnaires to assess all areas of this

research the authors were able to yield a large sample size, this is of considerable importance for generalisation of results.

It is clear therefore that use of questionnaires is acceptable for CSM based IBS research. Building from the Rutter and Rutter (2002) study it could be suggested that with a number of modifications accuracy of results and strength of findings could be increased. Possible suggestions include extending the symptom scale to allow for experience of each symptom more than once a day (to account for the multiple and fluctuating symptoms, which may yield increased variance at the top end of the scale), and by comparing symptom reports with a daily-diary will enhance the results (Meissner et al., 1977). In addition an IBS specific longer scale for assessing quality of life (QOL) may also be beneficial, as although significant findings were yielded here, individual item scales are still not used in a majority of papers.

CONSIDERATION OF OTHER THEORETICAL MODELS

A full justification of the model chosen for this research would be incomplete without brief mention of the superiority of the CSM over alternative models. It has already been justified why a specific model was felt to be superior to a basic biopsychosocial approach, and the suitability of the CSM has been detailed, however there were two other models considered in the initial design of this thesis. These were rejected because they were not found to be suitable.

HEALTH BELIEF MODEL

The first theory considered as the theoretical background to this thesis was the Health Belief Model (Hochbaum, 1958; Rosenstock, 1966, cited in Taylor, 1999). The Health Belief Model (HBM) was initially considered due to its focus on the relationship between attitudes and health behaviours. Briefly the model states that there are two factors which influence whether a person engages in a particular 'health behaviour'. The first of these factors is the degree to which the health threat is perceived as personal' and the second of these is the 'belief in the ability of a particular health practice to reduce that threat'. In the initial stages of literature searching it appeared that the three issues most related to experience of symptoms in

IBS were stress, depression (e.g. Dancey et al., 1995; 1998) and eating habits (e.g. Simrèn et al., 2001). Based on these assumed symptom triggers this model seemed a highly suitable theoretical basis for conducting a series of studies assessing sufferers' perception of these three factors as health threats and then designing an intervention based upon changing these risk behaviours. However, a more detailed assessment of the literature revealed that these were not the primary factors, and as chapter 2 demonstrated the aetiology of IBS symptoms is not easy to determine. As such, although this model has proved efficacious in diabetes prevention and management (Pinto et al., 2006), heart disease (Mirotznik et al., 1995) and a variety of other illnesses, it was not felt to be suitable for use in an IBS population.

TRANSTHEORETICAL MODEL OF BEHAVIOUR CHANGE

The second theory considered as the theoretical background for this thesis was the transtheoretical model of behaviour change (TTM). This model was proposed by Prochaska and collegues (Prochaska, 1994; Prochaska et al., 1992). Although it shares some of the background principles with the health belief model, this model was initially considered to be more useful due to its focus on the stages in which people change behaviours. The concept of stages of change seemed highly suitable to an IBS population as the model is robust enough to account for the considerable heterogeneity in this population. It also does not necessitate an understanding of how the symptoms occurred initially, and can therefore be adapted to each sufferer regardless to their individual illness and lifestyle factors. Briefly the model describes the stages that people work through in order to bring about a behavioural change. There are five stages to these model, *precontemplation, contemplation, preparation, action and maintenance*, these will be briefly described.

Precontemplation. This stage occurs when the person has no intention to alter their behaviour, in fact in this stage many individuals are not even aware that there is a necessity to alter their behaviour. This is highly typical for example in smoking and other addictive behaviours, such as alcoholism. In this stage treatment may be sought, but this is generally under coercion from family members or authority figures, and unsurprisingly people attempting change at this stage meet with limited success.

Contemplation. This can really be seen as the stage where conscious desires to alter risk behaviours emerge, but it is a reflective stage where there is a general consideration to alter the behaviour in the future but no sense of urgency and no attempt to set goals for attaining the behaviour change. Due to the lack of urgency it is possible to remain in this stage for years, and a process of weighing up the costs and benefits of altering risk behaviours may fluctuate between the precontemplation and the preparation stage.

Preparation. This is the first stage where a clear intention to change behaviour is seen, but this has not been actualised at this stage. There may be a slight modification to behaviour, such as reduction of amount of cigarettes smoked, or there may be real or assumed reasons for delay. The key issue at this stage is that no firm cognitive commitment has been made to altering the behaviour.

Action. This is the stage where the behaviour is actually modified, and requires emotional and behavioural commitment.

Maintenance. It is not sufficient to simply change a behaviour the behaviour must continue to be maintained, in this respect it is not just about cessation it is a cognitive commitment for the person to alter their self perception, e.g. from a smoker to a non-smoker.

In should be noted that although the stages are described separately here, this is to aid clarity but the model itself in generally considered to be a spiral where relapse is common and fluctuation between the stages either side of the current stage generally occurs. It may be that the cycle is enacted a number of times before the behaviour is successfully eliminated.

In some ways this model is appealing, as like any stage theory, it sets about clearly defining areas for research, and suggests a series of studies assessing current stages, concluding in an intervention to move participants to a further stage and an assessment of the impact on symptoms and quality of life. However, the TTM has also been widely criticised, and is even considered by Sutton (2001) to be 'logically

flawed'. In addition, albeit not to the same extent, the criticisms of the HBM are still prevalent here. The problem is that there is no clear behaviour for IBS sufferers to alter, at best there is a series of lifestyle factors, but as the TTM works best when it is focussed on setting about one (e.g. addictive behaviours, Prochaska et al, 1992) or if necessary a small number of clearly defined changes (e.g. eating habits, Povey et al, 1999), it is unlikely to prove useful for sufferers. Moreover, a majority of sufferers are already engaging in behaviour changes regarding diet (Niec, 1998), stress reduction (Dancey et al., 1995) and medications (Talley, 2001) and yet are meeting with limited success. It was therefore felt that unless clearly defined 'risk' behaviour could be identified designing an intervention based around this model would not be successful.

It is therefore clear from the exploration of the alternative theories that a model focussed on perceptions rather than specific behaviours is the most likely to achieve successful results for IBS sufferers, and as the systematic review (Chapter 2) and the justification for the CSM here shows it is felt that the most efficacious model was chosen.

This marks the end of the literature review portion of the thesis. It should be clear from this chapter and from the preceding chapters that psychologically based approaches are suitable for IBS research and that indeed there is justification for investigating the role of the CSM specifically. As such the next three chapters will detail the empirical studies that were designed around this model. Each study was designed to test a specific component of the model. The first two studies are exploratory in nature with both studies investigating potential contributory factors to the assessment of current illness representations and also looking independently at illness representations and outcomes. This was felt to be imperative as this is an extremely under-researched model in IBS and it was therefore felt that prior to the devising on an intervention a thorough background investigation of the model needed to be conducted. The final empirical chapter presents the intervention study that was designed around the CSM.

CHAPTER 4

STUDY 1

DOCTOR-PATIENT COMMUNICATION, ILLNESS REPRESENTATIONS AND OUTCOMES IN IRRITABLE BOWEL SYNDROME (IBS)

Aim

Chapter 4 reports the results of study 1. This was an exploratory study which investigated the role of doctor-patient communication in irritable bowel syndrome. The role of the doctor comes under the category of social messages in the interpretation part of the model. It is therefore the model's inclusion of the doctor as the primary external informational source in the development and maintenance of illness representations which attests to its suitability. Theoretically doctor-patient communications can impact on each of the five cognitive representations of: identity, cause, timeline, consequences and cure/control (e.g. Frostholm et al., 2005). To date there has been no research directly addressing the role of doctor-patient communication in the illness representations of IBS sufferers. Therefore this is an important area of study that needs to be explored, both for its own merits and also in so far as it will further understanding of the specific nature of the intervention.

There were a number of different research questions but they grouped into three main areas of interest. The first area was a comparison of patients' and doctors' perceptions of doctor-patient communication. The second area was an assessment of the potential impact of patients' perceptions of doctor-patient communication on their illness representations and their illness outcomes (perceived health related quality of life and symptom frequency). The third and final area of investigation was an exploration of the relationship between illness representations and illness outcomes independently from perceptions of doctor-patient communication.

INTRODUCTION

The original impetus for this study was driven by reports from sufferers at IBS Network meetings. At the meetings sufferers complained that medical professionals (doctors and gastroenterologists) did not show any sympathy for their condition, that medical professionals did not view IBS as a legitimate illness, and that medical professionals did not believe their quality of life was affected. Many sufferers reported feeling frustrated and disappointed following consultations. Following these reports from sufferers a search of relevant literature was initiated. Although there is only a handful of studies investigating IBS patients' perceptions of medical consultations, the research identified, both on doctor-patient communication in general and in IBS, does support the views expressed at the self help groups and therefore legitimises this as an area of study.

Over the past three decades research interest in the area of doctor-patient communication has begun to emerge. The complexity of this interaction means that there is currently only a limited amount of research available, but that which does exist serves to show the importance of this as an area of study, and defines the key components of this relationship. The clearest depiction to date of the area of doctor-patient communication provided by a review of the literature by Ong et al. (1995). In their review they use Cancer as an example; this is unsurprising as the majority of research conducted has been in this area. Although the potentially life threatening nature of Cancer makes direct comparisons to IBS difficult the two main conclusions drawn from the review persist across illness types.

The first conclusion is that there are three main areas of importance in doctor-patient communication, these are: 1) the rapport between the doctor and the patient, including creating a comfortable atmosphere. 2) The need to effectively communicate information about the specific nature of the illness, and to alleviate any unnecessary distress on the part of the patient and 3) the need for the doctor to work with the patient to make informed decisions regarding treatment.

The second conclusion is about the methods used to assess consultation efficacy. The review suggests that patients' perceptions should be considered the gold standard. In

fact they suggest that this is due to doctors' underestimating the level of information patients desire, and the potential impact that doctor-patient communication may have. They therefore suggest that although interaction analysis systems (IAS) are often used to code the components of consultations, this is not an accurate measure for evaluating the potential impact of the consultation on the patients.

The review concludes by suggesting that although there is limited research available there is evidence that patients' health outcomes for sufferers of chronic illness might be affected by doctor-patient communication. The main study cited is by Kaplan et al. (1989), they conclude that positive doctor-patient communication which serves to reinforce patients "self confidence, motivation and positive view of their health status", will have a direct impact on their perception of their health related quality of life, and will cause an indirect improvement to their illness symptoms. The results of this study are supported by recent research by Ong et al. (2000), with cancer patients. Ong et al. (2000) used content analysis to code the themes from 96 consultations, and multiple regression analyses were used to predict patient outcomes at one week and three months post consultation. The results indicated that the 'affective quality of the consultation' predicted the patients' quality of life, and their satisfaction with the medical consultation.

It can therefore be seen that the impact of doctor-patient communication is a theoretically viable, important and under researched area of study. Although research specifically investigating patients' perceptions of doctor-patient communication in IBS is limited, of the available research there are three studies (Coulson & Semper., 2004; Bertram et al., 2001; Kennedy et al., 2004) that provide useful evidence to support the anecdotal accounts of poor perceptions of doctor-patient communication. The research by Coulson & Semper (2004) will be detailed first.

In a novel approach to gaining information about patients' opinions this research collated and analysed the information posted by sufferers of IBS on internet message boards. This is a unique style of research which allows for the assessment of genuine opinions, rather than by asking questions which may bias or prime patient responses. The research assessed the messages (n=414) posted between February and July 2003, and coded the emerging themes. There were four main themes to emerge from this

research, interestingly all of them relate to doctor-patient communication to some degree.

The first theme was ***'symptom understanding and experience'***. The two sub themes were a) uncertainty over the multiple and mixed symptoms people were experiencing, with an implication that informational support given by medical professionals was insufficient, and b) discussions regarding the impact of symptoms on quality of life. The second theme was '***diagnosis***'. In this theme the two main postings were a) "anger and despair over the lack of a formal diagnosis", and b) "the lengthy process....before a confirmed IBS diagnosis can be made". The third theme was ***'interaction with health care professionals'***. In this theme the main postings were descriptions of experiences where health care professionals appeared to show a lack of sympathy towards both their symptoms, and the impact of their symptoms on their quality of life. The overall result of this theme was an often reported dissatisfaction with the consultation. The fourth theme was '***treatment options'***, specifically confusion over which treatment options were available and which were likely to yield success. Once again there is an implication that medical treatment is insufficient and that informational resources on alternative forms of treatment are not readily available from medical professionals. Overall this research provides clear evidence of patients' dissatisfaction with their medical consultations. Although all patients were members of the IBS Network, and may therefore represent a group who have a higher level of dissatisfaction than is observed in a more general cohort of IBS sufferers these concerns should nevertheless be addressed. Coulson & Semper (2004) recommend that further research in this area investigates whether these perceptions of poor communication actually impact on the progression of IBS. However, in order to assess this quantitative research, which takes into account doctors' perceptions alongside the sufferers' perception needs to be conducted.

The second study, by Bertram et al. (2001) also has a qualitative design. Using focus groups they investigated patients' perceptions of their interactions with medical professionals. The two main themes to emerge were that 'interaction with the medical community seldom clarified understanding of IBS', and sufferers felt 'frustration due to lack of medical validation'. The authors concluded that these two factors support the notion of lack of understanding and sympathy within the medical

profession, and moreover that many IBS sufferers are considered to be hypochondriacs.

The third study of Kennedy et al. (2003) is similar to the Bertram et al. (2001) study. Five focus groups were conducted, involving a total of 23 IBS sufferers who were asked to describe their experiences of the health care system (along with other variables). Although the study supports the results of this previous research it does not in itself extend the literature on this area. Therefore as its use is limited to showing consistency of perceptions of sufferers across cohorts no further detail will be provided here. Overall the results of these three studies match the themes derived by Coulson & Semper (2004), and together these pieces of research suggest that negative perceptions of doctor-patient communication amongst IBS sufferers have validity.

An additional study that investigates doctor-patient communication in IBS is by Van Dulmen et al. (1994). The study used 120 outpatients with functional abdominal complaints, including IBS. In the research participants completed a questionnaire about their illness and also any illness related cognitions, behaviour and anxiety, prior to an initial consultation with an internal medicine specialist. Following this consultation, doctors completed a parallel version of the questionnaire to record what they assumed to be the perceptions of their previous patient. The results showed that there was a discrepancy in the accuracy of doctors' perceptions of physical and non-physical complaints. Interestingly although there was a discrepancy of both physical and non-physical symptoms, the doctors' perceptions of the physical symptoms were more closely matched to patient's perceptions, than their perceptions of non-physical symptoms were. In addition the research found that doctors *underestimated* patients' expectations and secondary complaints, and *overestimated* their pain related attributions, catastrophising and self efficacy cognitions. This research therefore suggests that patient's and doctors' perceptions of communication may be incongruent. It is a useful piece of work and supports the qualitative studies reported earlier. The results are also in line with findings reported by Forshaw & Langley (2004) that doctors overestimate the amount of knowledge patients have. However, the evidence from this study is by no means conclusive. For example, it does not address IBS sufferers as an independent group, does not directly measure the main

elements of doctor-patient communication in a structured form, and does not suggest if there is an impact of perceptions of communication on illness outcomes. Therefore more research is clearly needed in this area.

From the above evidence it seems likely that there is a difference between patients' and doctors' perceptions of communication in medical consultations. However, as was seen with the research in other chronic illnesses, and specifically cancer it is not sufficient to merely show that there is a discrepancy in the views of doctors and patients, it is important to assess if there is an impact on quality of life and symptoms. Research by Letson & Dancey (1996) suggests that it is vital to assess the potential impact of negative attitudes held by medical professionals as negative attitudes may be widespread. Their research with a cohort of nurses suggests that "the majority of nurses hold negative attitudes towards IBS sufferers, which can only be detrimental to the treatment of patients with IBS". Although there is a danger generalising conclusions from nurses to doctors, this study is inline with the opinions of Maguire (1999), who opens his review of doctor-patient communication in cancer research with the didactic statement "how doctors and nurses communicate can profoundly affect the psychological adjustment and quality of life". The potential impact of doctor-patient communication is also demonstrated by Harrington et al.'s (2004) observation that the curriculum for training the medical profession has been revised to ensure that communication is an integral part of most courses.

It therefore appears likely that poor-doctor patient communication may have a real impact on IBS sufferers' subsequent health. However there is only one piece of research which directly and quantitatively investigates the potential long term-effects of doctor-patient communication in IBS. It was conducted by Owens et al. (1995) and is a prospective study whereby 112 patients were monitored (using medical records) from diagnosis for an average of 29 years (range 1-32 years). The findings from this study revealed that the number of return visits (specifically related to IBS) were lower in those patients that reported higher levels of doctor-patient communication. Significant aspects of doctor-patient communication were whether the doctor assessed the patient's psychosocial history, whether the doctor seemed interested in why the patient had booked the appointment, and discussing the illness with the patient. In addition a rapport with the patient was approaching significance.

It therefore seems likely that positive doctor-patient communication impacts on the long term prognosis of IBS, as evidenced by fewer return visits in patients reporting higher degrees of satisfaction. However, the claim that the outcome variable, 'amount of consultations for IBS symptoms equates to a genuinely lower mean frequency of symptoms (in patients who report a positive initial consultation)' is unsubstantiated. Whilst this may be the case, the research does not record any objective symptom measures and therefore this conclusion can at best be implied. However, the prospective nature of this study does suggest that there is a reduction in physician visits in those patients who report positive doctor-patient communication. This is a step forward in IBS research in this area, and supports the view that doctor-patient communication may impact on illness outcomes.

Overall the previous review of the literature suggests that doctors and patients perceive the communications differently, and that perceptions of poor communication may affect illness prognosis. Although more research is clearly needed before either of these conclusions can be drawn with any degree of certainty it does seem likely that the impact on symptom frequency will be an indirect consequence of health related quality of life (HRQOL). This is an idea that was originally suggested by Kaplan et al. (1989, cited in Ong et al., 1995). Although there is undoubtedly a reciprocal relationship between symptoms and quality of life the dominant directionality appears to be exacerbation of symptoms by perception of poor quality of life. This is consistent with the literature on other psychological variables, such as stress (Dancey et al., 1998), and the role of abuse in IBS aetiology (Drossman et al., 1999). Recent research by Brennan et al. (2004) supports this notion, and agrees that although symptoms (subdivided into seven independent predictors) do contribute to HRQOL, there are eight other quality of life components which independently predict illness prognosis. There are two main conclusions which can be drawn from this study. The first is that where symptoms and HRQOL are both included as outcomes, it is likely the two variables will be correlated. However, the predictive relationship between the two should use HRQOL as the predictor and symptoms as the dependent variable. The second conclusion, and of importance for the area of doctor-patient communication is that in addition to assessing symptom severity doctors should aim to improve patients' perceptions of HRQOL. This is an interesting implication as it suggests that doctor-patient

communication could influence the perceived HRQOL of patients. Although this supports the research of Van Dulmen et al. (1994) and therefore is a theoretically viable suggestion, as this research does not measure perception of doctor-patient communication as a conclusion it should be treated with caution.

One final paper which supports the conclusions drawn by Brennan et al. (2004) is by Salmon (2000) who suggests illnesses which show physical symptoms, but do not appear to have an underlying physical pathology (of which IBS conforms) are ones which are most likely to be influenced by doctor-patient communication. Although this is a descriptive article, rather that a study specifically investigating IBS consultations, there are a number of points raised that are worthy of mention. Firstly, supporting the views of Ong et al. (1995), Salmon (2000) agrees that the traditional approach to videotaped interaction analysis system (IAS) for recording consultation components, is unsuitable for use in an IBS population. He states that this approach is unsuitable because it is not the components of the interaction itself that impact on illness progression but on the patients' interpretation of these components. He goes on to suggest that whilst the view of the doctor as the 'expert' may be suited to physical illnesses where pharmacological solutions can be given, it is not suited to IBS. In fact he described the 'expert' approach as 'invalid', and explains, that the mere fact that patients continue to seek treatment despite being told that their pathology is untreatable by traditional solutions, means that the patients require something different from the consultation. Salmon (2000) suggests this to be 'sensitivity to the condition'. Judging by the findings from the Bertram et al. (2001), Coulson & Semper (2004) and Kennedy et al. (2004) this certainly appears to be a fair conclusion.

Overall the research points to the need to measure HRQOL and symptoms in the context of doctor-patient communication. However, it is sparse and the findings limited. One of the problems with the current research as evidenced by the Owens et al. (1995) study is that even when there appears to be a relationship between doctor-patient communication and illness outcomes this relationship is not adequately explained. This points to the need to base research on established theories, as without the inclusion of a theoretical model it is not possible to conclude with any degree of

certainty that the differences in symptoms (either within or between subjects) are actually related to doctor-patient communication.

A theoretical model which might explain the route from communication to illness outcomes is the common sense model of illness representations (CSM) (Leventhal et al., 1980; 1984). As this was described and justified in detail in chapter 4 this will not be reiterated here. However, it is important to emphasise that the role of the doctor comes under the category of social messages in the interpretation part of the model. It is therefore the model's inclusion of the doctor as the primary external informational source in the development and maintenance of illness representations which attests to its suitability. Theoretically doctor-patient communications can impact on each of the five cognitive representations of: identity, cause, timeline, consequences and cure/control. A recent study by Frostholm et al. (2005) exemplifies the suitability of the CSM to the study of doctor-patient communication, with an extremely large scale research involving one thousand seven hundred and eighty five participants recruited from twenty eight different GP practices. They found that poor perceptions of doctor-patient communication impacted on both the illness identity and the emotional representations components.

To date there has been no research directly addressing the role of doctor-patient communication in the illness representations of IBS sufferers. Therefore this is an important area of study that needs to be explored.

There is one component of the model which is worthy of more detailed consideration, this is the perceived cure / control dimension. There is some debate as to whether this dimension added by Lau and Hartman, (1983) is a true component of the illness representation model, or whether it will exert a direct effect. The role of perceived cure / controllability was considered by Leventhal et al. (1984), as the following statement demonstrates. They state:

"Although this factor clearly belongs within common sense models, it is debateable whether it should be defined as an attribute of illness representations or a summary of expectations with respect to coping"

Possibly because of the controversy surrounding its role the questionnaire used to assess the illness representation components only contains limited questions for assessing this component, therefore an additional, dedicated measure will be included. Although theoretically some research may choose not to include this component, in the literature on illness representations (e.g. Hagger & Orbell, 2003) its inclusion is shown to be widespread. The factor of cure/control is often researched outside the context of the CSM, as a large body of research attests to. This research serves to confirm the likelihood of a relationship between perceptions of control and illness outcomes across a number of different chronic illness groups. Examples of the range of illnesses include diabetes (Kohlmann et al., 1993), brain injuries (Moore et al., 1991) and epilepsy (Krakow et al., 1999). Although there has been no dedicated research directly investigating the relationship between health related locus of control (HRLOC) and IBS, this does not negate the likelihood of the same relationship being observed as is seen for other illnesses. It is therefore an important area of study. Two papers provide limited support for the role of control beliefs and quality of life. The first is a paper by Rutter and Rutter (2002). As part of their investigation of illness representations they report that 'weaker control styles' are associated with worse HRQOL and depression. However, this research does not include a dedicated locus of control measure, and there were no significant relationships between locus of control styles and symptoms. One other paper, Hobbis et al. (2003) investigated locus of control, alongside abnormal illness behaviour in IBS. They found that IBS sufferers were more prone to external locus of control styles than non FBD patients, but they did not investigate whether this affected illness outcomes. Despite the limited empirical support, the theoretical justification is clear.

The route by which locus of control is said to affect perceived quality of life and illness outcomes is related to coping strategies. It has been suggested by Wallston et al. 1994) that an internal locus of control might encourage more productive self-management behaviours and a greater sense of an ability to improve the condition. This is based on the rationale that people with an internal locus of control tend to assume both more personal responsibility for their own health, and more belief in their ability to influence their illness progression. External locus of control is actually two constructs, one type of external control focuses on fatalistic views, such as God,

luck or chance. The other is the belief in powerful others. Although both external views are considered less protective of health, the people with a fatalistic locus of control are theoretically more likely to be at least accepting of their illness state. The other type of externality is considered to be the most detrimental to health, this is the belief in powerful others. A high score on this dimension represents an individual who expects medical professionals (and other authority figures) to be responsible for their health. This locus of control is likely to be problematic for IBS sufferers as its chronic trajectory coupled with the ineffectiveness of medical treatments means that people with a powerful others external locus of control are unlikely to engage in self-management behaviours and as a consequence have worse symptoms and poorer health related quality of life (HRQOL) (Wallston et al., 1994).

It is theoretically viable therefore that the locus of control a person holds may be related to doctor-patient communication. The theoretical viability is derived both from the stance of the CSM as originally stated, and also from the locus of control construct itself. Although there is limited literature addressing the role of locus of control specifically within the context of doctor-patient communication, that which does exist suggests that illness outcomes are more severe for patients with external locus of control styles both for general illness (e.g. Burgoon et al., 1990) and epilepsy (Gopinath et al., 2000). There is no research which explores the relationship between doctor-patient communication and locus of control in IBS, and therefore this is a novel area of study.

The aims of this research are therefore to support and extend the literature in this area. Its broad aims are:

1) To compare patients' and doctors' perceptions of doctor-patient communication.
2) To assess if there is a real impact of perceived communication on illness representations (including locus of control) and on illness outcomes (HRQOL and symptom frequency).
3) To explore the role of illness representations (including locus of control) and illness outcomes, independently of doctor-patient communication.

METHOD

PARTICIPANTS

DOCTORS

Doctors were recruited via opportunity sampling, by sending request letters to their surgeries. 245 packs were distributed to doctors and 58 completed packs were returned (response rate 23.7%). The doctors group comprised both GPs (n=44) and consultant gastroenterologists (n=12, n=2 unspecified). Independent samples t-tests conducted for each of the communication dimensions showed that there were no significant differences between these groups on any of dimensions and therefore the data from the GPs and the gastroenterologists were combined to form one doctors group (n=58), which was used in the analysis. Further demographic information is given in table 10.

Table 10 - Additional demographic information (doctors)

Variable	Mean	S.D.	Range
Doctor participants age (years)	49.6	9.3	31-82
Amount of time worked as a doctor (years)	23.7	10.4	3-60
Number of IBS consultations doctors have per week	5.9	5.9	1-30

IBS PARTICIPANTS

IBS participants were recruited via opportunity and snowball sampling from a number of sources including universities, work places, self-help groups or by responding to advertisements placed in the IBS Network's quarterly publication and their website. The IBS Network is an independent national organisation set up to give advice, information, and support to sufferers of IBS. It is an important cohort for research in this area but it only represents just over half of the sample here. 139 packs were distributed to IBS sufferers and 58 completed packs were returned by use of free-post (response rate 41.7%). Participants had to be over the age of 18, able to read English, and have a confirmed diagnosis of IBS from a medical professional.

The vast majority of participants were female (86%). This is unsurprising as a gender bias in IBS populations has been reported by many researchers (e.g. Dancey et al., 1995; Drossman et al., 1999). It is currently unclear whether this bias is due to females actually being more likely to suffer from IBS, differential treatment seeking, or differential reporting in research. The important consideration here is that this sampling bias is congruent with that from previous research (e.g. Rutter and Rutter, 2002; Lackner et al., 2004). Participants' ages ranged from 19-78 years, with a mean age of 47.1 (SD 17).

The average time since diagnosis of IBS was 11.1 years (SD 9.4), with a range from less than a year to 37 years. The average time from first experiencing symptoms to being diagnosed was 4.4 years (SD 6.7), with a range from less than a year to 30 years. With the exception of one American all participants were resident in the UK. Just over half of the sample was highly educated with 58.6% achieving 'A' levels or higher, 19% of the sample reported having no academic qualification. Almost half (47%) of the sample reported having another illness. The most often reported illnesses were hypertension (8.6%) and asthma (8.6%), the only specified psychological illness was depression at 6.9% of the sample.

MEASURES

A disease specific version of the IPQ-R (Moss-Morris et al., 2002, *appendix 1*) was used to measure the illness representation components. This disease specific version was modified in accordance with standard procedures for its use with an IBS population. The items on the scale used as predictors in the multiple regression analyses in this research are identity (sum of symptoms believed to be related to IBS), perceived personal control (IP12-IP17), perceived treatment control (IP19-IP23), timeline acute/chronic (IP1-1P5, + IP18), perceived consequences (IP6-IP11), illness coherence (IP24-IP28) and emotional representations (IP33-IP38). The items in these scales are counterbalanced, and are rated on five point Likert scales from (1) strongly disagree to (5) strongly agree. The total score is averaged for each scale. All of the subscales have good internal consistency, with alpha values ranging from 0.79 to 0.89 (Moss-Morris et al., 2002).

The IBS-36 (Groll et al., 2002, *appendix2*) was used to measure Heath Related Quality of Life of sufferers. This is a disease specific questionnaire, consisting of 36 questions scored on a 7-point Likert scale; it addresses all areas of quality of life. The score used in the analysis is the 'total IBS related quality of life score, this is calculated by summing the responses to the 36 questions. Higher scores represent a *lower* perceived quality of life. It has a very high internal consistency (Cronbach's alpha = 0.95) and a high test-retest reliability (Spearman's r = 0.92, Groll et al., 2002). It is highly suitable for this study, and is considered by its authors to be superior to measures used in previous research.

The 7-day symptom diary (*appendix 3)* was designed for this study, as there is nothing suitable in the literature; however, it is based on traditional designs, and is considered to be a suitable measure based on Meissner et al.'s (1997) contention that a symptom diary should be the gold standard for measuring symptoms.

Medical Interview Satisfaction Scale MISS-21 (Meakin & Weinman, 2002) was used to measure doctor-patient communication; it is a revised version of the MISS, which has been used extensively. The internal consistency of the MISS-21 is satisfactory (alpha coefficient's range 0.67-0.92, Meakin & Weinman, 2002). It was used to assess four dimensions of doctor-patient communication: 'rapport', 'distress relief', 'consultation comfort', and 'compliance to treatment'. For the purposes of this study two modified versions of this measure were produced. The first was an IBS specific version for the IBS participants (*appendix 4)*. The alpha coefficient for this IBS specific version was 0.94. The second version of this questionnaire modified for this study was an IBS consultation specific version for the doctors (*appendix 5)*. The alpha coefficient for this version was 0.90. As the alpha coefficients demonstrate, despite the modifications to this measure the two versions created for this study can be considered to be highly suitable.

The Multidimensional Health Locus of Control Scale (MHLC, appendix 6) (Wallston et al., 1994) was used to provide additional data on locus of control. Although the IPQ-R does include scales for perceived personal control, and perceived treatment control, it was considered useful to add this additional measure for this specific study. This is because the cure / controllability dimension was not part of Leventhal

et al's. (1980) original design, and therefore the scale is rather limited. The inclusion of an additional (specific locus of control) measure was to increase the likelihood of revealing a relationship (if one exists) between perceived doctor-patient communication and locus of control The MHLC scale was used because it has been extensively validated and across hundreds of studies it Cronbach's alphas are satisfactory (range 0.60-0.75), the test-retest stability coefficients range from 0.60 - 0.70. This study utilized form C of the MHLC; this is an illness specific version, which in this case was modified for use in an IBS population. Responses were on a six point Likert scale from (1) strongly disagree to (6) strongly agree. It consists of 18 questions, which comprise the three locus of control dimensions (internal, external -fate, and external - powerful others).

Demographic Questionnaire There were two demographic questionnaires used in this study, one version was administered to the IBS participants (*appendix 7)*, and an alternative version was used for doctors (*appendix 8)*.

PROCEDURE

This was a postal based study; therefore both the doctors and the IBS participants received a research pack. The doctors' packs were posted to their surgery addresses, and the IBS participants' to their homes.

The doctors' pack contained an information sheet along with a letter inviting them to take part in the research (*appendix 9*), consent forms and confirmation of ethics approval (*appendix 10*), a demographic questionnaire (*appendix 8*), the doctors' version of the MISS-21 (*appendix 5*) and a free post envelope for return of completed research packs.

The IBS participants' pack contained an information sheet along with a letter inviting them to take part in the research (*appendix 11*), consent forms (*appendix 12*), a demographic questionnaire (*appendix 7*), the IBS patients' version of the MISS-21 (*appendix 4*), *a disease specific version of the IPQ-R* (Moss-Morris et al., 2002, *appendix 1*), *the IBS-36* (Groll et al., 2002, *appendix 2*), *the 7-day symptom diary* (*appendix 3)* and a free post envelope for return of completed research packs.

DATA TREATMENT

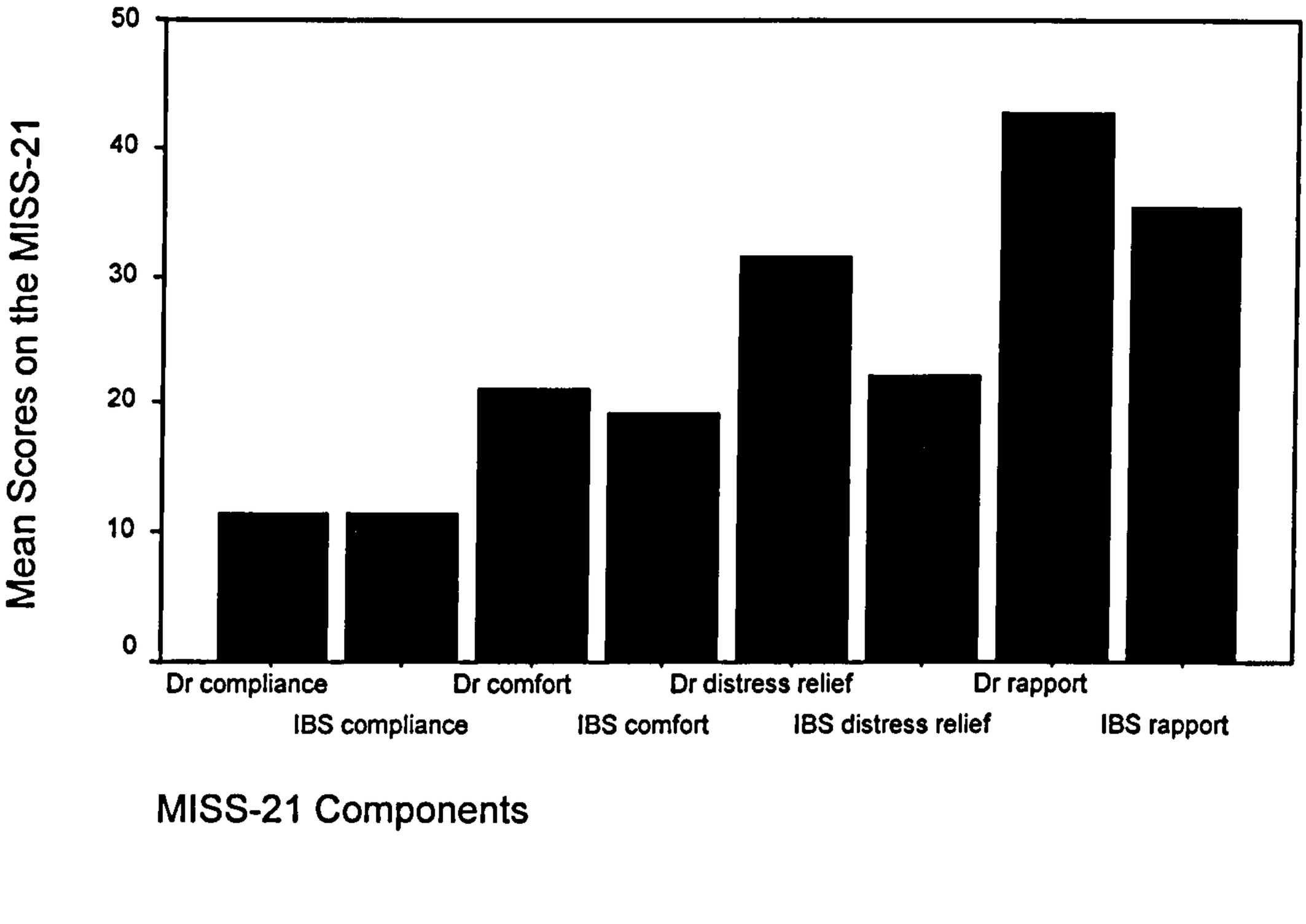
Raw data was entered into SPSS (version 14). There was fortunately very little missing data, the small quantity was dealt with by using mean substitution. As the variables were normally distributed and mean substitution only affects the variance this was felt to be the best method. In the raw data set many questions on each of the measures are reversed, these were transformed and using guidelines in the questionnaire manuals the variables to be used in the analysis were computed.

RESULTS

COMPARISON OF DOCTORS' AND PATIENTS' PERCEPTIONS OF DOCTOR-PATIENT COMMUNICATION

As is shown in figure 4, the mean scores for three out of the four dimensions of doctor-patient communication are higher in the doctors' group than the IBS patients' group. The largest difference is observed in perceived 'distress relief'. As figure 4 shows the dimension which appears to have identical means is perceived treatment compliance.

Figure 4 – Doctors' and IBS sufferers' perceived efficacy of communication



A series of one-way analyses of variance revealed that doctors reported significantly greater perceived efficacy of their communication than did IBS sufferers on all dimensions except treatment compliance. The significant differences were therefore between 'consultation comfort' ($F(1,114) = 8.87$, $p < 0.005$), 'distress relief' ($F(1,114) = 70.02$, $p < 0.0001$) and 'rapport' ($F(1,114) = 21.29$, $p < 0.0001$).

As the IBS sample was largely female biased it was not possible to split the data by gender. Although splitting the data by age was considered this was felt to be inappropriate as there may be interaction effects between age and length of time suffering from IBS. It was felt that with a data set of this size controlling for this would have left insufficient power to detect accurate effects, and as there was not felt be a legitimate reason why age might affect perception of communication this was not assessed.

There were however three grouping variables that were explored. The first of these was whether participants were members of the IBS Network. This was conducted in

order to assess if perceptions differed between these two groups. This is a legitimate variable to explore as it was the members of the IBS Network's self-help groups who first suggested this research was conducted, and it was members of the IBS Network that Coulson & Semper (2004) used in their research. Therefore it is possible that this represents a group who hold worse perceptions of medical consultations than the general IBS population; therefore in order to ensure the generalisability of results this needs to be explored. Of the 58 IBS participants who took part in this study 37 were members of the IBS Network and n=21 were not. A series of ANOVAs revealed no significant differences between Network and non-Network members on any of the dimensions of doctor-patient communication.

The second grouping variable was whether or not participants reported suffering from any other illness. Although participants were asked to only consider consultations relating to their IBS directly it may have been difficult for this to be actually achieved, especially if consultations had frequently covered the other illnesses too. As was discussed in chapter 2 prevalence of additional illnesses is common, and it was therefore felt that restricting the sample to only those participants who did not suffer from another illness would not have given an accurate representation of the IBS population as a whole. Therefore the decision was taken to include participants with additional illnesses, however, as a large proportion of the sample reported suffering from another illness (n=33) it was felt necessary to assess if there were differences in perceived communication between these groups. A series of ANOVAs revealed no significant differences between people with or without another illness on any of the dimensions.

The third and final grouping variable was between subgroups of IBS. Considering that IBS has been shown by factor analysis to group into the three distinct, and potentially opposite illness groups, it seems logical to explore the relationship between these groups and perceived communication. However, a a majority of studies only investigate effects on IBS sufferers as a homogeneous group (as can be observed in the systematic literature review). In order to gain a full understanding of the differences between doctors' and patients' perceptions of doctor-patient communication it is therefore essential to assess if there are differences across the IBS subgroups. In this study there were n=19 IBS-D sufferers, n=19 IBS-A sufferers,

and n=15 IBS-C sufferers. Although these categories were self defined by the sufferers, it is likely that these categories are correct as the proportion in each group is similar to that reported in previous research (e.g. Lackner et al., 2004). A series of ANOVAs revealed that there were no significant differences between the subgroups of IBS on any of the dimensions. Therefore for this study the investigation of IBS sufferers as one group appears to be legitimate.

PATIENTS' PERCEPTIONS OF DOCTOR-PATIENT COMMUNICATION AND ILLNESS REPRESENTATIONS

A series of multiple regression analyses were conducted to explore potential relationships between patients' perceptions of doctor-patient communication (predictors being the four dimensions of: consultation comfort, distress relief, rapport and treatment compliance) and illness representations. It should be noted that perceived cause is a categorical variable; therefore this was not included in the analyses.

The analysis revealed only one significant relationship between perceived doctor-patient communication and illness representations. This includes the additional measure to assess the cure / control component. This was that as perceived compliance to treatment increased perceived consequences of having IBS decreased (table 11).

Table 11 - Multiple Regression Predicting Illness Representation: Perceived Consequences of Having IBS (R^2 adj. 0.083)

Doctor-patient communication	β
Communication comfort	-0.10
Distress relief	0.01
Rapport	-0.22
Compliance intent	- 0.32*

*p < 0.05 level

As table 11 demonstrates the only dimension of doctor-patient communication that was predictive of illness representation dimensions was the one area which was shown not to differ between doctors and patients, namely compliance intent. It is

therefore possible that there is an independent theoretical construct underlying this relationship.

PATIENTS' PERCEPTIONS OF DOCTOR-PATIENT COMMUNICATION AND HRQOL

A multiple regression was carried out to assess if patients' perceptions of doctor-patient communication were predictive of their perceived HRQOL. None of the factors were found to be significant. It therefore does not appear that HRQOL is predicted by patients' perceptions of doctor-patient communication.

PATIENTS' PERCEPTIONS OF DOCTOR-PATIENT COMMUNICATION AND SYMPTOM FREQUENCY

A series of multiple regression analyses were undertaken to ascertain whether patients' perceptions of their doctor-patient communication were predictive of their symptom frequency. This was assessed for both total symptoms, and for each of the primary IBS symptom categories. There were no significant findings indicating that patients' perceptions of doctor-patient communication were not predictive of their symptom frequency.

Taken together the lack of significant findings relating to HRQOL and symptom frequency suggest that although their may be differences in perceptions of communication between patients' and doctors' these do not have an affect on their illness outcomes. However, the lack of significance observed for perceptions of doctor-communication as a predictor of illness representations, does not negate the possibility that illness representations may be predictive of illness outcomes independently of perceived communication. Consequently this was also included in the analysis.

ILLNESS PERCEPTIONS AND HRQOL

Two of the illness representation components were found to be predictive of HRQOL, these were illness identity, and emotional representations, as table 12 demonstrates. The results show that a greater illness identity (i.e. more symptoms

associated with IBS) results in increased quality of life (the score is negative because increased quality of life is measured by lower scores on the IBS-36). The results also show that the more emotional representations about the illness a sufferer holds the worse perceived quality of life is.

Table 12 - Multiple regression of illness representations predicting health related quality of life (IBS-36): (R^2 adj. 0.52)

Illness representation dimensions	β
Perceived personal control	-0.14
Perceived treatment control	-0.07
Identity	-0.36**
Time line	0.01
Consequences	0.11
Emotional representations	0.41*
Illness Coherence	0.07

*p < 0.05 level, **p < 0.001 level.

To supplement the data elicited from the IPQ-R, the data from the MHLC was also used to further investigate the relationship between perceived HRLOC and HRQOL. Having an internal locus of control was found to be predictive of increased HRQOL, as table 13 shows.

Table 13 - Multiple regression of MHLC predicting Health Related Quality of Life (IBS-36): (R^2 adj. 0.23)

Health Related Locus of Control	β
Internal locus of control	-0.53***
External powerful others	0.00
External fate / chance	0.17

***p < 0.0001 level

An internal locus of control is highly correlated with the IPQ-R dimension of perceived personal control ($r = 0.61$, $p < 0.0001$). This is expected as both variables are supposed to be measuring the same construct (using different measures). Therefore although perceived personal control was not predictive of HRQOL this is most probably a reflection of insufficient power in the IPQ-R to detect this relationship. This is understandable as the IPQ-R only contains a handful of

questions relating to this variable, where as the MHLC is a dedicated measure of locus of control.

ILLNESS PERCEPTIONS AND SYMPTOMS

None of the illness representation components (from the IPQ-R) were found to be predictive of either total symptom frequency, or any of the primary IBS symptoms. Emotional representations were however approaching significance, and this is in the same direction as was noted for quality of life (Table 14).

Table 14 - Multiple regression of illness representation predicting symptoms: (R^2 adj. 0.12)

Illness representation dimensions	β
Perceived personal control	-0.23
Perceived treatment control	0.10
Identity	-0.26[a]
Time line	0.13
Consequences	-0.12
Emotional representations	0.30[a]
Illness Coherence	0.03

[a]$p < 0.07$

There was however, a significant relationship between internal locus of control and total symptom scores (Table 15). This reveals that having an internal locus of control is predictive of decreased total symptoms.

Table 15 - Multiple regression of locus of control predicting total symptoms: (R^2 adj. 0.09)

Health Related Locus of Control	β
Internal locus of control	-0.40*
External powerful others	-0.21
External fate / chance	0.16

*$p < 0.05$ level

There was also a significant relationship between internal locus of control and abdominal pain (table 16). This indicates that an internal locus of control is predictive of decreased abdominal pain.

Table 16 - Multiple regression of locus of control predicting abdominal pain: (R^2 adj. 0.10)

Health Related Locus of Control	β
Internal locus of control	-0.38*
External powerful others	0.22
External fate / chance	-0.31

*p < 0.05 level

The final significant relationships between locus of control and individual symptoms were for diarrhoea. There were two significant findings, the first inline with variables was that having an internal locus of control was predictive of deceased frequency of diarrhoea. The second significant finding was that chance / fate was predictive of increased diarrhoea (table 17).

Table 17 - Multiple regression of locus of control predicting diarrhoea: (R^2 adj. 0.11)

Health Related Locus of Control	β
Internal locus of control	-0.46*
External powerful others	-0.16
External fate / chance	0.38*

*p < 0.05 level

RELATIONSHIP BETWEEN HRQOL AND SYMPTOMS

According to Brennan et al. (2004) (as detailed earlier) it is likely that HRQOL and total symptoms will be correlated, therefore a Pearson's correlation was calculated to assess if this was the case. The results indicate that the two variables are correlated ($r = 0.46$, $p < 0.0001$), as figure 5 demonstrates.

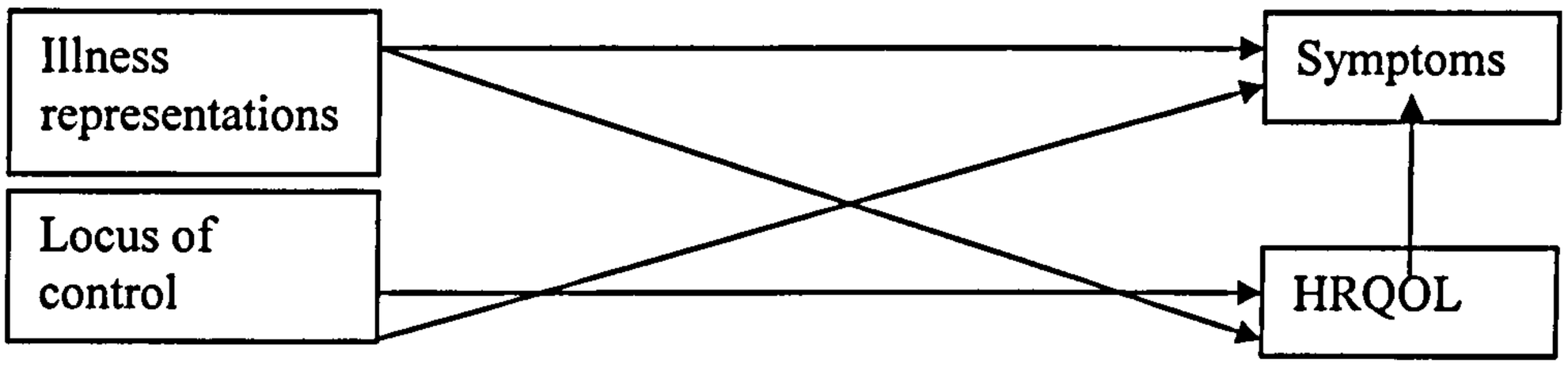
Figure 5 HRQOL and total symptoms

Based on Brennan et al.'s (2004) suggestion that the directionality of the prediction was from HRQOL to symptom outcomes, rather than the other way around a linear regression analysis was conducted to see if HRQOL was in fact predictive of symptom frequency. The linear regression indicated that positive HRQOL was predictive of decreased total symptom frequency, R^2 adj. 0.19, β 0.46, $p < 0.05$. As HRQOL was found to be predictive of total symptom frequency it is feasible that this an important implication for the relationships between variables reported earlier.

EXPLORATION OF THE RELATIONSHIP BETWEEN LOCUS OF CONTROL AND ILLNESS OUTCOMES

The implication of the prediction of symptoms by HRQOL is that when locus of control was found to be predictive of HRQOL and symptoms, the prediction of symptoms is actually not a direct consequence of locus of control. Instead the relationship between locus of control and symptoms maybe mediated by HRQOL. This suggestion would also explain why for the illness representation dimensions there was insufficient power to detect the relationship between illness representations and symptoms. This is represented pictorially in figure 6.

Figure 6 Potential relationships between illness representations, HRLOC and illness outcomes



In order to assess the validity of this theory a stepwise regression was conducted where internal locus of control was the first step and HRQOL was the second step. In line with Brennan et al. (2004) HRQOL was found to fully mediate the effect of HRLOC on symptoms with HRLOC no longer a significant predictor of symptoms in this second step (table 21).

Table 21 - Stepwise Multiple Regression HRLOC Predicting Symptoms mediated by HRQOL

Steps	R^2	ΔR^2	F change	Df 1	Df 2	Sig. F change	Final β
Step 1 – internal locus of control	0.09	0.09	5.65	1	56	0.02*	-0.10
Step 2 – IBS-36	0.22	0.13	8.70	1	55	0.005***	0.41*

*p < 0.05 level ***p < 0.005 level

DISCUSSION

The results revealed that there were significant differences between perceptions of consultations by patients and doctors. Specifically there were significant differences observed for three of the four communication dimensions, namely 'distress relief', 'consultation comfort', and 'rapport'. In all cases IBS participants scored lower on these dimensions than the doctors' group. Overall the findings of significant differences between groups is in line with the research by Van Dulmen et al. (1995),

and extends the ideas raised in the research by Coulson & Semper (2004) and the findings reported by Bertram et al. (2001).

It is interesting to consider why only three out of the four dimensions were significant, a closer look at the components for each of them may provide suggestions as to why this might be the case. The one which was not found to be significant was compliance intent. This is the extent to which both doctors and patients perceive that the patients will adhere to the advice given in the consultation. Although there was no difference in the mean scores for each group it is interesting to note that the mean score was only 11.5, the lowest score of any of the dimensions. As there were three questions which contributed to this factor this meant that the average score per question was 3.8, which fell between disagree and uncertain (the questionnaire comprised a seven point scale, where 1 was 'very strongly disagree' and 7 was 'very strongly agree'), indicating perhaps rather worryingly that neither the doctors or the patients have much faith that the advice is going to be followed.

The first of the three dimensions that were found to be significant is 'consultation comfort'. Doctors report a mean score of 21, whereas IBS patients report a mean score of 19. As there are four questions for this category, this represents the doctors' score of 5.25, referring to the agreement section of the scale, whereas IBS participants score of 4.75 falls between uncertain and agree, and is closer to agree. Although the doctors are significantly overestimating the level of comfort the IBS patients feel, on the whole it does not appear to be the case that either groups perceive the level of comfort derived from the consultation to be particularly poor.

The second of the three dimensions that was found to be significant is 'distress relief'. Doctors report a mean score of 31.5, whereas IBS patients report a mean score of 22.2. As there are six questions for this category, this represents the doctors' score of 5.25 referring to the agreement section of the scale, where as IBS participants score of 3.7 falling between disagree and uncertain. This shows that the doctors are significantly overestimating the level of comfort the IBS patients feel, and that in fact that their responses are on the opposite arm of the scale to the IBS sufferers. It is worrying that doctors perceive they alleviate sufferers' distress, whereas in actual fact this is something that is not achieved. Of all the dimensions of

doctor-patient communication this is the area that provides the greatest support for the ideas raised in the studies by Bertram et al. (2001) and Coulson & Semper (2004). An interesting implication of this study is that although sufferers' perceptions of poor levels of support from doctors at alleviating distress does appear to be valid it may be the case that this is accidental and therefore doctors' should be given more advice on providing adequate distress relief (e.g. Kennedy et al., 2003). From a social psychology perspective it makes sense that the patient seen by the doctor is only one of a number of people seen in any hour, whereas for the patient the significance of the interaction is much higher (Salmon, 2000).

The final of the three dimensions that was found to be significant is 'rapport'. Doctors report a mean score of 42.7, whereas IBS patients report a mean score of 35.3. As there are eight questions for this category, this represents the doctors' score (averaged as 5.34) referring to the agreement section of the scale, whereas IBS participants (averaged as 4.41) are uncertain. This shows that the doctors are significantly overestimating the level of rapport they develop with their IBS patients.

There were no significant differences between members of the IBS Network and non-members on any of the dimensions of doctor-patient communication. It therefore seems likely that the IBS Network is a representative group of IBS sufferers. In this respect this is useful for the future of IBS research as it provides a way of accessing a cohort of people suffering from the illness, but one that appears to still allow for generalisability of the results.

There were no significant differences between those patients who reported suffering from no additional illnesses, and those that reported suffering from additional illnesses. It therefore seems likely that the perceptions reported were not related to differences in general illness state, and therefore there can be greater confidence that these patient's perceptions can be attributed specifically to their IBS consultations. Although none of the participants were screened to ensure that they actually suffered from IBS, inclusion into the study required participants to have a confirmed diagnosis of IBS from a genuine medical professional. As this was a cross sectional study, with no immediate perceived benefits to participants (as may be the case with an intervention) it seems highly unlikely that any of the participants would have

chosen to take part in the study unless they actually suffered from IBS. It can therefore be assumed that all the participants actually suffered from IBS, and moreover that suffering from additional illnesses does not appear to alter the results.

There were no significant differences between subgroups of IBS; this suggests that despite the heterogeneous nature of the illness the same concerns are observed throughout the illness groups. This is likely to be a reflection of a general dissatisfaction with medical professionals, partly as a result of the lack of a clear understanding of symptoms or an established treatment regime. This supports the findings of Coulson & Semper (2004). But as this was a qualitative study, and there is no equivalent quantitative literature the comparison should be made with caution. This is especially relevant as although the observed results seem logical the overall sample size meant that there were not many cases in each group for comparison. Therefore more research exploring grouping variables is clearly needed before any clear conclusions can be drawn.

There was only one significant relationship between patients' perceptions of doctor-patient communication and their illness representations, which is as perceived compliance to treatment increased perceived consequences of having IBS decreased. This finding makes intuitive sense and is consistent with Markoul et al.'s (1995) research on adherence to medications. However, compliance to medical treatment is the only dimension of doctor-patient communication that does not differ between groups. In may therefore be the case that there is an underlying theoretical construct responsible for this observed relationship. Feasibly patients' could hold this prior to and independently of the medical consultations they experience. On the basis of this these results should be interpreted with caution.

There were no significant relationships between doctor-patient communication and either HRQOL or symptoms frequency. As there is no research directly investigating this hypothesis in IBS it is not possible to ascertain if this is a true finding, or the result of a limitation of the study. However, the closest comparative study of Owens et al. (1995) implies illness outcomes decrease, as a correlate of reduced use of health care services. The finding of no impact of perceived communication on illness outcomes is also in opposition to the findings in the Cancer literature (e.g. Ong et al.,

2000). It is essential that further research, in particular of a prospective nature is undertaken to establish if perception of doctor-patient communication affects illness progression.

Two of the illness representation components were found to be predictive of HRQOL, namely illness identity and emotional representations. It should be noted, however, that despite its significance illness identity was in the opposite direction to that suggested by previous research (e.g. Frostholm et al., 2005). The relationship between emotional representations and HRQOL, however match Frostholm et al. (2005). As the Frostholm study involved a vast sample size of almost two thousand patients, it seems likely that these results can be accepted with a high degree of certainty. It also strongly suggests that despite the heterogeneous nature of IBS its relationship to the CSM is similar to that of other illnesses. This is an important step forward for both research into IBS, and the CSM. However, as Leventhal et al. (1984) explain the model was specifically designed for heterogeneous illnesses, and therefore perhaps this robustness is unsurprising. Using the MHLC questionnaire to provide additional data on the locus of control component it was also discovered that an internal locus of control was predictive of increased quality of life, consistent with the theory of Wallston et al. (1994) and the research into other chronic illnesses (e.g. Moore et al., 1991).

Although none of the illness representation components were predictive of symptoms emotional representations were approaching significance. It therefore seems likely that the true finding is one of significance, but that study limitations did not reveal this using this data set. However, it is likely as Brennan et al. (2004) suggest that the relationship between illness representations and symptoms is indirect and is mediated by HRQOL. Although it is not possible to assess this as the relationship is not significant it does suggest why there was sufficient power to detect the relationship between illness representations and HRQOL, but not for symptoms. It is also logical as HRQOL and symptoms were shown to be correlated. Using the MHLC questionnaire it was shown that an internal locus of control was predictive of symptoms. Significance was observed for total symptom frequency, diarrhoea and abdominal pain. Having an external locus of control (the chance / fate dimension) was also significantly related to having a higher frequency of diarrhoea. In order to

fully assess the relationship between the variables as Brennan et al. (2004) suggest a step wise multiple regression with total symptoms as the dependent variable, HRLOC as step one, and HRQOL as step two was conducted. This revealed as suspected that the relationship between HRLOC and symptoms was fully mediated by HRQOL.

Overall the results show some significant relationships, but leave other areas in need of further research. One of the reasons for this is the lack of additional research to support the claims made here. Another reason is the limitations of this study. Although these do not negate the importance of these findings they should still be taken into account when conclusions are drawn.

STUDY LIMITATIONS AND SUGGESTED MODIFICATIONS

PARTICIPANTS

Although the significant findings suggest that participant numbers were not too low, it is still likely that insufficient participant numbers meant that there were less significant findings than might other wise have been found. This is because with only 58 participants, the statistics would have only detected a large effect size. Power analyses indicate that to detect medium effects with a multiple regression with the predictors used in this study a sample size of in excess of one hundred would have been necessary. Concerns over sample size are particularly worth noting for the analyses where further grouping variables were used. In order to establish therefore if small sample size was a contributory factor to the lack of a significant finding here it is advisable for further research to use larger sample sizes. Related to the amount of participants the second methodological issue is low response rates, with the implied potential for a volunteer bias in each of the participant groups. The doctors' group will be dealt with first.

Although it is not possible to know if a bias did occur it is theoretically possible that those doctors who agreed to participate in the study were those who had a higher perception of their efficacy at communication or showed more compassion to their patients in general, or to their IBS patients specifically than those who did not

respond. As the questionnaire only comprised twenty one questions and would have taken under ten minutes to complete the excuse of not having enough time seems highly unlikely, and therefore response rates are likely to reflect a greater interest in the specific research. It is not possible to establish if a more representative sample would increase or decrease the disparity in perceptions of communication and therefore again more research with a larger sample, is necessary before the results are generalized with certainty. An additional concern is that the questionnaire responses provided by the doctors might have been influenced by social desirability biases, and therefore perhaps a peer review of consultations maybe useful to ensure the responses are accurate.

For the participants, although the response rate was not as low, and the comparison between IBS Network and non network members suggests this is quite a representative group, it is still a possibility that participants were those who were more likely to have an interest in the field of doctor-patient communication. As no payment was offered to participants, there is a slight question over motivation for participation that should be taken into account in the reading of the results. In order to address these concerns in future, payment might be useful to alter the motivation for taking part in the research.

MEASURES

As this study was interested in participants' perceptions the use of questionnaires was highly suitable, the use of established measures (such as the IPQ-R and the MHLC) and IBS specific measures (such as the IBS-36) increases the suitability of these methodological choices. However, methodological concerns with the MISS-21 and the diary need to be considered.

The first methodological issue is the suitability of the MISS-21 to assess doctors' perceptions of the consultation. It was used as there was no superior questionnaire based method for eliciting perceived communications available, but it was originally intended as a measure of an individual consultancy. In this respect its psychometric properties were established over both immediate perceptions and with individual patients. It is therefore possible that doctors found it hard to think about their dealings with IBS patients as a whole, and indeed the personality of the patient may

be far more indicative of communication styles than the type of illness they possess. In addition for the purposes of this study a parallel version was created for patients to record their perceptions. It is therefore possible that although the measure was suitable for the use of ANOVA where only the mean scores were used, that the measure was not sensitive enough for use in the regression analyses where a range of responses is important. It should be noted in the defence of these concerns that the alpha coefficients elicited for the two versions used in this study were very high, and therefore although these limitations may be more theoretical than actual.

Although the diary methodology for recording symptoms is less prone to recall bias then retrospective questionnaires one problem with this methodology is that without financial incentives participants are reluctant to complete diaries over long periods of time (Patten et al., 2003). This may be problematic in IBS research as symptoms are cyclic and indeed may vary on a daily basis. To minimise daily fluctuations in symptoms the mean score over the week was taken to assess the impact of perceived communication on Illness representations, HRQOL and symptoms. However, in order to gain a full assessment of the relationships it is necessary to take diary recordings at a number of times, preferably for a couple of weeks before and after consultations on different occasions.

DESIGN

There is a possibility that the assessment of symptoms and the quality of life referred to a different time period than the perception questionnaire. For the perception questionnaire participants were asked to think about their experiences in previous consultations, but the symptoms measured one week only and quality of life questionnaire measured perceptions over the previous two months. Therefore in order to fully assess whether doctor-patient communication does indeed impact on illness outcomes it is necessary to have a longitudinal study design where assessment of symptoms is taken at baseline, and following a consultation.

Another potential concern is the use of unrelated doctor-patient dyads. In the initial design of the study it was thought suitable to compare a general doctors' group with an IBS patients' group as a way of assessing if scores between the two groups were different. Whilst this does show a lower mean score for the IBS group the results also

report a greater degree of variance in the IBS sufferers group, particularly for distress relief and rapport. Although the variables are normally distributed, it does suggest that the relationship between individual patients and their specific doctors may prove to be a more worthwhile comparison. However, it would still be perceived communication not actual communication which would be the important independent variable. It should be noted that the use of unrelated doctor-patient dyads does not negate the findings, but it does mean that it is potentially harder to find a difference between groups. It may therefore be the case that the significant difference between doctors' and patients' observed here actually demonstrates that the underlying theory is strong.

CONCLUSIONS AND FURTHER RESEARCH

This chapter has demonstrated that the CSM is a model which should be investigated in IBS research. However, the constraints of the study mean that the specific relationships between doctor-patient communication and illness representations are currently unclear. However, the results of this study offer an important insight to the development of intervention research in IBS as they do not provide any firm justification for focussing on the therapeutic relationship in the intervention. This conclusion echoes the results of a study by Ilyckyj et al. (2003) who found that an intervention to improve the 'therapeutic value' of a GP visit had no impact on subsequent IBS symptoms.

The next stage of this thesis is to examine the other proposed external contributing factor to illness representations, social support. Accordingly the next chapter (chapter 5) will report the results of a study investigating the role of perceived social support and attitudes to IBS. In addition to this being an important component of the model and therefore as worthy of investigation as the potential role of doctor-patient communication further justification is provided by the results to the current study. This justification comes from the results relating to HRQOL. This research strongly suggests that illness representations impact on perceived HRQOL, and on symptoms (at least indirectly). It therefore appears that an intervention that includes a component addressing HRQOL will be efficacious. It is therefore essential that the role of social support in illness representations be investigated. The results of this study are presented in chapter 5.

CHAPTER 5

STUDY 2

ATTITUDES TO IRRITABLE BOWEL SYNDROME (IBS), ILLNESS REPRESENTATIONS AND OUTCOMES

Aim

Chapter 5 reports the results of study 2. This was an exploratory study which investigated the role of perceived social support in irritable bowel syndrome. This study complements the research on doctor-patient communication as it investigates the other external contributing factor to illness representations. The aim of this chapter is to assess the importance of perceived social support in current illness representations. As with the previous study it is important to investigate the factors that impact on the illness representations sufferers hold in order to identify those areas that need to be challenged in order to alter illness representations.

There were a number of different research questions but they are grouped into four main areas of interest. The first area was an investigation of the attitudes that the general population held towards sufferers of IBS (in comparison with other illnesses). The second was a comparison of the general populations' attitudes towards IBS sufferers, with IBS sufferers' perceptions of the general populations' attitudes towards them. The third area of investigation was an assessment of the potential impact of IBS sufferers' perceptions of the general populations' attitudes, on their illness representations and illness outcomes. The fourth and final area of investigation was an exploration of the relationship of illness representations and illness outcomes independently from perceived attitudes to IBS.

INTRODUCTION

As with the previous study (doctor-patient communication) the original impetus for this study was driven by reports from sufferers at IBS Network meetings. At the meetings sufferers expressed concern over the attitudes that non-sufferers held

towards their illness. Many sufferers reported that people held negative opinions towards them. In some cases sufferers reported these negative attitudes, in particular amongst friends and family, as resulting in a perceived lack of social support. The emotion expressed by many sufferers shows their strength in their belief of the perceived lack of social support. In order to assess the validity of the claims of the IBS sufferers a literature search was initiated. This was divided into two main areas. The first area is literature relating to the attitudes of the general population. The second area is literature relating to IBS sufferer's perceptions of other people's attitudes towards them. Although both the IBS Network and the Chicago division of gastroenterology are currently conducting research into attitudes of the general population to IBS there is no literature to date investigating perceptions of the general population. This is because the literature on attitudes to IBS is either from the patient's perspective (dealt with in the next section) or from the medical profession (as was described in chapter 5). As the present study compares perceptions of IBS with asthma and epilepsy the example of epilepsy will be given here. Epilepsy was chosen because there is a wealth of literature available investigating attitudes towards epilepsy amongst many different population groups and cultures. Although direct comparisons between IBS and epilepsy are not possible it is hoped that this example with place the results of this study in the context of the current literature as attitudes towards IBS reported here, can be compared to the attitudes towards epilepsy. Although there is also a large literature on other chronic illnesses, it was not felt worthwhile to include additional examples as their results may not be generalisable to IBS.

ATTITUDES OF THE GENERAL POPULATION

The literature relating to the attitudes of the general population towards sufferers of chronic illness falls into a number of different terms. Some studies specify attitude as a continuum from a positive to negative (e.g. Young et al., 2003), other studies investigate negative attitudes in the context of stigma (e.g. Snadden & Brown, 1992), and others consider attitudes to be inherently linked to social support (Hogan et al.,

2002). Whilst arguably these terms have distinct meanings[1], in the literature the boundaries are often blurred. However, each of these pieces of research shares a commonality, in that they aim to elucidate the views of society in the context of chronic illness.

ATTITUDES TOWARDS EPILEPSY

One of the most researched areas in the context of attitudes to chronic illness (aside from mental illnesses, and HIV/AIDS) is epilepsy. The literature on attitudes to epilepsy covers a wide range of different groups and cultures. Although not directly relevant here there are a number of studies investigating attitudes towards children with epilepsy, and in particular teachers' perceptions of epileptic students (e.g. Sanya et al., 2005; Sharkawy et al., 2006; Birbeck et al., 2006). In addition a large number of studies have been conducted cross culturally, showing a large discrepancy in the attitudes held (Doughty et al., 2003). Two examples of countries that report particularly negative attitudes are Vietnam (Le et al., 2006) and India (Radhakrishnan et al., 2000).

Le et al. (2006) conducted a large scale population survey of one thousand randomly selected people in Vietnam. The findings revealed a large degree of stigma towards epileptics with 56% reporting that they would not allow one of their children to marry someone with epilepsy, and 42% believing that epileptics should not be employed in mainstream employment. It is suggested that these negative attitudes result from a lack of understanding of epilepsy and indeed this does appear to be the

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[1] **Stigma** – There are a number of different definitions of stigma, but essentially it is considered to be a social construction whereby there is recognition of a difference based on some distinguishing factor. This can either be visible, such as in the case of a physical deformity, or race, or can be less obviously visible, such as homosexuality, or chronic illness. In the less obviously visible illnesses disclosure (either full or partial is more relevant). The essential component of stigma is that the knowledge of the 'distinguishing factor' results in a devaluation of the person.
Social Support – There are a number of different conceptualisations of social support, but essentially it comprises four main components. Firstly the structural aspects of a social network e.g. size of social network and the resources available. Secondly functional aspects of social support, this involves emotional support and a sense of acceptance (this can be related to stigma). Thirdly the actual enacting of the support, that is it is not just the availability of the resources, but the provision of these when they are needed. Finally the subjective perception of whether support will, or has been given.
Attitudes – Attitudes are the opinions people hold on topics and issues. Attitudes are complex differing in degrees of negativity, and in strength. It is also possible for conflicting attitudes to be held, such as in the form of cognitive dissonance. The attitudes a person / group have can in an extreme form be considered a stigma, and will necessarily affect the social support they will provide.

case with 24% of participants reporting epilepsy to be a form of dementia. The results of the study by Radhakrishnan et al. (2000) suggest that a large degree of stigma is also observed in south India. Their exceptionally large study was based on 238,102 people, all of which were from households without an epileptic. Their results showed that 27% of the sample thought that epilepsy was a form of insanity, and 40% did not think that epileptics should be employed in mainstream employment. They do not report opinions regarding marriage of offspring to epileptics, but their results do report that 11% of parents would object to their children being friends with a child who has epilepsy. These results are consistent with Le et al. (2006) and suggest that even the most recent research shows some countries hold negative attitudes towards epileptics. Although there have been many studies conducted in a variety of countries the ones most relevant to the attitude study presented here is that of western countries. In contrast to the negative attitudes seen in some cultures the western research suggests that attitudes towards epilepsy have improved since the 1940s (the first study was conducted in 1947). It would appear that the most marked changes have occurred from late 80s. It should be noted that despite the negative attitudes in some cultures there is still a general trend towards improvement since the 80s, as research in the Czech Republic demonstrates (e.g. Novotna & Rektor, 2002). A study by LaMartina (1989) in the USA revealed that one in three Americans held negative attitudes towards epileptics and their families, and one in six believed that epilepsy is a form of mental illness. Although recent research suggests that some groups, e.g. adolescents may perceive stigma in relation to their epilepsy (MacLeod & Austin, 2003), research investigating the perceptions of the general population towards epileptics suggests that negative attitudes are not generally the norm, although they still stress people should be better educated about epilepsy (Kobau & Price, 2003)

A recent study by Young et al. (2002) gives a clear indication of the current research findings regarding attitudes towards epilepsy. This was a questionnaire based study of Canadian college students (n=191). The questionnaire comprised three sections, demographic information, knowledge and attitudes. Although the study design could be criticised for its limited sample and use of closed questions to assess attitudes, the results yielded are extremely strong and clear. They show that attitudes to epilepsy are 'uniformly favourable' with more than 80% of students answering each of the

attitude items favourably, these were: 1) children associating with persons with epilepsy 95%, 2) relative marrying someone with epilepsy 95%, 3) whether epileptics should have children 84%, 4) whether epileptics should be employed in the same jobs as other people 84%. In addition for attitudes towards the work place it is likely that the slightly lower positive rating was related to concerns over safety rather than stigma relating to abilities.

The results of the previous study are supported but studies conducted in other countries, such as the research of Jacoby et al. (2004) in the UK, which found that on the whole people's attitudes towards epileptics were positive, but a fifth of the sample (total sample size n= 1600) agreed with the statement that 'people with epilepsy have more personality problems, than people without epilepsy'. Research by Spatt et al. (2005) in Austria reported that only ten percent of the sample (total sample size n= 2128) reported having negative attitudes to epileptics. Further support is provided by Hills & MacKenzie (2002) in New Zealand. Their study, conducted on 400 participants showed that 'attitudes towards epilepsy were favourable', with only five percent of the sample reporting negative attitudes.

In the Young et al. (2002) study it was suggested that negative attitudes towards epileptics in mainstream employment may be one area of negativity that is still observed in western cultures. Although they suggest that this is due to 'concern' rather than 'stigma', it is still a cause for concern. Therefore two final papers investigating attitudes towards epilepsy specifically within the context of the workplace will be discussed. The first study is by Harden et al. (2004). This is in a slightly different style from the standard questionnaire based research as it used vignettes. 200 employees (in two companies in New York) were given three vignettes describing a co-worker. One had depression, one multiple sclerosis (MS) and the other one had epilepsy. It should be noted that the epilepsy vignette did not describe a seizure. Of the 74 returned study packs it was discovered that participants reported more anxiety with regards to potentially working with an epileptic, although this was not significantly different from the other groups. There were however significant differences between groups with worry about 'sudden, unpredictable behaviour' scoring significantly higher for epilepsy than for MS. Interestingly the finding of significantly less comfort providing first aid for epileptics compared with

both other groups, suggests that negative attitudes towards epileptics in the work place are perceived by those that hold them to be as a result of health concerns, rather than stigma. However, it could be argued that the uninformed opinion of the working abilities of epileptics as a whole, as opposed to individual's abilities and level of expertise is still discrimination, and is based on a lack of understanding about the condition. Whilst it may be the case that some environments are unsuitable for epileptics, due to seizure triggers, such as strobe lighting in a night club, this certainly does not mean that negative attitudes towards general employment are acceptable. A recent study by Jacoby et al. (2005) provides useful information relating to the employment of epileptics and shows that although there is an overall improvement of attitudes towards epilepsy within the general population, this is not held when employment is specifically referenced. Their cohort comprised 204 employers who were sent a survey asking about employment opportunities for epileptics. The results revealed that 16% said that there company did not offer any jobs suitable for epileptics, 21% thought that employment of an epileptic would be a "major issue", and rather worryingly around 50% of the sample reported that the thought of working with an epileptic person caused them to feel "major concern".

Although only a small selection of research is reviewed here there are three findings which can clearly be taken from the previous review. Firstly that attitudes to epilepsy differ as a function of culture with western cultures generally reporting more positive findings. Secondly that attitudes towards epilepsy in all cultures have become more positive in the last couple of decades, and lastly that attitudes towards epileptics in the work place are more negative than attitudes towards epileptics in general. The literature on epilepsy is useful as it provides a clear report on people's attitudes to this chronic illness, by comparing IBS to epilepsy it will be possible to gain some idea of the strength of people's attitudes to IBS specifically.

POTENTIAL IMPACT OF IBS SUFFERERS' PERCEPTIONS OF OTHER PEOPLE'S ATTITUDES TOWARDS THEM

Although it is not ideal to draw too many implications from the research on epilepsy it should be noted that within the context of the common sense model (CSM Leventhal et al., 1980; 1984) it is not the actual attitudes held by the general

population, but the perceived attitudes held by the IBS sufferers that are of importance. As the CSM was described in detail in chapter 4 this will not be repeated here, however, the rationale behind the investigation of perceived attitudes will be briefly described below. The relationship between perceived attitudes and illness outcomes is considered to act on similar processes as perceived doctor-patient communication. That is the perception of attitudes forms part of the social messages component in the interpretation part of the model, however, as was explained earlier each stage of this model impacts on the other stages. It is possible that the attitudes of significant others will show a stronger relationship with the illness representation components, than doctor-patient communication. This is because, of the three primary sources of information, 1) social communication and cultural knowledge, 2) external social environment and significant and authoritative others, 3) current (including previous) symptom experience (Leventhal et al., 1980; 1984) doctor-patient communication only relates to category 2, whereas the attitudes of the general population encompass both category 1, and also (specifically within the context of social support) category 2. This is therefore a much broader category than the unique relationship between the doctor and the patient, and one that is much more integral to the daily experience of the patient.

The suggestion of a relationship between perceived attitudes and health outcomes is not unique to the CSM. It is integral to the underlying theory of biopsychosocial approaches to health. A review by Gaynes & Drossman (1999) reports a clear and protective relationship of social support to health. They state:

"The degree to which individuals maintain close personal relationships with others can promote health status and help protect against the various stressors on ones health"

Numerous pieces of research confirm this relationship across a range of illnesses, as the review by Hogan et al. (2002) demonstrates. Echoing the views of Gaynes & Drossman (1999) they comment that research repeatedly provides evidence of the protective nature of social support for long term health outcomes. This is stated to be primarily a function of the two interconnected aspects of better immune function and lower blood pressure. In fact the article goes on to say that the beneficial relationship

of social support is so strong that interventions based on improving social support are efficacious at improving health outcomes across a range of illnesses. It should be noted however, that the active components of these interventions are not currently established. Although there were no intervention studies investigating the role of social support in IBS at the time of this review, the range of illnesses included (e.g. cancer, obesity, cardiovascular disease etc.) suggest that the results should be generalisable. This is a view that is shared by Gaynes & Drossman (1999) who in fact considered the relationship between social support and illness outcomes to be so well established, that they made two key recommendations specifically relating to social support in IBS. The recommendations they made were 1) that the way the family interact with the IBS sufferer has an impact of their illness outcomes, and 2) that the patients' overall social network is vital to their illness outcomes. It is therefore important to conduct research to assess the validity of these claims, and it is therefore important not just to assess the actual attitudes held by the general population, but the patients' perceptions of these attitudes.

There is only a handful of papers that investigate 'perceived attitudes' in IBS specifically, but what does exist suggest that this is both an important and under researched area of study. These papers will briefly be described here.

Dancey & Backhouse (1993) conducted a cross-sectional questionnaire based study which asked 148 IBS sufferers (IBS Network members) a number of questions about the perceived impact of their illness across a range of different dimensions. Their results showed that IBS affects all aspects of sufferers' lives and only one of these aspects was their relationships with other people, of which perceived attitudes was a contributing factor. Although this research is useful as it provides preliminary evidence for the potential impact of the perception of negative attitudes of the general population, and of those people who make up the sufferer's social network, there are clearly a number of limitations to this study. The first limitation is the questionnaire based design, which may have elicited more negative responses, than an interview or a focus group. Secondly although there are over one hundred respondents it is possible that there is a sampling bias towards people with more negative attitudes taking part in the studies. The third and main limitation of this study is that the variable of perceived attitudes is very limited, and therefore research

which is specifically focussed on this aspect is clearly needed before any firm conclusions can be drawn.

In a further study Dancey et al. (2002) investigated the factors which contribute to illness intrusiveness and quality of life in IBS sufferers. This study is similar in design and aim to the Dancey & Backhouse (1993) study, but differs in that it directly investigates perceived stigma as an independent construct. This cross sectional questionnaire based research used a different cohort of IBS Network members, but participant numbers (n=117) and potential concerns regarding biases are similar. The results indicated that perceived stigma negatively correlated with quality of life; that is as perceived stigma increased reported quality of life reduced. In addition an interesting finding was that although perceived stigma was negatively correlated with quality of life for the sample as a whole, significantly worse effects were noted for men. This suggests that studies investigating the impact of perceived attitudes on IBS outcomes should compare the effects on males and females, as there may be some differences between these two groups.

The previous studies are useful because together they provide preliminary evidence both for IBS sufferers holding negative perceptions of the attitudes of the general population towards them, and also for the potential impact of these perceptions on quality of life. Certainly the Dancey et al. (2002) study is consistent with the views proposed by the CSM, although the relationship between attitudes and symptom outcomes was not found to be significant. Clearly more research is needed to fully explore these relationships.

In a different style of research Munir et al. (2005) investigated predictors of disclosure of chronic illness at work. They looked at a range of chronic illnesses, including IBS, with a large sample of 610 participants. Partial disclosure (informing line managers about the presence of a chronic illness) and full disclosure (informing line managers how that chronic illness affected them at work) were predicted by discrete management factors. The study showed that for partial disclosure greater experience of illness was predictive, and this was said to be related to the need to receive practical support at work. However, when considering the context of full

disclosure although illness experience was still found to be predictive, social support factors were additionally found to be independent predictors of disclosure. Therefore full disclosure was significantly more likely if colleagues had already been supportive to illness disclosure, and if the sufferer perceived their line managers as supporting their disclosure. An interesting finding was that academics were less likely to disclose their illness, but whether this is a function of a perceived lack of social support or whether the flexibility of working practices meant that it is not essential for a majority of sufferers is unclear. One of the most useful findings to emerge from this research is homogeneity of disclosure across illness groups, with only diabetes sufferers reporting significantly more partial disclosure to their line managers. The authors suggest that this may be due to the specific management strategy employed in diabetes, but more research is needed to clarify this distinction. The results relating to the other illness groups suggest that prediction of disclosure for IBS is therefore not distinct from other medical illnesses. This is interesting as in their introduction the authors suggest that IBS is a more 'stigmatising health condition' than established organic illnesses, but this was not shown by the study itself. There are a number of possible reasons why this difference was not observed. 1) There is no difference between stigmatising and non-stigmatising illnesses, 2) IBS is not stigmatised, 3) a measure of stigma was not actually included in the study, 4) a response bias meant that highly stigmatised individuals / very severe sufferers were not included in the sample, 5) that conducting the study in one UK university (despite the range of professions within the environment) may not be truly generalisable.

Although the lack of research in this area makes it difficult to fully establish the role of perceived attitudes in IBS health outcomes (Jones et al., 2006; Koloski et al., 2001) the growth in the research effort in this area over the next few years by Dancey and the Chicago division of gastroenterology, means that many unresolved questions may be answered. To date the most informative research, as it places IBS within the context of both other functional illnesses, and illnesses with an established organic cause it that of Looper & Kirmayer (2004). The aim of their research was to compare levels of perceived stigma between illness groups. It was a cross-sectional questionnaire based design that compared three functional somatic symptom illnesses (FSS), with three matched organic illnesses. There were a total of 238 participants

divided between six different illnesses, these were chronic fatigue syndrome (CFS - n=42) paired with multiple sclerosis (MS - n=33), fibromyalgia (FM - n=35) paired with rheumatoid arthritis (RA - n=39) and IBS (n=38) paired with inflammatory bowel disease (IBS - n=51). The results showed that there were greater levels of perceived stigma overall when comparing the combined FSS group with the organic illness group. However, for IBS specifically there was no difference with the matched illness of IBD. The authors suggest that this is due to the symptoms of IBS being a universal experience, albeit in a less intense form. However, this is speculation rather than evidenced and is inconsistent with the research by Dancey et al. (2002). Therefore further research is clearly needed to clarify these issues. The only pair where the FSS illness was reported to have higher levels of perceived stigma was for CFS, the authors suggest that this may be due to the ambiguity of its status as a medical condition. Whilst this claim is logical the difference observed may also be a function of the pair, which was MS, which may not be as 'matched' as the researchers suggest. Overall this is a very useful piece of research, its only major limitation is that it does not address whether perceived stigma impacts on sufferers' HRQOL or symptoms. These are obviously important areas that warrant further study.

One study which implies attitudes of others and the need to obtain social support impacts on sufferers' illness outcomes is that of Coulson (2005). In a novel style of research, which he has been utilising across illness types Coulson (2005) investigated the use of IBS specific internet message boards as a means of gaining social support from other sufferers and sympathisers. He used deductive thematic analysis on the 572 messages posted during an eight month study period in 2004. He found that the primary function of the internet message group was the provision of social support, both informational support (symptom interpretation, illness management and interaction with health care professionals) and also in the other forms of social support most closely related to attitudes (emotional support and self-esteem).

It is therefore clear that this is an under researched area, and one where there is justification for conducting further research. The aims of this research are therefore to support and extend the literature in this area. Its broad aims are:

1) To investigate the attitudes that the general population hold towards sufferers of IBS (in comparison with epilepsy and asthma).
2) To compare the general populations' attitudes towards IBS sufferers, with IBS sufferers' perceptions of the general populations' attitudes towards them.
3) To assess the potential impact of IBS sufferers' perceptions of the general populations' attitudes, on their illness representations and illness outcomes.
4) To explore the role of illness representations and illness outcomes independently of perceived attitudes to IBS.

METHODS

PARTICIPANTS

GENERAL POPULATION

Opportunity and snowball sampling was used to recruit from the general population. Questionnaires were administered by hand, through the post or via e-mail. A total of 350 questionnaires were administered, of which 252 were returned (response rate 72%). Of the 252 questionnaires returned 13 were excluded from the analysis due to missing data. Therefore there were 239 participants included in the analysis. Of the 239 participants there were 83 men and 155 females (one unspecified), the mean age of participants was 36.4 (SD 15), and ages ranged from 18-81. The majority of participants were British (87%).

IBS PARTICIPANTS

Although this was a different cohort of IBS participants than was used for study 1 the methods for recruiting were the same (opportunity and snowball sampling – for details see chapter 5). 130 packs were distributed to IBS sufferers (same inclusion and exclusion criteria as for study 1) and 62 packs were returned (response rate 48%). This is an almost identical response rate to study 1. Of the participants there were 53 females, and 6 males (3 unspecified). This means the percentage of females was between 85% and 90%, this is again similar to the reported percentage of females in study 1 (86%) and in other studies (e.g. Dancey et al., 1995; Lackner et al., 2004). Participants' ages ranged from 19-71 years, with a mean age of 43 (SD

14). This is slightly lower, but again similar to study 1 (19-78 years, mean 47.1 SD 17). 51 % of the sample were members of the IBS Network.

The average time since diagnosis of IBS was 10.5 years (SD 9.6), with a range from less than a year to 33 years. The average time from first experiencing symptoms to being diagnosed was 5.5 years (SD 8.3), with a range from less than a year to 33 years. Within the main IBS group the numbers of participants in the three IBS subgroups were as follows, IBS-D (n=26), IBS-C (n=15), IBS-A (n=18), NB three participants did not specify their subgroup. With the exception of two Americans all participants were resident in the UK. Just over half of the sample was highly educated with 53% achieving 'A' levels or higher and only 10% of the sample reported having no academic qualification. Exactly 50% of the sample reported having another illness. The most often reported illnesses were arthritis (8%) and asthma (5%), the only specified psychological illness was depression at 15 % of the sample. All of these participant characteristics are very similar to the sample for study one, the two main differences are that the percentage of the sample that have no qualifications is approximately half in this cohort, and that hypertension was not reported as a frequent additional illness.

MEASURES

A number of the measures used are the same as in study 1, so these will not be detailed here. The measures which are the same are:

A disease specific version of the IPQ-R (Moss-Morris et al., 2002, *appendix 1*)

The IBS-36 (Groll et al., 2002, *appendix 2*)

The 7-day symptom diary (*appendix 3*)

There were two versions of the 'Attitudes to Chronic Illness Questionnaire' designed for the purposes of this study. There was one version for the general population (*appendix 13*), and one for the IBS participants (termed *PSSS, appendix 14*). The general population version will be detailed first.

General population version of the attitudes to chronic illness questionnaire. An important feature of the general population version of the questionnaire is that it did not only ask questions relating to IBS. The questionnaire also contained parallel questions for asthma and epilepsy. There were two main reasons for the inclusion of these additional illnesses. Firstly including the other illnesses minimises the potential for bias within the questionnaire as it allowed for the individual symptoms to be listed, rather than asking direct questions about IBS. This means that the participants were not aware that the direct aim of the study was to assess attitudes towards IBS, and therefore it is hoped that the responses are more accurate. Secondly, rather than simply reporting in a qualitative manner the percentages of people reporting positive / negative attitudes, the inclusion of other illnesses allows for an assessment of attitudes to IBS in comparison with other illnesses, in particular those which have been more extensively studied, such as epilepsy. Care was taken in the illness selection to choose illnesses with some similar components to IBS, the main components were:

- Variety of symptoms
- Differing levels of severity
- Chronic but characterised by periods of symptoms and remissions
- Unpredictability of symptoms
- Perceived embarrassment of symptoms
- Restrictions to social activities

Despite the desire to have similar illnesses the decision was chosen to include illnesses with an established organic component in order to provide comparative data in the same style as Looper & Kirmayer (2004).

The questionnaire was divided into five sections.

Section 1

This section asked participants about the level of comfort they felt *discussing* illness symptoms. It consisted of an eight point Likert scale which ran from (1) extremely comfortable to (8) not prepared to discuss this symptom. It contained a list of the 28 symptoms most commonly associated with each of the illnesses. Of these 28

symptoms eight refer to IBS (numbered 7,10,20,18,26,12,15,2), twelve refer to epilepsy (1,22,16,21,17,8,27,24,5,14,11,4) and the remaining eight refer to asthma (6,9,13,28,19,25,23,3). It is important to note that as there are unequal numbers of symptoms in each group the scores reported in the analysis are the mean scores (i.e. total IBS / 8, total epilepsy / 12) rather than the total scores which would have necessarily resulted in epilepsy scoring higher.

Section 2

This section asked participants about the level of comfort they felt *witnessing* illness symptoms. In all other characteristics (other than now saying witnessing) this section was identical to section 1.

Section 3

This was a parallel version to the perceived consequences scale of the IPQ-R. There are six sub scales within this section (although the questions are counterbalanced to that they appear as one scale of 30 questions). The first scale relates to perceptions of the physical consequences of having each of the illnesses, the second scale relates to perceptions of the social support impact of having each of the illnesses. Although the questions in the two scales were different they contained the same amount of questions and were scored the same. For each illness there were five questions per scale. The responses were scored on a 5 point Likert scale from (1) strongly disagree to (5) strongly agree. An example of one of the questions on the perceived physical consequences scale is, "IBS is a serious condition". An example of one of the questions on the social support impact scale is, "if a person had epilepsy it would strongly affect the way I viewed them". With the exception of the asthma physical consequences sub scale where the alpha coefficient was quite low at 0.39, the alpha coefficients of the other scales were reasonable. The coefficient for the IBS physical consequences sub scale was 0.60 and it was 0.72 for the social support impact sub scale. The coefficient for the epilepsy physical consequences sub scale was 0.63, and it was 0.75 for the social support impact sub scale. The coefficient for the asthma social support impact sub scale was 0.70.

Section 4

This scale asked participants to imagine that they had a friend who suffered from each of the illnesses, and to report the concessions and favours that they would be prepared to undertake for a friend. This is referred to in the results section as the social support concessions scale. In total this scale comprises eighteen questions, scored on a 7 point Likert scale from (0) never, to (6) always. There are three sub scales (one per illness) of 6 questions each. An example of a question in this section is "I would be happy to avoid travelling on public transport if my friend did not want to due to worry about having an IBS attack". This section is scored by summing the 6 questions in each section (note questions 5, 13 and 18 are reversed and therefore need to be recoded prior to computation of the total score). The alpha coefficients for the three illness subscales were fair at IBS 0.79, epilepsy 0.77, and asthma 0.82.

Section 5

This was a simple scale which listed fourteen common social activities that are either not possible or difficult for sufferers of one or more of the illnesses to be involved in. This is a 6 point Likert scale scored from (0) never, to (6) always. It includes going out to dinner, night clubs and the cinema. Participants are asked to indicate how often, on average they would be prepared to avoid each of the activities when planning a social event, in order to allow their friend with the illness to be included. These can either be taken as individual activities or summed to provide a total 'social activity' score.

IBS version of the attitudes to chronic illness questionnaire termed the perceived social support scale (PSSS). The IBS version of the Attitudes to Chronic Illness Questionnaire is similar to the general population's version. It differs in three main ways.

The first difference is that this version only asks questions relating to IBS, this means that for sections 1 and 2 there are 8 symptoms per section, and for section 4 there are six questions. The section 5 social activity section is identical, and the Likert scale and scoring for each of these sections are the same. An example of one of the questions in section 4, which is the perceived social concessions and favours section would be, "on average my friends and family would be happy to avoid travelling on

public transport if I did not want to due to worry about having an IBS attack'. The alpha coefficient elicited for this scale is 0.84.

The second difference is that it does not ask sufferers to record their own attitudes to their illness; instead they have to record the attitudes that they think other people have towards their illness. This will be referred to as perceived attitudes, because it related to the IBS sufferer's perceptions of the attitudes of others. Because the general population questionnaire specifically asks participants to respond to the questionnaire on the basis of the person with the illness being a friend or family member, the IBS version replicates this by asking participants to consider the attitudes of their friends and family towards their illness.

The third and final way in which this version differs is that it does not include the perceived physical and social consequences subscales (section 3). These are excluded they would be an exact replica of the IPQ-R. As the participants already have to complete the IPQ-R the responses to this scale of the IPQ-R will be used in the analysis.

Demographic Questionnaire There were two demographic questionnaires used in the study, one version was administered to the IBS participants (*appendix 7*), and an alternative version for the general population (*appendix 15*).

PROCEDURE

The procedure was slightly different for the general population and for the IBS participants. For the general population the research pack was administered either by hand or by post (77%), or via the internet (33%). For the IBS participants a research pack was sent to their home addresses.

For the general population the research pack contained an information sheet along with a letter inviting them to take part in the research (*appendix 16)*, consent forms (*appendix 17*), a demographic questionnaire (*appendix 15*), and the attitudes to chronic illness questionnaire (*appendix 13*). The postal participants were also given a free post envelope for the return of completed research packs.

For the IBS participants the research pack contained an information sheet along with a letter inviting them to take part in the research (*appendix 18)*, consent forms and ethics approval (*appendix 19*), a demographic questionnaire (*appendix 7*), the IBS participants version of the attitudes to chronic illness questionnaire (*appendix 14*), *a disease specific version of the IPQ-R* (Moss-Morris et al., 2002, *appendix 1*), the *IBS-36* (Groll et al., 2002, *appendix 2*), the *7-day symptom diary* (*appendix 3*) and a free post envelope for the return of completed research packs.

DATA TREATMENT

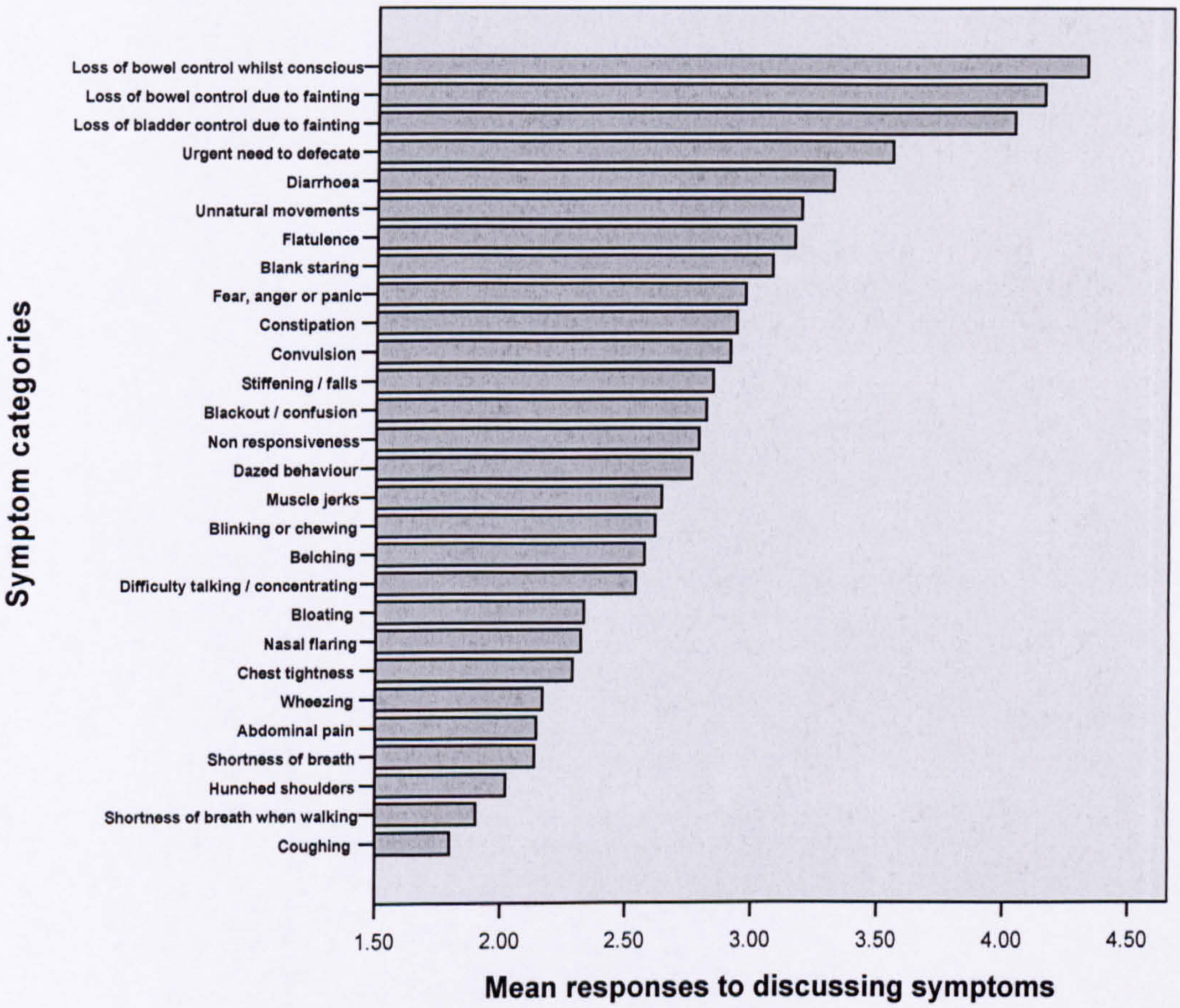
Raw data was entered into SPSS (version 14). As there was a large amount of returned questionnaires the ones with a large quantity of missing data were excluded from the analysis. With the data that remained, as with the previous research there was very little missing data, and again as the variables were normally distributed mean substitution was used. As with the previous research the functions of transformation and compute was used to produce the variables that were used in the analysis. In addition, in accordance with normal statistical procedures where multiple t-tests were used a Bonferoni correction was employed, whereby statistics were only recorded as significant if the p value exceeded that required after applying the correction.

RESULTS

ATTITUDES OF THE GENERAL POPULATION TOWARDS DISCUSSING ILLNESS SYMPTOMS

Descriptive statistics (figure 7) reveal that people do not hold negative views towards discussing any of the illness symptoms. The original scale ranged from of (1) extremely comfortable to (8) not prepared to discuss this symptom. In the responses given by the population no mean responses were above 5 (slightly uncomfortable), this shows that the majority of the responses were on the 'comfortable' side of the scale.

Figure 7 –Attitudes of the general population towards discussing illness symptoms

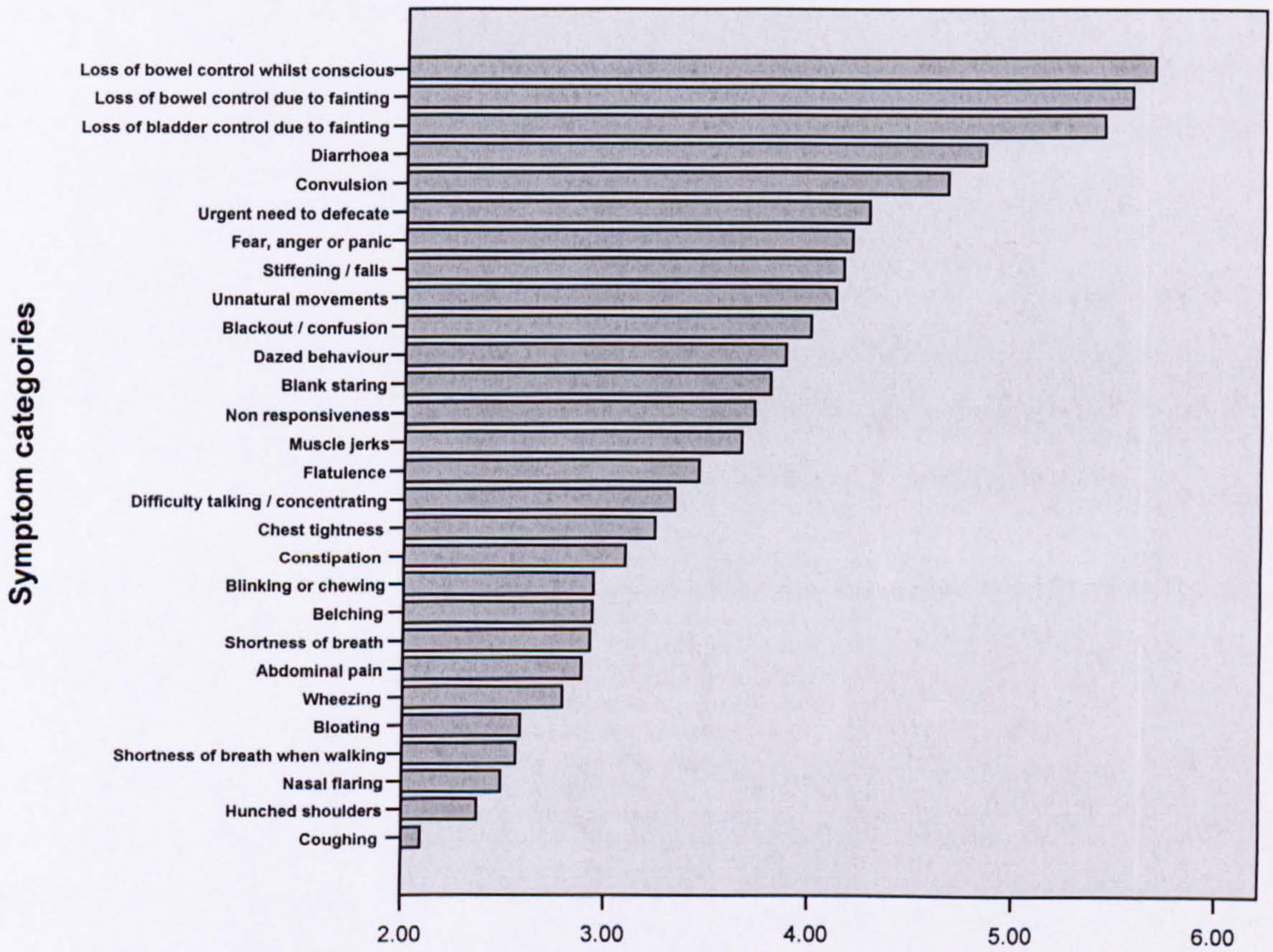


As figure 7 demonstrates there are only three symptoms leaning towards slightly uncomfortable. These are a) discussing loss of bowel control whilst conscious, b) discussing fainting spells where bowel control was lost, and c) discussing fainting spells where bladder control was lost. The first of these is an IBS symptom, although it is less commonly experienced (and closely related to an urgent need to defecate as opposed to general incontinence). The other two are related to epilepsy.

ATTITUDES OF THE GENERAL POPULATION TOWARDS WITNESSING ILLNESS SYMPTOMS

Descriptive statistics (figure 8) reveal that people do not hold negative views towards witnessing any of the illness symptoms. Although the mean scores were higher than for discussing the symptoms, the highest reported mean was still below 6 indicating that at most people felt (5) slightly to (6) moderately uncomfortable.

Figure 8 –Attitudes of the general population towards witnessing illness symptoms



As figure 8 demonstrates the three least comfortable symptoms are in the same rank order as for discussing.

ATTITUDES OF THE GENERAL POPULATION TOWARDS DISCUSSING IBS, ASTHMA AND EPILEPSY

Although it is interesting to report the responses to the individual symptoms, in order for meaningful comparisons to be drawn it is necessary to transform the individual symptoms into the three illness variables. The overall responses to the three illnesses revealed that people were least comfortable discussing epilepsy, followed by IBS and asthma (figure 9). It is however, important to note that the poorest recorded mean was 'slightly comfortable'. Paired samples t-tests revealed no significant differences between discussing IBS and epilepsy, but that people were significantly more comfortable discussing asthma than either IBS or epilepsy: asthma and IBS $t(239) = 15.03$, $p < 0.0001$, asthma and epilepsy $t(239) = 17.20$, $p < 0.0001$.

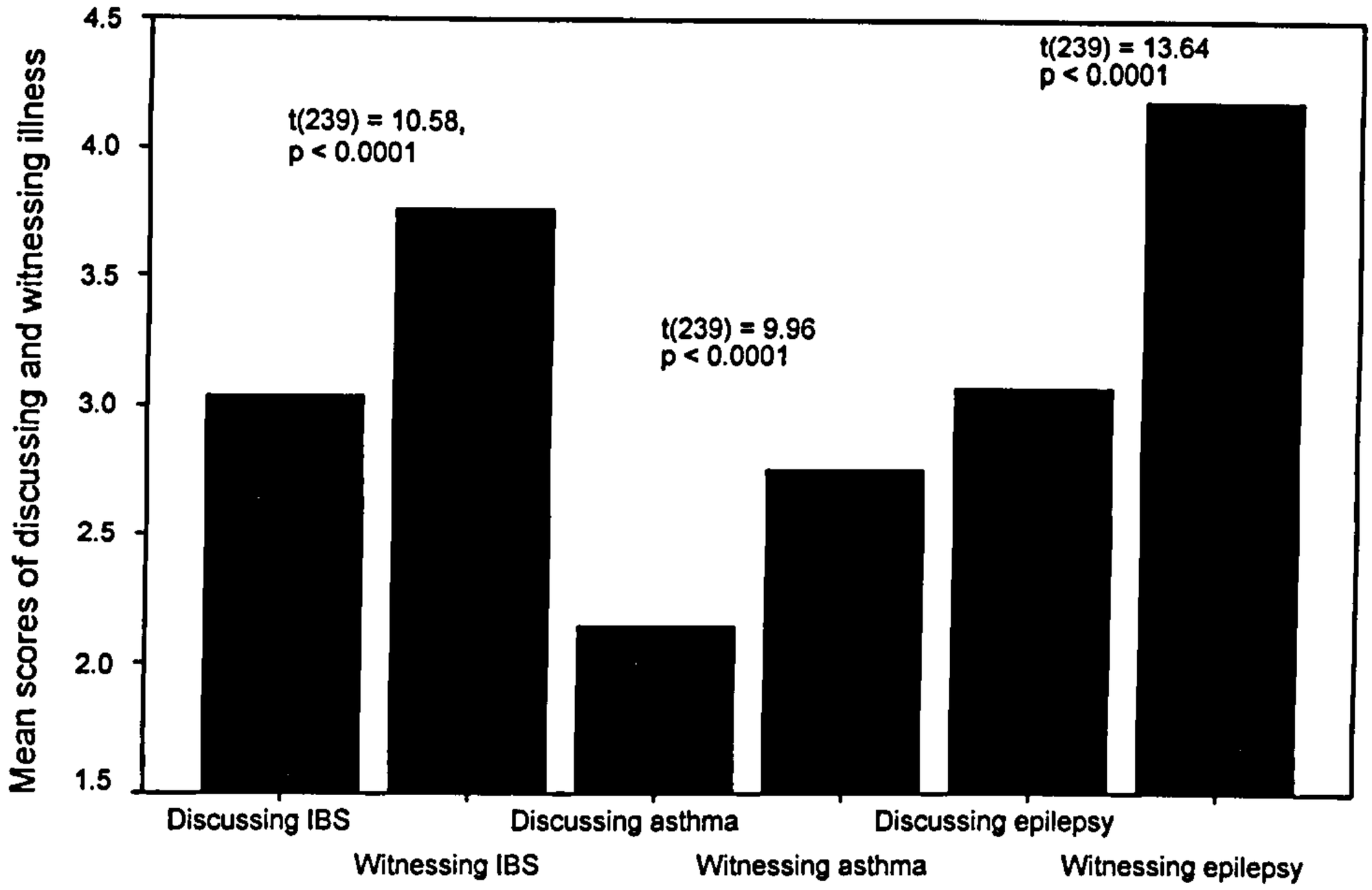
ATTITUDES OF THE GENERAL POPULATION TOWARDS WITNESSING IBS, ASTHMA AND EPILEPSY

Overall responses to witnessing the three illnesses revealed the same order as discussing. Paired samples t-tests revealed significant differences between all three variables: asthma and IBS $t(239) = 15.94$, $p < 0.0001$, asthma and epilepsy $t(239) = 23.97$, $p < 0.0001$, IBS and epilepsy $t(239) = 6.89$, $p < 0.0001$.

COMPARISON OF THE GENERAL POPULATION ATTITUDES TOWARDS DISCUSSING AND WITNESSING IBS, ASTHMA AND EPILEPSY

Overall differences for discussing and witnessing symptoms showed that for all three illnesses people felt more comfortable discussing the illnesses than they did witnessing them (figure 9).

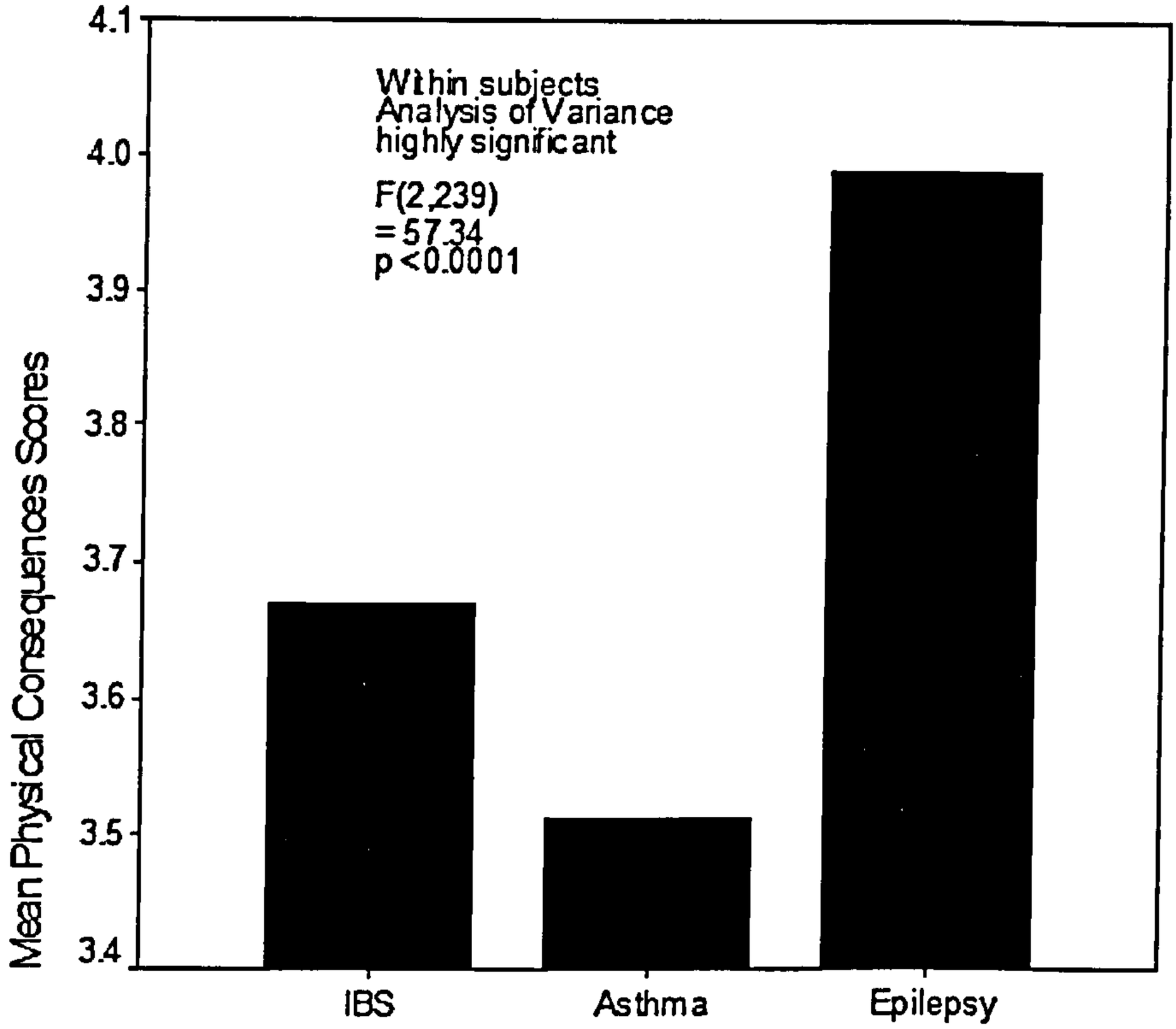
Figure 9 - Comparison of discussing and witnessing symptoms



ATTITUDES OF THE GENERAL POPULATION REGARDING THE PERCEIVED PHYSICAL CONSEQUENCES OF IBS, ASTHMA AND EPILEPSY

For the perceived physical consequences of having the illnesses the same pattern was observed as for the discussing and witnessing variables, i.e. epilepsy being considered the most serious, with IBS and asthma following. It is important to note that for each of the illnesses the mean scores were between 3 and 4 indicating that the scores were between (3) 'neither agree nor disagree' and (4) 'agree'. This indicates that none of the illnesses were judged to have serious physical consequences.

Figure 10 – Means of physical consequences scale

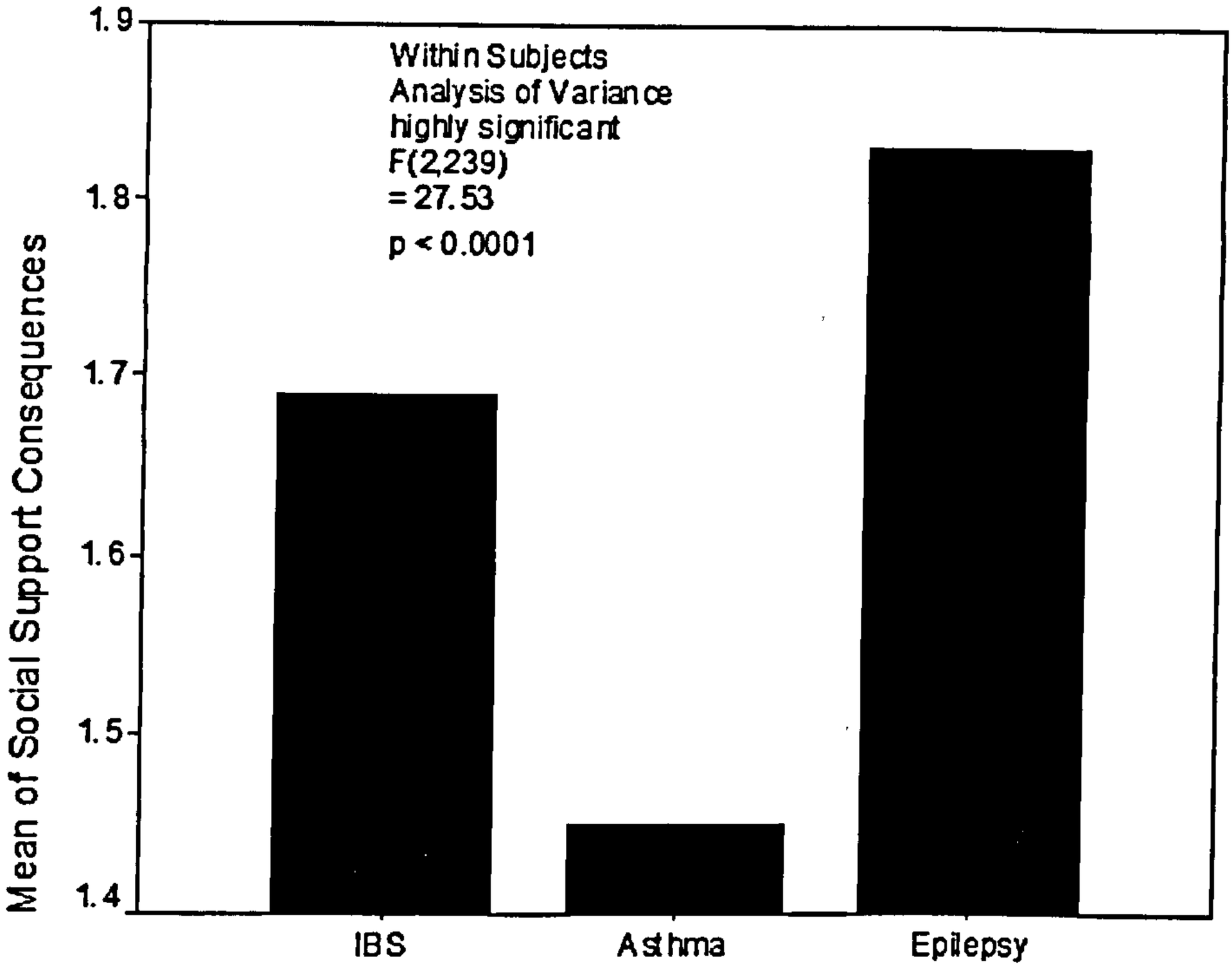


As figure 10 demonstrates there was a main effect of group. Scheffe post hoc tests found significant differences between all groups, differences between IBS and asthma, $p < 0.005$, between IBS and epilepsy, $p < 0.0001$ and finally between epilepsy and asthma, $p < 0.0001$.

ATTITUDES OF THE GENERAL POPULATION REGARDING THE PERCEIVED SOCIAL CONSEQUENCES OF IBS, ASTHMA AND EPILEPSY

For the perceived social consequences data the same pattern was observed. The mean scores were under 2, which is disagree, with asthma being closer to 1, which is strongly disagree. This indicates that people do not hold negative feelings to providing social support to sufferers of any of these illnesses.

Figure 11 – Means of social support consequences scale

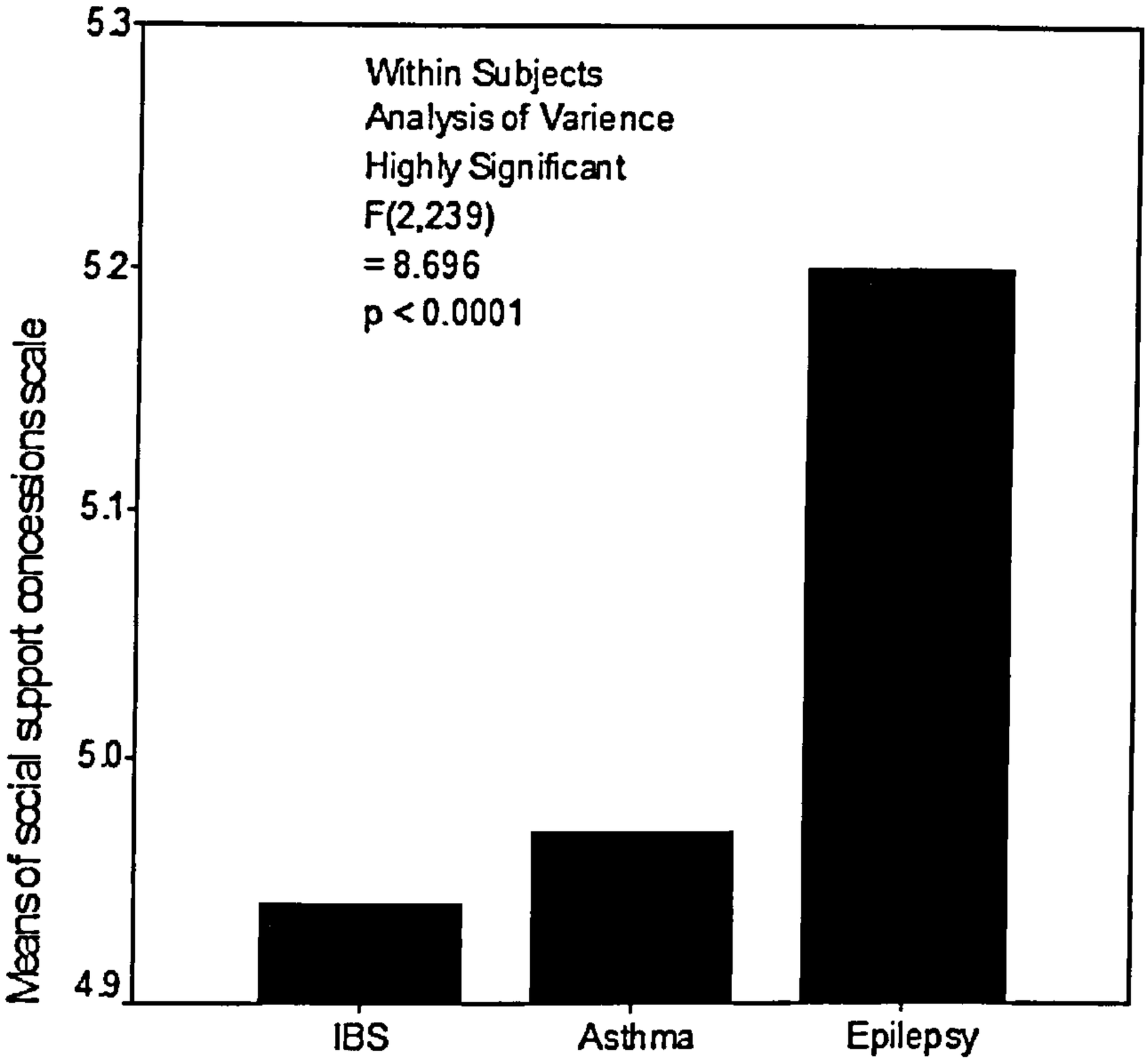


As figure 11 demonstrates there was a main effect of group. Scheffe post hoc tests found significant differences between all groups, differences between IBS and asthma, $p < 0.0001$, between IBS and epilepsy, $p < 0.05$ and finally between epilepsy and asthma, $p < 0.0001$.

SOCIAL SUPPORT CONCESSIONS SCALE

For the social support concessions scale, the mean responses were approximately 5. As the scale was from 0 to 6, where 0 indicated never prepared to make the concession, and 6 indicating always prepared to make the concession a score of five is very pleasing. This indicates that the majority of the time people are prepared to make concessions when planning social activities to allow a friend with a chronic illness to be included. Once again significant differences were observed between groups with epilepsy eliciting the greatest amount of concessions.

Figure 12 – Means of social support concessions scale

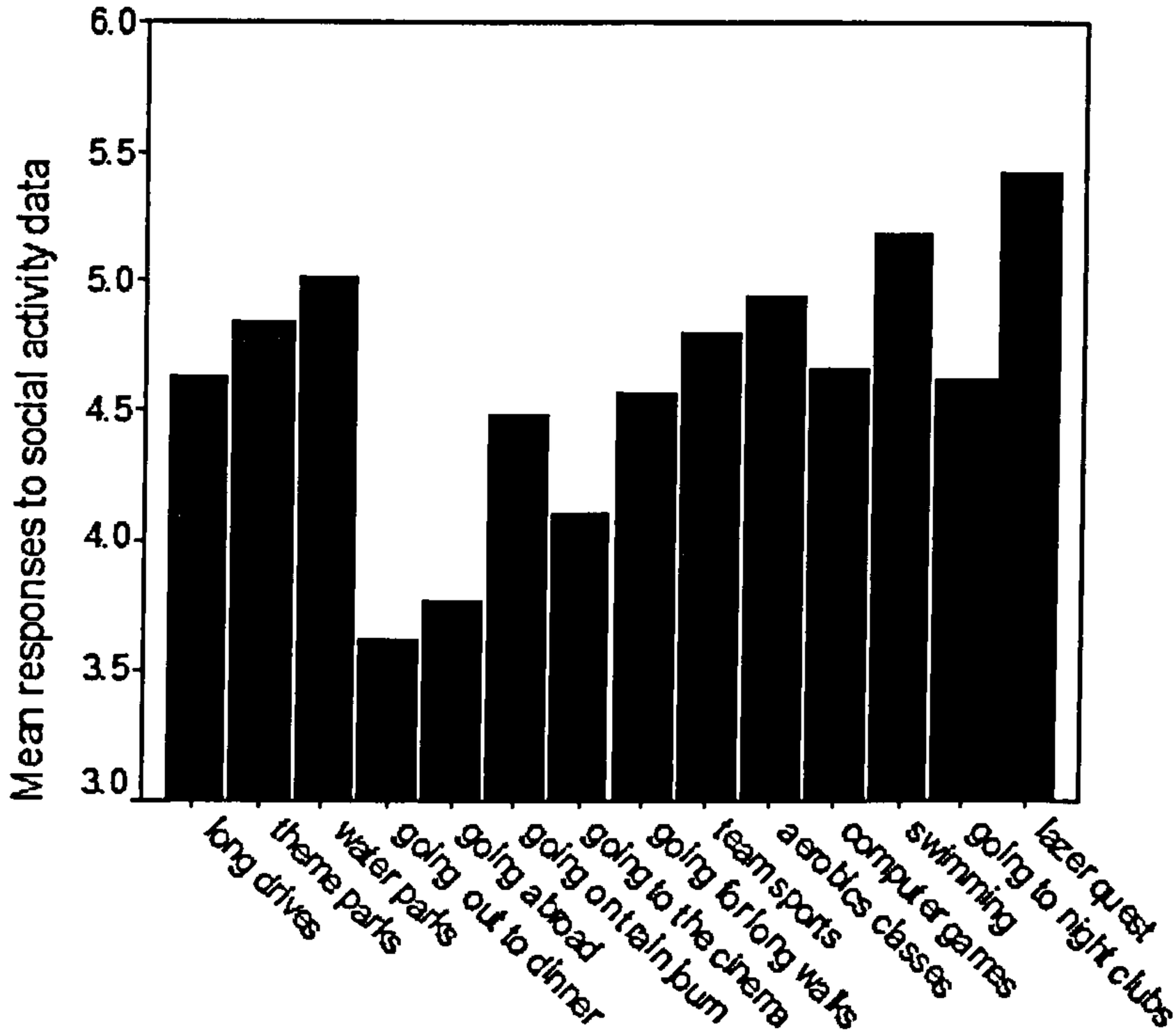


Scheffe post hoc tests found significant differences between two of the three groups. There were no differences observed between IBS and asthma, but there were significant differences between IBS and epilepsy, $p < 0.001$ and between epilepsy and asthma, $p < 0.005$.

SOCIAL ACTIVITY SCALE

Supplementing the social concession scale, the social activity scale (also scored from 0 never - 6 always) shows that for a large range of different activities people are on average prepared to avoid activities to allow their friends to be involved (figure 13).

Figure 13 – Means of social activity scale



Within subjects ANOVA revealed significant differences between activities $F(13, 3303) = 18.64$, $p < 0.0001$. Tukeys' HSD revealed that these significant differences lie between a vast number of different activities, as was expected from the p value. The most meaningful differences from the perspective of IBS sufferers are that the two activities people are least happy to avoid are going abroad and going out to dinner. However, despite these being the two activities people are least happy to avoid the mean figures indicate that for all activities at least half of the time people are prepared to come up with alternative activities.

KNOWLEDGE OF IBS FROM THE GENERAL POPULATION

The attitude scale was specifically designed to elicit responses to symptoms, and therefore did not require the participants to have knowledge of the three illnesses. However, the final part of the questionnaire comprised a qualitative section asking participants to describe what they considered to be each of the three illnesses. These responses were coded to produce a frequency table (table 22) to show the amount of

knowledge participants had. For the purposes of this thesis it is only the knowledge of IBS that is relevant (as the other illnesses were included for comparison) and therefore only the data relating to IBS will be described here. Of the 239 participants in this study data is available for 228 participants. The categories which are correct are indicated by the use of bold type font.

Table 19 – Knowledge of IBS symptoms

Category	Frequency of reported category %
Food Sensitivity	26
Diarrhoea	**41**
Pain	**37**
Bowel movement problems	**43**
Constipation	**30**
Digestion problems	**9**
Flatulence	**11**
Abdominal discomfort	**10**
Frequency of defecation	**3**
Urgent need to defecate	**15**
Bloating	**14**
Loss of bowel control	13
Episodic	**6**
Vomiting	3
Affects quality of life	**5**
Different degrees of severity	**4**
Triggered by stress	**16**

As table 19 demonstrates the vast majority of the categories were correct, but that in no case was the reporting of a particular category above half of the sample.

COMPARISON OF IBS SUFFERERS PERCEIVED ATTITUDES WITH THE GENERAL POPULATIONS REPORTED ATTITUDES

Table 20 – Significant differences between groups on attitude variables

VARIABLE	IBS MEAN	POP. MEAN	SIGNIFICANCE
Discussing symptoms	3.61	3.16	$t(298) = 2.881$, $p < 0.005$
Witnessing symptoms	4.26	3.76	$t(298) = 2.637$, $p < 0.005$
Social support concessions	4.21	4.94	$t(78) = 5.178$, $p < 0.001$
Social activity concessions	3.61	4.06	$t(78) = 3.052$, $p < 0.005$

As demonstrated in table 20 independent t-tests reveal that all four variables IBS sufferers perceive attitudes of the general population to be worse than the general population report them to be. Specifically the table demonstrates that higher means were observed for the IBS participants for discussing and witnessing symptoms (higher scores indicate more negative views), and lower means were observed for the social support and social activity concession scales (lower scores indicate more negative views). In addition to the data reported in the table a paired samples t-test was also conducted to compare the means of IBS participant's perceptions between discussing and witnessing symptoms. It was found that the mean score for witnessing symptoms is significantly higher $t(60) = 6.048$, $p < 0.0001$. One final point regarding the data here is that for the social support concessions and the social activity scales the Levene's test for equality of variance revealed the groups were non-homogeneous, therefore the statistic reported is for 'equal variance not assumed', which is why the degrees of freedom are 78.

THE RELATIONSHIP BETWEEN IBS SUFFERERS PERCEPTIONS OF THE GENERAL POPULATIONS ATTITUDES AND ILLNESS REPRESENTATIONS, HRQOL AND SYMPTOM FREQUENCY

A series of linear regressions were conducted to explore the relationships between IBS sufferers' perceived attitudes towards the four independent variables of discussing symptoms, witnessing symptoms, social support concessions and social activities, with the dependent variables of illness representations, HRQOL, total symptom frequency, and individual symptom frequency. The only significant relationship was between witnessing IBS symptoms and HRQOL R^2 adj. 0.056, β 0.27, $p < 0.05$. This shows that negative attitudes were predictive of a worse perceived HRQOL. It should however be noted that there were in excess of 60 linear regressions conducted, and chance would suggest that at least three of the relationships should emerge as significant.

ILLNESS PERCEPTIONS AND HRQOL

The analysis conducted in study 1 investigating the relationship between illness representations and illness outcomes is repeated here, as this is a different cohort. Only emotional representations were found to be predictive of HRQOL, R^2 adj. 0.370, β 0.543, $p < 0.005$. Whereby the more emotional representations about the illness the suffer holds the worse perceived quality of life is. Emotional representations were also found to be predictive of HRQOL in study 1, R^2 adj. 0.52, β 0.41, $p < 0.05$.

ILLNESS PERCEPTIONS AND SYMPTOMS

None of the illness representation components were predictive of total symptoms; this was the same as the finding observed for study 1. In contrast to study 1, however, some significant findings were observed for the individual symptoms. Both chronic timeline (R^2 adj. 0.128, β -0.378, $p < 0.05$) and illness identity (R^2 adj. 0.128, β 0.490, $p < 0.01$) were predictive of diarrhoea. The results indicate that a view that the IBS was likely to be chronic (rather than acute) was predictive of a decreased frequency of diarrhoea, and that a greater illness identity (i.e. more symptoms associated with IBS) was predictive of increased diarrhoea. Finally illness identity

was also predictive of an increased frequency of the urgent need to defecate (R^2 adj. 0.017, β 0.414, $p < 0.05$).

A final analysis was conducted between HRQOL and symptom frequency (both total and individual). In this cohort of IBS sufferers' HRQOL was neither predictive, nor correlated with frequency of IBS symptoms. This is in contrast to study 1 where HRQOL was found to predict symptom frequency.

DISCUSSION

RESEARCH AIM 1 - TO INVESTIGATE THE ATTITUDES THAT THE GENERAL POPULATION HOLD TOWARDS SUFFERERS OF IBS (IN COMPARISON WITH OTHER ILLNESSES)

The results for the first aim are highly significant and very clear. Essentially the results show that:

1) People do not hold negative attitudes towards any of the variables associated with IBS or the other two illnesses (discussing, witnessing, physical consequences, social consequences, social support and social activities)
2) Of the three illnesses for all variables epilepsy was perceived as worse than IBS, followed by asthma (discussing, witnessing, physical consequences, social consequences, social support and social activities)
3) Attitudes to witnessing IBS, epilepsy and asthma were significantly worse than for discussing
4) Knowledge of IBS was largely accurate.

Overall these results suggest that attitudes towards IBS are not associated with the stigma that has been suggested by Dancey et al. (2002), and are more consistent with the results of Looper & Kirmayer (2004). This research may therefore provide some validation to Looper & Kirmayer's (2004) suggestion that IBS symptoms are not perceived badly due to the general population having personal experience of them.

The finding that epilepsy was perceived as worse than the other illnesses is consistent with the views of LaMartina (1989), who attests that epilepsy is more stigmatised because it is less well understood. However, despite epilepsy being significantly more negatively perceived relative to the other illnesses, it was still perceived on the positive end of the scale for each of the dimensions. Therefore the findings are also consistent with the more recent research of MacLeod & Austin (2003) and Young et al. (2002) who report that negative attitudes are not generally the norm. The observed finding that people perceive epilepsy to be associated with more serious physical consequences than IBS or asthma is also consistent with research suggesting that negative attitudes towards epileptics in the working environment are due to concerns over the perceived severity of epilepsy (Young et al., 2002).

The interpretation of the finding that witnessing illness symptoms is significantly worse than discussing symptoms is difficult to interpret. In the original design of the study it was assumed that if witnessing scored more highly than discussing symptoms then this meant that IBS sufferers' concerns over the embarrassing nature of their symptoms had validity, however, this may not be necessarily the case. Part of the reason for the difficulty in interpreting this finding is that the scale asked people to rate on a scale on 'comfort' rather than 'embarrassment'. A number of people gave feedback on the questionnaire and reported that their scores on the witnessing scale were related to not knowing how to help the person, rather than a problem with witnessing the symptom per se. This is a logical explanation; it is consistent with the scoring of epilepsy being consistently higher across all variables, and with the conclusions drawn by Harden et al. (2004). Further research is needed to clarify this issue.

Knowledge of IBS is largely accurate, although this is only a descriptive statistic the results still show that there were only three reported misconceptions, and with the exception of food sensitivity (which is contentious amongst researchers) the percentages were very low: food sensitivity 26%, loss of bowel control 13%, and vomiting 3%. It should be noted that whilst vomiting is not generally considered a symptom of IBS and loss of bowel control is very rare (and related to urgency), these are not particularly strong misconceptions. In addition considering the section on knowledge was open, asking participants to write a brief paragraph to show their

understanding the lack of misconceptions is more revealing than the percentages in each category. These findings are pleasing and again provide support for the results of Looper & Kirmayer (2004) that knowledge of IBS in the general population is fairly high. One slight concern however is that knowledge of IBS may have been biased by the earlier questions and therefore future research that asks people to show their understanding prior to filling in the questionnaire is advisable.

RESEARCH AIM 2 - TO COMPARE THE GENERAL POPULATIONS' ATTITUDES TOWARDS IBS SUFFERERS, WITH IBS SUFFERERS' PERCEPTIONS OF THE GENERAL POPULATIONS' ATTITUDES TOWARDS THEM

The research findings for this aim show a clear distinction between the two groups on all variables, these are as follows:

1) IBS sufferers perceive the attitudes of the general population towards discussing IBS symptoms to be worse that the attitudes reported by the general population.
2) IBS sufferers perceive the attitudes of the general population towards witnessing IBS symptoms to be worse that the attitudes reported by the general population.
3) IBS sufferers perceive the attitudes of the general population towards providing social support concessions to be worse that the attitudes reported by the general population.
4) IBS sufferers perceive the attitudes of the general population towards providing social activity concessions to be worse that the attitudes reported by the general population.

The findings for this aim clearly show a discrepancy in the reported attitudes of the general population and the perceptions of the IBS sufferers. Although there have not been any studies conducted so far that compare perceptions of the general population with sufferers of IBS these findings are in line with the combination of research papers detailed in the introduction. That is, it is consistent with the studies that report perceived stigma amongst sufferers, such as the studies by Dancey et al. (2002) and

Coulson (2005), but it is also in line with the studies that report no actual stigma from the general population, such as the Munir et al. (2005) study and the Looper & Kirmayer (2004) study. It is clear however, that more research is needed to explain why these differences exist, as a number of hypotheses are equally viable. It could be the case that IBS sufferers perceive levels of social support to be lower than they actually are, or it may be the case that respondents from the general population overestimated their level of positive attitudes. An overestimation could emerge through either a social desirability bias, or a simple miscalculation of an idealised view of reactions, rather than how they would actually respond in a given situation. Therefore future research investigating social interactions may be useful to clarify the reasons for these consistent distinctions between groups. However, as the issue of primary concern is not specifically the differences between perceptions but whether the perceptions of IBS sufferers impact on their illness outcomes, it is the next section of results that are of most interest.

RESEARCH AIM 3 - TO ASSESS THE POTENTIAL IMPACT OF IBS SUFFERERS' PERCEPTIONS OF THE GENERAL POPULATIONS' ATTITUDES, ON THEIR ILLNESS REPRESENTATIONS AND ILLNESS OUTCOMES

Unfortunately the majority of results of this aim are not significant and due to the lack of previous research are therefore less easy to interpret; the results are therefore divided into non-significant and significant.

SIGNIFICANT FINDINGS

There was only one significant finding that is perceived attitudes to witnessing IBS symptoms predicted HRQOL of sufferers, i.e. the worse the attitudes were perceived the worse the quality of life was reported to be.

NON SIGNIFICANT FINDINGS

1) Perceived attitudes towards discussing IBS symptoms were not predictive of illness representations.
2) Perceived attitudes towards discussing IBS symptoms were not predictive of HRQOL.

3) Perceived attitudes towards discussing IBS symptoms were not predictive of symptom frequency.
4) Perceived attitudes towards witnessing IBS symptoms were not predictive of illness representations.
5) Perceived attitudes towards witnessing IBS symptoms were not predictive of symptom frequency.
6) Perceived attitudes towards the social support concessions scale were not predictive of illness representations.
7) Perceived attitudes towards the social support concessions scale were not predictive of symptom frequency
8) Perceived attitudes towards the social activity scale were not predictive of illness representations.

The finding that none of the variables are predictive of the illness representation dimensions is difficult to interpret. It is not possible to say whether the findings are true or due to methodological artefacts as there has been no previous research for comparison. They do however, contradict the closest research, that by Dancey et al. (2002) on contributors to illness intrusiveness. More research is clearly needed before any conclusions can be drawn.

The lack of a relationship between attitudes and HRQOL is rather more worrying, as this is a relationship that has been established across illness types (e.g. Gaynes & Drossman., 1999; Hogan et al., 2002) and suggests that maybe the measure is not sensitive enough to elicit the true findings. This suggestion is made more likely by the fact that the only significant finding that emerged for this research aim is that perceived attitudes to witnessing IBS symptoms predicted HRQOL of sufferers. Although it is possible that this finding is a function of running a number of regressions, it is consistent with the primary outcome of the Dancey et al. (2002) study. In addition the lack of significant findings regarding symptoms is also consistent with the Dancey et al. (2002) study, but it is unclear whether this means that the observed finding of no relationship is a true finding or a reflection of methodological artefacts with both studies.

Overall the results for this aim are disappointing and no real conclusions can be drawn without further research.

RESEARCH AIM 4 – TO EXPLORE THE ROLE OF ILLNESS REPRESENTATIONS AND ILLNESS OUTCOMES INDEPENDENTLY OF PERCEIVED ATTITUDES TO IBS

Using the same rationale as for study 1 the role of illness representations and illness outcomes was assessed independently. There were three significant findings which were as follows:

1) Emotional representations were predictive of HRQOL
2) Chronic time line was predictive of decreased symptom frequency
3) Illness identity was predictive of diarrhoea

Although it is disappointing that the results with this cohort did not exactly replicate those of study 1, as HRQOL is not predictive of symptom frequency, they do provide partial support for the previous findings. The role of emotional representations was predictive of HRQOL in both studies and therefore it seems likely that this represents a true finding. This is strengthened further by the same results in the Frostholm et al. (2005) study. A further point to note is that that in study 1 illness identity was found to be predictive of HRQOL, however as this relationship was in the opposite direction to that expected the finding was hypothesized to be spurious. The lack of a replication of this relationship here supports the notion that the relationship observed in study 1 was not a true finding. This is further strengthened by the finding that in this study *high* illness identity was predictive of diarrhoea, which is in line with the expectations of the CSM.

The finding that belief in a chronic time line of IBS is predictive of a reduced frequency of diarrhoea is difficult to interpret, as this has not be reported in previous research and is intuitively in the wrong direction, it is therefore possible that this finding is spurious. Further research is clearly needed to clarify this issue.

One final non significant finding that is worthy of note is that HRQOL was not found to be predictive or even correlated with symptom outcome. This is in contradiction to study 1 and also with the research by Brennan et al. (2004). It is therefore unclear why this finding was not replicated here.

Overall this research reports many significant findings. This study therefore makes a valuable contribution both to the aims of this thesis as a whole, and to research into attitudes to IBS. The main findings are that people do not report negative attitudes towards IBS, that perceptions of attitudes differ between IBS sufferers and the general population, that the illness representations appear to be important predictors of illness outcomes, in IBS, but that overall perceived attitudes do not appear to contribute to illness interpretation as suggested. It is of course possible that features of this study are responsible for this observed lack of significance, and that the theory itself is accurate. Although this is speculative study limitations which may have resulted in the observed findings will now be detailed.

STUDY LIMITATIONS AND SUGGESTED MODIFICATIONS

PARTICIPANTS

As there were two groups of participants the general population group will be discussed first. This was a large and diverse group, and therefore despite the response rate of 48% the generalisability of these results can be accepted with a high degree of certainty, certainly within the UK. As far as the IBS group is concerned low participant numbers may be partially responsible for the lack of reported significance. This is a concern that could be easily addressed by conducting further research using the same design, but recruiting more people. In addition further research using large sample sizes is desirable to assess if there are any gender or IBS sub-group effects, neither of which were practical to investigate here due to the sample size and the largely female bias. However, despite the sample size this may be taken as a representative sample as participants were recruited from a number of different sources, and appear similar to that reported in previous research (e.g. Dancey et al., 1995; Lackner et al., 2004). Therefore it is likely that the comparative data of the attitudes are accurate and generalisable to other IBS sufferers. It should be

noted, as was mentioned earlier, that this assumes that people report their true feelings. Overall whilst IBS participant numbers may have resulted in less significant findings, there are no major problems with either participant group and in this respect participants should not be considered a major limitation.

MEASURES

As this study was concerned with participants' perceptions the use of questionnaires was highly suitable. The use of established measures (such as the IPQ-R) and IBS specific measures (such as the IBS-36) increases the suitability of these methodological choices. However, the two versions of the Attitudes to Chronic illness questionnaires were not established measures, and therefore may have contributed to the lack of significant findings relating to illness perceptions. However, this may be a slightly pessimistic view as the questionnaires were based on the scales of the IPQ-R, and the IBS-36 as well as literature searching about the main components of the illnesses. In addition, with the exception of the asthma version of the perceived physical consequences scale the alpha coefficients elicited for each of the scales on both versions of the questionnaire suggest it to be a legitimate tool. It would however, be useful to conduct further research with additional measures of attitude perceptions, such as that currently being designed at the University of East London, and The Chicago Illinois division of gastroenterology. It is therefore likely that future research will clarify these relationships.

One final methodological consideration concerns the use of diaries to report symptoms, this is particularly of note as HRQOL and symptom frequency were not correlated in this cohort. Concerns over the reliability of a one week diary were raised in study 1, but the findings here strongly suggest the need to include a questionnaire based measure of symptoms for comparison in future research.

DESIGN

Although the design was highly suitable for this study, it is clear that to fully establish the impact of perceived attitudes on illness outcomes in IBS longitudinal and intervention based research is needed.

FURTHER RESEARCH

This is an area where research is still in its infancy and therefore there are many future research directions. Suggestions include:

1) The recording of physiological measure to assess whether reported levels of comfort discussing symptoms are accurate.
2) The use of the implicit association test (IAT, Greenwald et al., 1998) as an additional means of increasing a finding relating to true attitudes, rather than reported (explicit) attitudes.
3) To use quota sampling to investigate perceptions of different groups of society.
4) Cross cultural research is also important as the literature on epilepsy strongly suggests these findings are unlikely to be generalisable across different cultural groups.

CONCLUSIONS

The perceptions held by IBS sufferers that people hold negative views towards them are inaccurate. This is an important finding in the context of both intervention research and general counselling as it strongly suggests that challenging patients' perceptions concerning social support are both legitimate and potentially beneficial in improving representations of IBS and related illness outcomes. Taken together with study 1 (chapter 4) these two exploratory chapters provide strong justification for the utility of the CSM in IBS. In addition to supporting the use of the CSM as a theoretical model these exploratory chapters provide insight into components which should or should not be emphasised in an intervention. Essentially they have shown that in addition to challenging every part of a person's illness representations there should be explicit advice to seek out social support.

Based on the results of these two empirical chapters and copious literature reviewing an intervention was designed based around the CSM. The intervention took the form of an evidence based self-help book. The description and results of this study are described in the next chapter (chapter 6)

CHAPTER 6

STUDY 3

A SELF-HELP BOOKLET INTERVENTION STUDY FOR IRRITABLE BOWEL SYNDROME (IBS) BASED ON THE COMMON SENSE MODEL (CSM)

Aim

Chapter 6 reports the results of study 3, the final study in this thesis.

The overall aim for this study was to design an informed evidence based intervention for IBS sufferers, based on the principles of the CSM (Leventhal et al., 1980; 1984). As expected of intervention research the aim of this study was to improve sufferers' illness outcomes, post the intervention. Illness outcomes comprised a number of different areas, the primary ones were illness perceptions, health related quality of life (HRQOL) and symptom frequency. The design of this study (as was suggested at the end of the previous chapter) is heavily influenced by the preceding chapters in this thesis. The contribution of each of the previous chapters to this study is briefly described in the following section.

INTRODUCTION

It was not felt necessary to provide the standard literature based introduction to this study, as the introduction to this intervention is the culmination of the previous chapters, all of which are aimed at justifying both the need and the design specifics of the study presented here. Therefore the background to this study will be in the form of a summary of the preceding chapters.

Chapter 1 – This chapter is important as it provides an overview to IBS and by doing so demonstrates the suitability of psychologically based perspectives to studying this illness. Chapter 1 also demonstrates the gaps in current knowledge relating to IBS and therefore justifies the continued need for research in this area. By the end of

chapter 1 it can be seen that there is a clear need for research into this area and that the approach taken by this thesis is highly suitable.

Chapter 1 clearly shows that there is a need for effective illness management techniques for sufferers of IBS. Firstly it shows that the current management options (both medical and alternatives) are lacking in efficacy. In fact in Talley's (2001) consideration of the main medical options available to sufferers of IBS (medical, complementary and life style based) he concludes that none of the current management options are effective at curing, or even controlling the multiple and fluctuating symptoms that characterise IBS. There is therefore clearly a need to devise alternative methods of treatment for sufferers of IBS. The need to provide effective treatments is strengthened by the percentage of people who suffer from IBS, with prevalence rates as high as 20% reported (e.g. Dancey et al., 1999). However, it is not just the prevalence of IBS that makes it important to find a way of treating, or at last controlling its symptoms, it is the degree to which sufferers' lives are affected. In fact, as chapter 1 details research of this type in IBS specifically is essential because of the burden IBS places not just on sufferers, but on 'health care systems' and 'society as a whole' (Gilkin, 2005). In addition to identifying a clear need for effective intervention research to be conducted chapter 1 also provides the general background regarding the form this intervention should take. There is a clear need for future treatment research to adopt a holistic approach, whereby the IBS sufferer is considered, not just the symptoms. This will therefore enable a treatment that can encompass the idiosyncratic elements to IBS. Therefore an integrated model to the treatment of IBS is clearly the way forward in the design of effective management techniques. Chapter 1 justifies the use of a biopsychosocial model, and the brain-gut axis (Drossman et al., 1999). Further support for this model is provided by Camilleri (2001) who states that "the brain-gut axis is the key to the development of effective therapies in IBS".

Chapter 2 is one of the most influential chapters in terms of providing a background to the design of this study. This is because it is a systematic literature review specifically addressing the efficacy of psychologically based interventions in IBS. The review strongly suggests that conducting psychologically based research into IBS is both viable and justifiable, with the majority of studies showing significant

improvements of psychologically based interventions. In addition no study reported illness outcomes to worsen as a result of the intervention, admittedly there is a possibility that this could be due to a publication bias. An important outcome of the review was the finding that not only were psychologically based interventions successful, in many cases they were significantly more efficacious than medical care, for both psychological and symptom based illness outcomes (e.g. Guthrie et al., 1991; Kennedy et al., 2005). Although psychologically based interventions in general are justified by the review, there is no one model that emerges as dominant. This is important as it strongly suggests that further research into alternative models is necessary. In addition to justifying the design of psychologically based interventions for IBS in general, the review also provides useful information regarding the specifications the intervention should take, these will be briefly detailed.

The first design feature is the clear need for the treatments, and intervention studies to be based on established psychological models, as those studies where the psychological component was limited (e.g. Colwell et al., 1998: illness education) were the ones least likely to find conclusive results. In contrast the studies based on established models, such as cognitive behavioural theory (e.g. Lynch & Zamble, 1989; Schwarz et al., 1990) were most likely to show significant and conclusive results, and are therefore clearly superior to any of the other, less well defined theories. In addition to the general need to include a psychological model, the superiority of cognitive behavioural (CBT) based approaches strongly suggests that any intervention that shares similar principles, in particular the need to challenge maladaptive thoughts, feelings and behaviours, is likely to meet with success. One of the most informative features of the systematic review as, Mulrow (1994) suggests is that it allows for a clear assessment of the intervention components which are most likely to improve IBS, and allow for the improvement to be measured effectively. These are as follows:

1) There needs to be a measure included to assess whether the components of the model used have altered, e.g. in the context of a relaxation intervention a measure to assess self-reported relaxation could be included.
2) The intervention should encourage participation by being as short as possible, without affecting the ability to effect change.

3) Unless essential any alterations to standard medical care should be avoided.
4) Waitlist control groups, are not appropriate and can result in elevated symptoms prior to the intervention.
5) Measures used need to be sensitive enough to detect subtle changes.
6) It is not sufficient to include a psychological model as a general background, its principles must be rigorously adhered to in the design of the intervention.
7) The intervention must be practical for the participants to continue the behaviours after the intervention period, and therefore increase the likelihood of maintenance of changes, or ideally continued improvement. It therefore needs to teach self management behaviours (e.g. Keefer & Blanchard, 2002).

As the systematic review of chapter 2 provided a strong argument for the necessity of an established model in IBS, and moreover one that was not included in the review, chapter 4 assessed the viability of the common sense model (CSM) of Leventhal et al. (1980; 1984). Although it is not necessary to repeat the detail of this model here it should be noted that this model is highly suitable for the specific characteristics of IBS, in particular its heterogeneous nature. As chapter 3 reveals the CSM is superior to other similar models, such as health belief models (HBM) and the transtheoretical model (TTM, Prochaska et al., 1992). Justification for the viability of the CSM in IBS research comes from its application to illnesses with similar unknown aetiological features, such as chronic fatigue syndrome (Edwards et al., 2001), and from research investigating the relationship between illness representations and coping in IBS specifically (Rutter & Rutter, 2002). The key features of the CSM which are therefore necessary to take into consideration when designing treatments based on its principles are:
1) That illness beliefs are structured and management behaviours are dependent on the beliefs held.
2) That emotional factors can influence both illness beliefs and illness features.
3) That self-regulation (management) is an important feature of suffering from an illness, and therefore the sufferer will aim to re-establish a health state.
4) There are three interlinking components to the CSM, these are illness interpretation, coping and appraisal. Although their interconnected nature means that an intervention targeted to one component will necessarily impact on the other two,

in order for maximum efficacy an intervention should aim to incorporate all three components.

Although chapter 3 clearly detailed the components of the model necessary for the design of an intervention there were two aspects of the illness interpretation stage where it was felt that current literature was not sufficient for firm conclusions to be drawn. These two aspects were the role of perceived doctor-patient communication and the role of perceived social support. Therefore studies 1 (chapter 4) and two (chapter 5) were designed to gain an understanding of these two factors and the results of these studies were taken into consideration in the design of this intervention.

The overall conclusion drawn from study 1 is that perception of doctor-patient communication differed between patients and doctors, although it was not possible to establish which groups (or potentially both) perceptions are inaccurate. In addition the conclusion that perceived communication does not appear to affect IBS sufferers' illness outcomes suggests that it is not necessary to include a section of the intervention specifically targeted at improving patients' communication with doctors.

In contrast the conclusion drawn from study 2 strongly suggests that sufferers' perceptions that other people hold negative attitudes towards them and their condition are inaccurate. Therefore an intervention should include a section which informs participants that poor social support is not a necessary consequence of IBS and therefore encouraging them to alter this perception and actively seek social support.

Overall based on the results of the literature reviews and the exploratory studies it was decided to design an intervention based on the principles of the CSM. To ensure that the intervention was inline with the suggestions raised by the systematic review a self-help booklet based intervention was designed. A self-help booklet was felt to be an improvement on previous study designs since its flexibility allowed sufferers to complete the intervention in their own homes. Allowing for completion of the study in the sufferers' homes was an important design feature as it would not restrict the study to only those sufferers' whose symptoms were mild enough to travel, a

consideration which is often overlooked in intervention research. Secondly it was hoped that by the initial intervention taking place within the participants' home it would be easier for them to continue with the practices suggested after the intervention was over. Although an IBS self-help booklet was recently designed by Kennedy et al. (2003) it is in no way sensitive to either the intelligence, or differences in illness knowledge of sufferers, the idiosyncratic nature of the illness, treatment options or to the concept of empowering sufferers. The principles behind the booklet are that it is:

1) Evidence based
2) Allows the sufferer to appraise their current behaviour and to think of changes
3) Has the aim of empowering patients to take responsibility for their own health
4) Encouraging them to adopt productive coping strategies

The ultimate goal of this research is to improve patient's illness representations and related illness outcomes (symptom frequency and HRQOL). Although use of a self-help booklet is not in itself unique the specific design of this study, in particular the use of the CSM and the detailed consideration of the limitations of previous research, means that this study is both unique and highly evidence based.

Aims

The aim of this research was therefore to design an effective, theory based, self-help booklet style, intervention for sufferers of irritable bowel syndrome (IBS). The primary research question is therefore to assess the efficacy of this intervention. The efficacy of the intervention will be assessed on a number of dimensions, these are illness representation, symptom frequency and HRQOL.

Based on the previous literature in this thesis there was felt to be sufficient evidence to make three one tailed hypotheses:

H1: There will be a significant reduction in total symptom frequency from pre intervention to immediately post the intervention

H2: There will be a significant reduction in total symptom frequency from pre intervention to two moths post the intervention.

CSM self-help booklet intervention

H3: There will be a significant improvement in health related quality of life (HRQOL) from pre intervention to two months post the intervention (NB, it is not suitable to assess changes in HRQOL immediately post the intervention).

In addition to the hypotheses there were a number of research questions that were also addressed. These were:

1) To investigate whether there are reductions in any of the individual symptoms.
2) To explore the relationship between HRQOL and symptom frequency.
3) To investigate whether any there are any changes in medication post intervention.
4) To assess whether any changes have occurred in the different scales of perceived social support immediately following the intervention and at two month follow up.
5) To investigate if there are any changes in the illness representation components post intervention.
6) To assess if any observed improvements post intervention are a result of the changes in the illness representation components.

METHOD

PARTICIPANTS

There was only one group of participants used in this study, this was IBS sufferers. However as this was a longitudinal design consisting of 4 phases, there were participant dropouts over the course of the study. Therefore the participant characteristics at each phase will be detailed.

PHASE 1 – PRE INTERVENTION PHASE

The participants in this research were the same cohort who participated in the attitudes to chronic illness research (study 2, Chapter 5). It should be noted that participation in the attitudes to chronic illness research was prior to the commencement of this study, and therefore the results of study 2 were not affected by the intervention. As the cohort is the same as was used in the previous study it will only be briefly described here. There were a total of 130 pre intervention research packs distributed to participants (phase 1). A total of 62 completed packs were returned (response rate 48%). Of the participants there were 53 females, and 6

males (3 unspecified). Participants' ages ranged from 19-71 years, with a mean age of 43 (SD 14). 51 % of the sample were members of the IBS Network. The average time since diagnosis of IBS was 10.5 years (SD 9.6), with a range from less than a year to 33 years. The average time from first experiencing symptoms to being diagnosed was 5.5 years (SD 8.3), with a range from less than a year to 33 years. Within the main IBS group the numbers of participants in the three IBS subgroups were as follows, IBS-D (n=26), IBS-C (n=15), IBS-A (n=18) (NB three participants did not specify their subgroup). With the exception of two Americans all participants were resident in the UK. Just over half of the sample was highly educated with 53% achieving 'A' levels or higher, only 10% of the sample reported having no academic qualification. Exactly 50% of the sample reported having another illness. The most often reported illnesses were arthritis (8%) and asthma (5%), the only specified psychological illness was depression at 15 % of the sample. As stated previously all of these participant characteristics are very similar study 1 and to previous research (e.g. Dancey et al., 1995; Lackner et al., 2004).

Because the response rate was fairly low at 48%, the 68 participants who did not return completed research packs were sent a short questionnaire *(appendix 20)* asking them to indicate their reasons why they did not return their pack. In addition they were asked to fill in the demographic questionnaire so that the characteristics of those who participated and those who did not could be compared so as to gain an indication of how generalisable the cohort was. A total of 28 (41%) people returned their questionnaires. The reasons for not participating in the intervention study, along with the number of people who reported the same reason are shown in table 21

Table 21 – Reasons why people did not return completed research packs

REASON	NUMBER
It was discovered that the diagnosis of IBS was inaccurate	5
I am too unwell to have the time to participate	2
Did not like the fact that it was a psychological study, do not think the mind plays a role in IBS	2
No reason specified just did not wish to take part	3
Do not have time to participate	14
Sudden improvement in IBS symptoms	1
Objected to the quantitative nature of the study, stated " I would have been more interested in just writing down my experiences rather than ticking boxes which makes me feel like a statistic"	1

As expected the most commonly reported reason for not returning the research packs was not having time to participate (50%). The second most commonly reported reason was inaccuracy of diagnosis (18%). Demographic data was available for 15 people, due to eight people not completing the questionnaires, and the data from the five people who did not actually suffer from IBS being excluded. Of the 15 people who completed the demographic questionnaires there were 12 females, and 3 males. Participants' ages ranged from 17-60 years, with a mean age of 42 (SD 14). 33 % members of the IBS Network. The average time since diagnosis of IBS was 7.6 years (SD 5), with a range from less than a year to 18 years. The average time from first experiencing symptoms to being diagnosed was 7.6 years (SD 5), with a range from less than a year to 20 years. Within the main IBS group the numbers of participants in the three IBS subgroups were as follows, IBS-D (n=2), IBS-C (n=6), IBS-A (n=7). All participants were resident in the UK. One third of the sample were highly educated with 33% achieving 'A' levels or higher, and no one 0% reported having no academic qualification. 47% of the sample reported having another illness. The most often reported illnesses was asthma (14%), the only specified psychological illness was depression at 7 % of the sample. These characteristics are similar to those who did not return their research packs; the only difference is that there were proportionally less IBS-D sufferers. It is therefore the case that sample biases towards IBS-D reported in previous research may reflect a bias towards IBS-D sufferers being more likely to participate in research, rather than a bias in actual symptom clustering amongst IBS sufferers.

PHASE 2 – INTERVENTION PHASE

At the end of the pre intervention stage (the day after filling in the last day of the diary / the day after filling in the questionnaires if no diary was completed) the intervention booklet was completed.

PHASE 3 – POST INTERVENTION PHASE

15 participants did not return the post intervention packs, and therefore only 47 participants took part in this stage of the study. Of the participants there were 39 females, and 5 males (3 unspecified). Participants' ages ranged from 19-68 years, with a mean age of 45 (SD 14). 57% of the sample were members of the IBS Network. The average time since diagnosis of IBS was 11.4 years (SD 10.3), with a

range from less than a year to 41 years. The average time from first experiencing symptoms to being diagnosed was 6.4 years (SD 9.2), with a range from less than a year to 33 years. Within the main IBS group the numbers of participants in the three IBS subgroups were as follows, IBS-D (n=21), IBS-C (n=11), IBS-A (n=12) (NB three participants did not specify their subgroup). All participants were resident in the UK. Just over half of the sample were highly educated with 52% achieving 'A' levels or higher, only 11% of the sample reported having no academic qualification. 52% of the sample reported having another illness. The most often reported illnesses were arthritis (9%) and asthma (6%), the only specified psychological illness was depression at 14 % of the sample. Although the participant numbers are lower in this phase the participant's characteristics are largely the same.

PHASE 4 – TWO MONTH POST INTERVENTION PHASE

Unfortunately there were more participant drop outs between the post intervention stage and the two months post intervention stage, and therefore only 36 participants took part in this stage of the study. It should be noted however, that the two month post intervention pack was sent to all participants; therefore some of the people who did not complete the post intervention pack still returned their two month post intervention pack. Of the participants at this stage there were 30 females, and 4 males (2 unspecified). Participants' ages ranged from 19-71 years, with a mean age of 47 (SD 15). 59% of the sample were members of the IBS Network. The average time since diagnosis of IBS was 13.2 years (SD 10.7), with a range from less than a year to 41 years. The average time from first experiencing symptoms to being diagnosed was 5.8 years (SD 8.5), with a range from less than a year to 33 years. Within the main IBS group the numbers of participants in the three IBS subgroups were as follows, IBS-D (n=15), IBS-C (n=10), IBS-A (n=9) (NB two participants did not specify their subgroup). All participants were resident in the UK. Just over half of the sample were highly educated with 54% achieving 'A' levels or higher, only 15% of the sample reported having no academic qualification. 59% of the sample reported having another illness. The most often reported illnesses were arthritis (11%) and asthma (9%), the only specified psychological illness was depression at 14 % of the sample. Although the participant numbers are lower in this phase the participant's characteristics are largely the same as in the other two phases.

DESIGN

This is quantitative postal based research. It has a within subjects longitudinal design, comprising four phases. Phase 1 is a pre intervention phase where participants' baseline characteristics are measured prior to commencement of the intervention. Phase 2 is the intervention stage where participants fill in the intervention booklet. The booklet is completed in one sitting on the day following the completion of the 7 day diary (or upon completion of the questionnaires if no diary is being used). Phase 3 is a post intervention phase, where measures suitable for immediate test-retest assessment are re-administered immediately post the intervention to assess if any changes have occurred. The final phase, phase 3 is included to assess the short term effects of the intervention, and therefore the measures are re administered at two months post the intervention. There are three main independent variables these are participants' illness representations (number of dimensions), perceived health related quality of life (HRQOL), and symptom frequency (total symptoms and individual symptoms). The dependent variables are the changes in these variables at phase 2 and phase 3.

MEASURES

A number of the measures used in this study are the same as in the previous two studies, so these will not be detailed here. The measures which are the same are:

A disease specific version of the IPQ-R (Moss-Morris et al., 2002, *appendix 1*)

The IBS-36 (Groll et al., 2002, *appendix 2*)

The 7-day symptom diary (*appendix 3*)

IBS participant's version of the Attitudes to Chronic Illness Questionnaire (termed *PSSS, appendix 14*)

Demographic Questionnaire (*appendix 7*)

In addition there are two questionnaires and an intervention booklet designed for this study.

The first questionnaire is termed the IBS symptom scale (*ISS, appendix 21*). This is a supplementary measure to the 7-day symptom diary. It was included for two reasons. The first reason is that relationships between the independent variables and symptom frequency in the previous two studies were either weak or not significant. It is currently unclear whether this represents a true finding or a methodological factor. As it is important to assess the efficacy of the intervention in terms of symptom changes it was felt useful to include an additional symptom measure for comparison. The second reason for its inclusion was due to worries over low participant numbers for diary based research. This worry is based on the time commitment required for diary based studies. In this case each diary takes a week to complete, and as this is a three phase study means that three weeks worth of diaries would need to be completed over a two month period. In contrast each questionnaire takes under half an hour, and its therefore more appealing to some participants. Although participants were obviously encouraged to complete both the diaries and the ISS throughout the study, where people specified that they would only take part without the diaries (as happened in a few cases) the ISS questionnaire provided a useful way of still including a symptom outcome variable. The design of the ISS was informed by previous literature in this area. A review article by Naliboff et al. (1999) provides detailed assessment measures used to record symptom frequency, and the suggestions raised provided the framework for the questionnaire designed. The ISS is similar to the questionnaire designed by Dancey et al. (1998).

The ISS asks participants to retrospectively recall their symptoms over the previous week and indicate the frequency of their symptoms on a Likert scale from 0 (not experienced this symptom) to 6 (experienced this symptom constantly). There are a total of nineteen symptoms listed, this includes the primary IBS symptoms and also a number of extra-intestinal symptoms that have been suggested to be experienced by sufferers of IBS, e.g. joint pain and nausea and the psychological variables of perceived stress and depression levels. This is considered to be superior to the questionnaire used by Dancey et al. (1998) as their questionnaire only included the seven dominant IBS symptoms, whereas this questionnaire allows for a more global

assessment of symptoms. In addition the ISS included a category of 'not applicable', this was only to be circled if the symptom had never been experienced since being diagnosed with IBS. The 'not applicable' category is distinct from the category of not experienced this symptom, which refers to symptoms which had been experienced in the past but had not been experienced in the preceding week. The ISS is scored, in the same manner as the IBS-36 by summing the responses to each of the symptoms. However, in order to provide comparable data to the symptom diary the total score only includes the primary IBS symptoms. As with the diary frequency of the individual symptoms will also be investigated, this is where potential changes in the non-IBS symptoms can be determined. As this questionnaire was administered twice in this study, one pre intervention, and again at two months post intervention internal reliability analysis was performed twice. The alpha coefficients show the questionnaire to be highly reliable, with the pre intervention administration being 0.763, and the two month post intervention administration being 0.868.

The final questionnaire is a short post-intervention questionnaire (*appendix, 22*), which is to be completed at two months post the intervention, it contains an open ended question asking sufferers if they have made any changes since the intervention. As this is a qualitative section the responses will be shown using a frequency table.

MATERIALS

A self-help booklet was designed for the purposes of the intervention (*appendix 23*). As stated earlier although the recent research by Kennedy et al. (2003) provides a useful justification of the viability of self-help booklets in IBS intervention research there are a number of flaws in its design that make it unsuitable as a measure. Therefore prior to the detailed, section based description, of the self-help booklet the main features will be described. As the design of this self-help booklet was largely based on addressing the flaws in the Kennedy et al. (2003) research these will be described along with the modifications made.

1) Firstly Kennedy et al. (2003) entitle their paper an 'evidence based' self-help booklet, however, this 'evidence' comes from qualitative reports, from only 25 IBS

sufferers at focus groups. It could therefore be argued that rather than evidence based as they suggest the Kennedy et al. (2003) research is actually opinion based. This is particularly worrying in light of the results of study 2 which show a marked discrepancy in the attitudes of IBS sufferers and the general population. In order for a booklet to be truly evidence based there has to be a considerable effort extended in reviewing the literature, and ensuring that all the information provided to sufferers is accurate according to current knowledge. This is particularly important in irritable bowel syndrome as the information available to sufferers is often unclear, conflicting or completely inappropriate for an individual's symptom presentation (e.g. Dancey et al., 1999; Stenner et al., 2000). Therefore the only information included in this self-help booklet was for areas where reliable references could be given. In addition next to each piece of information about IBS was a number which corresponded to the reference section. This way participants could be assured of the reliability of the information, and should they desire, obtain the original reference for further detail. The need to include only evidence based information means that any areas of uncertainty, for example over some nutritional aspects were excluded from the booklet.

2) There is no model underlying the Kennedy et al. (2003) booklet, therefore even if its efficacy was established by research (no research has currently been published assessing its efficacy) there would be no way of identifying why improvements were observed. As shown by the systematic review it is not sufficient to conduct general psychologically based interventions in IBS, the greatest success both theoretically and practically is for those studies that are driven by theory. Therefore the design of this self-help booklet adhered rigidly to the principles of the CSM (Leventhal et al., 1980; 1984), as detailed in Chapter 4.

3) The information in the self-help booklet by Kennedy et al. (2003) is provided in a passive manner. It is therefore largely descriptive providing opinions from other sufferers with an assumption that this will help sufferers by showing that other people have encountered similar experiences. Whilst this is undoubtedly the case as Coulson (2005) shows with his research, it still assumes that the information provided will be relevant. However, it is possible that some people (especially those who have suffered for a long time) will feel it patronising to simply read about the

experiences of other people, when they were expecting useful information concerning their specific symptoms. On the basis of this criticism, and in line with the CSM it was felt important to design a booklet that would enable people to answer the questions in a manner that was relevant to them, by providing as much or as little detail as they wanted and by providing sections which asked about current knowledge levels rather than assuming all participants would have the same level of knowledge. It also asks people to actively think about and list changes relevant to them. In this respect, although not tailored in its truest sense the booklet is designed in a manner that will result in it being completed in a different way by each person. The result of this is that whilst the Kennedy et al. (2003) booklet is limited to one reading with this booklet a sufferer can fill it in as many times as they wish over the course of their illness. In addition as it is divided into clearly defined sections, on subsequent completions it is possible for a particular section, such as the knowledge section, to be used without the need to read the entire booklet again.

4) As a final point of consideration Kennedy et al. (2003) report that their cohort were not good at suggesting coping strategies, this strongly suggest that the booklet must not be limited to merely providing information. Sufferers require and therefore must be given suggestions to aid them in their self management. Therefore in this booklet a variety of suggestions will be provided, again taking into consideration what is practical and desirable to one person will not be to another.

Despite the criticisms of the Kennedy et al. (2003) booklet the overall aim of both booklets is to help sufferers adjust to their illness identity as an IBS sufferer. However, in addition to this aim the ultimate goal of the booklet designed for this study is to empower sufferers to make positive changes which help their illness representations, HRQOL and symptom frequency throughout their illness.

THE IBS INTERVENTION BOOKLET

In line with the CSM there were three main components to the booklet. Sufferers were asked to a) consider their current illness interpretations (on each illness perception dimension) b) encourage positive representations and c) produce action plans for the future. These components are inherent throughout the booklet, which comprises 6 sections, which are as follows:

Section 1

Following an instruction page section one starts with the illness representation dimensions of illness identity. The first part of this section is a) to consider current illness representations. This section asks participants to write down how they feel about being 'labelled' an IBS sufferer. In line with the CSM they are instructed that it is their current views that they are required to report, and therefore it does not matter how they have felt in the past. This is important as it takes into account that all experiences contribute to the illness identity a person has, and with this in mind the responses may differ, if not from day to day, certainly throughout other periods of time. This is important as it enables the booklet to be as relevant to both newly diagnosed sufferers as to those who have suffered for a long time. Sufferers are asked to list as many (or as few) feelings as they feel helpful, and are provided an example of both a positive and a negative feeling. Sufferers are assured that there are no right or wrong answers. This is important as research, e.g. Bertram et al. (2001) has shown that people are frustrated by unhelpful advice in particular from medical professionals whom many perceived as having no understanding of their condition. Therefore from the start this booklet allows the sufferer to be in control. An example of the kinds of responses a sufferer may include in this section are, "I feel slightly embarrassed and don't want to advertise the fact I have IBS", or "IBS is being recognised by more people, which makes it easier to talk about and share experiences". Following on from this section is section b) encouraging positive illness representations. In this section participants are asked to concentrate only on the positive aspects of having IBS. Initially participants are asked to look back over their list of feelings, and to re-write any that are positive. Next they are asked to think of anything positive relating to their being an IBS sufferer. It is noted in the instructions that some people may initially find this hard but to take the time to reflect. An example of the responses in this section include "having IBS has encouraged me to have more empathy for other people", and "I am happy that it is a genuine medical condition". The final part of this section, part c) to produce action plans for the future asks sufferers which action(s) they could take that would help them to feel more positive about their illness in the future. An example of a response in this section is "sharing personal experiences with others who also suffer from IBS". Participants are also asked to rate on a scale from very easy to very hard how

easy it would be for them to act on the changes they had suggested. By making people think about the procedures involved in actually undertaking the action step this takes it from an abstract idea to something which is directly considered.

Section 2

Section 2 relates to the illness representation dimension of illness coherence, the first part of this section a) to consider current illness representations, provides a list of 8 IBS 'key facts', and asks participants to indicate (with a tick or a cross) which ones they were aware of. For example "IBS affects one in five people", and "there are three main subtypes of IBS". Detail is provided for the 8 key facts (along with references). This is important as research, e.g. Dancey et al. (1999) suggests that IBS sufferers hold many misconceptions about their illness. In the second part of this section b) encouraging positive illness representations sufferers are asked if there are any changes they would like to make on the basis of the new information they have gained about IBS. Participants are asked to indicate whether these changes are in feelings or behaviour, e.g. behaviour change would be "to go to the doctor if I found blood in my stool". Section c) to produce action plans for the future asks people to rate how easy it would be for them to act on these changes, using the same scale as with section 1.

Section 3

Section 3 relates to the illness representation dimension of cause. The first part of this section a) to consider current illness representations asks participants to list what they believe caused their IBS. Following this they are asked to write the cause / causes under common subheadings, such as 'caused by an illness'. Following on from this section is a list of the current knowledge regarding causes of IBS. This is as important as the IBS 'key facts' section as it aims to clear up any misconceptions people have regarding causes of their illness. By learning which causes are evidence based and which are not participants are able to b) alter their illness representations concerning any maladaptive causes, such as a food allergy. Again participants are asked to reflect on the information given, to specify if their opinion regarding the cause of their symptoms has changed and to c) to produce action plans for the future asking people to rate how easy it would be for them to act on these changes, using the same scale as with section 1.

Section 4

Section 4 relates to the illness representation dimension of timeline (both chronic and cyclical). The first part of this section a) to consider current illness representations provides participants with a list of potential beliefs relating to the timeline of IBS, and asks participants to circle which category they feel best describes their symptoms. An example is 'chronic but controllable'. The second part of this section b) to alter illness representations lists any categories which are inaccurate, e.g. 'IBS is terminal', and tells participants who have circled an incorrect category to think about their IBS and indicate which of the accurate categories their IBS most relates to. Consistent with the semi-tailored nature of this booklet section c) producing action plans for the future is only relevant for those people who have to change their perceptions of their timeline. For those people who are unsure they are recommended to monitor their IBS for a few weeks until they have a better understanding of their illness.

Section 5

Section 5 relates to the illness representation dimension of perceived consequences. The first part of this section a) to consider current illness representations asks people to list any consequences to their life as a result of having IBS, these can be either negative or positive. An example of a negative consequence is "scared to travel too far from home". An example of a positive consequence is "found enjoyment in going for short walks". In a similar style to section 1, part b) to alter illness representations reminds participants that focusing on negative outcomes is not productive and asks them to think of more positive consequences of having IBS. Participants are told that as one of their action plans for the future (c) they should keep the list of positive thoughts and whenever they feel negative they should look over the list. In addition they are instructed that whenever they think of an additional positive consequence that they should add it to the list. In addition a list of misconceptions about consequences, such as 'poor social support is not a necessary consequence of IBS' is included to help people rethink some of their inaccurate perceptions. Finally in addition to encouraging positive views on consequences sufferers are also asked to think about how any of the negative consequences can be minimised. An example of this is the negative consequence of 'feeling that quality of life has reduced' can be

minimised by thinking of new hobbies that are compatible with IBS, such as a book club. Again people are asked to rate how easy it would be for them to act on these changes, using the same scale as with section 1.

Section 6

Section 6 relates to the illness representation dimension of cure / control. The first part of this section a) to consider current illness representations asks people to list any actions that they currently undertake as a way of controlling their symptoms. An example is 'take long baths'. The second part of this section, b) to alter illness representations lists a number of suggestions that may help people to control their IBS, this is divided into 'general help' and 'symptom specific help'. It provides a number of different evidence based suggestions, such as thinking positively, increasing exercise or having cognitive behavioural therapy. This section aims to alter peoples' illness representations concerning controlling, and potentially curing their IBS by suggesting things that they may not have been aware of as potentially beneficial. The final section of the booklet c) action plan for the future, asks participants to list up to three suggestions for improving their IBS that they would like to try, again along with the scale to indicate how easy this is to achieve.

As the previous sections demonstrate the booklet strictly adheres to the principles of the CSM, it incorporates all the illness representation dimensions, and each of the stages of the model.

PROCEDURE

PRE INTERVENTION STAGE, INTERVENTION, IMMEDIATE POST INTERVENTION STAGE

Participants received the research pack which contained two envelopes and the intervention booklet. The first envelope was marked pre intervention pack and contained an information sheet along with a letter inviting them to take part in the research (*appendix 24)* consent forms and ethics approval (*appendix 19*), a demographic questionnaire (*appendix 7*), *a disease specific version of the IPQ-R* (Moss-Morris et al., 2002, *appendix 1*), the *IBS-36* (Groll et al., 2002, *appendix 2*),

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IBS participant's version of the Attitudes to Chronic Illness Questionnaire (termed *PSSS, appendix 14*), the ISS, *(appendix 21*), the *7-day symptom diary* (*appendix 3*) and a free post envelope. The second envelope was marked post intervention pack and contained some of the same materials as the pre-intervention pack. It contained *a disease specific version of the IPQ-R* (Moss-Morris et al., 2002, *appendix 1*), IBS participant's version of the Attitudes to Chronic Illness Questionnaire (termed *PSSS, appendix 14*), the *7-day symptom diary* (*appendix 3*) and a free post envelope. Participants are instructed to complete the pre intervention pack, then to seal it and post it back. Immediately following the pre intervention pack (i.e. within a day or two of completing the pre intervention measures) they are to complete the intervention booklet, and following this (again within a day or two of completing the intervention to complete the post intervention pack and post it back.

TWO MONTH POST INTERVENTION STAGE

Two months after the completion of the post intervention pack, participants received the two month post intervention pack. This pack was identical to the pre intervention pack, however it also included the short post intervention questionnaire (*appendix, 22*) and a letter reminding people that they are participating in the study and ask them to fill in the pack if they still wish to take part *(appendix 25).*

DATA TREATMENT

Raw data was entered into SPSS (version 14). As with the previous research where a questionnaire was completed there was very little missing data, therefore as the variables were normally distributed mean substitution was used. However, in a number of cases a particular measure, such as the daily diary was not completed by a number of participants therefore case wise deletion was used (using the select cases function) for those variables where there was too much missing data for meaningful results to be derived. This is visible in the results section where the degrees of freedom differ for each variable. As with the previous research the functions of transformation and compute was used to produce the variables that were used in the analysis. In addition, in accordance with normal statistical procedures where multiple t-tests were used a Bonferoni correction was employed, whereby statistics were only

recorded as significant if the p value exceeded that required after applying the correction.

RESULTS

DESCRIPTIVE STATISTICS

As statistical analysis is focussed primarily on average responses it was felt to be useful to provide some descriptive information on the pattern of symptoms and changes experienced over the study. Table 21 therefore provides detailed information for each patient's symptoms at all three time points. The data presented are for the total symptoms and for the individual symptoms. The table shows both the 7-day diary and the ISS (symptom questionnaire). It should be noted that the ISS was not administered at immediate follow up. There appears to be a large quantity of missing data in the table; this refers to participants not completing the measures either due to drop outs or not wishing to complete the diaries. The amount of participants used in each stage of the analysis can clearly be seen by the degrees of freedom presented later on.

Table 21 – Descriptive statistics of IBS symptom frequency at pre-intervention, immediately post intervention and at two months post intervention.

Case Number	Pre intervention	Post intervention	2m Post intervention
Total symptoms using the 7-day diary			
1	25.00	22.00	Missing data
2	57.00	59.00	21.00
3	51.00	47.00	46.00
4	15.00	4.00	11.00
5	17.00	5.00	4.00
6	25.00	22.00	Missing data
7	19.00	8.00	22.00
8	25.00	34.00	23.00
9	20.00	14.00	10.00
10	18.00	4.00	2.00
11	48.00	34.00	Missing data
12	50.00	43.00	10.00
13	Missing data	Missing data	.00
14	13.00	3.00	26.00
15	62.00	32.00	39.00

16	Missing data	Missing data	34.00
17	10.00	11.00	Missing data
18	29.00	24.00	Missing data
19	17.00	15.00	15.00
20	3.00	11.00	10.00
21	Missing data	Missing data	Missing data
22	Missing data	Missing data	Missing data
23	57.00	32.00	Missing data
24	Missing data	Missing data	Missing data
25	Missing data	Missing data	Missing data
26	Missing data	Missing data	Missing data
27	Missing data	Missing data	30.00
28	Missing data	Missing data	8.00
29	6.00	8.00	10.00
30	52.00	37.00	Missing data
31	28.00	2.00	Missing data
32	Missing data	Missing data	11.00
33	80.00	4.00	36.00
34	22.00	17.00	Missing data
35	19.00	13.00	7.00
36	22.00	39.00	9.00
37	4.00	2.00	3.00
38	Missing data	Missing data	Missing data
39	Missing data	Missing data	Missing data
40	Missing data	Missing data	Missing data
41	39.00	41.00	25.00
42	26.00	18.00	Missing data
43	Missing data	Missing data	Missing data
44	Missing data	Missing data	Missing data
45	6.00	10.00	17.00
46	26.00	40.00	20.00
47	Missing data	Missing data	Missing data
48	Missing data	Missing data	Missing data
49	33.00	15.00	8.00
50	44.00	8.00	Missing data
51	Missing data	Missing data	Missing data
52	91.00	112.00	Missing data
53	Missing data	Missing data	Missing data
54	66.00	45.00	39.00
55	Missing data	Missing data	Missing data
56	Missing data	Missing data	Missing data
57	Missing data	Missing data	46.00
58	Missing data	Missing data	Missing data
59	6.00	9.00	Missing data
60	13.00	4.00	Missing data
61	23.00	14.00	Missing data
62	Missing data	Missing data	Missing data
Total symptoms using the ISS questionnaire			

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1	24.00	[redacted]	Missing data
2	38.00		40.00
3	26.00		25.00
4	31.00		10.00
5	9.00		5.00
6	24.00		Missing data
7	25.00		14.00
8	Missing data		22.00
9	29.00		15.00
10	28.00		10.00
11	24.00		18.00
12	31.00		20.00
13	29.00		17.00
14	19.00		15.00
15	23.00		25.00
16	28.00		31.00
17	19.00		Missing data
18	30.00		35.00
19	17.00		12.00
20	18.00		28.00
21	20.00		Missing data
22	21.00		Missing data
23	36.00		38.00
24	24.00		32.00
25	19.00		Missing data
26	28.00		Missing data
27	13.00		9.00
28	28.00		20.00
29	17.00		15.00
30	21.00		Missing data
31	8.00		Missing data
32	32.00		17.00
33	28.00		31.00
34	31.00		Missing data
35	18.00		9.00
36	20.00		29.00
37	Missing data		19.00
38	26.00		Missing data
39	22.00		Missing data
40	22.00		Missing data
41	32.00		36.00
42	28.00		Missing data
43	20.00		Missing data
44	22.00		Missing data
45	28.00		29.00
46	21.00		18.00
47	Missing data		Missing data
48	22.00		Missing data

49	29.00	[redacted]	20.00
50	13.00		Missing data
51	31.00		27.00
52	17.00		20.00
53	13.00		Missing data
54	27.00		Missing data
55	23.00		24.00
56	36.00		Missing data
57	21.00		21.00
58	Missing data		Missing data
59	27.00		Missing data
60	14.00		Missing data
61	23.00		Missing data
62	31.00		Missing data
Diarrhoea assessed using the 7-day diary			
1	.00	3.00	Missing data
2	3.00	6.00	.00
3	6.00	.00	.00
4	4.00	3.00	1.00
5	.00	.00	.00
6	.00	3.00	Missing data
7	.00	.00	.00
8	3.00	4.00	3.00
9	.00	.00	.00
10	3.00	1.00	.00
11	.00	.00	Missing data
12	.00	4.00	.00
13	Missing data	2.00	.00
14	.00	.00	.00
15	.00	3.00	.00
16	4.00	13.00	1.00
17	.00	1.00	Missing data
18	.00	1.00	.00
19	.00	.00	.00
20	1.00	5.00	2.00
21	3.00	Missing data	Missing data
22	.00	Missing data	Missing data
23	1.00	.00	.00
24	Missing data	Missing data	Missing data
25	Missing data	Missing data	Missing data
26	1.00	Missing data	Missing data
27	2.00	Missing data	1.00
28	.00	2.00	2.00
29	5.00	7.00	.00
30	.00	.00	Missing data
31	1.00	.00	Missing data
32	.00	Missing data	.00
33	3.00	.00	.00

34	4.00	1.00	Missing data
35	.00	.00	.00
36	1.00	2.00	.00
37	4.00	2.00	3.00
38	2.00	Missing data	Missing data
39	2.00	Missing data	Missing data
40	1.00	.00	Missing data
41	.00	.00	1.00
42	3.00	1.00	Missing data
43	Missing data	Missing data	Missing data
44	Missing data	Missing data	Missing data
45	.00	.00	.00
46	.00	.00	.00
47	.00	Missing data	Missing data
48	Missing data	Missing data	Missing data
49	.00	.00	1.00
50	1.00	.00	Missing data
51	Missing data	Missing data	Missing data
52	45.00	Missing data	46.00
53	Missing data	Missing data	Missing data
54	3.00	4.00	4.00
55	Missing data	Missing data	Missing data
56	2.00	Missing data	Missing data
57	.00	.00	.00
58	Missing data	Missing data	Missing data
59	2.00	4.00	Missing data
60	5.00	.00	Missing data
61	7.00	2.00	Missing data
62	Missing data	Missing data	Missing data
Diarrhoea assessed using the ISS questionnaire			
1	3.00	[redacted]	Missing data
2	2.00		5.00
3	4.00		3.00
4	5.00		1.00
5	.00		.00
6	3.00		Missing data
7	2.00		.00
8	4.00		4.00
9	2.00		.00
10	6.00		3.00
11	.00		.00
12	5.00		1.00
13	4.00		1.00
14	.00		.00
15	.00		.00
16	4.00		5.00
17	.00		Missing data
18	2.00		4.00

19	.00	[redacted]	4.00
20	3.00		5.00
21	.00		Missing data
22	.00		Missing data
23	6.00		6.00
24	2.00		4.00
25	.00		Missing data
26	4.00		Missing data
27	3.00		1.00
28	5.00		3.00
29	5.00		4.00
30	.00		Missing data
31	2.00		Missing data
32	.00		.00
33	.00		5.00
34	4.00		Missing data
35	4.00		.00
36	1.00		1.00
37	Missing data		6.00
38	3.00		Missing data
39	3.00		Missing data
40	3.00		Missing data
41	.00		5.00
42	.00		Missing data
43	2.00		Missing data
44	.00		Missing data
45	.00		6.00
46	1.00		.00
47	.00		Missing data
48	4.00		Missing data
49	3.00		3.00
50	1.00		Missing data
51	1.00		2.00
52	6.00		5.00
53	.00		Missing data
54	4.00		999.00
55	3.00		4.00
56	6.00		Missing data
57	.00		.00
58	Missing data		Missing data
59	5.00		Missing data
60	4.00		Missing data
61	6.00		Missing data
62	6.00		Missing data

Constipation assessed using the 7-day diary			
1	3.00	5.00	Missing data
2	11.00	11.00	3.00
3	1.00	10.00	1.00

4	.00	.00	1.00
5	.00	.00	.00
6	3.00	5.00	Missing data
7	.00	.00	.00
8	.00	.00	.00
9	2.00	4.00	2.00
10	3.00	.00	.00
11	4.00	.00	Missing data
12	2.00	5.00	1.00
13	Missing data	.00	.00
14	.00	.00	.00
15	9.00	3.00	3.00
16	.00	.00	.00
17	1.00	.00	Missing data
18	.00	.00	.00
19	3.00	3.00	1.00
20	.00	.00	.00
21	1.00	Missing data	Missing data
22	2.00	Missing data	Missing data
23	.00	1.00	.00
24	Missing data	Missing data	Missing data
25	Missing data	Missing data	Missing data
26	.00	Missing data	Missing data
27	.00	Missing data	.00
28	Missing data	3.00	.00
29	.00	.00	.00
30	2.00	1.00	Missing data
31	2.00	.00	Missing data
32	1.00	Missing data	4.00
33	.00	.00	1.00
34	.00	2.00	Missing data
35	.00	.00	.00
36	3.00	.00	.00
37	.00	.00	.00
38	2.00	Missing data	Missing data
39	5.00	Missing data	Missing data
40	4.00	1.00	Missing data
41	2.00	2.00	2.00
42	2.00	2.00	Missing data
43	Missing data	Missing data	Missing data
44	Missing data	Missing data	Missing data
45	.00	.00	.00
46	2.00	4.00	2.00
47	.00	Missing data	Missing data
48	Missing data	Missing data	Missing data
49	12.00	5.00	.00
50	6.00	1.00	Missing data
51	Missing data	Missing data	Missing data

52	.00	.00	.00
53	Missing data	Missing data	Missing data
54	.00	.00	.00
55	Missing data	Missing data	Missing data
56	.00	Missing data	Missing data
57	1.00	5.00	4.00
58	Missing data	Missing data	Missing data
59	.00	.00	Missing data
60	.00	.00	Missing data
61	.00	.00	Missing data
62	Missing data	Missing data	Missing data
Constipation assessed using the ISS questionnaire			
1	.00	[redacted]	Missing data
2	6.00		6.00
3	.00		1.00
4	4.00		1.00
5	.00		.00
6	.00		Missing data
7	2.00		1.00
8	Missing data		.00
9	5.00		2.00
10	1.00		1.00
11	3.00		3.00
12	.00		.00
13	.00		2.00
14	.00		.00
15	6.00		6.00
16	.00		.00
17	5.00		Missing data
18	.00		1.00
19	4.00		3.00
20	.00		1.00
21	3.00		Missing data
22	4.00		Missing data
23	.00		2.00
24	4.00		4.00
25	.00		Missing data
26	2.00		Missing data
27	1.00		.00
28	1.00		3.00
29	.00		.00
30	2.00		Missing data
31	.00		Missing data
32	6.00		5.00
33	6.00		5.00
34	2.00		Missing data
35	.00		.00
36	3.00		1.00

37	Missing data	[redacted]	.00
38	5.00		Missing data
39	4.00		Missing data
40	4.00		Missing data
41	4.00		5.00
42	3.00		Missing data
43	.00		Missing data
44	6.00		Missing data
45	4.00		.00
46	4.00		3.00
47	1.00		Missing data
48	2.00		Missing data
49	3.00		3.00
50	4.00		Missing data
51	4.00		2.00
52	.00		.00
53	4.00		Missing data
54	.00		Missing data
55	3.00		5.00
56	.00		Missing data
57	5.00		5.00
58	Missing data		Missing data
59	2.00		Missing data
60	.00		Missing data
61	.00		Missing data
62	.00		Missing data
Bloating assessed using the 7-day diary			
1	7.00	7.00	Missing data
2	6.00	6.00	6.00
3	4.00	4.00	14.00
4	1.00	.00	1.00
5	.00	.00	.00
6	7.00	7.00	Missing data
7	3.00	1.00	7.00
8	1.00	3.00	1.00
9	2.00	1.00	.00
10	2.00	.00	.00
11	8.00	1.00	Missing data
12	2.00	.00	5.00
13	Missing data	1.00	.00
14	3.00	.00	4.00
15	14.00	2.00	6.00
16	6.00	6.00	6.00
17	2.00	2.00	Missing data
18	2.00	.00	18.00
19	5.00	3.00	7.00
20	2.00	1.00	4.00
21	18.00	Missing data	Missing data

22	9.00	Missing data	Missing data
23	9.00	4.00	16.00
24	Missing data	Missing data	Missing data
25	Missing data	Missing data	Missing data
26	2.00	Missing data	Missing data
27	3.00	Missing data	8.00
28	Missing data	.00	6.00
29	.00	.00	.00
30	9.00	11.00	Missing data
31	4.00	.00	Missing data
32	3.00	Missing data	5.00
33	42.00	.00	10.00
34	4.00	2.00	Missing data
35	4.00	3.00	.00
36	.00	5.00	2.00
37	.00	.00	.00
38	5.00	Missing data	Missing data
39	1.00	Missing data	Missing data
40	1.00	15.00	Missing data
41	8.00	14.00	12.00
42	4.00	2.00	Missing data
43	Missing data	Missing data	Missing data
44	Missing data	Missing data	Missing data
45	2.00	4.00	4.00
46	7.00	14.00	4.00
47	1.00	Missing data	Missing data
48	Missing data	Missing data	Missing data
49	6.00	.00	.00
50	19.00	6.00	Missing data
51	Missing data	Missing data	Missing data
52	.00	2.00	.00
53	Missing data	Missing data	Missing data
54	5.00	.00	.00
55	Missing data	Missing data	Missing data
56	6.00	Missing data	Missing data
57	30.00	36.00	27.00
58	Missing data	Missing data	Missing data
59	.00	.00	Missing data
60	2.00	1.00	Missing data
61	.00	.00	Missing data
62	Missing data	Missing data	Missing data
Bloating assessed using the ISS questionnaire			
1	6.00	[redacted]	Missing data
2	6.00		6.00
3	5.00		5.00
4	5.00		1.00
5	5.00		.00
6	6.00		Missing data

7	6.00	[redacted]	4.00
8	3.00		4.00
9	4.00		1.00
10	4.00		1.00
11	5.00		3.00
12	5.00		5.00
13	3.00		2.00
14	3.00		2.00
15	5.00		5.00
16	5.00		5.00
17	3.00		Missing data
18	6.00		6.00
19	3.00		.00
20	3.00		5.00
21	6.00		Missing data
22	5.00		Missing data
23	6.00		6.00
24	3.00		4.00
25	5.00		Missing data
26	4.00		Missing data
27	2.00		2.00
28	6.00		2.00
29	.00		.00
30	4.00		Missing data
31	1.00		Missing data
32	6.00		3.00
33	6.00		3.00
34	4.00		Missing data
35	4.00		2.00
36	3.00		6.00
37	Missing data		.00
38	4.00		Missing data
39	.00		Missing data
40	.00		Missing data
41	6.00		6.00
42	5.00		Missing data
43	3.00		Missing data
44	6.00		Missing data
45	6.00		5.00
46	6.00		6.00
47	1.00		Missing data
48	3.00		Missing data
49	5.00		3.00
50	6.00		Missing data
51	5.00		5.00
52	2.00		2.00
53	.00		Missing data
54	5.00		Missing data

55	3.00	[redacted]	5.00
56	6.00		Missing data
57	6.00		5.00
58	Missing data		Missing data
59	4.00		Missing data
60	1.00		Missing data
61	.00		Missing data
62	4.00		Missing data
Abdominal pain assessed using the 7-day dairy			
1	.00	.00	Missing data
2	22.00	19.00	7.00
3	2.00	2.00	.00
4	3.00	.00	.00
5	10.00	2.00	1.00
6	.00	.00	Missing data
7	6.00	1.00	5.00
8	6.00	5.00	9.00
9	10.00	7.00	4.00
10	1.00	1.00	.00
11	2.00	.00	Missing data
12	22.00	18.00	1.00
13	Missing data	2.00	.00
14	6.00	2.00	16.00
15	21.00	17.00	25.00
16	8.00	13.00	1.00
17	2.00	2.00	Missing data
18	1.00	1.00	.00
19	1.00	1.00	2.00
20	.00	3.00	.00
21	1.00	Missing data	Missing data
22	2.00	Missing data	Missing data
23	15.00	1.00	21.00
24	Missing data	Missing data	Missing data
25	Missing data	Missing data	Missing data
26	2.00	Missing data	Missing data
27	20.00	Missing data	19.00
28	Missing data	.00	.00
29	.00	.00	.00
30	14.00	7.00	Missing data
31	13.00	1.00	Missing data
32	3.00	Missing data	.00
33	23.00	.00	3.00
34	7.00	5.00	Missing data
35	2.00	1.00	.00
36	7.00	2.00	5.00
37	.00	.00	.00
38	3.00	Missing data	Missing data
39	3.00	Missing data	Missing data

40	2.00	4.00	Missing data
41	8.00	5.00	.00
42	10.00	6.00	Missing data
43	Missing data	Missing data	Missing data
44	Missing data	Missing data	Missing data
45	1.00	2.00	5.00
46	2.00	1.00	.00
47	.00	Missing data	Missing data
48	Missing data	Missing data	Missing data
49	.00	2.00	1.00
50	1.00	.00	Missing data
51	Missing data	Missing data	Missing data
52	1.00	1.00	.00
53	Missing data	Missing data	Missing data
54	3.00	15.00	11.00
55	Missing data	Missing data	Missing data
56	7.00	Missing data	Missing data
57	3.00	8.00	3.00
58	Missing data	Missing data	Missing data
59	2.00	3.00	Missing data
60	2.00	.00	Missing data
61	7.00	3.00	Missing data
62	Missing data	Missing data	Missing data
Abdominal pain assessed using the ISS questionnaire			
1	4.00	[redacted]	Missing data
2	6.00		5.00
3	2.00		3.00
4	4.00		.00
5	3.00		2.00
6	4.00		Missing data
7	3.00		1.00
8	3.00		3.00
9	5.00		3.00
10	3.00		.00
11	2.00		1.00
12	6.00		3.00
13	5.00		1.00
14	5.00		4.00
15	5.00		5.00
16	4.00		5.00
17	3.00		Missing data
18	4.00		6.00
19	3.00		.00
20	5.00		4.00
21	2.00		Missing data
22	5.00		Missing data
23	6.00		6.00
24	2.00		5.00

25	4.00	[redacted]	Missing data
26	5.00		Missing data
27	3.00		3.00
28	1.00		.00
29	4.00		1.00
30	5.00		Missing data
31	1.00		Missing data
32	4.00		2.00
33	4.00		1.00
34	6.00		Missing data
35	2.00		1.00
36	3.00		5.00
37	Missing data		2.00
38	3.00		Missing data
39	4.00		Missing data
40	4.00		Missing data
41	6.00		4.00
42	5.00		Missing data
43	6.00		Missing data
44	1.00		Missing data
45	6.00		2.00
46	1.00		.00
47	Missing data		Missing data
48	5.00		Missing data
49	4.00		3.00
50	.00		Missing data
51	5.00		4.00
52	.00		2.00
53	6.00		Missing data
54	1.00		Missing data
55	1.00		1.00
56	6.00		Missing data
57	2.00		1.00
58	Missing data		Missing data
59	5.00		Missing data
60	1.00		Missing data
61	4.00		Missing data
62	6.00		Missing data

Urgent need to defecate assessed using the 7-day diary

1	5.00	5.00	Missing data
2	4.00	4.00	1.00
3	5.00	5.00	11.00
4	1.00	1.00	4.00
5	1.00	1.00	1.00
6	5.00	5.00	Missing data
7	.00	.00	.00
8	9.00	9.00	4.00
9	.00	.00	1.00

10	2.00	2.00	1.00
11	6.00	6.00	Missing data
12	2.00	9.00	2.00
13	Missing data	2.00	.00
14	1.00	1.00	4.00
15	1.00	1.00	.00
16	10.00	10.00	12.00
17	.00	.00	Missing data
18	6.00	6.00	2.00
19	2.00	2.00	1.00
20	.00	.00	2.00
21	2.00	Missing data	999.00
22	1.00	Missing data	Missing data
23	4.00	4.00	11.00
24	Missing data	Missing data	Missing data
25	Missing data	Missing data	Missing data
26	5.00	Missing data	Missing data
27	2.00	Missing data	.00
28	Missing data	.00	.00
29	1.00	1.00	10.00
30	.00	.00	Missing data
31	1.00	1.00	Missing data
32	.00	Missing data	1.00
33	.00	.00	.00
34	3.00	3.00	Missing data
35	1.00	1.00	3.00
36	1.00	1.00	1.00
37	.00	.00	.00
38	.00	Missing data	Missing data
39	2.00	Missing data	Missing data
40	.00	.00	Missing data
41	1.00	1.00	.00
42	2.00	2.00	Missing data
43	Missing data	Missing data	Missing data
44	Missing data	Missing data	Missing data
45	.00	.00	2.00
46	2.00	2.00	.00
47	5.00	Missing data	Missing data
48	Missing data	Missing data	Missing data
49	4.00	4.00	6.00
50	.00	.00	Missing data
51	Missing data	Missing data	Missing data
52	19.00	19.00	17.00
53	Missing data	Missing data	Missing data
54	5.00	5.00	5.00
55	Missing data	Missing data	Missing data
56	.00	Missing data	Missing data
57	4.00	4.00	3.00

58	Missing data	Missing data	Missing data
59	2.00	2.00	Missing data
60	1.00	1.00	Missing data
61	6.00	6.00	Missing data
62	Missing data	Missing data	Missing data
Urgent need to defecate assessed using the ISS questionnaire			
1	2.00	[redacted]	Missing data
2	6.00		6.00
3	5.00		4.00
4	5.00		4.00
5	.00		.00
6	2.00		Missing data
7	2.00		2.00
8	6.00		6.00
9	4.00		3.00
10	5.00		3.00
11	3.00		2.00
12	5.00		3.00
13	5.00		3.00
14	4.00		4.00
15	.00		1.00
16	5.00		5.00
17	2.00		Missing data
18	6.00		6.00
19	2.00		4.00
20	3.00		5.00
21	.00		Missing data
22	3.00		Missing data
23	6.00		6.00
24	4.00		5.00
25	4.00		Missing data
26	5.00		Missing data
27	2.00		1.00
28	5.00		5.00
29	4.00		5.00
30	.00		Missing data
31	.00		Missing data
32	5.00		.00
33	2.00		5.00
34	5.00		Missing data
35	2.00		2.00
36	2.00		4.00
37	Missing data		4.00
38	1.00		Missing data
39	5.00		Missing data
40	5.00		Missing data
41	4.00		5.00
42	4.00		Missing data

43	2.00	[redacted]	Missing data
44	.00		Missing data
45	4.00		6.00
46	.00		.00
47	3.00		Missing data
48	3.00		Missing data
49	5.00		4.00
50	.00		Missing data
51	5.00		4.00
52	4.00		4.00
53	1.00		Missing data
54	5.00		Missing data
55	1.00		1.00
56	6.00		Missing data
57	.00		2.00
58	Missing data		Missing data
59	4.00		Missing data
60	1.00		Missing data
61	6.00		Missing data
62	4.00		Missing data
Feelings of incomplete evacuation assessed using the 7-day diary			
1	5.00	1.00	Missing data
2	2.00	3.00	.00
3	8.00	5.00	.00
4	4.00	.00	1.00
5	.00	.00	.00
6	5.00	1.00	Missing data
7	.00	.00	.00
8	.00	1.00	.00
9	2.00	1.00	.00
10	6.00	.00	.00
11	7.00	18.00	Missing data
12	13.00	2.00	.00
13	Missing data	1.00	.00
14	3.00	.00	1.00
15	6.00	1.00	.00
16	8.00	23.00	8.00
17	1.00	1.00	Missing data
18	5.00	6.00	2.00
19	4.00	3.00	1.00
20	.00	.00	.00
21	.00	Missing data	Missing data
22	2.00	Missing data	Missing data
23	16.00	1.00	20.00
24	Missing data	Missing data	Missing data
25	Missing data	Missing data	Missing data
26	3.00	Missing data	Missing data
27	.00	Missing data	.00

28	Missing data	.00	.00
29	.00	.00	.00
30	13.00	10.00	Missing data
31	1.00	.00	Missing data
32	.00	Missing data	.00
33	2.00	.00	1.00
34	2.00	2.00	Missing data
35	4.00	2.00	.00
36	3.00	6.00	1.00
37	.00	.00	.00
38	3.00	999.00	999.00
39	1.00	999.00	Missing data
40	1.00	3.00	Missing data
41	9.00	3.00	1.00
42	1.00	1.00	Missing data
43	Missing data	Missing data	Missing data
44	Missing data	Missing data	Missing data
45	1.00	1.00	1.00
46	4.00	4.00	5.00
47	2.00	Missing data	Missing data
48	Missing data	Missing data	Missing data
49	2.00	3.00	.00
50	.00	.00	Missing data
51	Missing data	Missing data	Missing data
52	14.00	27.00	28.00
53	Missing data	Missing data	Missing data
54	2.00	4.00	.00
55	Missing data	Missing data	Missing data
56	1.00	Missing data	Missing data
57	11.00	10.00	3.00
58	Missing data	Missing data	Missing data
59	.00	.00	Missing data
60	2.00	.00	Missing data
61	2.00	3.00	Missing data
62	Missing data	Missing data	Missing data
Feelings of incomplete evacuation assessed using the ISS questionnaire			
1	4.00	[redacted]	Missing data
2	6.00		6.00
3	5.00		4.00
4	4.00		.00
5	.00		.00
6	4.00		Missing data
7	4.00		.00
8	1.00		.00
9	4.00		2.00
10	4.00		1.00
11	5.00		4.00
12	6.00		4.00

13	6.00	[redacted]	2.00
14	5.00		4.00
15	4.00		4.00
16	5.00		6.00
17	1.00		Missing data
18	6.00		6.00
19	3.00		.00
20	2.00		4.00
21	4.00		Missing data
22	3.00		Missing data
23	6.00		6.00
24	4.00		5.00
25	3.00		Missing data
26	3.00		Missing data
27	1.00		1.00
28	5.00		5.00
29	4.00		4.00
30	5.00		Missing data
31	.00		Missing data
32	5.00		2.00
33	6.00		6.00
34	5.00		Missing data
35	2.00		1.00
36	3.00		6.00
37	Missing data		4.00
38	4.00		Missing data
39	1.00		Missing data
40	1.00		Missing data
41	6.00		5.00
42	5.00		Missing data
43	3.00		Missing data
44	4.00		Missing data
45	5.00		6.00
46	3.00		3.00
47	3.00		Missing data
48	2.00		Missing data
49	4.00		2.00
50	.00		Missing data
51	5.00		5.00
52	2.00		4.00
53	1.00		Missing data
54	6.00		Missing data
55	6.00		4.00
56	6.00		Missing data
57	3.00		4.00
58	Missing data		Missing data
59	4.00		Missing data
60	3.00		Missing data

61	4.00	[redacted]	Missing data
62	6.00		Missing data
Flatulence assessed using the 7-day diary			
1	5.00	1.00	Missing data
2	9.00	10.00	4.00
3	25.00	21.00	20.00
4	2.00	.00	3.00
5	6.00	2.00	2.00
6	5.00	1.00	Missing data
7	10.00	6.00	10.00
8	6.00	12.00	6.00
9	4.00	1.00	3.00
10	1.00	.00	1.00
11	21.00	9.00	Missing data
12	9.00	5.00	1.00
13	Missing data	1.00	.00
14	.00	.00	1.00
15	11.00	5.00	5.00
16	5.00	6.00	6.00
17	4.00	5.00	Missing data
18	15.00	10.00	33.00
19	2.00	3.00	3.00
20	.00	2.00	2.00
21	13.00	Missing data	Missing data
22	4.00	Missing data	Missing data
23	12.00	21.00	3.00
24	Missing data	Missing data	Missing data
25	Missing data	Missing data	Missing data
26	10.00	Missing data	Missing data
27	1.00	Missing data	2.00
28	Missing data	3.00	.00
29	.00	.00	.00
30	14.00	8.00	Missing data
31	6.00	.00	Missing data
32	1.00	Missing data	1.00
33	10.00	4.00	21.00
34	2.00	2.00	Missing data
35	8.00	6.00	4.00
36	7.00	23.00	.00
37	.00	.00	.00
38	4.00	Missing data	Missing data
39	1.00	Missing data	Missing data
40	2.00	15.00	Missing data
41	11.00	16.00	9.00
42	4.00	4.00	Missing data
43	Missing data	Missing data	Missing data
44	Missing data	Missing data	Missing data
45	2.00	3.00	5.00

46	9.00	15.00	9.00
47	.00	Missing data	Missing data
48	Missing data	Missing data	Missing data
49	9.00	1.00	.00
50	17.00	1.00	Missing data
51	Missing data	Missing data	Missing data
52	12.00	13.00	27.00
53	Missing data	Missing data	Missing data
54	48.00	17.00	19.00
55	Missing data	Missing data	Missing data
56	5.00	Missing data	Missing data
57	19.00	19.00	6.00
58	Missing data	Missing data	Missing data
59	.00	.00	Missing data
60	1.00	2.00	Missing data
61	1.00	.00	Missing data
62	Missing data	Missing data	Missing data
Flatulence assessed using the ISS questionnaire			
1	5.00	[redacted]	Missing data
2	6.00		6.00
3	5.00		5.00
4	4.00		3.00
5	1.00		3.00
6	5.00		Missing data
7	6.00		6.00
8	3.00		5.00
9	5.00		4.00
10	5.00		1.00
11	6.00		5.00
12	4.00		4.00
13	6.00		6.00
14	2.00		1.00
15	3.00		4.00
16	5.00		5.00
17	5.00		Missing data
18	6.00		6.00
19	2.00		1.00
20	2.00		4.00
21	5.00		Missing data
22	1.00		Missing data
23	6.00		6.00
24	5.00		5.00
25	3.00		Missing data
26	5.00		Missing data
27	1.00		1.00
28	5.00		2.00
29	.00		1.00
30	5.00		Missing data

31	4.00	[redacted]	Missing data
32	6.00		5.00
33	4.00		6.00
34	5.00		Missing data
35	4.00		3.00
36	5.00		6.00
37	Missing data		3.00
38	6.00		Missing data
39	5.00		Missing data
40	5.00		Missing data
41	6.00		6.00
42	6.00		Missing data
43	4.00		Missing data
44	5.00		Missing data
45	3.00		4.00
46	6.00		6.00
47	.00		Missing data
48	3.00		Missing data
49	5.00		2.00
50	2.00		Missing data
51	6.00		5.00
52	3.00		3.00
53	1.00		Missing data
54	6.00		Missing data
55	6.00		4.00
56	6.00		Missing data
57	5.00		4.00
58	Missing data		Missing data
59	3.00		Missing data
60	4.00		Missing data
61	3.00		Missing data
62	5.00		Missing data

SYMPTOM FREQUENCY

TOTAL SYMPTOMS – 7 DAY DIARY

There was a reduction in total symptom frequency from pre intervention (30.71, SD 21.7) to immediately post the intervention (22.68, SD 21.4). A paired samples t-test revealed that this reduction was significant $t(37) = 2.974$, $p < 0.005$. Therefore the first hypothesis was supported.

There was a reduction in total symptom frequency from pre intervention (28.65, SD 21) to two months post the intervention (18.77, SD 12.5). A paired samples t-test

revealed that this reduction was significant $t(25) = 3.332$, $p < 0.005$. Therefore the second hypothesis was supported.

Although there was a reduction in total symptom frequency from immediately post intervention (22.88, SD 21) to two months post the intervention (17.96, SD 13.7) this was not found to be significant. However, as there was no significant increase in symptoms it does show that symptom improvements at phase 2 (immediately post the intervention) were maintained at phase 3 (two months after the intervention)

INDIVIDUAL SYMPTOMS – 7 DAY DIARY

The only significant changes observed for individual symptoms were for constipation and diarrhoea. However reductions in feelings of incomplete evacuation and abdominal pain were approaching significance (were significant prior to the application of the Bonferroni correction). The change in diarrhoea was between immediate post intervention (2.03, SD 2.9) and at two months post intervention (0.62, SD 1.1). A paired samples t-test revealed that this reduction was significant $t(28) = 2.698$, $p < 0.05$. Reductions between pre intervention and two months post intervention were approaching significance (were significant prior to the application of the Bonferroni correction). The change in constipation was also between immediate post intervention (1.73, SD 3.2) and at two months post intervention (0.83, SD 1.3). A paired samples t-test revealed that this reduction was significant $t(29) = 2.638$, $p < 0.05$.

TOTAL SYMPTOMS – ISS QUESTIONNAIRE

The ISS was not included in the immediate post intervention pack, but there was a reduction in total symptom frequency from pre intervention (24.93 SD 6.6) to two months post the intervention (21.66, SD 9.2). A paired samples t-test revealed that this reduction was significant $t(33) = 2.433$, $p < 0.05$. This provides additional support for hypothesis 2, that total symptom frequency was reduced at two months post intervention. The ISS and the symptom diary were correlated $r = .398$, $p < 0.05$.

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INDIVIDUAL SYMPTOMS – ISS QUESTIONNAIRE

Three of the individual symptoms were found to reduce from pre intervention to two months post intervention. This was for abdominal pain (pre intervention 3.58, SD 1.7 – two months post intervention 2.56, SD 1.8) $t(33) = 3.334$, $p < 0.005$, bloating (pre intervention 4.44, SD 1.5 – two months post intervention 3.53, SD 2) $t(33) = 2.876$, $p < 0.005$, and feelings of incomplete evacuation (pre intervention 4.12, SD 1.6 – two months post intervention 3.41, SD 2.1) $t(33) = 2.352$, $p < 0.05$.

HRQOL

There was a significant reduction in scores on the IBS-36 post intervention (pre intervention, 115.83, SD 36.9 – two months post intervention, 99.17, SD 36.5). This reduction was found to be significant $t(34) = 4.667$, $p < 0.0001$. As a reduction in score indicates an improvement in HRQOL, this finding provides support for hypothesis three.

THE RELATIONSHIP BETWEEN HRQOL AND SYMPTOMS

HRQOL at two months post intervention was neither predictive nor correlated with total symptoms measured by the symptom diary. However, HRQOL at two months post intervention was predictive of total symptoms at two months post intervention when measured by the questionnaire R^2 adj. 0.364, $p < 0.001$.

MEDICATION

The improvements in HRQOL and symptoms post intervention were not as a result of increases in medication. In fact medication intake in the week immediately post the intervention (5.76, SD 8) was less than medication intake in the week preceding the intervention (7.24, SD 9.4). A paired samples t-test revealed that this reduction was significant $t(36) = 2.537$, $p < 0.05$.

CHANGES IN PERCEIVED SOCIAL SUPPORT (PSS)

PERCEIVED ATTITUDES TO DISCUSSING SYMPTOMS

There were significant reductions in scores on the perceived attitudes to discussing symptoms scale from pre intervention (35.15, SD 11.5) to post intervention (29.75,

SD 9.3). A paired samples t-test revealed that this reduction was significant $t(51) = 3.267$, $p < 0.005$. It should be noted that lower scores on this scale indicate more positive perceptions, which is the IBS sufferers perceived people as being more prepared to discuss their symptoms after the intervention. There were no significant reductions from pre intervention to two months post intervention or for immediately post intervention to two months post intervention. Whilst there were no significant reductions in scores as there was no significant increase it does show that improvements in perceived attitudes to discussing symptoms is maintained at phase 3 (two months after the intervention).

PERCEIVED ATTITUDES TO WITNESSING SYMPTOMS

There were significant reductions in scores on the perceived attitudes to witnessing symptoms scale from pre intervention (35, SD 10.6) to post intervention (30.2, SD 9.1). A paired samples t-test revealed that this reduction was significant $t(39) = 13.961$, $p < 0.0001$. It should be noted that lower scores on this scale indicate more positive perceptions, which is the IBS sufferers perceived people as being more prepared to witness their symptoms after the intervention. There were no significant reductions from pre intervention to two months post intervention or for immediately post intervention to two months post intervention. Whilst there were no significant reductions in scores as there was no significant increase it does show that improvements in perceived attitudes to discussing symptoms is maintained at phase 3 (two months after the intervention).

PERCEIVED SOCIAL SUPPORT CONCESSION SCALE AND PERCEIVED SOCIAL ACTIVITY SCALE

There were no significant improvements in the responses to the social support concessions scale or the social activity scale at either immediately post intervention or at two months post intervention.

PERCEIVED SOCIAL SUPPORT (PSS) AND ILLNESS OUTCOMES

A series out multiple regressions were conducted (with attitudes towards discussing and witnessing symptoms as predictors) to explore the relationship between

perceived attitudes and illness outcomes. Neither attitudes towards discussing or witnessing symptoms were predictive of symptom outcomes (on either the ISS or daily diary) immediately post intervention. Attitudes towards discussing symptoms were also not predictive of any of the illness outcomes at two months post intervention. However, attitudes towards witnessing symptoms at two months post the intervention were predictive of HRQOL, that is quality of life increased as attitudes towards witnessing symptoms were perceived as being more positive, R^2 adj. 0.273, $p < 0.05$. Attitudes towards witnessing symptoms at two months post the intervention were also predictive of total symptoms, on both the diary, R^2 adj. 0.277, β 0.673, $p < 0.05$, and the ISS, R^2 adj. 0.185, β 0.581, $p < 0.05$.

CHANGES IN THE ILLNESS REPRESENTATION COMPONENTS

Paired samples t-tests revealed a number of significant changes between pre intervention, immediately post intervention and two month post the intervention on several of the illness representation dimensions. All of these significant changes were in the direction anticipated, that is where lower scores were associated with more positive representations lower scores were found post intervention, and when higher scores were associated with more positive representations higher scores were found post intervention. The significant illness representation components, means and significance levels are shown in tables 22 and 23.

Table 22 – Illness representation components pre intervention and significant changes immediately post intervention

ILLNESS REPRESENTATIONS	PRE INTERVENTION MEAN	POST INTERVENTION MEAN	t	df	p
CHRONIC TIMELINE	25.96 SD 3.1	24.71 SD 3.7	**4.547**	**44**	**0.0001**
PERCEIVED PERSONAL CONTROL	17.98 SD 3.6	19.85 SD 3.2	**3.850**	**46**	**0.0001**
EMOTIONAL REPRESENTATIONS	21.58 SD 4.8	19.82 SD 5.4	**2.854**	**45**	**0.01**

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As table 22 demonstrates there were three significant improvements in illness representations immediately post the intervention, these were in chronic time line, perceived personal control and emotional representations. Illness coherence was also approaching significance (was significant prior to the Bonferoni correction).

Table 23 – Illness representation components pre intervention and significant changes at two months post intervention

ILLNESS REPRESENTATIONS	PRE INTERVENTION MEAN	2 MONTHS POST INTERVENTION MEAN	t	df	p
CHRONIC TIMELINE	26.37 SD 3.2	24.66 SD 3.8	2.908	31	0.01
PERCEIVED PERSONAL CONTROL	18.47 SD 3.7	19.85 SD 3	2.638	33	0.05
EMOTIONAL REPRESENTATIONS	21.58 SD 5.8	19.73 SD 4.6	3.295	32	0.005
ILLNESS COHERENCE	16.23 SD 4.2	13.31 SD 4	5.166	34	0.0001
ILLNESS IDENTITY	22.97 SD 2.5	21.3 SD 2.1	3.169	32	0.005

As table 23 demonstrates five illness representations showed significant improvements from pre intervention to immediately post the intervention, these were in chronic time line, perceived personal control, illness coherence, emotional representations and illness identity. The only components of illness representations which did not alter were cyclical timeline, perceived consequences and perceived treatment control.

The only significant change from immediately post intervention (mean 23.39, SD 2.3) to two months post intervention (mean 21.33, SD 2.1) was illness identity, $t(32) = 6.338$, $p < 0.0001$. However, there were no significant decreases in any of the illness representations either, therefore the changes immediately post intervention were maintained at two month follow up.

REPORTED CHANGES AT TWO MONTHS POST INTERVENTION

The short post intervention questionnaire asked people to report if they had made any changes as a result of taking part in the intervention. Data was available for 23 participants. Of these three did not report any changes, of the other twenty participants some reported only one, whereas others reported more than one. As no meaningful information can be derived from this questionnaire in a statistical sense, the responses are just listed in the frequency table, table 24.

Table 24 - Reported changes at two months post intervention

Change made	Number of people	Psychological change or practical change
Dietary alterations	5	practical
Feeling empowered to make changes to effect IBS	1	psychological
Making a conscious effort to use relaxation techniques	2	psychological & practical
Trying to have less anxiety about symptoms	3	psychological
Concentrating on the positive aspects about having IBS	5	psychological
Making efforts to deal with stress	3	psychological
Removing key stressors	2	practical & psychological
Trying alternative therapies	2	practical
Taking time for myself	1	psychological
Improved communication with GP	1	practical & psychological
Not letting IBS affect my [perceived] quality of life	2	psychological
Undergoing further medical tests	2	practical
Cognitive Behavioural Treatment	2	psychological & practical
Exercise	2	practical
Obtain information from IBS Network about IBS	1	practical
Hypnosis	1	practical & psychological
Acceptance of past experiences, and trying to let go	1	psychological

As table 24 demonstrates the varied nature of the booklet means that different sources of advice appeal to different participants. Some of these changes are practical, some psychological and some a combination. Where there is a combination the dominant feature is listed first. The two changes which are tied for most frequently mentioned are dietary changes and positive thinking.

THE RELATIONSHIPS BETWEEN ILLNESS REPRESENTATIONS AND ILLNESS OUTCOMES

Based on the original rationale for this research the final stage of the analysis was to assess if the increase in positive illness representations was predictive of the improvement in symptoms and HRQOL following the intervention. Therefore a series of hierarchical multiple regressions were conducted to assess the relationships between variables both immediately following the intervention and at two months post the intervention. As there is insufficient power in this sample to include all of the predictor variables in the analysis the regression only used a handful. The decision as to which variables were used was based on the analysis presented earlier in this chapter showing which representations change from pre to post intervention. Accordingly the predictors used to assess change from pre to immediately post the intervention were: chronic timeline, personal control and emotional representations. For this hierarchical multiple regression the dependent variable was change in illness perceptions from time 1 (pre intervention) to time 2 (immediately post intervention). Accordingly the predictor variables at time one were entered in block one and the time two variables in block two. The predictors used to assess change from pre to two months post the intervention were chronic timeline, personal control, emotional representations, illness coherence and illness identity. For this hierarchical multiple regression the dependent variable was change in illness perceptions from time 1 (pre intervention) to time 3 (immediately post intervention). Accordingly the predictor variables at time one were entered in block one and the time three variables in block two.

The multiple regressions that were conducted were as follows:

1) Illness representations and total symptoms using the daily diary (pre to immediately post the intervention)

2) Illness representations and individual symptoms using the daily diary (pre to immediately post the intervention)
3) Illness representations and total symptoms using the daily diary (pre to two months post the intervention)
4) Illness representations and individual symptoms using the daily diary (pre to two months post the intervention)
5) Illness representations and total symptoms using the ISS questionnaire (pre to two months post the intervention)
6) Illness representations and individual symptoms using the ISS questionnaire (pre to two months post the intervention)
7) Illness representations and HRQOL at two months post the intervention

ILLNESS REPRESENTATIONS AND TOTAL SYMPTOMS

There were no significant relationships between illness representations either immediately post the intervention or at two months. The finding of non significance was reported using both the diary and questionnaire measures.

ILLNESS REPRESENTATIONS AND INDIVIDUAL SYMPTOMS

There were no significant predictors of change in any of the individual symptoms between pre intervention and immediately post the intervention. There were also no significant predictors of change for pre and two months post the intervention.

ILLNESS REPRESENTATIONS AND HRQOL

There were no significant predictors of HRQOL at two months, after pre intervention scores had been partialed out.

NB the IBS-36 questionnaire (Groll et al., 2002, *appendix 2*) used to assess HRQOL asks participants to average their responses based on their experiences over the previous two months. This is therefore not suitable for assessment of change immediately post the intervention, as an average score of the previous two months will cover largely the same time period as the pre-intervention questionnaire.

INTER – ITEM CORRELATIONS BETWEEN ILLNESS REPRESENTATIONS COMPONENTS

The final stage of the analysis was to explore the relationships between the illness representation components both immediately post intervention and at two months post intervention, in both cases Pearsons' revealed several variables were highly correlated. The inter-item correlations for immediately post the intervention are shown in table 25 and the inter-item correlations for two months post the intervention are shown in table 26. NB only the variables which have significant correlations are shown.

Table 25 – Inter-item correlations between illness representation components immediately post intervention

	Perceived consequences	Perceived personal control	Timeline (cyclical)	Emotional reps.	Perceived treatment control	Timeline (chronic)
Perceived consequences						
Perceived personal control	**-.350 (*) n=45**					
Timeline (cyclical)	0.188 n=45	-.090 n=47				
Emotional reps.	**.583 (**) n=45**	-.115 n=47	.236 n=47			
Perceived treatment control	-.349 n=29	**.578 (**) n=30**	-.168 n=30	-.122 n=30		
Timeline (chronic)	.262 n=44	-.263 n=46	-.067 n=46	.145 n=46	**-.501 (**) n=29**	
Illness coherence	.189 n=44	-.147 n=46	**.327 (*) n=46**	.187 n=46	-0.93 n=29	-.183 n=45

** Correlation is significant at the 0.01 level (2 tailed)

- Correlation is significant at the 0.05 level (2 tailed)

Table 26 – Inter-item correlations between illness representation components at two months post intervention

	Perceived consequences	Perceived personal control	Timeline (cyclical)	Emotional reps.	Perceived treatment control	Timeline (chronic)	Illness identity
Perceived consequences							
Perceived personal control	-.143 n=34						
Timeline (cyclical)	.063 n=34	.064 n=33					
Emotional reps.	**.494 (**) n=33**	-.249 n=33	0.163 n=33				
Perceived treatment control	-.081 n=33	**.737 (**) n=33**	.233 n=32	-.176 n=32			
Timeline (chronic)	-.105 n=32	**-.361 (*) n=32**	.096 n=31	-.110 n=31	**-.365 (*) n=31**		
Illness identity	**-.354 (*) n=33**	.164 n=32	-.264 n=32	**-.443 (*) n=31**	0.87 n=31	-0.81 n=31	

** Correlation is significant at the 0.01 level (2 tailed)
* Correlation is significant at the 0.05 level (2 tailed)

The inter-item correlations reported here are consistent with previous research as they demonstrate that there are significant inter-item correlations between some of the illness representation dimensions (measured by the IPQ-R). Importantly they show that none of the inter-item correlations are of such magnitude that they indicate a conceptual overlap demonstrating the legitimacy of the multiple dimensions of illness representations, rather than a global representation of illness (Hagger & Orbell, 2003)

DISCUSSION

SUMMARY OF FINDINGS

As the results section details there are a number of significant research findings. The first findings relate to the change in symptoms post intervention. There were significant reductions in symptom frequency (assessed using the diary) from both pre intervention to immediately post intervention, and from pre intervention to two months post intervention. In addition there was also a significant reduction in symptom frequency from pre intervention to two months post intervention using the ISS (symptom questionnaire). Therefore hypothesis one, that there would be a reduction in symptom frequency immediately following the intervention was supported. Hypothesis two, that there would be a reduction in symptom frequency from pre the intervention to two months post the intervention, was also supported by both the diary and the perceived frequency of symptoms using the ISS. The ISS and the 7 day diary were found to be correlated, this is an important finding as theoretically the sufferers' perceptions of their symptom frequency may have differed from their actual symptoms. This suggests that the ISS is therefore a suitable measure for assessing symptom frequencies where using a diary based format is not practical.

The exploratory research question as to whether there would be significant reductions between immediately post the intervention and two months post the intervention was not found to be significant. Although this was not found to be significant there was still a reduction in symptoms, this suggests that symptoms did continue to improve after the intervention. At the very least the lack of a significant difference in the opposite direction demonstrates that symptoms did not revert back to pre intervention frequencies after the intervention. These research findings have important implications for the future of treatment research in IBS as they strongly suggest that this intervention booklet is efficacious at reducing symptom frequency, at least in the short term, this is consistent with a number of other psychologically based research, such as Blanchard et al. (1993) and Heyman-Mönnikes et al. (2000).

Using the 7 day diary there were significant reductions in diarrhoea and constipation. The reductions in diarrhoea occurred between pre intervention and two months post intervention. The reductions in constipation occurred between immediately post intervention and two months post intervention. These were the only symptoms that were significant after the Bonferoni correction had been employed, and on this basis it can be suggested that the amount of symptoms suffered for each of the individual symptoms was too low for there to be sufficient power to detect changes. This is why Dancey et al. (1995; 1998) propose that computation of total symptom scores is the only meaningful measure of IBS symptoms. Using the ISS there were also significant changes in reported frequency of symptoms between pre intervention and two months post intervention. These were for abdominal pain, bloating and feelings of incomplete evacuation. Although none of these symptoms were significant using the diary, both abdominal pain and feelings of incomplete evacuation were approaching significance, this provides further support for the likelihood that there were significant changes in multiple symptoms, but there was insufficient power to detect it in this instance.

There was a significant improvement in HRQOL from pre intervention to two months post intervention and therefore, hypothesis three was supported. The improvement in HRQOL is consistent with previous research, such as Gonsalkorale et al. (2002) and Boyce et al. (2000).

The relationship between HRQOL and total symptom frequency at two months post the intervention differed as a function of the measure used to assess symptom frequency. Consistent with the findings of study 2, and of Brennan et al. (2004) but inconsistent with the findings in study 1 HRQOL was neither predictive nor correlated with symptoms when the diary was used as the outcome measure. In the limitations of study 2 it was suggested that this may have been a result of the measure rather than a relationship not existing. This idea is supported by the finding here that HRQOL significantly predicted symptom frequency when the ISS was used. However, it should be noted that the ISS technically measures perceived symptom frequency, and in this respect the predictive relationship could potentially be a result of perceived HRQOL being correlated with perceived symptom

frequency, rather than actual symptom frequency. This concern is however made less likely by the observed correlation of the diary and the ISS.

The finding that medication use significantly decreased immediately post the intervention is important as it shows that the improvements in symptoms were purely as a result of the changes in the illness representation dimensions, and not due to increased symptom usage. Moreover it provides further support for the observed finding that symptoms decrease, because it logically follows that if symptoms are less that less medication will be taken. Although there were no further reductions in medication use from immediately post intervention to two months post intervention, there were no significant increases either. This means that medication decreases following the intervention were maintained up till at least two month follow up. This finding is again consistent with the maintenance of symptom improvements from immediately post to two months post intervention.

There were changes in perceived social support in both the discussing and witnessing symptoms scale from pre intervention to immediately post intervention. Although there were no further changes from post intervention to two months post intervention, the improvements were maintained. In order to evaluate the impact on perceived social support on illness outcomes a series of multiple regressions were conducted. There were no significant relationships between perceptions of discussing symptoms and illness outcomes (HRQOL and symptoms). However perceived attitudes towards witnessing symptoms at two months post intervention were predictive of HRQOL and total symptom frequency (on both the diary and ISS). Although study 2 suggested that the only predictive relationship was between perceived attitudes towards witnessing symptoms and HRQOL, this study strongly suggests that perceived attitudes towards witnessing symptoms do affect symptoms too. This supports the notion that this relationship existed in study 2 but that this was not revealed due to insufficient power in the previous study.

There were changes in the illness representation components at pre and post intervention, pre and two months post the intervention and post and two months post the intervention. All of the changes were denoted a positive improvement (although dimensions are counterbalanced so scores on some variables are negative). The only

illness representations that did not change at all were cyclical timeline, perceived consequences and perceived treatment control. The illness representations that changed between pre and immediately post the intervention were chronic timeline, perceived personal control and emotional representations. These same illness representations changed between pre and two month post and in addition illness coherence and illness identity also improved. These findings demonstrate that the intervention booklet did in fact adhere rigidly to the principles of the CSM, that improvements in illness representations occurred both immediately post the intervention and at two months post the intervention, and moreover that both illness coherence and illness identity were additionally significant at two months post intervention, suggesting that participants continued to gain a better understanding of their IBS following the intervention. Only illness identity significantly improved from immediately post intervention to two months post intervention, and illness coherence was significant prior to the Bonferoni correction.

Participants were asked to list any changes they had made between the intervention and two months post the intervention. From the twenty three participants who returned the post intervention forms a total of seventeen different changes were reported. This is interesting as it shows that the booklet inspired different changes in different individuals. Of these changes the two changes that were most frequent were dietary alterations, and concentrating of the positive aspects of IBS. The decision to concentrate on the positive aspect of IBS is consistent with the aims of the CSM, and also with similar changes, such as having less anxiety over symptoms, and not letting IBS affect my quality of life. There were some dietary alterations suggested, although this was not the focus of the self-help booklet, however, this change is unsurprising as dietary alterations form a large part of IBS sufferers' self-management approaches (e.g. Atkinson et al., 2004). It is unfortunately not possible to tell whether these dietary changes were as a result of the advice in the booklet, or an alternative way of managing symptoms. Regardless to the reason however it does suggest a more positive self-management strategy and this is clearly related to the changes in illness representations.

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There were no significant predictors of change between pre intervention and post intervention (either immediately post or at two months post intervention) for total symptoms or for individual symptomd (on both measures). There were no significant predictors of change between pre intervention and two months post intervention for HRQOL.More research is needed to ascertain if the lack of significance if a true finding or due to a methodological factor, such as a insufficient power.

It was hoped that as so many of the illness representations changed from pre to post intervention that there would be predictors of both symptoms and HRQOL at both immediately post the intervention and at two months post the intervention. Although the lack of multiple predictors in might be partly explained by the number of illness representation dimensions that are correlated, it may also be the result of another variable mediating the relationship between illness representations and illness outcomes. Coping has been shown by previous research to mediate this relationship (Rutter & Rutter, 2002), and therefore its role should be addressed more thoroughly in subsequent research.

STUDY LIMITATIONS

The number of participants in this study could be considered a limitation, and indeed in the original design of the research it was intended that an approximate sample size of n=110 would be attempted as this is the number of participants recommended to detect medium sized effects (GPower, Erdfelder et al., 1996). However, as many significant findings were yielded it can be suggested both that low participant numbers are not as much of a limitation and moreover that the effect sizes found in this research were large. In addition participant numbers are not low compared to participant numbers reported in previous psychologically based intervention research in IBS specifically. In fact as the systematic review in chapter 3 showed only thirteen of the forty two papers included in the study involved more than 60 participants. The main weakness of the low participant numbers, with a highly female bias was that is was not possible to legitimately assess any grouping variables, in particular an investigation of differences in efficacy of the intervention between males and females, IBS-subgroups and length of time suffering from IBS would also be useful.

The participant drop outs could also be considered a potential limitation, but as the method section details the characteristics in phases two and three are almost identical to the participant characteristics in the phase one the drop outs should not be considered to be troublesome. However, although the analysis of the data from participants who did not return their research packs suggests that the demographic characteristics are the same as those who did the responses from sufferers detailing why they did not participate includes reasons such as 'too ill', 'not enough time' and 'did not want to take part in psychologically based research'. These responses are concerning as they suggest that sufferers who experience more symptoms, who are not prepared to engage in self-management behaviours and those who do not accept a biopsychosocial approach to chronic illness as not going to participate in this research. Therefore although the characteristics of those who participated and those who did not appear to be the same it is possible that those sufferers with different characteristics were the ones who did not even fill in the 'non-responder' questionnaire, therefore although the results of this study may be generalisable to IBS sufferers as a whole they should be treated with caution until further research can support these claims. It should also be noted that five out of the twenty eight 'drop outs' reported 'finding out that they had something other than IBS'. This is concerning as potentially participants used in the analysis may later discover that they did not in fact suffer from IBS, this is an idea discussed further in the general discussion. However, from the stance of this study the intervention does appear to be highly successful and if some of the participants discovered that their symptoms were not in fact IBS as a later date this only serves to justify the utility of the CSM model across a range of illnesses. In addition an interesting point that is raised by the participant dropouts is that the proportion of IBS-D sufferers that 'dropped out' was much less, and therefore further exploration as to whether the bias towards IBS-D sufferers participating in research that is often observed (e.g. Rutter & Rutter, 2002) is worthy of further investigation.

There are no major limitations to the IBS booklet itself, although in order to ensure that it remains relevant it does need to be updated as new research findings emerge. The main limitation of the booklet is in its use in this research specifically. The limitation is that except for a few cases the intervention booklets were not returned. It should be noted that this was a conscious decision whereby participants were

informed that the booklet would be confidential. It was felt that this was necessary in order for the intervention booklet to be completed honestly, as the success of the intervention relied on people realising and changing their illness representations. However, the few booklets that participants chose to return showed a marked difference in the detail of the responses, in one case where a participant was asked to list positive aspects of having IBS the response was "there are none". It is therefore a limitation not to have the intervention booklets returned as it is theoretically likely that the intervention would be more successful for sufferers who engaged with the booklet, unfortunately this could not be assessed here.

In studies 1 and 2 it was discussed that the use of diaries to report symptom outcomes might be considered a limitation, because although it is an objective measure it is difficult to show improvements in symptom outcomes over a one week period. However, the improvements in total symptom frequency both immediately post the intervention and at two months post the intervention suggest that it in fact is a suitable measure. However, despite Meissner et al. (1997) contention that a symptom diary should be considered the gold standard for assessing symptoms, the significant reduction in symptoms observed when the ISS was used, coupled with its correlation with the diary suggest that this is an equally suitable measure. The limitation to the ISS in the context of this study, however, is that is was only administered at two months post intervention. Although it could have and should have been administered one week after the intervention (as it asked about symptoms over the previous week) it was not, and therefore although not detrimental here as the diary did show that significant symptom changes were obtained, this should still be considered a limitation.

Although the efficacy of the self-help book is shown here this study is arguably not as scientific as a true randomized control trial (RCT) in terms of its scientific quality (Mulrow, 1994). From a purely theoretical stance the superiority of an RCT design is clear, however, a number of practical constraints for IBS specifically, demonstrate that control groups are largely unsuitable for research into IBS. As the systematic review shows both prospective longitudinal (PLD) and RCT designs are prevalent. Although it therefore appears that either a PLD or an RCT design could have been employed a close reading of the study characteristics demonstrates that none of the

potential options for a control group are suitable. Firstly a waitlist control group (e.g. Blanchard et al., 1998) is not a true control as 'wait group' is not homogeneous as the experiences and treatment experienced by sufferers prior to the intervention will show a marked degree of variability depending on symptom fluctuations and self-medication practices. Secondly a waitlist control, where normal medical care is suspended (e.g. Bennet and Wilkinson, 1995) is unsuitable because, as the Bennet and Wilkinson (1995) study showed any improvements in symptoms post intervention are attributed to an increase in symptoms following suspension of medical care. Therefore in addition to not being a suitable control group this also has ethical considerations. Thirdly a symptom monitoring control, which was used in a majority of early research (e.g. Blanchard et al., 1987) has been shown in increase symptoms, and has suggested by Blanchard et al. (1987) to be due to increasing an awareness of being an IBS sufferer, coupled with the frustration of being in the control group. The only potential control group that has any possibility of providing legitimate comparisons is a matched control. However, taking into account the key features of the illness, such as sub group, length of time suffering, sex, co-morbid illnesses and many other factors, a vast sample size would be needed, and as the systematic review demonstrates large participant numbers are not usually achieved. However, the difficulty of achieving a matched control group in terms of the resources needed is secondary to the argument that a true between subjects control will never be possible as within these broad categories many idiosyncratic differences exist. It is therefore clear that an RCT is a highly unsuitable design and that for research of this type the most applicable control group is the participants themselves, therefore the PLD design used here is the most suitable. This is a view supported by many previous researchers, such as, Saito et al. (2002) and Colwell et al. (1998). Although the use of use of a PLD means it is not possible to guarantee with certainty that the results are not due to placebo effects (Bengtsson et al., 2005), the changes observed on the illness representation components from pre to post intervention suggest that the changes in illness outcomes can be attributed to the intervention.

MODIFICATIONS AND FURTHER RESEARCH

1) Due to time constraints it was not possible to reassess the efficacy of the intervention beyond the two month period. It would therefore be useful to reassess whether there have been further improvements, or at least maintenance of illness outcomes at six months and a year post the intervention. This is of particular interest for HRQOL where it is expected that improvements will not be immediate.

2) Although the philosophy of this self-help booklet is based on it being tailored to the needs of the individual sufferers, this is not truly possible with a paper based format. There would be clear benefits to this intervention being administered on a website with a detailed demographic and personality questionnaire which influenced which information was delivered to people. Since this research was conducted the IBS Network have launched their self-management programme on their website, this validates this as a mode of presentation, but does not negate the importance of this booklet being presented in this way as their programme is not based on the principles of the CSM, which as the results show is efficacious as an intervention.

3) The limitations regarding the completion of the booklet suggest that a modification could be to have a therapist working through the booklet with the sufferer, this will allow for each area to be fully explored and enable the therapist to challenge the perceptions of sufferers who are reluctant to alter their perceptions.

4) Future research with more people and in particular using cohort sampling to ensure that various grouping variables can be explored would be very useful, in terms of assessing the efficacy of the intervention in specific groups.

CONCLUSIONS

The self-help booklet appears to be effective at improving IBS sufferers' illness representations, perceived quality of life and at reducing both actual and perceived symptom frequency. This study therefore provides support for the theoretical utility of Leventhal et al's. (1980; 1984) common sense model in the devising of illness interventions. It also suggests that a short self-help booklet based intervention is a a cost effective and easily administered way of improving IBS sufferers' health and quality of life for at least two months post the intervention. Although the relationship between illness representations and illness outcomes is worthy of further exploration overall this intervention was very successful.

CHAPTER 7
GENERAL DISCUSSION
Aims

The aim of this chapter is to bring together the implications and limitations of the studies reported in this thesis. The first part of this chapter will discuss the overall findings of the studies in the context of current research in this field, and show how this thesis has made a valid contribution of advancing knowledge in this area. The second part of this chapter will discuss the limitations of this thesis along with suggestions for future research in this field. There are three empirical chapters to this thesis, all of which individually and collectively make a valid contribution to advancing knowledge of the CSM, and of IBS specifically.

OVERALL FINDINGS OF THE THESIS

DOCTOR-PATIENT COMMUNICATION

The area of doctor-patient communication was addressed in the first study of this thesis. There were two primary areas of doctor-patient communication that were of interest, these were whether differences existed in perceptions of communication between doctors and patients, and whether patients' perceptions of doctor-patient communication were predictive of their current illness representations and illness outcomes. The results relating to the question of differences between doctors and patients were highly significant. The results showed that patients perception of communication were less positive than doctors on three out of four dimensions of doctor-patient communication. The dimensions that differed between groups were 'distress relief', 'consultation comfort', and 'rapport'. The only dimension that did not differ between groups was 'compliance intent'. The results of this research are consistent with the current literature in this field, and also provide a novel contribution as IBS specific, quantitative research addressing perceived doctor-patient communication is lacking. The findings observed here therefore support and extend the qualitative studies of Coulson & Semper (2004) and Bertram et al. (2001), who showed that patients have negative perceptions of doctor-patient communication, but did not include doctors' perceptions as a comparison. The

findings also support the research on functional abdominal complaints by Van Dulmen et al. (1995).

In the initial design of this study it was hoped to gain sufficient participant numbers to compare perceptions of both GPs and gastroenterologists, however due to low participant numbers these were merged to form one group. As a one way analysis of variance showed there were no significant differences between the two groups this merge was deemed statistically legitimate. Upon reflection it is interesting to consider possible reasons why no difference was observed between groups. It is possible that a difference does exist but low participant numbers meant that this relationship was not revealed. However, it is also possible that the observed finding is accurate, and that despite being specialists in their field gastroenterologists' perceptions are comparable with GPs. Although it is not possible to conclude which of these (or potentially an alternative explanation) is correct, the suggestion that both groups perceive the communication in a similar manner is congruent with previous research (e.g. Letson & Dancey, 1996; Maguire, 1999).

Overall the results clearly demonstrate that there is a discrepancy in perceptions of doctor-patient communication between doctors and patients. Furthermore they suggest that this discrepancy may be observed for medical professionals in general, rather than an IBS specific interaction. Although more research is clearly needed to fully establish the differences between medical professionals and sufferers perceptions of communication, in IBS specifically, it is clear that this study makes a valuable contribution to the literautre on perceived doctor-patient communication in IBS. In addition the findings reported here are consistent with the literature on cancer (e.g. Ong et al., 2002) and therefore suggest that communication training for doctors would be a logical practical implication of these research findings. This suggestion is consistent with Harrington et al.'s (2004) observation that the medical curriculum has been revised to include doctor-patient communication. This research suggests that communication training should be mandatory to all medical professionals as part of continued professional development, this is in line with the focus groups conducted by Kennedy et al. (2003) and with Owens et al. (1995) who showed that repeat visits to the doctor were lower in patients who reported positive doctor-patient communication.

The results relating to the relationship between patients' perceptions of doctor-patient communication and their illness representations were less clear. Although it was hypothesised that perceived communication would relate to illness representations as Leventhal et al. (1980; 1984) suggest, this was not evidenced. Although the observed finding that 'treatment compliance' was predictive of perceived consequences of IBS (as perceived compliance increased perceived consequences decreased) is in line with Markoul et al.'s (1995) research on adherence to medications, it does not appear to be related to perceived communication as expected. This is because 'treatment compliance' did not differ between groups. It is therefore not possible to conclude with any degree of certainty whether perceived communication impacts on illness representations of IBS sufferers. However, Leventhal et al. (1980; 1894) suggest interaction with doctors to be integral to the interpretation stage of the CSM and both Frostholm et al.'s (2005) large scale study, and Hagger & Orbell's (2003) meta-alanysis show illness representations to be consistent amongst illness types. It does therefore seem more likely that the observed finding is inaccurate. Although there are a number of reasons why the observed finding may be inaccurate such as the questionnaire used, participant numbers, the length of time since diagnosis etc. these are little more than speculative. Further research is therefore necessary to clarify these issues.

None of the dimensions of perceived communication were predictive of HRQOL or symptom frequency. Although this finding is clear it is inconclusive and is inconsistent with Owens et al. (1995). However, the lack of literature in this specific area means it is not possible to ascertain whether the observed finding is true or the result of a methodological artifact. This research is therefore useful as a springboard for future research into this relationship, and in order to ensure the best chance of yielding accurate results this should be a prospective longitudinal study.

ATTITUDES TOWARDS IBS SUFFERERS

The investigation of attitudes towards IBS sufferers was addressed in the second study of this thesis. It complements the research on doctor-patient communication as perceived attitudes of the general population are also suggested by Leventhal et al. (1980; 1984) to contribute to the interpretation stage of the CSM.

When comparing the perceptions of attitudes of the general population and IBS sufferers perceived attitudes of the general population there was a clear distinction between the two groups on all variables. Briefly the results showed that IBS sufferers perceive the attitudes of the general population towards discussing IBS symptoms, witnessing IBS symptoms, providing social support concessions, and providing social activity concessions to be worse than the attitudes reported by the general population. However, the results showed that people do not hold negative attitudes towards any of the variables associated with IBS. The results of this study are important as they suggest that the concerns IBS sufferers hold regarding negative attitudes of the general population (e.g. Dancey & Backhouse, 1993; Dancey et al., 2002) are not valid. These results are consistent with the findings of Munir et al. (2005) and Looper & Kirmayer (2004) who suggest that IBS is not a stigmatised condition. The implication from this study is that these inaccurate perceptions should be challenged as part of a therapeutic approach for IBS sufferers.

When attitudes towards IBS were compared to attitudes towards asthma and epilepsy the results showed that none the illnesses were perceived negatively, but that significant differences did exist between the illnesses in the degree to which perceptions were positive. In all cases more negative attitudes were reported towards epilepsy, followed by IBS, then asthma. This pattern of findings is in line with research that compares attitudes towards epilepsy to other illnesses, for example LaMartina (1989) and Young et al. (2002) who report attitudes towards epilepsy were more negative than other illnesses, but that they are still largely positive. The findings are also in line with Looper & Kirmayer (2004) who suggest that whilst functional illnesses as a whole appear to be perceived negatively, looking at IBS specifically this is not the case. Looper & Kirmayer (2004) suggest the reason for this is due to everybody experiencing bowel disruption at some point in their lives,

this suggestion does appear to be supported by the results of this study, as knowledge of IBS was largely accurate. Although further research is needed before attitudes towards IBS can be conclusively placed in the context of other illnesses the results of this study are promising.

As was observed for doctor-patient communication perceived attitudes were not found to relate to illness representations. This is inconsistent with Leventhal et al. (1980; 1894) who suggest perception of social support to be integral to the interpretation stage of the CSM. Although the relationship between perceived social support and illness representations has not been specifically addressed in IBS, this observed finding is inconsistent with qualitative research showing the need for sufferers to obtain social support (e.g. Coulson, 2005) and with a vast literature relating to interaction between perceived social support and illness outcomes (e.g. Hogan et al., 2002; Gaynes & Drossman, 1999). It is therefore unclear why perceived attitudes were not found to be related to illness representations and more research would be desirable to explore this relationship.

The only significant relationship between perceived attitudes and illness outcomes, was between witnessing IBS symptoms and HRQOL, i.e. the worse the attitudes were perceived the worse the quality of life was reported to be. Although this does not appear to be related to illness representations it is likely that this is a true research finding as this is supported by the previous research on HRQOL in IBS (e.g. Dancey & Backhouse, 1993), and the literature on perceived social support and illness outcomes (e.g. Hogan et al., 2002) in general. In addition this finding is supported and extended by study 3 which found that perceived attitudes towards witnessing symptoms at two months post intervention were predictive of both HRQOL and total symptom frequency (on both the diary and ISS) at two months post the intervention. This finding is of interest as it suggests that attitudes towards witnessing symptoms are predictive of both HRQOL and symptom frequency and suggests that the lack of significance for symptom frequency in study 2 is a result of low statistical power (Brennan et al., 2004).

Although the relationship between perceived attitudes and illness representations are unclear this research clearly complements the existing literature and shows that

perception of poor social support negatively impacts on illness outcomes. However, as perceptions of negative social support have been shown to be inaccurate it is vital that these are challenged in order to improve illness outcomes for sufferers.

ILLNESS REPRESENTATIONS AND ILLNESS OUTCOMES

As the overall aim of this thesis was to assess the efficacy of the CSM in IBS research the exploration of illness representations is pervasive throughout the studies included in this thesis. In the all three studies the relationship between illness representations and illness outcomes was assessed independently of the other variables included in the research. Firstly the relationship between illness representations and HRQOL is clear and consistent across studies. In all three studies emotional representations were predictive of HRQOL. The replication of this finding across three studies strongly suggests that this relationship can be accepted with a high degree of certainty. Further support is offered from the literature (e.g. Frostholm et al., 2005). Frostholm et al. (2005) also reported illness identity to be a significant predictor of illness outcomes. Although illness identity was found to be predictive of HRQOL in study 1 a close inspection of the results revealed that this was in the wrong direction (i.e. lower illness identity scores resulted in worse HRQOL). However, in study three illness identity was approaching significance in the correct direction. Therefore a more detailed assessment of this dimension is necessary to clarify the results. In addition support for the general concept of illness representations predicting HRQOL is provided by Rutter & Rutter (2002), although the specific variable of 'perceived consequences' was not elicited as a predictor in this thesis. Although an additional measure to assess locus of control was only included in study 1 it was of note that an internal locus of control was predictive of increased quality of life. This is consistent with the theory of Wallston et al. (1994) and research into other chronic illnesses (e.g. Moore et al., 1991).

The relationship between illness representations and symptoms across studies is less clear. For total symptom frequency there were no significant relationships in either study 1 or study 2, although emotional representations were approaching significance in study 1. In study 3 however there was a significant relationship between perceived treatment control and total symptoms at two months post the intervention. It is

difficult to interpret these findings although a number of alternative suggestions may be viable. Firstly it is possible that there is no relationship between illness representations and symptoms. This suggestion seems unlikely as significant findings for individual symptoms were found in studies 2 and 3 (specifically that chronic time line and illness identity predict diarrhoea and that illness identity predicted the urgent need to defecate). Secondly it is possible that the measures used to assess symptoms were not sensitive enough. This is a concern that was addressed in study 3 with the inclusion of an additional questionnaire to supplement the 7-day diary but this still did not reveal significant relationships between illness representations and symptoms. Connected to the sensitivity of the measures is the possibility that the timeframe for assessing symptoms was too brief. This is possible and therefore future research should assess symptoms over a longer period. The most likely suggestion is that the relationship between illness representations and symptoms is indirect and is mediated by another variable. This is a suggestion raised by Brennan et al. (2004) who suggests that HRQOL is predictive of symptom outcomes. In addition, Rutter and Rutter (2002) report 'satisfaction with health' to be correlated with symptoms. Although not observed in study 2 both studies 1 and 3 show that HRQOL is predictive of total symptom frequency. It does therefore appear that there is a relationship between illness representations and outcomes, but that this is indirect. This would provide a plausible explanation why there was insufficient power to detect a relationship between illness representations and symptoms. Further support for the mediation of illness representations and symptoms is provided by the data on locus of control included in study 1. Although internal locus of control initially appeared to be predictive of symptoms, this relationship was fully mediated by HRQOL as Brennan et al. (2004) suggested.

INTERVENTION

One of the main aims of the first two studies was to assess the utility of the CSM as a model to explain illness outcomes in IBS. As studies 1 and 2 showed a clear relationship between illness representations and HRQOL and suggested an indirect relationship between illness representations and symptoms it was considered legitimate in study 3 to devise an intervention based on the principles of the CSM (Leventhal et al., 1980; 1984). The results showed that the intervention was

efficacious with significant reductions in symptom frequency (assessed using the diary) from both pre intervention to immediately post intervention, and from pre intervention to two months post intervention (on both the diary and symptom questionnaire). Using the 7 day diary there were significant reductions in diarrhoea and constipation. The reductions in diarrhoea occurred between pre intervention and two months post intervention. The reductions in constipation occurred between immediately post intervention and two months post intervention. Using the ISS there were also significant changes in reported frequency of abdominal pain, bloating and feelings of incomplete evacuation between pre intervention and two months post intervention. These research findings have important implications for the future of treatment research in IBS as they strongly suggest that this intervention booklet is efficacious at reducing symptom frequency, at least in the short term, this is consistent with a number of other psychologically based interventions, such as Blanchard et al. (1993) and Heyman-Mönnikes et al. (2000).

There was a significant improvement in HRQOL from pre intervention to two months post intervention The improvement in HRQOL is consistent with previous research, such as Gonsalkorale et al. (2002) and Boyce et al. (2000). There were also changes in perceived social support in both the discussing and witnessing symptoms scale from pre intervention to immediately post intervention. It is interesting that medication use significantly decreased immediately post the intervention, suggesting that the findings can truly be attributed to the CSM based intervention rather than to increases in medication.

The illness representations that changed between pre and immediately post the intervention were chronic timeline, perceived personal control and emotional representations. These same illness representations changed between pre and two month post and in addition illness coherence and illness identity also improved. These findings demonstrate that the intervention booklet did in fact adhere rigidly to the principles of the CSM, that improvements in illness representations occurred both immediately post the intervention and at two months post the intervention, and moreover that both illness coherence and illness identity were additionally significant at two months post intervention, suggesting that participants maintained their better understanding of their IBS following the intervention. In addition illness identity

significantly improved from immediately post intervention to two months post intervention. There were however no significant predictors of change in HRQOL or symptoms (total and individual) between pre intervention and immediately post the intervention There were also no significant predictors of change in symptoms (total and individual) between pre intervention and at two months post the intervention. As these findings may be due to insufficient power no conclusions can be drawn until more research has been conducted.

The self-help booklet appears to be effective at improving IBS sufferers' illness representations, perceived quality of life and at reducing both actual and perceived symptom frequency. This study therefore provides support for the theoretical utility of Leventhal et al's. (1980; 1984) common sense model in the devising of illness interventions. It also suggests that a short self-help booklet based intervention is a cost effective and easily administered way of improving IBS sufferers' health and quality of life for at least two months post the intervention. Further support for the usefulness of self-help booklet based interventions in IBS comes from the recent study of Robinson et al. (2006). Although this booklet is not based on a specific model and its results are therefore inconclusive it does show that at one year post intervention there is a 60% reduction in medical consultations and a reduction in perceived symptom severity.

STRENGTHS OF THE RESEARCH

Although proponents of the qualitative approach may feel that the use of questionnaires and diary data may not provide as much detailed scope for exploring perceptions of individuals, it was felt that the use of quantitative measures was vital in order to assess the components of IBS in a meaningful and structured way. In the literature reviews, in particular for study 1 there was a bias towards qualitative research, which although providing a useful background does not go far enough in providing meaningful data. Research into the psychological aspects of IBS has only emerged relatively recently and therefore the qualitative studies are understandable and indeed provide a useful background. However, the ideas raised by earlier research (both qualitative and quantitative) have now reached a stage where more scientific quantitative research is needed. Although in some respects research in this

area is still exploratory this data is more useful then qualitative research which simply replicates previous findings.

The use of questionnaires is prevalent in research, this is unsurprising as it is extremely convenient, both for the researcher (especially on restricted budgets) and for the participants. In particular it is highly suited to an IBS cohort who may be reluctant to leave the house, especially if long distances are involved. It is therefore a highly suitable method to have used in this thesis. In terms of the specific questionnaires used care was taken to use established measures where suitable ones were available, to modify measure where necessary, and to design measures where nothing suitable existed. As is detailed in the methods sections of the various studies the studies designed for the research are highly literature based, and all measures reported high degrees of internal consistency. Therefore the specific measures used are highly suited to the aims of the research. One final point regarding the specific use of the IBS-36 to measure quality of life is that whilst some researchers (e.g. Drossman et al., 2003; Heyman-Mönnikes et al., 2000) champion the use of the IBS-QOL (Patrick et al., 1998) the two month recall period of the IBS-36 (Groll et al., 2002) was felt to be superior to the current day recall period of the IBS-QOL which was felt would not take into account the fluctuating nature of the IBS symptoms.

A challenge for all researchers in this field is how to accurately record symptoms, as a truly objective way of measuring symptoms is both impractical and arguably unethical. It was therefore felt that a diary methodology was the most accurate way of recording the symptoms. Although there is no guarantee that participants will remember to record their symptoms immediately there is much less chance of the retrospective recall bias likely in a basic questionnaire design. The superiority of diary methodology is noted by Meissner et al. (1997) who are key researchers in this field and regard diary methodology as the 'gold standard'. Therefore whilst the diary format in itself should not necessarily be a limitation, the difficulty of finding significant relationships using this measure suggests that one week was perhaps not an appropriate timeframe. Although one week initially appeared to be appropriate as in order to be classified as suffering from IBS symptoms must be experienced at least once a week, and this is the recommendation by Keefer & Blanchard (2002) in some cases very few symptoms were reported leading to little variance in total symptom

scores. Although a longer time for recording symptoms would not have been achievable here both due to time constraints and the potential for lower participant numbers (especially in phases 2 and 3 of the intervention) in future research it is clearly advisable to record symptoms for at least a two week period, and at a number of times throughout at least a six month period, to take into account the fluctuating and cyclic nature of symptoms. However, a strength of this thesis is that the difficulty in obtaining significant findings using the diary in studies 1 and 2 meant that an additional questionnaire measure of symptoms was included in study 3. The Likert scale questionnaire was similar to that used in previous research (e.g. Dancey et al., 1998) and based on the suggestions from the review by Naliboff et al. (1999). The questionnaire and the diary were found to be correlated as expected and therefore the addition of the questionnaire for study 3 shows the benefit of addressing potential weaknesses in previous research in the design of subsequent studies.

LIMITATIONS OF THE RESEARCH

Although the limitations regarding the participants are detailed in the individual studies, with varying degrees of limitations depending on participant group, it is worth noting that there is a general limitation to the participants recruited in these studies. Although care was taken to recruit as many, and as representative cohorts as possible the inability to offer financial incentives, coupled with the comparatively short time frame for data collection in PhD research means that it is notoriously difficult to entice people to take part in research. As the motivations for those who participated was not established there is still a concern that the results of these studies may not be truly generalisable. This concern is potentially more worrying for the doctors group (study 1) where participant numbers were so low (n = 58) that the original design of recruiting both gastroenterologists and doctors had to be altered to produce one single medical professional group. Although ANOVA suggested that it was legitimate to combine these two groups it would obviously have been superior to recruit sufficient numbers of participants to allow for detailed comparisons to be made. Although care was taken in the study design not to burden the doctors, and therefore only a 21 item Likert scale questionnaire was administered response rates were still very low (23.7%). The low response rate means that a volunteer bias is a genuine concern. Although this is not a concern which is valid for the general

population group in the attitudes research where the cohort was considerably higher (n =239) and the generalisability of these results can therefore be accepted with a high degree of certainty (certainly within the UK), this is a concern that is valid, albeit to a lesser extent, in the IBS sufferers group. Although the participant characteristics match those reported in other studies (e.g. Dancey et al., 1995; Lackner et al., 2004) it is possible that this represents a volunteer bias inherent in research in this area in general, rather than a truly representative group. This potential bias comes from approximately half of the participants in all studies being recruited from the IBS Network. This is a common cohort for research in this area, and the IBS Network warns that participants recruited from the Network may be "over researched". In addition, in particular for the intervention study there is likely to be a personal significance bias towards the recruiting of participants who consider IBS to have a psychological component, which is not true of all sufferers. These suggest that more research is needed in this under researched area in order to ensure the true generalisability of the results found in this thesis; however these limitations are relatively minor and in no way negate the significant results reported.

In addition although the many significant results attest to the legitimacy of the theory behind each of the studies it is possible that there are additional significant relationships which were not revealed due to insufficient power, therefore replications with greater participant numbers are desirable. This is particularly relevant for the investigation of gender and IBS subgroups, both for main and interaction effects. The lack of data concerning IBS subgroups is something which is common to psychologically based research in IBS, as the systematic review demonstrates, but it is definitely an area that should be addressed in the future, in this respect recruiting using cohort sampling is advisable. One final minor limitation is that the results cannot be generalised cross culturally, however, as there is limited research investigating the concepts covered in this thesis, this not too problematic at this stage, and care was taken in the use of a postal based design to ensure that there was no specific local bias. Overall whilst there are undoubtedly limitations to the participants recruited in this thesis these are no worse than those seen in similar research and do not in any way invalidate the results of the thesis.

An additional concern is whether the IBS participants that participated in the study did in fact suffer from IBS. Although participants were only recruited in the studies if they reported confirmed diagnosis of IBS from a medical professional, there were no checks of medical records to ensure that this was the case. Although this was beyond the scope of this thesis in terms of securing ethics approval, it provides a limitation whereby a number of participants may not have in fact suffered from IBS. Although it is highly unlikely that this would have been deliberate, concerns over legitimacy of diagnosis detailed in chapter 2, coupled with the five participants who 'dropped out' prior to the commencement of study 3, due to receiving a confirmed diagnosis of an organic cause of their symptoms means that it cannot be accepted without reservation that all of the participants did in fact suffer from IBS as anticipated. It should be noted that this is not a limitation specific to this research, it is indicative of the areas of overlap between IBS and other illnesses (both functional and organic). In fact a recent study by Babak et al. (2006) reported the same problem with 25 participants withdrawing from the research due to discovering an organic cause for their symptoms. Although in a larger funded study medical professionals could have been enlisted to confirm IBS using the Rome II criteria (e.g. Gralnek et al., 2000), this was simply beyond the scope of this thesis. Although ensuring accuracy of diagnosis in this way is obviously advisable, as the research by Babak et al. (2006) demonstrates reliance on patient reports in smaller studies is common (e.g. Rutter & Rutter, 2002) and should therefore not be considered a major flaw in this thesis. In addition concerns over legitimacy of diagnosis is somewhat reduced by the diary methodology, which allows for an assessment of the symptoms to be made, and therefore if, the symptoms reported did not appear to be representative of IBS the participant could have been removed from the analysis. As this was not observed here it can be assumed to some extent that although verification of IBS status would therefore have been desirable there is no reason to consider that the data collected does not reflect a sample of true IBS sufferers.

One final potential limitation is the lack of a control group in study 3, however the justification for the lack of a control group was detailed in chapter 7 and therefore it is not necessary to reiterate this here. The conclusion reached however was that due to an inability to create a legitimate control group the PLD design was the most suitable for the intervention study.

THEORETICAL IMPLICATIONS

Although detailed consideration of the justification for the use of the Leventhal et al. (1980; 1984) CSM was given in chapter 4 in light of the results of this thesis its utility must be evaluated. The direct relationship between illness representations and HRQOL, the indirect relationship between illness representations and symptoms observed in all three studies, coupled with efficacy of the CSM based intervention booklet strongly suggests that the CSM is a viable model for use in IBS. This is perhaps unsurprising as Hagger and Orbell (2003) have demonstrated that the CSM is robust over a wide range of chronic illnesses and Rutter and Rutter (2002) demonstrate its applicability for IBS specifically. In particular the efficacy of the intervention booklet which adheres rigidly to the components of the CSM marks an important step forward in establishing the CSM as a reliable model upon which to base illness interventions, in IBS. It has been commented by Saito (2002) that "because of the heterogeneity in symptoms and diagnostic findings patients with IBS remain a challenge to treat and to study". This thesis has demonstrated that the CSM is a sound theoretical model which as Leventhal et al. (1980; 1984) intended is highly suited to chronic illnesses of heterogeneous nature, and therefore if research investigating this model continues, based on the results observed here, it seems fair to conclude that the 'challenge' may be met.

Although the results of this thesis strongly support the role of the CSM in explaining sufferers representations of their illness and subsequent illness outcomes, it is likely that the observed findings do not fully represent the complexities of the relationship between illness representations and illness outcomes. Although there would need to be many further studies to fully assess the various aspects of this model there are two areas that should be addressed in all subsequent research. The first area is the ability of the IPQ-R (Moss-Morris et al., 2002) to accurately measure the illness representation dimensions. Although the revised version, used in this study, is suggested by Hagger & Orbell (2003) to be superior to the original version and highly accurate at the majority of illness representation dimensions across illness types, it is not a good measure of 'cause'. Although low participant numbers meant that the 'cause' variable could not be constructed and was therefore not included in this thesis the difficulty of analysing the 'cause' component is noted by Hagger and

Orbell (2003) who 'dropped' the cause component from their meta-analysis due to the difficulties in accurately coding it both within and between different studies. This is obviously problematic as 'cause' is one of the primary illness representation dimensions and therefore perhaps the IPQ should be modified a third time to address this factor.

The second area that should be addressed in future research is the role of coping. Despite the success of the intervention in improving illness outcomes and in the changes observed on multiple illness representations the predictive ability of illness representations and illness outcome was weak in all studies. On reflection it seems highly likely that this is due to an additional variable mediating this relationship; this variable is likely to be coping. Support for coping mediating the relationship between illness representations and outcomes has been reported in IBS (Rutter & Rutter, 2002), and was consistently found to mediate the relationship between illness representations and outcomes across illness types in a recent meta-analytic review of the CSM by Hagger & Orbell (2003). Although improving coping techniques were integral to the advice of the intervention booklet a measure to assess coping was not included. Upon reflection it was an oversight and a mistake not to include a measure to assess coping in this thesis, and if any of the studies presented here were to replicated this is without hesitation the fundamental change that should be made, and in this respect it is the largest limitation of this research. However, despite the lack of an investigation into coping as a mediating variable the results clearly show that illness representations, and changes in illness representations are related to illness outcomes, and therefore it is the role of future research to fully explore these relationships.

One final theoretical consideration is the relationship between perceived attitudes, both of doctor-patient communication and of the general population and illness representations. Although studies 1 and 2 only provide weak evidence of these factors is unclear why this is. It is possible that this is due to a weakness in the methodology of the studies resulting in insufficient power to detect any thing below large effects. A further suggestion is that the impact of other people's attitudes is limited to the initial stages of illness diagnosis, not pervasive as the CSM suggests. However, the most likely explanation is that the CSM states that illness interpretation

is a complex process comprising multiple cues, therefore whilst perceived attitudes may play a role their predictive quality may be overshadowed by a stronger predictor. Further research is needed to clarify these issues.

PRACTICAL IMPLICATIONS

The practical implications of this thesis are clear as the overall aim was to devise a successful self-help booklet based intervention. Therefore as the intervention was successful the primary practical implication is to improve IBS sufferers' illness outcomes. Therefore it will obviously be productive to make the booklet available to IBS sufferers. This can be done in a number of formats: as a book, on a website or administered in a clinical setting. In addition the theoretical implications suggest that further intervention research based around the principles of the CSM, for example education classes should also prove efficacious. There is a potential benefit in improving the individualised nature of the intervention in order to make it a truly tailored intervention. Personality questionnaires, full case histories and a much longer symptom monitoring duration pre intervention should be employed. Although this would require considerable effort it is likely that this would yield positive results, and whilst the costs versus benefits of the current booklet compared with a more tailored approach would need to be assessed it is an important area of study in terms of both theoretical and practical applications.

One important practical implication that comes out of this thesis is the possibility of assessing the illness representations of patients reporting acute bowel dysfunction with an aim to identify those factors which influence the development of IBS. If these factors can be identified then theoretically development of IBS can be prevented, which is clearly the ultimate goal for chronic illness research.

FUTURE DIRECTIONS

As this is an area that is relatively under researched there are numerous research directions suggested by the thesis. A selection of some of the most worthwhile further areas of interest are:

1) A detailed comparison of the attitudes of different medical professionals towards IBS, coupled with an intervention aimed at improving medical professionals communication and advice on how to help sufferers form and maintain positive illness representations.
2) A detailed investigation of the attitudes of specific groups of society, such as employers, teachers, parents, and cross culturally.
3) An assessment of the role of coping and other potential mediating variables in the relationships between illness representations and outcomes.
4) An exploration of the role of personality factors and the CSM in IBS.
5) A large scale prospective longitudinal study which investigates the development of illness representations in a cohort of newly diagnosed sufferers.
6) A comparison of the efficacy of the intervention booklet in different administration styles, such as in a group setting or with a facilitator.
7) An assessment of the long-term effects of the self-help booklet

CONCLUSION

The studies in this thesis clearly link together to investigate the role of the CSM in IBS. According to the findings it is clear that the CSM is a viable model to explain the interaction between illness representations and illness outcomes. This thesis therefore clearly demonstrates a novel and important contribution to knowledge of both IBS and the CSM. In addition it suggests the viability of a one time self-help booklet based intervention in improving illness outcomes in IBS.

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The Common Sense Model, Quality of Life and Symptom Frequency in Irritable Bowel Syndrome (IBS)

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APPENDICES

APPENDIX 1

DISEASE SPECIFIC VERSION OF THE IPQ-R (MOSS-MORRIS ET AL., 2002)

Version 1 07/04/2005

ILLNESS PERCEPTION QUESTIONNAIRE (IPQ-R)

Code Word..... *Date*.....

YOUR VIEWS ABOUT YOUR IRRITABLE BOWEL SYNDROME

Listed below are a number of symptoms that you may or may not have experienced since your IBS. Please indicate by circling *Yes* or *No*, whether you have experienced any of these symptoms since your illness, and whether you believe that these symptoms are related to your IBS.

	I have experienced this symptom *since my IBS*			This symptom is *related to my IBS*	
Pain	Yes	No	_____	Yes	No
Sore Throat	Yes	No	_____	Yes	No
Nausea	Yes	No	_____	Yes	No
Breathlessness	Yes	No	_____	Yes	No
Weight Loss	Yes	No	_____	Yes	No
Fatigue	Yes	No	_____	Yes	No
Stiff Joints	Yes	No	_____	Yes	No
Sore Eyes	Yes	No	_____	Yes	No
Wheeziness	Yes	No	_____	Yes	No
Headaches	Yes	No	_____	Yes	No
Upset Stomach	Yes	No	_____	Yes	No
Sleep Difficulties	Yes	No	_____	Yes	No
Dizziness	Yes	No	_____	Yes	No
Loss of Strength	Yes	No	_____	Yes	No

We are interested in your own personal views of how you now see your current IBS.

Please indicate how much you agree or disagree with the following statements about your illness by ticking the appropriate box.

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IPI*	My IBS will last a short time					
IP2	My IBS is likely to be permanent rather than temporary					
IP3	My IBS will last for a long time					
IP4*	This IBS will pass quickly					
IP5	I expect to have this IBS for the rest of my life					

	VIEWS ABOUT YOUR ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
IP6	My IBS is a serious condition					
IP7	My IBS has major consequences on my life					
IP8*	My IBS does not have much effect on my life					
IP9	My IBS strongly affects the way others see me					
IP10	My IBS has serious financial consequences					
IP11	My IBS causes difficulties for those who are close to me					
IP12	There is a lot which I can do to control my symptoms					
IP13	What I do can determine whether my IBS gets better or worse					
IP14	The course of my IBS depends on me					
IP15*	Nothing I do will affect my IBS					
IP16	I have the power to influence my IBS					
IP17*	My actions will have no affect on the outcome of my IBS					
IP18*	My IBS will improve in time					
IP19*	There is very little that can be done to improve my IBS					
IP20	My treatment will be effective in curing my IBS					
IP21	The negative effects of my IBS can be prevented (avoided) by my treatment					
IP22	My treatment can control my IBS					
IP23*	There is nothing which can help my condition					
IP24	The symptoms of my condition are puzzling to me					
IP25	My IBS is a mystery to me					
IP26	I don't understand my IBS					
IP27	My IBS doesn't make any sense to me					
IP28*	I have a clear picture or understanding of my condition					
IP29	The symptoms of my IBS change a great deal from day to day					
IP30	My symptoms come and go in cycles					
IP31	My IBS is very unpredictable					
IP32	I go through cycles in which my IBS gets better and worse					
IP33	I get depressed when I think about my IBS					
IP34	When I think about my IBS I get upset					
IP35	My IBS makes me feel angry					
IP36*	My IBS does not worry me					
IP37	Having this IBS makes me feel anxious					
IP38	My IBS makes me feel afraid					

CAUSES OF MY IBS

We are interested in what <u>you</u> consider may have been the cause of your IBS. As people are very different, there is no correct answer for this question. We are most interested in your own views about the factors that caused your IBS rather than what others including doctors or family may have suggested to you. Below is a list of possible causes for your IBS. Please indicate how much you agree or disagree that they were causes for you by ticking the appropriate box.

	POSSIBLE CAUSES	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
C1	Stress or worry					
C2	Hereditary - it runs in my family					
C3	A germ or virus					
C4	Diet or eating habits					
C5	Chance or bad luck					
C6	Poor medical care in my past					
C7	Pollution in the environment					
C8	My own behaviour					
C9	My mental attitude e.g. thinking about life negatively					
C10	Family problems or worries caused my illness					
C11	Overwork					
C12	My emotional state e.g. feeling down, lonely, anxious, empty					
C13	Ageing					
C14	Alcohol					
C15	Smoking					
C16	Accident or injury					
C17	My personality					
C18	Altered immunity					

In the table below, please list in rank-order the three most important factors that you now believe caused <u>YOUR IBS.</u> You may use any of the items from the box above, or you may have additional ideas of your own.

The most important causes for me:-

1. _____
2. _____
3. _____

Items for IPQ-R Subscales

1. **Identity (sum of yes-rated symptoms in column 2 on p. 1)**

2. **Timeline (acute/chronic) items IP1 - IP5 + IP18**

3. **Consequences items IP6 - IP11**

4. **Personal control items IP12 - 1P17**

5. **Treatment control items IP19 – IP23**

6. **Illness coherence items IP24 – IP28**

7. **Timeline cyclical IP29 – IP32**

8. **Emotional representations IP33 – IP38**

9. **Causes C1 - C18 - do not use these as a scale. Start analysis with separate items - used as grouping variables (ie those who do/do not believe in a specific causal factor). With a sufficient sample size (n=85 or more), factor analysis can be used to identify groups of causal beliefs (eg lifestyle ; stress etc) which can then be used as sub-scales** (e.g. *see* Weinman et al, *in press).*

Reference

Weinman, J, ,Petrie, KJ, Sharpe, N & Walker, S . Causal attributions in patients and spouses following first-time myocardial infarction and subsequent lifestyle changes. *Br. J. Health Psychology, in press.*

APPENDIX 2

IBS-36 (GROLL ET AL., 2002)

The IBS - 36 Quality of Life Measure

Please circle the number that explains how you have been **IN THE PAST TWO MONTHS.**
Please say "In the Past two months" ahead of each question as you think about the answer.
If the question does not apply to you, please circle **not applicable.**

Example: /----------/----------/----------/----------/----------/----------/ Not applicable
0 1 2 3 4 5 6
Never Always

IN THE PAST TWO MONTHS

1) Have you been afraid to eat out because of food causing bowel symptoms?

/----------/----------/----------/----------/----------/----------/ Not applicable
0 1 2 3 4 5 6
Never Always

2) Have you felt angry as a result of your bowel problem?

/----------/----------/----------/----------/----------/----------/ Not applicable
0 1 2 3 4 5 6
Never Always

3) Did you need to go suddenly when you had a bowel movement?

/----------/----------/----------/----------/----------/----------/ Not applicable
0 1 2 3 4 5 6
Never Always

4) Did your bowel symptoms interfere with your relationship with your children and/or partner?

/----------/----------/----------/----------/----------/----------/ Not applicable
0 1 2 3 4 5 6
Never Always

5) Did you avoid foods that you like because you were afraid that they might cause bowel symptoms?

/----------/----------/----------/----------/----------/----------/ Not applicable
0 1 2 3 4 5 6
Never Always

6) Did your bowel symptoms interfere with being able to do well at work/school/usual daily activities?

/----------/----------/----------/----------/----------/----------/ Not applicable
0 1 2 3 4 5 6
Never Always

7) Have you felt tearful or discouraged as a result of your bowel problem?

/----------/----------/----------/----------/----------/----------/ Not applicable
0 1 2 3 4 5 6
Never Always

8) Did you feel that your family/friends thought your symptoms were not real?

/----------/----------/----------/----------/----------/----------/ Not applicable
0 1 2 3 4 5 6
Never Always

9) How often, while participating in leisure or sport activities did you have to stop because of your bowel symptoms?

/----------/----------/----------/----------/----------/----------/ Not applicable
0 1 2 3 4 5 6
Never Always

10) Have you felt worried or anxious about never feeling any better?

/----------/----------/----------/----------/----------/----------/ Not applicable
0 1 2 3 4 5 6
Never Always

11) Did you miss work/school/usual daily activities because of your bowel problem?

/----------/----------/----------/----------/----------/----------/ Not applicable
0 1 2 3 4 5 6
Never Always

12) Did your bowel symptoms interfere with being able to concentrate?

/----------/----------/----------/----------/----------/----------/ Not applicable
0 1 2 3 4 5 6
Never Always

13) Have you felt alone or isolated from your family because of bowel symptoms?

/----------/----------/----------/----------/----------/----------/ Not applicable
0 1 2 3 4 5 6
Never Always

14) Were you embarrassed because of your bowel symptoms?

/----------/----------/----------/----------/----------/----------/ Not applicable
0 1 2 3 4 5 6
Never Always

15) Were you troubled by pain in your abdomen?

/----------/---------/---------/---------/---------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

16) Were you afraid that your bowel symptoms were getting worse?

/----------/---------/---------/---------/---------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

17) Were you troubled by bowel movements that were hard/difficult to pass?

/----------/---------/---------/---------/---------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

18) Did you check your diet from the previous day trying to find foods that might cause bowel symptoms?

/----------/---------/---------/---------/---------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

19) Did you avoid traveling due to worry about bowel symptoms?

/----------/---------/---------/---------/---------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

20) Did your bowel problems shorten the length of time you could work each day?

/----------/---------/---------/---------/---------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

21) Did your bowel symptoms keep you from sleeping soundly during the night?

/----------/---------/---------/---------/---------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

22) Were you troubled by loose bowel movements?

/----------/---------/---------/---------/---------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

23) Did your bowel condition interfere with having sexual relations?

/----------/----------/----------/----------/----------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

24) Has being bloated troubled you?

/----------/----------/----------/----------/----------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

25) Did your bowel symptoms interfere with your enjoyment of leisure or sport activities?

/----------/----------/----------/----------/----------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

26) Was passing large amount of gas a problem?

/----------/----------/----------/----------/----------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

27) Were you concerned that your symptoms may be due to cancer?

/----------/----------/----------/----------/----------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

28) Have you had to delay or cancel going out socially because of your bowel problem?

/----------/----------/----------/----------/----------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

29) Were you tired in the morning because of your bowel symptoms?

/----------/----------/----------/----------/----------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

30) Did your bowel symptoms interfere with your desire to have sexual relations with your partner?

/----------/----------/----------/----------/----------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

31) Has feeling that you need to go to the bathroom even though your bowels are empty troubled you?

/----------/----------/----------/----------/----------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

32) Did you feel that your doctor/health professionals did not believe that your bowel symptoms were real?

/----------/----------/----------/----------/----------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

33) How often do you immediately need to find where washrooms are when you are in a new place?

/----------/----------/----------/----------/----------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

34) Did you avoid planning activities ahead of time because you were unsure of how your bowel symptoms would be?

/----------/----------/----------/----------/----------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

35) Has accidental soiling of your underwear troubled you?

/----------/----------/----------/----------/----------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

36) Were you late for or did you delay work/school/usual daily activities because of your bowel symptoms.

/----------/----------/----------/----------/----------/----------/ Not applicable

0 1 2 3 4 5 6

Never Always

APPENDIX 3

7-DAY SYMPTOM DIARY
(INSTRUCTIONS AND SAMPLE PAGES)

Version 1 19/05/2004 **Instructions for filling in the IBS daily diary**

- Please fill in the diary every day for one week
- One page is allocated for each day, but there are extra pages included if you require. Use as many pages as necessary per day, but please start each day with a new page.
- Prior to starting the diaries please write the date, day of the week and the code word you specified on your consent form.
- Please record every time you experience a symptom and every time you take medication.
- The key at the top of the page is designed to aid you by minimising the amount of writing required, e.g. instead of diarrhoea, you may write in the letter A. If the key is confusing you are welcome to write everything in instead.
- The first page of the Diary is a sample page, this should help to clarify what is required. Note that where mistakes have been made simply cross them out.
- When a symptom lasts for longer than fifteen minutes please include the time taken, e.g. bloating for 1 hour.

If you have any queries regarding the completion of the diary then please contact

Carly Jacobs

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School of Human Sciences

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GU2 7XH

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Version 1 17/05/04 IBS Daily Diary

Code word: Chilly

Date: Tuesday

Symptoms
A. Diarrhoea
B. Constipation
C. Abdominal Pain
D. Flatualence
E. Urgent Need to Defecate
F. Feeling of Incomplete Evacuation
G. Bloating
H. Normal Stool
I. Thin Stool
J. Loose Stool
K. Hard (pellet like) Stools
L. Belching
M. Other (please specify)

Medication
B. Immodium Plus
C. Immodium Instants
D. Other Anti-diarrhoeal (please specify)
E. Senacot
F. Other Laxitives (please specify)
G. Fibrogel
H. Antidepressants (please specify)
I. Antispasmodics (please specify)
J. Herbal Supplements (please specify)
K. Other (please specify)

If you did not experience any symptoms today please tick this box ☐
If you did not take any medication today please tick this box ☐

Time	Symptoms	Medication
9.15	A	
10.05	BA	
10.10	A	
12.00	E	tick
2.00	G (40mins)	
6.00	D	
6.10	D	
6.45	D	
7.22	A (20 minutes)	
7.55		A
10.00	L	

APPENDIX 4

IBS SPECIFIC VERSION OF THE MISS-21
(MEAKIN & WEINMAN, 2002)

Version 1 19/05/2004 **Adapted MISS-21 For IBS Sufferers**

I am interested in your views about the consultations you had with your doctor concerning your IBS. Please think back to all of the consultations you have had regarding your IBS including your first informing your GP of your bowel complaints.
Please think about all the consultations you have had and indicate overall the extent to which you agree or disagree with each of the following statements.

Circle one number for each statement.

	very strongly disagree	strongly disagree	disagree	uncertain	agree	strongly agree	very strongly agree
1. My doctor told me exactly what IBS is.	1	2	3	4	5	6	7
2. After talking with my doctor, I know whether IBS is serious.	1	2	3	4	5	6	7
3. My doctor told me all I wanted to know about my IBS.	1	2	3	4	5	6	7
4. I am not really certain about how to follow my doctor's advice.	1	2	3	4	5	6	7
5. After talking with my doctor, I have a good idea of my chance of recovery	1	2	3	4	5	6	7
6. My doctor seems interested in me as a person.	1	2	3	4	5	6	7
7. My doctor seems warm and friendly to me.	1	2	3	4	5	6	7
8. My doctor seems to take my IBS seriously.	1	2	3	4	5	6	7
9. I feel embarrassed while talking with my doctor.	1	2	3	4	5	6	7
10. I feel free to talk to my doctor about private matters.	1	2	3	4	5	6	7
11. The doctor gives me a chance to say what was really on my mind.	1	2	3	4	5	6	7

	very strongly disagree	strongly disagree	disagree	uncertain	agree	strongly agree	very strongly agree
12. I really feel understood by my doctor.	1	2	3	4	5	6	7
13. My doctor does not allow me to say everything I want about my problems.	1	2	3	4	5	6	7
14. My doctor does not really understand my main reason for coming.	1	2	3	4	5	6	7
15. Mine is a doctor I would trust with my life.	1	2	3	4	5	6	7
16. My doctor seems to know what (s)he was doing.	1	2	3	4	5	6	7
17. My doctor has relieved my worries about my illness.	1	2	3	4	5	6	7
18. My doctor seems to know just what to do for my problem.	1	2	3	4	5	6	7
19. It has been easy for me to follow my doctor's advice.	1	2	3	4	5	6	7
20. It has been difficult for me to do exactly what my doctor told me to do.	1	2	3	4	5	6	7
21. I'm not sure the doctor's treatment is worth the trouble it has taken.	1	2	3	4	5	6	7

PLEASE CHECK THAT YOU HAVE GIVEN YOUR OPINION ON EACH STATEMENT.

THANK YOU FOR YOUR TIME.

APPENDIX 5

DOCTOR SPECIFIC VERSION OF THE MISS-21 (MEAKIN & WEINMAN, 2002)

Version 1 19/05/2004 **Adapted MISS-21 for Doctors**

I am interested in your views about the consultations you had with your IBS patients, concerning their IBS. Please think back to all of the consultations you have given to people with IBS, including when they first informed you of experiencing bowel complaints. Please think about all the consultations you have given and indicate on average the extent to which you agree or disagree with each of the following statements.

Circle one number for each statement.

	very strongly disagree	strongly disagree	disagree	uncertain	agree	strongly agree	very strongly agree
1. I inform my patients exactly what IBS is.	1	2	3	4	5	6	7
2. After talking with my patients, they know whether IBS is serious.	1	2	3	4	5	6	7
3. I tell my patients all they want to know about their IBS.	1	2	3	4	5	6	7
4. They are not really certain about how to follow my advice.	1	2	3	4	5	6	7
5. After talking with my IBS patients, they have a good idea of their chance of recovery	1	2	3	4	5	6	7
6. I appear to be interested in my IBS patients as people.	1	2	3	4	5	6	7
7. I appear warm and friendly to my IBS patients	1	2	3	4	5	6	7
8. I take patients with IBS seriously.	1	2	3	4	5	6	7
9. My IBS patients feel embarrassed when talking to me	1	2	3	4	5	6	7
10. My IBS patients feel free to talk to me about private matters.	1	2	3	4	5	6	7
11. I give my IBS patients a chance to say what is really on their minds.	1	2	3	4	5	6	7

	Very strongly disagree	strongly disagree	disagree	uncertain	agree	strongly agree	Very strongly agree
12. My IBS patients really feel understood by me	1	2	3	4	5	6	7
13. I do not allow my IBS patients to say everything they want to about their problems.	1	2	3	4	5	6	7
14. I did not really understand their main reason for coming.	1	2	3	4	5	6	7
15. I am a doctor my IBS patients would trust with their life.	1	2	3	4	5	6	7
16. I appear to my IBS patients to know what I am doing	1	2	3	4	5	6	7
17. I relieve my IBS patient's worries about their illness.	1	2	3	4	5	6	7
18. I appear to my IBS patients to know just what to do for their problem.	1	2	3	4	5	6	7
19. I expect that it is easy for my IBS patients to follow my advice.	1	2	3	4	5	6	7
20. It may be difficult for my IBS patients to do exactly what I told them to do.	1	2	3	4	5	6	7
21. I'm not sure the treatment I suggest will be worth the trouble it will take.	1	2	3	4	5	6	7

PLEASE CHECK THAT YOU HAVE GIVEN YOUR OPINION ON EACH STATEMENT.

THANK YOU FOR YOUR TIME.

APPENDIX 6

MHLC (WALLSTON ET AL., 1994)

Version 1 19/05/2004 **Multidimensional Health Locus of Control Scale (Form C)**

Instructions: Each item below is a belief statement about your medical condition 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 agree or disagree with that statement. The more you agree with a statement, the higher will be the number you circle. The more you disagree with a statement, 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.

1=STRONGLY DISAGREE (SD) 2=MODERATELY DISAGREE (MD) 3=SLIGHTLY DISAGREE (D)				4=SLIGHTLY AGREE (A) 5=MODERATELY AGREE (MA) 6=STRONGLY AGREE (SA)			
		SD	**MD**	**D**	**A**	**MA**	**SA**
1	If my IBS worsens, it is my own behaviour which determines how soon I will feel better again.	1	2	3	4	5	6
2	As to my IBS, what will be will be.	1	2	3	4	5	6
3	If I see my doctor regularly, I am less likely to have problems with my IBS.	1	2	3	4	5	6
4	Most things that affect my IBS happen to me by chance.	1	2	3	4	5	6
5	Whenever my IBS worsens, I should consult a medically trained professional.	1	2	3	4	5	6
6	I am directly responsible for my IBS getting better or worse.	1	2	3	4	5	6
7	Other people play a big role in whether my IBS improves, stays the same, or gets worse.	1	2	3	4	5	6
8	Whatever goes wrong with my IBS is my own fault.	1	2	3	4	5	6
9	Luck plays a big part in determining how my IBS improves.	1	2	3	4	5	6
10	In order for my IBS to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
11	Whatever improvement occurs with my IBS is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing which affects my IBS is what I myself do.	1	2	3	4	5	6
13	I deserve the credit when my IBS improves and the blame when it gets worse.	1	2	3	4	5	6
14	Following doctor's orders to the letter is the best way to keep my IBS from getting any worse.	1	2	3	4	5	6
15	If my IBS worsens, it's a matter of fate.	1	2	3	4	5	6
16	If I am lucky, my IBS will get better.	1	2	3	4	5	6
17	If my IBS takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
18	The type of help I receive from other people determines how soon my IBS improves.	1	2	3	4	5	6

APPENDIX 7

DEMOGRAPHIC QUESTIONNAIRE FOR IBS PARTICIPANTS

Version 1 7/04/2005 – Demographic Questionnaire for IBS Sufferers

Please answer the questions below prior to completing the questionnaires

1. Date of birth.....
2. Age in years.....
3. Sex.....
4. Country of Residence.....
5. Nationality.....
6. Highest Qualification Obtained ..... (e.g. O level, A level)
7. Occupation..... (if unemployed go to q7)
8. Is your unemployment due to you illness?.....
9. Where did you hear about the research?.....
10. Do you smoke?.....
11. Which hand do you write with?.....
12. When were you diagnosed as having IBS?..... Please specify the year, and how many years ago, e.g. 1999 (4years ago)
13. Were you diagnosed by a medical professional?.....
14. How long was it from your first experience of symptoms before your diagnosis?.....
15. Please specify on average which sub-group of IBS most accurately describes your symptoms by circling below:

predominately diarrhoea predominately constipation alternating

It is really important that you are classified into one of these three groups, so please think carefully about your answers to this question, if you really feel that you do not fit into one of these categories, please provide an explanation of your primary symptoms

below.....

.....

.....

Do you suffer from any other illnesses? (please specify)

.....

APPENDIX 8

DEMOGRAPHIC QUESTIONNAIRE FOR DOCTORS

Version 1 19/05/2004 – Demographic Questionnaire for Doctors

Please answer the questions below prior to completing the questionnaire

1. Date of birth.....

2. Age in years.....

3. Sex.....

4. Nationality.....

5. Highest Qualification Obtained .....(e.g. Medical degree, doctorate)

6. Occupation / specialisation.....(e.g. GP or Gastroenterologist)

7. How long have you worked as a Doctor for? .....

8. Where did you hear about the research?.....

9. On average how many consultations per week involve sufferers of IBS.....

APPENDIX 9

LETTER TO DOCTORS AND INFORMATION SHEET

Carly Jacobs
Bsc (Hons) MSc

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UniS
Department of Psychology

20 December 2006

Dear Doctor (name),

I am studying for my PhD in Health Psychology at the University of Surrey. As part of my research I am investigating doctor-patient communication in irritable bowel syndrome. I would be grateful if you are willing to participate in my research. This involves completion of a short (21 item) questionnaire. All of the necessary information is contained on the information sheet provided.

Thank you for your time

Yours truly,

Carly Jacobs

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Bsc (Hons) MSc

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Department of
Psychology

23 August 2004

Patient Information Sheet For Doctors

1. Study Title

Doctor Patient Communication in IBS and Outcomes

2. Invitation Paragraph

You are being invited to take part in a research study. Before you decide if you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Contact me if there is anything that is unclear to you, or if you would like more information. Take time to decide whether or not you with to take part

Thank you for reading this.

3. What is the purpose of the study?

Thank you for your interest in participating in this study. The purpose of the study, is to gain a better understanding of the factors that affect the severity of symptoms experienced, and the factors which affect how much sufferers feel their daily lives are affected by their IBS. It is necessary to gain a better understanding of these processes in order to provide a back ground for designing interventions to reduce symptoms and improve quality of life. It will take up to ten minutes of your time (the proposed duration if this study is a year). There are three main questions to be investigated there are as follows. The first question is whether quality of doctor-patient communication is related to IBS outcomes. Outcomes involve both quality of life, related to having IBS, and the frequency of symptoms you have. The second question is whether this relationship is affected by a theory in health psychology known as illness representations, focussing on one aspect of it called the 'control component'. The final question is whether doctors' and patients' views of the quality of consultations for IBS patients are the same or different.

4. Why have I been chosen?

You have been chosen because you are a GP, or a consultant gastroenterologist, and therefore have experience of consultations involving sufferers of IBS. You are one of approximately 150 medical professionals participating in this study

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form, which you will receive a copy of. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect you ability to participate in future research.

6. What will happen to me if I take part?

Your involvement in this research will be for a period of ten minutes. All that is required is the fill out a short (21 item) questionnaire and return it using the pre-paid envelope provided.

7. What do I have to do?

The research is designed to involve minimal disruption to your routine, and can be completed at a location convenient to you. There are no lifestyle restrictions and you can therefore continue to undertake all normal activities.

8. What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks for participating in this study

9. What are the possible benefits of taking part?

There are two main potential benefits for your participation in this study. The first is the necessity to isolate potential problem areas in order to improve practice. The second is that IBS sufferers constitute a large proportion of clinic appointments, which contributes to the pressures faced in managing to see all patients in the working day. This study investigates, which factors result in less repeat doctors appointments. Isolation of these factors will shape intervention programs potentially resulting in a reduction of the proportion of sufferers regularly visiting their GP.

10. What if new information becomes available?

This is unlikely to occur as the research is cross sectional and there is no treatment involved. However, in the event of further contact being necessary, inclusion of your address on the consent form will allow for you to be contacted.

11. What if something goes wrong?

In the unlikely event you are harmed by taking part in this research, there are no special compensation arrangements, but standard university insurance cover is in place. If you are harmed due to someone's negligence, then you may have grounds for a legal action, but you may have to pay for it. Regardless of this if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the standard university complaints mechanisms should be available to you.

12. Will my taking part in this study be kept confidential?

All personal data will be anonymous and processed in the strictest of confidence and in accordance with the Data Protection Act (1988). By consenting to participate in this study you are indicating your agreement not to restrict the results of the study on the understanding that your anonymity is preserved. It is necessary for you to sign the consent form to indicate your consent, but this is the only place where your name will appear, all other data will be identified by coding only. If you would like to be contacted in the event of any further information regarding this research becoming available, then please include a contact address on the consent form.

13. What happens to the results of the research study?

It is anticipated that the results of this study will be published. Participants should note that they will not be able to be identified in any publication. Publication may be in academic journals, in the journal of the IBS NETWORK, and on the IBS NETWORK's website. The findings may also be presented at academic conferences. The IBS NETWORK's website has no access restrictions and can therefore be accessed by the general public. Requests can also be made to myself the chief investigator for a summary of the research findings.

14. Who is organising and funding the research?

The research is funded by the University of Surrey.

15. Who has reviewed the study?

This study has been revieved by the Multi-centre Research Ethics Committee.

16. Contact for further information

If you have any questions regarding any aspects of the study, or would like further information and advice please do not hesitate to contact me prior to the commencement of the study. The signing of the consent form indicates that you fully understand the study, and therefore if this is not the case please contact me prior to indicating your consent.

Carly Jacobs
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APPENDIX 10

CONSENT FORM FOR DOCTORS AND ETHICS APPROVAL FOR THE STUDY

West Midlands Multi-centre Research Ethics Committee

04 August 2004

27 Highfield Road
Edgbaston
Birmingham
B15 3DP

Tel: 0121 245 2544
Fax: 0121 245 2519

Miss Carly Jacobs
Department of Psychology
Guilford
GU2 7XH

Dear Miss Jacobs,

Full title of study: Role of doctor-patient communication in the control component of illness representations, and outcomes, for sufferers of irritable bowel syndrome (IBS)
REC reference number: 04/MRE07/29
Protocol number: 1

Thank you for your letter of 19 July 2004, responding to the Committee's request for further information on the above research.

The further information has been considered on behalf of the Committee by the Chairman.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation.

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type: Application
Version:
Dated: 19/05/2004
Date Received: 20/05/2004

Document Type: Investigator CV
Version:
Dated: 19/05/2004
Date Received: 20/05/2004

Document Type: Protocol
Version: 1
Dated: 19/05/2004
Date Received: 20/05/2004

Document Type: Summary/Synopsis
Version: 1
Dated: 19/05/2004
Date Received: 20/05/2004

1/...

UniS

Ethics Committee

19 August 2004

Ms Carly Jacobs
Department of Psychology
School of Human Sciences

Dear Ms Jacobs

Role of doctor-patient communication in the control component of illness representations, and outcomes, for sufferers of irritable bowel syndrome (IBS) (EC/2004/82/Psych - FAST TRACK

I am writing to inform you that the University Ethics Committee has considered the above protocol under its 'Fast Track' procedure, and has approved it on the understanding that the Ethical Guidelines for Teaching and Research are observed and the following condition is met:

- That the Information Sheet for Participants and the advertisement material include the University's telephone number in addition to your personal mobile number, as some participants may prefer to use this to contact you.

For your information, and future reference, these Guidelines can be downloaded from the Committee's website at http://www.surrey.ac.uk/Surrey/ACE/.

This letter of approval relates only to the study specified in your research protocol (EC/2004/82/Psych - Fast Track. The Committee should be notified of any changes to the proposal, any adverse reactions and if the study is terminated earlier than expected, with reasons.

I should be grateful if you would confirm in writing your acceptance of the condition above, forwarding a copy of the amended documents for the Committee's records.

Date of approval by the Ethics Committee: **19 August 2004**
Date of expiry of approval by the Ethics Committee: **18 August 2009**

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee
Registry

cc: Professor T Desombre, Chairman, EC
PROF R SHEPHERD PSYCHOLOGY

Carly Jacobs
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Department of
Psychology

10 August 2004

CONSENT FORM

Title of Project: Doctor-Patient Communication in Irritable Bowel Syndrome (IBS)

Name of Researcher: Carly Jacobs

Please initial box

1. I confirm that I have read and understand the information sheet dated ...19/05/04 (version 1) for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I agree to take part in the above study. ☐

Name of Volunteer (Block Capitals)	Date	Signature

Address of Volunteer (optional)

Researcher	Date	Signature

APPENDIX 11

LETTER TO IBS SUFFERERS AND INFORMATION SHEET

Version 1 19/05/04

Information for advertisement to appear in newspapers, magazines and on websites:

UniS

Department of Psychology

Participants required for a research investigating doctor-patient communication in irritable bowel syndrome (IBS). The research is administered by post and can therefore be completed at your convenience. The total time required for participation is one hour. There is no payment for this research but postage costs are included by use of free post.

There are two parts to this research. The first stage involves completion of four short questionnaires. The second stage involves completion of a symptom and medication diary for one week.

All sufferers who have been diagnosed by a medical professional (e.g. GP or Gastroenterologist) are eligible to participate.

For more information please contact Carly Jacobs

Psychology Department

School of Human Sciences

University of Surrey

GU2 7XH

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Department of
Psychology

23 August 2004

Patient Information Sheet For IBS Participants

1. Study Title

Doctor-Patient Communication in Irritable Bowel Syndrome (IBS)

2. Invitation Paragraph

You are being invited to take part in a research study. Before you decide if you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Contact me if there is anything that is unclear to you, or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

3. What is the purpose of the study?

Thank you for your interest in participating in this study. This study will investigate whether doctor-patient communication is related to frequency of IBS symptoms and quality of life. Patients' views on doctor-patient communication and beliefs about IBS will be measured. In addition Doctors' views on the quality of their consultations are also being measured so that their views can be compared with the patients' views to see if they are the same. Research of this type is necessary to gain a better understanding of what affects IBS has in order to design interventions to reduce symptoms and improve quality of life. It will take up to one hour of your time spread over eight days (proposed duration of the study one year).

4. Why have I been chosen?

You have been chosen because you are a sufferer of IBS, with a confirmed diagnosis from a medical professional. You are one of approximately 150 patients participating in this study.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form, which you will have a copy of. If you decide to take part you are still free to withdraw at any time and without

giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the care you receive from the NHS.

6. What will happen to me if I take part?

Your involvement in this research will be for a period of eight days. It is anticipated that the total duration of the study is no more than one hour. There are two parts to the research. The first stage involves filling in questionnaires, and the second stage filling in a symptom and medication diary for a one week period. The questionnaires are to be filled in first, and they are to be completed in the order they are presented to you. After filling in the questionnaires you are to return them, along with the consent form using one of the prepaid envelopes provided. Starting the next day you are required to fill in the symptom diary for a one week period, before returning it using the second prepaid envelope provided.

7. What do I have to do?

The research is designed to involve minimal disruption to your routine, and can be completed at a location convenient to you. There are no lifestyle restrictions and you can therefore continue to undertake all normal activities.

8. What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks from participating in this study.

9. What are the possible benefits of taking part?

There are many potential benefits from your participation in this study. The first is that knowledge of IBS may be increased. This is important as many sufferers report frustration at the current lack of knowledge concerning this illness. No previous research has addressed the role of doctor-patient communication in IBS, this is necessary as the quality of doctor-patient communication must first be established to see if changes need to be made. Finally the potential effect of doctor-patient communication needs to be established as this will shape the designing of a future intervention programme.

10. What if new information becomes available?

This is unlikely to occur as the research takes place over a short time period. However, in the event of further contact being necessary, inclusion of your address on the consent form will allow for you to be contacted.

11. What if something goes wrong?

In the unlikely event you are harmed by taking part in this research, there are no special compensation arrangements, but standard university insurance cover is in place. If you are harmed due to someone's negligence, then you may have grounds for a legal action, but you may have to pay for it. Regardless of this if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the standard university complaints mechanisms should be available to you.

12. Will my taking part in this study be kept confidential?

Your doctor will not be informed of your participation in this study. All personal data will be anonymous and processed in the strictest of confidence and in accordance with the Data Protection Act (1988). By consenting to participate in this study you are indicating your agreement not to restrict the results of the study on the understanding that your anonymity is preserved. It is necessary for you to sign the consent form to indicate your consent, but this is the only place where your name will appear, all other data will be identified by coding only. It is essential that you include an identifying code word on the consent form, and the same word on the diary, this will allow for your questionnaire data to be matched to your diary. If you would like to be contacted in the event of any further information regarding this research becoming available, then please include a contact address on the consent form.

13. What happens to the results of the research study?

It is anticipated that the results of this study will be published. Participants should note that they will not be able to be identified in any publication. Publication may be in academic journals, in the journal of the IBS NETWORK, and on the IBS NETWORK's website. The findings may also be presented at academic conferences. The IBS NETWORK's website has no access restrictions and can therefore be accessed by the general public. Requests can also be made to myself the chief investigator for a summary of the research findings.

14. Who is organising and funding the research?

The research is funded by the University of Surrey.

15. Who has reviewed the study?

This study has been reviewed by the Multi-centre Research Ethics Committee.

16. Contact for further information

If you have any questions regarding any aspects of the study, or would like further information and advice please do not hesitate to contact me prior to the start of the study. The signing of the consent form indicates that you fully understand the study, and therefore if this is not the case please contact me prior to indicating your consent.

Carly Jacobs
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University of Surrey
GU2 7XH

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Tel: (University) +44 (01438) 686883 (Mob) 07931 565820

APPENDIX 12

CONSENT FORM FOR IBS PARTICIPANTS

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Fax: +44 (0)1483 689553
Email: c.jacobs@surrey.ac.uk

Department of
Psychology

10 August 2004

CONSENT FORM

Title of Project: Doctor-Patient Communication in Irritable Bowel Syndrome (IBS)

Name of Researcher: Carly Jacobs

Please initial box

1. I confirm that I have read and understand the information sheet dated ...19/07/04 (version 2) for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I agree to take part in the above study. ☐

Name of Volunteer (Block Capitals)	Date	Signature

Address of Volunteer (optional)

Researcher	Date	Signature

Code word for identification _____

APPENDIX 13

GENERAL POPULATION VERSION OF ATTITUDES TO CHRONIC ILLNESS QUESTIONNAIRE

Attitudes to Chronic Illness Questionnaire

I am interested in your views concerning chronic illnesses, please answer the questions below honestly and in the order they are presented to you. There are no right or wrong answers, and you do not need to look up a definition of any of the illnesses, just answer the questions on the basis of how you feel, and based on your current knowledge. You may, however, use a dictionary or translator if you do not understand the symptoms listed in section one.

Section 1

All chronic illnesses have a number of symptoms associated with them. The symptoms listed below are either experienced by sufferers of Epilepsy, Asthma or Irritable Bowel Syndrome (IBS). A particular symptom might be related to one, or a number of these illnesses. Please indicate the number that best represents your feelings towards **discussing the symptom** described below. Imagine that you have a friend who has just disclosed to you that they suffer from these symptoms and rate your answers according to how comfortable / uncomfortable you would feel discussing them. Write the number that best indicates how you feel on the line next to the symptom.

Discussing this symptom, I would feel...
1= extremely comfortable
2= moderately comfortable
3= slightly comfortable
4= neither
5= slightly uncomfortable
6= moderately uncomfortable
7= extremely uncomfortable
8= not be prepared to discuss this symptom

e.g. If the symptom was vomiting and discussing this made you moderately uncomfortable your response would look like this:

Vomiting.....6.....

1. A convulsion.....
2. Belching.....
3. Nasal flaring (nostril size increases with breathing).....
4. Muscle jerks of arms, legs or body.....
5. Dazed behaviour (unable to communicate).....
6. Wheezing.....
7. Diarrhoea.....

8. Brief periods of no response to questions / instructions.....
9. Coughing.....

Discussing this symptom, I would feel...
1= extremely comfortable
2= moderately comfortable
3= slightly comfortable
4= neither
5= slightly uncomfortable
6= moderately uncomfortable
7= extremely uncomfortable
8= not be prepared to discuss this symptom

10. Constipation.....
11. Sudden fear, anger or panic for no reason.....
12. Bloating.....
13. Shortness of breath.....
14. Repeated out of place / unnatural movements.....
15. Loss of bowel control whilst fully conscious.....
16. "Fainting spells" where bladder control is lost.....
17. Episodes of blank staring.....
18. Flatulence.....
19. Difficulty talking or concentrating.....
20. Abdominal pain.....
21. "Fainting spells" where bowel control is lost.....
22. Short periods of blackout or confused memory.....
23. Hunched shoulders.....
24. Episodes of blinking / chewing at inappropriate times.....
25. Shortness of breath when walking.....
26. Urgent need to defecate.....
27. Sudden stiffening or falls for no apparent reason.....
28. Tightness in the chest.....

Please indicate the number that best represents your feelings towards witnessing the symptom described below. Imagine that you have a friend who suffers from these symptoms, and rate your answers according to how comfortable / uncomfortable you would feel **witnessing them experiencing each symptom**. Write the number that most indicates how you feel on the line next to the symptom.

Witnessing this symptom, I would feel...
1= extremely comfortable
2= moderately comfortable
3= slightly comfortable
4= neither
5= slightly uncomfortable
6= moderately uncomfortable
7= extremely uncomfortable
8= not be prepared to witness this symptom

e.g. If the symptom was vomiting and witnessing this made you moderately comfortable your response would look like this:

Vomiting.....2.....

1. A convulsion.....
2. Belching.....
3. Nasal flaring (nostril size increases with breathing).....
4. Muscle jerks of arms, legs or body.....
5. Dazed behaviour (unable to communicate).....
6. Wheezing.....
7. Diarrhoea.....
8. Brief periods of no response to questions / instructions.....
9. Coughing.....
10. Constipation.....
11. Sudden fear, anger or panic for no reason.....
12. Bloating.....
13. Shortness of breath.....
14. Repeated out of place / unnatural movements.....
15. Loss of bowel control whilst fully conscious.....
16. "Fainting spells" where bladder control is lost.....
17. Episodes of blank staring.....
18. Flatulence.....
19. Difficulty talking or concentrating.....
20. Abdominal Pain.....

Witnessing this symptom, I would feel...
1= extremely comfortable
2= moderately comfortable
3= slightly comfortable
4= neither
5= slightly uncomfortable
6= moderately uncomfortable
7= extremely uncomfortable
8= not be prepared to witness this symptom

21. "Fainting spells" where bowel control is lost.....
22. Short periods of blackout or confused memory.....
23. Hunched shoulders.....
24. Episodes of blinking / chewing at inappropriate times.....
25. Shortness of breath when walking.....
26. Urgent need to defecate.....
27. Sudden stiffening or falls for no apparent reason.....
28. Tightness in the chest.....

Please mark the box which best represents your opinion.

	VIEWS ABOUT CHRONIC ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
1	**If a person had ASTHMA it would strongly affect the way I viewed them**					
2	**Having EPILEPSY has major consequences on a sufferers life**					
3	**ASTHMA is a serious condition**					
4	**If a person I was close to had EPILEPSY it would cause difficulties for me**					
5	**Having IBS does not have much effect on a sufferers life**					
6	**Having ASTHMA has serious financial consequences for sufferers**					
7	**If a person had EPILEPSY it would strongly affect the way I viewed them**					
8	**Having IBS has major consequences on a sufferers life**					
9	**If a person I was close to had ASTHMA it would cause difficulties for me**					
10	**If a person had IBS it would strongly affect the way I viewed them**					
11	**Having EPILEPSY has serious financial consequences for sufferers**					

	VIEWS ABOUT CHRONIC ILLNESS	STRONGLY DISAGREE	DISAGREE	NEITHER AGREE NOR DISAGREE	AGREE	STRONGLY AGREE
12	If a person I was close to had IBS it would cause difficulties for me					
13	Having EPILEPSY does not have much effect on a sufferers life					
14	IBS is a serious condition					
15	EPILEPSY is a serious condition					
16	Having ASTHMA has major consequences on a sufferers life					
17	Having IBS has serious financial consequences for sufferers					
18	Having ASTHMA does not have much effect on a sufferers life					
19	I would be embarrassed of a friend because of their EPILEPSY					
20	I do not think that EPILEPSY symptoms are real					
21	If my partner developed ASTHMA it would affect my relationship with them					
22	I would choose not to be friends with someone if I knew they had EPILEPSY					
23	I would be embarrassed of a friend because of their IBS					
24	I would choose not to be friends with someone if I knew they had ASTHMA					
25	I do not think IBS symptoms are real					
26	I would be embarrassed of a friend because of their ASTHMA					
27	If my partner developed IBS it would affect my relationship with them					
28	I would choose not to be friends with someone if I knew they had IBS					
29	I do not think ASTHMA symptoms are real					
30	If my partner developed EPILEPSY it would affect my relationship with them					

Section 3

Having a chronic illness limits the variety of activities a person is able to engage in. The types of activities that are limited obviously vary depending on the nature of the illness, but there are some features which are common to many illnesses. Imagine that you are friends with a person who suffers from each of the three illnesses described (IBS, epilepsy, asthma) and answer the questions below to indicate (by circling or

highlighting) how often you would be prepared to make these concessions in planning social activities.

1) I would be happy to avoid travelling on public transport if my friend did not want to due to worry about having an IBS attack

/----------/----------/---------/---------/---------/---------/

0 1 2 3 4 5 6

Never Always

2) I would be happy to cancel going out socially because of my friend's Epilepsy

/----------/----------/---------/---------/---------/---------/

0 1 2 3 4 5 6

Never Always

3) I would be happy to collect Epilepsy medication for my friend if they were too unwell to collect it themselves

/----------/----------/---------/---------/---------/---------/

0 1 2 3 4 5 6

Never Always

4) I would be happy to cancel going out socially because of my friend's IBS

/----------/----------/---------/---------/---------/---------/

0 1 2 3 4 5 6

Never Always

5) I would be happy to collect Asthma medication for my friend if they were too unwell to collect it themselves

/----------/----------/---------/---------/---------/---------/

0 1 2 3 4 5 6

Never Always

6) I would be sympathetic if my friend was reluctant to plan activities ahead of time because of their Asthma symptoms

/----------/----------/----------/----------/----------/----------/

0 1 2 3 4 5 6

Never Always

7) I would be happy to delay going out socially because of my friend's IBS

/----------/----------/----------/----------/----------/----------/

0 1 2 3 4 5 6

Never Always

8) I would be understanding if my friend was late because of their Epilepsy

/----------/----------/----------/----------/----------/----------/

0 1 2 3 4 5 6

Never Always

9) I would be happy to cancel going out socially because of my friend's Asthma

/----------/----------/----------/----------/----------/----------/

0 1 2 3 4 5 6

Never Always

10) I would be sympathetic if my friend was reluctant to plan activities ahead of time because of their IBS symptoms

/----------/----------/----------/----------/----------/----------/

0 1 2 3 4 5 6

Never Always

11) I would be happy to avoid travelling on public transport if my friend did not want to due to worry about having an Epileptic attack

/----------/----------/----------/----------/----------/----------/

0 1 2 3 4 5 6

Never Always

12) I would be understanding if my friend was late because of their IBS

/----------/----------/----------/----------/----------/----------/
0 1 2 3 4 5 6
Never Always

13) I would be happy to delay going out socially because of my friend's Epilepsy

/----------/----------/----------/----------/----------/----------/
0 1 2 3 4 5 6
Never Always

14) I would be happy to avoid travelling on public transport if my friend did not want to due to worry about having an Asthma attack

/----------/----------/----------/----------/----------/----------/
0 1 2 3 4 5 6
Never Always

15) I would be sympathetic if my friend was reluctant to plan activities ahead of time because of their Epileptic symptoms

/----------/----------/----------/----------/----------/----------/
0 1 2 3 4 5 6
Never Always

16) I would be happy to delay going out socially because of my friend's Asthma

/----------/----------/----------/----------/----------/----------/
0 1 2 3 4 5 6
Never Always

17) I would be understanding if my friend was late because of their Asthma

/----------/----------/----------/----------/----------/----------/
0 1 2 3 4 5 6
Never Always

18) I would be happy to collect IBS medication for my friend if they were too unwell to collect it themselves

/----------/----------/----------/----------/----------/----------/

0 1 2 3 4 5 6

Never Always

Below is a list of common social activities that are restricted to sufferers of Epilepsy, Asthma or IBS. A particular activity may be restricted to one, or a number of these illnesses. Please indicate the number which best represents how prepared you are to avoid these activities when planning group social activities to allow your friend to be involved. As with the previous section the items are scored on a scale from 0-6, where 0 is never and 6 is always

e.g. If the activity was bowling and you were always prepared to avoid this when planning group activities your response would look like this:

- **Bowling**.....6.....

- Swimming.....
- Going to night clubs.....
- Lazer quest.....
- Long drives.....
- Theme Parks.....
- Water Parks.....
- Going out to dinner.....
- Going abroad.....
- Going on train journeys.....
- Going to the cinema.....
- Going for long walks.....
- Team sports.....
- Aerobics classes.....
- Playing computer games.....

<u>Section 4</u>

Please provide a short description of what you understand Epilepsy to be:

.....

.....

.....

.....

.....
.....

Do you know anybody who suffers from Epilepsy?.....Yes / No

If yes: would you consider this person(s) to be a friend?.....Yes / No

If no: what is your relationship with them?.....

If you consider this person to be a friend do you feel that there have been situations when their illness has had a negative impact on you or your relationship with them, if so please explain below:

.....
.....
.....
.....
.....
.....

Please provide a short description of what you understand IBS to be:

.....
.....
.....
.....
.....
.....

Do you know anybody who suffers from IBS?.....Yes / No

If yes: would you consider this person(s) to be a friend?.....Yes / No

If no: what is your relationship with them?.....

If you consider this person to be a friend do you feel that there have been situations when their illness has had a negative impact on you or your relationship with them, if so please explain below:

.....
.....
.....
.....

.....

.....

Please provide a short description of what you understand Asthma to be:

.....

.....

.....

.....

.....

.....

Do you know anybody who suffers from Asthma.....Yes / No

If yes: would you consider this person(s) to be a friend?.....Yes / No

If no: what is your relationship with them?.....

If you consider this person to be a friend do you feel that there have been situations when their illness has had a negative impact on you or your relationship with them, if so please explain below:

.....

.....

.....

.....

.....

.....

Of the three illnesses described please rank which condition you think would most impact on your friendship with a person. 1= greatest impact, 2= middle impact, 3=least impact.

EPILEPSY.....

IBS.....

ASTHMA.....

Thank you very much for your time.

Please check you have answered every question. If you have any additional comments please write them on the back page of the questionnaire.

Carly Jacobs

Chronic Illness Questionnaire Scoring:

For section 1 scoring is computed in two different ways.

1) Using descriptive stats, like a bar chart so see which symptoms are scores the highest, and to see where abouts on the range the IBS symptoms are, and then using an ANOVA to compare the mean responses for each of the symptoms (for discussing and witnessing respectively), to see if the differences between symptoms are significantly different
2) Summing and averaging each group of symptoms (IBS questions 7,10,20,18,26,12,15,2, epilepsy 1,22,16,21,17,8,27,24,5,14,11,4, asthma 6,9,13,28,19,25,23,3) and comparing the means of the three groups, to look at the overall impact of the illness as compared with each other.

For section 2 the parallel version of the IPQ-R consequences scale scoring would be done in the same way as on the original IPQ-R. This just involves summing the 6 questions in each section (except that questions 5, 18 and 13 are inverted and needs to be recoded first). This will then allow for a comparison of the perceived consequences from the general population about each of the illnesses, which can then be compared to each other to see which illness scores the highest, and if the means are sig different. The IBS version can also be compared to the data from the IBS participants to see if the perceptions of people match the assumed perceptions the IBS people have, which will have implications for the intervention study. I have also added onto this for each illness the other perception questions I wanted to ask because I think they fit in this section, when I analyse the data I will also look at factor analysis of this section to see if it can be effectively added in, and if so I will also do that.

For section three concession scale. To just be summed for each illness

For section 4 I have gone for a more qualitative style just to get some more info, I can then code the descriptions of the illnesses to give them a score to see accurate the definitions are. I can then as past of the data analysis include accuracy of knowledge as an interaction variable

APPENDIX 14

PERCEIVED SOCIAL SUPPORT SCALE (PSSS)

Version 1 07/04/2005

Perceived Social Support Scale (PSSS)

I am interested in your views concerning the level of social support you ***think*** your friends and family provide with regards to your suffering from Irritable Bowel Syndrome (IBS). Please answer the questions below honestly and in the order they are presented to you. As different friends and family members may respond differently you are required to think about all of their likely responses and record the ***average response*** of how you think your friends and family are likely to respond. In the case of a particular symptom not being relevant to your experience of IBS please write N/A next to the question. DO NOT JUST LEAVE IT BLANK.

Section 1

Think about how your friends and family would feel discussing each of your symptoms of IBS with you. Please indicate the number that best represents the average response your friends and family would have towards **discussing the symptom** described below. Imagine that you have initiated a conversation with them about these symptoms and rate how comfortable / uncomfortable you think they would feel discussing them. Write the number that best indicates how you think they feel on the line next to the symptom. If a symptom is not relevant to your experience of IBS then write N/A next to the question, do not just leave it blank.

Discussing this symptom, my friends / family would feel...
1= extremely comfortable
2= moderately comfortable
3= slightly comfortable
4= neither
5= slightly uncomfortable
6= moderately uncomfortable
7= extremely uncomfortable
8= not be prepared to discuss this symptom

e.g. If the symptom was vomiting and you think discussing this with your friends and family would on average make them feel moderately uncomfortable your response would look like this:

Vomiting.....6.....

1. Belching.....
2. Diarrhea.....
3. Coughing.....

4. Constipation.....
5. Bloating.....
6. Flatulence.....
7. Abdominal pain.....
8. Urgent need to defecate.....

Section 2

Think about how your friends and family would feel witnessing each of your symptoms of IBS. Please indicate the number that best represents the average response your friends and family would have towards **witnessing the symptoms** described below. Imagine that are experiencing this symptom in front of them and rate how comfortable / uncomfortable you think they would feel witnessing them. Write the number that best indicates how you think they feel on the line next to the symptom. If a symptom is not relevant to your experience of IBS then write N/A next to the question, do not just leave it blank.

Witnessing this symptom, my friends and family would feel...
1= extremely comfortable
2= moderately comfortable
3= slightly comfortable
4= neither
5= slightly uncomfortable
6= moderately uncomfortable
7= extremely uncomfortable
8= not be prepared to witness this symptom

e.g. If the symptom was vomiting and think witnessing this would on average make your friends and family feel moderately comfortable your response would look like this:

Vomiting.....2.....

1. Belching.....
2. Diarrhea.....
3. Coughing.....
4. Constipation.....
5. Bloating.....
6. Flatulence.....
7. Abdominal pain.....
8. Urgent need to defecate.....

Section 3

Having IBS can affect the social activities you are able to engage in, depending on your illness sub-type and severity of your symptoms on different occasions. Below are a number of concessions that your friends and family may have to make when arranging social activities in order to allow you to be included. Please indicate on average (as with the previous section) how often you think your friends and family would be prepared to make these concessions.

On average my friends and family would....

1) Be happy to avoid travelling on public transport if I did not want to due to worry about having an IBS attack

/----------/----------/----------/----------/----------/----------/

0 1 2 3 4 5 6

Never Always

2) Be happy to cancel going out socially because of my IBS

/----------/----------/----------/----------/----------/----------/

0 1 2 3 4 5 6

Never Always

3) Be happy to delay going out socially because of my IBS

/----------/----------/----------/----------/----------/----------/

0 1 2 3 4 5 6

Never Always

4) Be sympathetic if I was reluctant to plan activities ahead of time because of my IBS symptoms

/----------/----------/----------/----------/----------/----------/

0 1 2 3 4 5 6

Never Always

5) Be understanding if I was late because of my IBS

/----------/----------/----------/----------/----------/----------/

0 1 2 3 4 5 6

Never Always

6) Be happy to collect IBS medication for me if I was too unwell to collect it myself.

/----------/----------/----------/----------/----------/----------/

0 1 2 3 4 5 6

Never Always

Below is a list of common social activities that may be difficult for you to engage in. Please indicate the number which best represents on average how prepared you think your friends and family would be to avoid these activities when planning group social activities to allow you to be involved. As with the previous section the items are scored on a scale from 0-6, where 0 is never and 6 is always. It does not matter if a particular activity is one you do not engage in please mark it any way.

e.g. If the activity was bowling and your friends and family were always prepared to avoid this when planning group activities your response would look like this:

- **Bowling**……6…….

- Swimming……
- Going to night clubs……
- Lazer quest……..
- Long drives……..
- Theme Parks……
- Water Parks……
- Going out to dinner……
- Going abroad……
- Going on train journeys……
- Going to the cinema……
- Going for long walks……
- Team sports……..
- Aerobics classes……
- Playing computer games……

APPENDIX 15

DEMOGRAPHIC QUESTIONNAIRE FOR GENERAL POPULATION

Demographic Questionnaire – Paper Version

Please answer the questions below prior to completing the questionnaires

1. Age in years.....
2. Gender.....
3. Country of Residence.....
4. Nationality.....
5. Religion.....
6. Highest Academic Qualification .....
7. Occupation.....
8. Where did you hear about the research?.....
9. Do you smoke?.....
10. Do you suffer from any chronic illness(s)?..... Yes / No
11. If yes, please list the illness(s) below:

.....

APPENDIX 16

LETTER AND INFORMATION SHEET FOR ATTITUDES STUDY, GENERAL POPULATION

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Department of
Psychology

20 December 2006

Dear Sir / Madame

My name is Carly Jacobs and I am a PhD student at the University of Surrey, I am currently conducting some research on attitudes to chronic illness. Please will you take part in my research by filling in a questionnaire for me it should take no more than 20 minutes and I need 1000 people to fill it in, so I am sure you can appreciate how grateful I would be for your participation. If you are unable to take part then please hand the questionnaire to someone you know who would be happy to take part (they must be 18 or over).

Thank you for your time, I do look forward to hearing from you in due course.

Carly Jacobs

Carly Jacobs
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Participant information sheet for Attitudes to Chronic Illness Research

Thank you for your interest in participating in this study. This study is interested in investigating people's attitudes towards chronic illness, specifically focused on attitudes towards three chronic illnesses, namely asthma, irritable bowel syndrome (IBS) and epilepsy. The study involves completion of a questionnaire, which should take no more than twenty minutes.

There are three main objectives for this study. The first is to compare the attitudes to the three illnesses to see if attitudes are similar or different between illnesses. The second objective it to compare these attitudes with the perceptions sufferers of chronic illnesses have of people's attitudes. The third objective is to incorporate the information yielded into the designing of a chronic illness intervention study.

There are many potential benefits from your participation in this study. The first is that by participating in this research knowledge of attitudes towards chronic illness will be increased, this is important as scientific discoveries and improvements in current management of chronic illness cannot be made unless people participate in research. Secondly one of the primary influences on how a sufferer views their illness is their perceptions of people's attitudes towards them. In psychological intervention studies inaccurate perceptions must be challenged and changed before improvements can result, however, there is currently no data detailing what people's attitudes actually are. Consequently the data from this study is vital, and a necessary precursor for designing effective illness interventions of this type.

The research is designed to involve minimal constraints on your time, and can be completed quickly and at a location convenient to you. The total duration of your involvement is no more than twenty minutes. The questionnaire can either be returned to me in person, returned to my pigeon hole in the Psychology Department staff room (6AD02), or posted using the freepost address below.

It is necessary for you to sign the consent form to indicate your consent, but this is the only place where your name will appear, all other data will be identified by coding only. If you would like to be contacted in the event of any further information regarding this research becoming available, then please include a contact address on the consent form. You have the right to withdraw from the study at any time without specifying your reason for doing so.

All personal data will be anonymous and processed in the strictest of confidence and in accordance with the Data Protection Act (1988). By consenting to participate in this study you are indicating your agreement not to restrict the results of the study on the understanding that your anonymity is preserved. The results of this study will be available from myself at the conclusion of the study, and they may be published in academic journals, and presented at academic conferences.

If you have any questions regarding any aspects of the study, or would like further information and advice please do not hesitate to contact me prior to starting the study. The signing of the consent form indicates that you fully understand the study, and therefore if this is not the case please contact me prior to indicating your consent.

CARLY JACOBS
FREEPOST G1197
J3 – Dept of Psychology
Guildford
GU2 5BR
01 12040 DF3000 3204

E-mail – c.jacobs@surrey.ac.uk
Telephone (Office) 01483 686883
Telephone (Mob) 07931565820

APPENDIX 17

CONSENT FORM FOR GENERAL POPULATION

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Consent Form – Paper Version

I, the undersigned, voluntarily agree to take part in the study on **"Attitudes to Chronic Illness".**

I have read and understood the information sheet provided. I have been given a full explanation by the investigators of the nature, purpose, location and likely duration of the study, and of what I will be expected to do. I have been given the opportunity to ask questions on all aspects of the study and have understood the advice and information given as a result.

I understand that all personal data relating to volunteers will be anonymous and will be processed in the strictest confidence, and in accordance with the Data Protection Act (1998). I agree that I will not seek to restrict the use of the results of the study on the understanding that my anonymity is preserved.

I understand that I am free to withdraw from the study at any time without reason, without needing to justify my decision and without prejudice.

I confirm that I have read and understood the above and freely consent to participating in this study. I have been given adequate time to consider my participation and agree to comply with the instructions and restrictions of the study.

Name of Volunteer (Block Capitals)

.....

Signature / Date

.....

Address of volunteer (optional)

.....

.....

APPENDIX 18

INFORMATION SHEET FOR ATTITUDES STUDY, IBS PARTICIPANTS

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Department of
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20 December 2006

INFORMATION SHEET FOR IBS PARTICIPANTS FOR THE ATTITUDE

RESEARCH

Version 1 07/04/2005

Perceived Social Support Scale (PSSS)

I am interested in your views concerning the level of social support you ***think*** your friends and family provide with regards to your suffering from Irritable Bowel Syndrome (IBS). Please answer the questions below honestly and in the order they are presented to you. As different friends and family members may respond differently you are required to think about all of their likely responses and record the ***average response*** of how you think your friends and family are likely to respond. In the case of a particular symptom not being relevant to your experience of IBS please write N/A next to the question. DO NOT JUST LEAVE IT BLANK

APPENDIX 19

CONSENT FORM AND ETHICS APPROVAL FOR IBS PARTICIPANTS IN THE ATTITUDE / INTERVENTION STUDY

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Department of Psychology

20 December 2006

CONSENT FORM

Title of Project: Self Regulatory Model (SRM) based interventions in irritable bowel syndrome (IBS)

Name of Researcher: Carly Jacobs

Please initial box

1. I confirm that I have read and understand the information sheet dated 9/06/05 (version 2) for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐
3. I agree to take part in the above study. ☐

Name of Volunteer (Block Capitals)	Date	Signature

Address of Volunteer (optional)

Researcher	Date	Signature

Participant's Code word for identification _____

Berkshire Research Ethics Committee
Orchid Suite
Prospect Park Hospital
Honey End Lane
Reading
RG30 4EJ

Telephone: 0118 960 5194
Facsimile: 0118 960 5368

24 June 2005

Prof Richard Shepherd
Department of Psychology
University of Surrey
Guildford
Surrey
GU2 7XH

Dear Prof Shepherd,

Full title of study: **Self Regulatory Model (SRM) based interventions in irritable bowel syndrome (IBS)**
REC reference number: **05/Q1602/53**

The Research Ethics Committee has reviewed the above application in accordance with the standard operating procedures for RECs.

The Committee has issued a favourable ethical opinion of the application.

The Chief Investigator has been notified of the Committee's opinion in our letter of 24 June 2005. The letter gives full details of the documents reviewed.

The Committee has designated this study as having "no local investigators". There is no requirement for Local Research Ethics Committees to be informed or for site-specific assessment to be carried out at each site.

Statement of compliance

The Committee is fully compliant with the Regulations as they relate to ethics committees and the conditions and principles of good clinical practice.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

05/Q1602/53 **Please quote this number on all correspondence**

Yours sincerely

Mrs Jo Jones
Committee Co-ordinator

Email: jo.jones@berkshire.nhs.uk

UniS

Ethics Committee

20 July 2005

Ms Carly Jacobs
Department of Psychology
School of Human Sciences

Dear Ms Jacobs

Self Regulatory Model (SRM) based interventions in irritable bowel syndrome (IBS) (EC/2005/70/Psych) – FAST TRACK

On behalf of the Ethics Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the submitted protocol and supporting documentation.

Date of confirmation of ethical opinion: **20 July 2005**

The list of documents reviewed and approved by the Committee under its Fast Track procedure is as follows:-

Document Type: Application
Dated: 03/07/05
Received: 12/07/05

Document Type: Approval Letter from the Berkshire Research Ethics Committee
Dated: 24/06/05
Received: 12/07/05

Document Type: NHS REC Application Form
Version: 4.0
Dated: 07/04/05
Received: 12/07/05

Document Type: Research Protocol
Version: 1.0
Received: 12/07/05

Document Type: Patient Information Sheet for IBS Participants
Version: 2.0
Dated: 01/07/05
Received: 12/07/05

This opinion is given on the understanding that you will comply with the University's Ethical Guidelines for Teaching and Research.

The Committee should be notified of any amendments to the protocol, any adverse reactions suffered by research participants, and if the study is terminated earlier than expected with reasons.

You are asked to note that a further submission to the Ethics Committee will be required in the event that the study is not completed within five years of the above date.

Please inform me when the research has been completed.

Yours sincerely

Catherine Ashbee (Mrs)
Secretary, University Ethics Committee
Registry

cc: Professor T Desombre, Chairman, Ethics Committee
Professor R Shepherd, Supervisor, Dept of Psychology

APPENDIX 20

SHORT QUESTIONNAIRE FOR PEOPLE WHO DID NOT RETURN THEIR INTERVENTION PACKS

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Department of
Psychology

20 December 2006

Dear sir / Madame,

According to my records you have not yet returned your pre and post intervention pack for the self-help booklet based study in IBS. There may be a number of reasons as to why the pack has not been returned, and it would be really helpful if you could indicate the reason below. Once again I thank you for your time and if you have any further questions please do not hesitate to contact me.

.....

Name of Volunteer (Block Capitals) _____

Date_____ Signature_____

Address of Volunteer (optional)

_____

_____

_____

_____

I returned my pack; you sent me this letter by mistake ☐

I never received my pack and I am still interested in taking part please send me another one ☐

I have misplaced my pack please could you send me another one ☐

I have not had the time / forgot about the study, but I still have the pack and will start filling it in now ☐

I never received my pack but I am no longer interested in taking part ☐

Upon receiving the pack I have decided not to take part, and still do not wish to do so ☐ - Please Fill in the further boxes below to indicate your reasons

It was discovered that I had something other then IBS ☐

I did not want to fill in the diary section of the pack ☐ Please select one option below

I would be prepared to take part in the study as long as I could just fill in the questionnaires and the booklet, and not fill in the diaries ☐

Even without the diaries I still do not wish to take part in the study ☐ -

If you still do not wish to take part then I would like to thank you once again for your time and wish you well in the future.
Included with this letter is a one page demographic questionnaire, if you are able to complete this and return it with this form it would be really helpful.

Thank you

Carly Jacobs

APPENDIX 21

IBS SYMPTOM SCALE (ISS)

Version 1 07/04/05

IBS Symptoms Scale (ISS)

Please circle the number that indicates how severe each of your symptoms has been over the past week. The scale is from 0 to 6 where 0 indicates that you have **not experienced the symptom** at all in the previous week and 6 indicates that you have **experienced this symptom constantly**. Some of the symptoms listed are not used specifically in the diagnosis of IBS, but if you have experienced them in the last week please circle the number that best applies. If you have never experienced a symptom since being diagnosed with IBS then please circle **not applicable.**

Example:

0 1 2 3 4 5 6 Not applicable

Not experienced this symptom — Experienced this symptom constantly

.....

IN THE PAST WEEK I HAVE EXPERIENCED:

1. DIARRHOEA

0 1 2 3 4 5 6 Not applicable

Not experienced this symptom — Experienced this symptom constantly

2. CONSTIPATION

0 1 2 3 4 5 6 Not applicable

Not experienced this symptom — Experienced this symptom constantly

3. BLOATING

0 1 2 3 4 5 6 Not applicable

Not experienced this symptom — Experienced this symptom constantly

4. ABDOMINAL PAIN

Not applicable

0 1 2 3 4 5 6

Not experienced this symptom — Experienced this symptom constantly

5. URGENT NEED TO DEFECATE

Not applicable

0 1 2 3 4 5 6

Not experienced this symptom — Experienced this symptom constantly

6. FEELINGS OF INCOMPLETE EVACUATION

Not applicable

0 1 2 3 4 5 6

Not experienced this symptom — Experienced this symptom constantly

7. PASSAGE OF MUCUS

Not applicable

0 1 2 3 4 5 6

Not experienced this symptom — Experienced this symptom constantly

8. FLATULANCE

Not applicable

0 1 2 3 4 5 6

Not experienced this symptom — Experienced this symptom constantly

9. BELCHING

Not applicable

0 1 2 3 4 5 6

Not experienced this symptom — Experienced this symptom constantly

10. NORMAL STOOLS

Not applicable

0 1 2 3 4 5 6

Not experienced this symptom — Experienced this symptom constantly

11. THIN STOOLS

Not applicable

0 1 2 3 4 5 6

Not experienced this symptom — Experienced this symptom constantly

12. HARD (PELET LIKE) STOOLS

Not applicable

0 1 2 3 4 5 6

Not experienced this symptom — Experienced this symptom constantly

13. LOOSE STOOLS

Not applicable

0 1 2 3 4 5 6

Not experienced this symptom — Experienced this symptom constantly

14. JOINT PAIN

Not applicable

0 1 2 3 4 5 6

Not experienced this symptom — Experienced this symptom constantly

15. PAIN IN THE LOWER BACK

Not applicable

0 1 2 3 4 5 6

Not experienced this symptom — Experienced this symptom constantly

16. NAUSEA

Not applicable

0 1 2 3 4 5 6

Not experienced this symptom — Experienced this symptom constantly

17. DIFFICULTY SLEEPING

Not applicable

0 1 2 3 4 5 6

Not experienced — Experienced this

this symptom symptom constantly

18. FEELING DEPRESSED

Not applicable

0 1 2 3 4 5 6

Not experienced this symptom — Experienced this symptom constantly

19. FEELING STRESSED

Not applicable

0 1 2 3 4 5 6

Not experienced this symptom — Experienced this symptom constantly

APPENDIX 22

SHORT POST INTERVENTION QUESTIONNAIRE

Version 1 7/04/2005 – Post-Intervention Questionnaire for IBS Sufferers

Please answer the questions below prior to completing the questionnaires

1. Code word.....

2. Please specify on average which sub-group of IBS most accurately describes your symptoms by circling below:

predominately diarrhoea predominately constipation alternating

It is really important that you are classified into one of these three groups, so please think carefully about your answers to this question, if you really feel that you do not fit into one of these categories, please provide an explanation of your primary symptoms below.....

.....

.....

Have you made any changes since filling in the intervention? These can be changes in ways of thinking or in behaviour. These may be things you included in your action steps or something you thought of afterwards. Please write any changes below, you may continue on another page if you desire.

.....

.....

.....

.....

.....

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.....

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.....

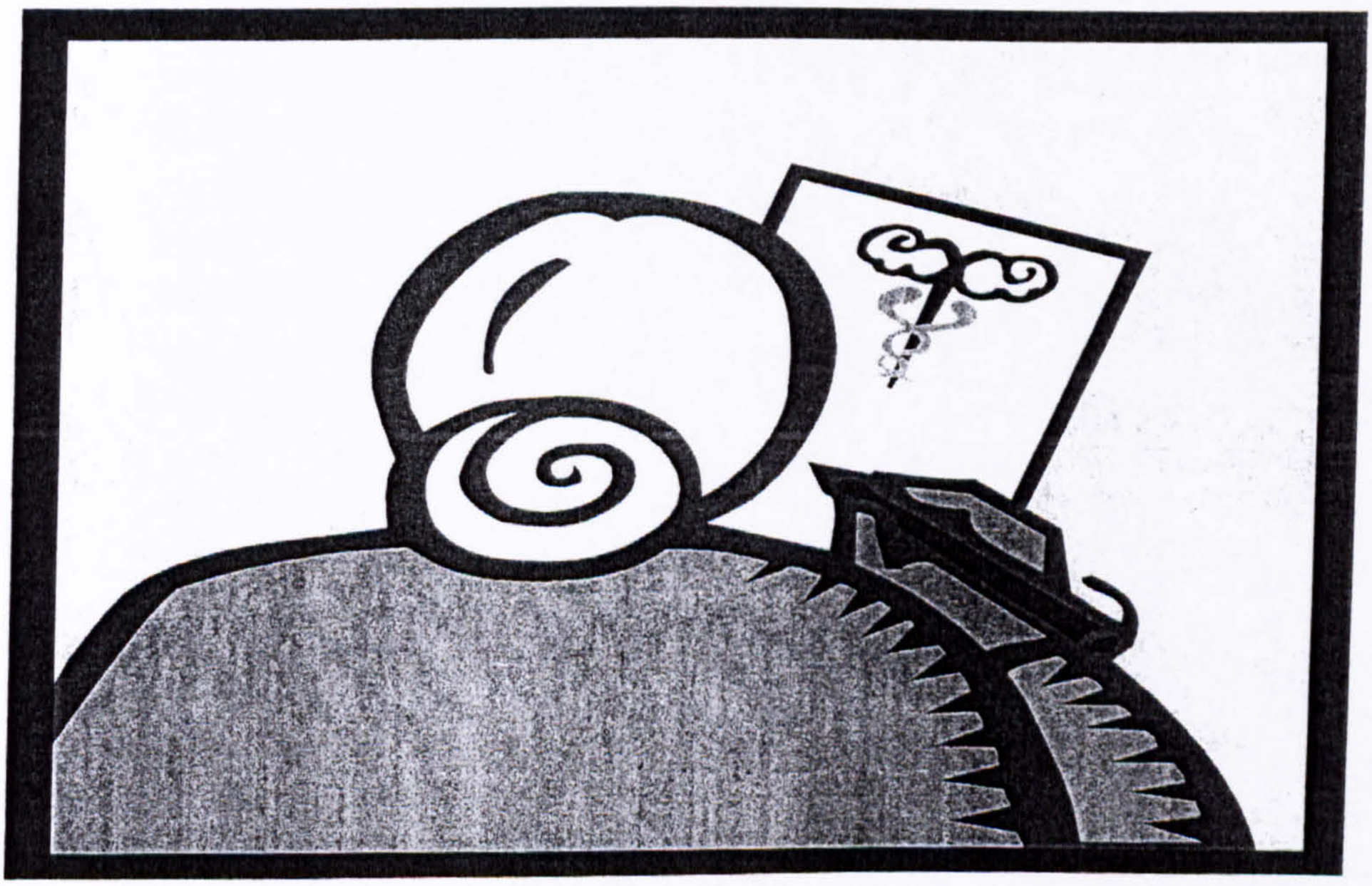
.....

APPENDIX 23

IBS SELF-HELP BOOKLET

Version 1 07/04/05

IBS INTERVENTION BOOKLET



Carly Jacobs (BSc, MSc)

INSTRUCTIONS

- This booklet is designed to provide a mixture of information and advice for actions you can take to help improve your symptoms. Some of the information will not be relevant to your particular type of IBS, when this is the case it will be clearly marked.
- All of the information included in this booklet has been thoroughly researched and is accurate at the time of compiling. There is a footnote and reference section at the end detailing the sources of the original information.
- In order to get the best out of this intervention it is necessary to work through the booklet in the order the sections are presented to you. In some cases you may already know the information, or have answered similar questions in the past, this is not important, as it is your feelings and behaviours now that the intervention will work on.
- No one will see this booklet but you; you do not need to return it. With this in mind you should answer all sections honestly taking the time to reflect on your feelings and providing as much (or as little) information as you feel is beneficial for improving you IBS.

Section 1 – Illness Identity

Your thoughts about being an IBS sufferer

When people are first diagnosed with suffering from IBS they may experience a variety of different emotions. Examples of positive emotions include feeling relieved the diagnosis is not Cancer, and being glad to finally have an explanation for the symptoms. Examples of negative emotions include feelings of embarrassment and concerns over sharing the diagnosis with others. Some people will think of their IBS as being a 'handicap' where as others will think of it as being 'just one of those things'. It can often be overlooked that these feelings surrounding being an IBS sufferer do not disappear after initial diagnosis, and moreover your feelings towards having IBS may alter, perhaps even on a daily basis. It does not matter what your feelings regarding being an IBS sufferer have been in the past, what matters is how you feel about suffering from IBS at this moment.

For this exercise you are required to write below how you feel about being labelled an IBS sufferer. This might be something that you know straight away, or something you need to think about for a few minutes. It might be something that you have one main feeling about, or a number of different feelings (they may even be conflicting). There are no right or wrong answers just write about how you feel about being called an IBS sufferer.

.....

.....

.....

.....

.....

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.....

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.....

.....

You may continue over the page if necessary.

Action Step 1 – Identifying Positive Feelings towards being an IBS sufferer

You will have now written one or a number of thoughts on the previous page. Some of these thoughts may be some negative and some positive. As thinking about negative thoughts is not a good coping strategy for any illness[i] this section will focus on your positive thoughts regarding being an IBS sufferer. For some people it may be hard at first to think of positive things but it is really important for the improvement of your IBS to get out of a negative mind set, so really think about anything positive you can say about being labelled with IBS. This can include positive things relating to the illness in general, such as the fact that it is not terminal, or it can be positive things relating to your illness label, such as feeling happy that it is a genuine medical condition not something you are imagining. First look back at the comments you made in the previous section and write below any positive comments you made there first, and after this list any other positive things you can say.

1).....

.....

2).....

.....

3).....

.....

4).....

.....

5).....

.....

6).....

.....

You may continue over the page if necessary.

Action Step 2 – Encouraging Positive Feelings about being an IBS sufferer

Is there any action you have taken or think you could take that would help you to feel more positive about being an IBS sufferer. For example you could become a 'befriender' (someone who other sufferers write to have someone to talk to about having IBS), or go to regular support groups. It is important to take a few minutes to think about this as there are many positive behaviours you can undertake though they might not automatically come to mind. I have done the first one for you to get you started.

1) Taking part in IBS research is a really positive step both because it can help your individual symptoms to improve, and because you are being very helpful to both the other people who suffer from IBS and to the researchers who want to advance knowledge of the illness. So by taking part in this research you are already demonstrating one positive action about being an IBS sufferer.

.....

2).....

.....

3).....

.....

4).....

.....

5).....

.....

6).....

.....

You may continue over the page if necessary.

Action Step 3 – How easy is it to act on the positive steps you have mentioned above?

Think about the behaviours you have written on the previous page, below are a number of scales ranging from 1-6, where 1 indicates the behaviour is very easy to do and 6 indicates that it is very hard to do. Write the name of the behaviour on the dotted line above the scale and circle the number that most applies to your feelings about undertaking this behaviour. For a behaviour you have a done in the past please write any comments you think might be relevant, for example how it made you feel; if you changed anything as a result, or if you would do it again. For a behaviour that you have not done yet please write any things that would help you to achieve it, for example in order to be a 'befriender' you would need to contact the IBS NETWORK.

1) **Taking part in IBS research:**

/----------/----------/----------/----------/----------/----------/

(1) 2 3 4 5 6

v. easy v. hard

Comments.....

.....

.....

2) .....

/----------/----------/----------/----------/----------/----------/

1 2 3 4 5 6

v. easy v. hard

Comments.....

.....

.....

3) .....

/----------/---------/---------/---------/---------/---------/

1 2 3 4 5 6

v. easy v. hard

Comments.....

.....

.....

4) .....

/----------/---------/---------/---------/---------/---------/

1 2 3 4 5 6

v. easy v. hard

Comments.....

.....

.....

5) .....

/----------/---------/---------/---------/---------/---------/

1 2 3 4 5 6

v. easy v. hard

Comments.....

.....

.....

6) .....

/----------/---------/---------/---------/---------/---------/

1 2 3 4 5 6

v. easy v. hard

Comments.....

.....

You may continue over the page if necessary.

Section 2 – Illness Knowledge

Your Knowledge about IBS

Research suggests that it can sometimes be difficult for sufferers to get accurate knowledge about IBS as sources of accurate information may not be readily available.[ii] In order to clear up some of the areas of uncertainty key IBS FACTS will be given below. For each fact that is listed tick or cross to indicate whether you knew or did not know this fact prior to being told. Remember nobody is going to see your answers except for you so be honest with your self as this is the only way to learn.

1) **IBS[iii] is very common; it affects about <u>one in five people</u>, this means that you most probably know at least two other people who suffer from IBS!**
2) **IBS has a majority of female sufferers (in the UK and the USA)[iv], it seems like that there are twice as many female suffers as males[v]. However, as IBS affects so many people this would still mean that around <u>one in 15 men</u> suffer from IBS.**
3) **IBS is <u>not</u> associated with getting older[vi], it can start at any time, and the most usual time is early adulthood[vii].**
4) **IBS is called a <u>functional</u> illness, this means that nothing has so far been identified in the body to explain the symptoms, however this does not mean that the symptoms aren't real.[viii]**
5) **There are 8 primary symptoms experienced by IBS[ix] sufferers these are: abdominal pain, diarrhoea, constipation, bloating, passage of mucus, the urgent need to defecate, feelings of incomplete evacuation and flatulence. However, not all sufferers will experience all of these symptoms over the course of their having IBS.**
6) **There are three main subtypes[x] of sufferers of IBS these are: diarrhoea predominant (IBS-D), constipation predominant (IBS-C) and alternating (IBS-A). As the categories suggest the sub-type of IBS you have depends on your most frequent experience of diarrhoea or constipation, all of the other symptoms can occur in each sub-type. If you generally have diarrhoea then you have IBS-D, if you generally have constipation then you have IBS-C, if however you are constantly alternating between constipation and diarrhoea then you have IBS-A. On the first questionnaire you were asked to record which of these subtypes you fit into, tick if you think the answer you circled was right, and mark a cross if you now think that you are in a different subtype to the one you first thought.**
7) **Each person's experience of IBS is unique, but the types of symptoms that you suffer from may actually alter on a daily basis. Therefore in some respects you are the best source of knowledge for your own IBS, and just because another sufferer is unable to eat a particular food or has found a certain tablet to be very helpful it does not mean that they will necessarily**

work for you. On a daily basis it is therefore important to listen to your body, you are the expert.

8) It is unusual for IBS sufferers to have blood in their stools[xi]. In most cases where there is blood in the stool it is nothing more serious than a slight irritation of the skin in the back passage. However, if you do experience blood in the stools, especially if they are black and sticky it is important to go to the GP and have a check-up.

Action step 1 – Reflecting and making changes based on IBS FACTS

Whilst reading the IBS facts you might have read some information you did not know previously. Because of this you might now feel that there are changes that you would like to make. These changes could take the form of feelings for example knowing that so many people suffer from IBS might make you feel less isolated. Or these changes could take the form of actions for example if you found blood in your stools but thought that this was a symptom of IBS you might not have gone to the GP but reading the FACTS and discovering that it is not a normal symptom might now make up decide to go to the GP. Look back over the IBS FACTS paying particular attention to any you did now know previously and write down any changes you are going to make to your behaviours or feelings on the action steps below. Please circle either feelings or behaviours prior to writing the action step.

1) Action – feelings / behaviour

.....

.....

.....

2) Action – feelings / behaviour

.....

.....

.....

3) Action – feelings / behaviour

.....

.....

4) Action – feelings / behaviour

.....

.....

.....

5) Action – feelings / behaviour

.....

.....

6) Action – feelings / behaviour

.....

.....

.....

You may continue over the page if necessary.

Action Step 2 – How easy is it for you to make the changes you have mentioned above?

Think about the actions you have written on the previous page. Below are a number of scales ranging from 1-6, where 1 indicates the action is very easy to do and 6 indicates that it is very hard to do. Write the name of the action on the dotted line above the scale, including whether it is a feeling or behaviour. Circle the number that best applies to how easy it will be for you to make this change. Below the scale on the dotted line write any help that is needed for you to be able to achieve this behaviour, for example reducing feelings of isolation might involve speaking to other people with IBS, for which you would need access to another sufferer, for example through a self-help group. Please include any other comments you have too.

1) Feeling / Behaviour

.....

/---------/--------/--------/--------/--------/--------/

(1) 2 3 4 5 6

v. easy v. hard

Comments.....

.....

.....

2) Feeling / Behaviour

.....

/---------/--------/--------/--------/--------/--------/

(1) 2 3 4 5 6

v. easy v. hard

Comments.....

.....

.....

3) Feeling / Behaviour

.....

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(1) 2 3 4 5 6

v. easy v. hard

Comments.....

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4) Feeling / Behaviour

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/---------/--------/--------/--------/--------/--------/

(1) 2 3 4 5 6

v. easy v. hard

Comments.....

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5) Feeling / Behaviour

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(1) 2 3 4 5 6

v. easy v. hard

Comments.....

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You may continue over the page if necessary.

Section 3 – Your beliefs about the causes of your IBS

Please write below a description of the factor or factors, which you think caused your IBS. Do not think about causes of IBS in general or what other people think caused their IBS this section is about what <u>you</u> think caused <u>your</u> IBS. Remember only you have access to this booklet so be honest, even if you may think a possible suggestion is unlikely.

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Action step 1– Your beliefs about the causes of your IBS

Looking back at the factors you have mentioned that you view as causing your IBS, list them over the page under the subheadings provided. Do not write any additional causes only write the ones you have written above. The subheadings are 1) Caused by an illness, e.g Gastroenteritis, 2) Caused by food, e.g. poor diet or food poisoning, 3) Caused by myself, e.g. worrying too much, 4) Caused by other people, e.g. poor medical care 5), Caused by God / Fate, 6) Caused by genetic / hereditary factors or 7) Caused by bad luck. If there are any you feel do not fit into these categories place them in the closest matching category, do not leave any of your listed causes out.

CAUSED BY AN ILLNESS

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CAUSED BY FOOD

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CAUSED BY MYSELF

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CAUSED BY OTHER PEOPLE

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CAUSED BY GOD / FATE

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CAUSED BY GETIC / HERIDITARY FACTORS

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CAUSED BY BAD LUCK.

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Action step 2– Learning about the possible causes of your IBS

Of the causes that you have listed above it is possible that they might all be causes of your IBS. However, it is likely that some of them will be right and some of them will be wrong. It is important to know which causes are and are not likely as what you believe to cause your IBS will impact both on the symptoms you have and on the coping behaviours you undertake[xii]. In order to clear up any areas of uncertainty 'IBS CAUSES' will be listed overleaf. As with the IBS FACTS section for each cause you suggested that is listed below put a tick. Some commonly suggested causes for which there is no evidence are listed overleaf in the section labeled 'NOT CAUSES OF IBS', if any of your suggestions are in this section tick to indicate that you have noticed this. If you have specified any possible causes that are not listed this means they are NOT causes of IBS and you should add them onto the NOT CAUSES list on the dotted lines below.

IBS CAUSES

Current research suggests that there are a number of different factors that can result in the development of IBS, your own IBS may have been caused by one or a number of these factors. These are:

- **A biological abnormality that has not been identified yet[xiii]**
- **Following a bout of gastroenteritis[xiv]**
- **A single extremely stressful or traumatic event[xv]**
- **Sexual abuse[xvi]**
- **A tendency to turn negative thoughts inwards[xvii]**
- **Major depression[xviii]**
- **Having severe anxiety[xix]**
- **Following a course of antibiotics[xx]**
- **Following an unrelated abdominal operation[xxi]**
- **Severe life stress[xxii]**
- **Severe food poisoning[xxiii]**

NOT CAUSES OF IBS

- **Ageing[xxiv]**
- **Alcohol**
- **Hereditary[xxv]**
- **Food allergy[xxvi]**
- **Smoking**
- **Pollution in the environment**

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You may continue over the page if necessary.

Action step 3 – Reflecting and making changes based on IBS CAUSES

Whilst reading the facts about possible causes IBS you might have read some information you did not know previously. Because of this you might now feel that your views on what causes IBS are inaccurate, either because something you thought caused your IBS is not listed as a cause, or because you see a cause in the list that you had not previously considered but that now seems likely. Based on this write below if you have made any changes to your views on the cause of your IBS and if so in what way?

Have you made any changes to your views on what caused your IBS?

YES / NO

If yes please specify below what these changes are:

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You may continue over the page if necessary.

Action step 4 – Acting on changes to views on the cause of your IBS

Has the section on causes of IBS made you think about any actions that you would now like to take? Think about any actions you would now like to take, below are a number of scales ranging from 1-6, where 1 indicates the action is very easy to do and 6 indicates that it is very hard to do. Write the name of the action on the dotted line above the scale, including whether it is a feeling or behaviour. Circle the number that best applies to how easy it will be for you to make this change. Below the scale on the dotted line write any help that is needed for you to be able to achieve this behaviour. For example if you now believe a possible cause of your IBS is severe depression you might choose an action step of seeing a counsellor to help your feelings of depression. Please include any other comments you have too.

1) **Feeling / Behaviour**

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1 2 3 4 5 6

v. easy v. hard

Comments.....

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2) **Feeling / Behaviour**

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/---------/---------/---------/---------/---------/---------/

(1) 2 3 4 5 6

v. easy v. hard

Comments.....

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3) Feeling / Behaviour

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/----------/--------/--------/--------/--------/--------/

(1) 2 3 4 5 6

v. easy **v. hard**

Comments.....

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4) Feeling / Behaviour

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/----------/--------/--------/--------/--------/--------/

(1) 2 3 4 5 6

v. easy **v. hard**

Comments.....

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5) Feeling / Behaviour

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/----------/--------/--------/--------/--------/--------/

(1) 2 3 4 5 6

v. easy **v. hard**

Comments.....

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You may continue over the page if necessary.

Section 4 – Your beliefs about the course of your IBS

Based on the information you have received from the GP and other health professionals; other sufferers, general information sources, and your own pattern of symptoms circle ONE of the below options to indicate which best describes how you would describe your illness.

ACUTE –a short term illness which the body naturally cures or can be cured with medical or alternative help.

TERMINAL – will ultimately result in death.

CHRONIC BUT CURABLE –a long term condition which it is possible to cure with the right treatment.

CHRONIC NOT CURABLE –a long term condition which it is not possible to cure.

CHRONIC BUT CONTROLLABLE–a long term condition which it is possible to control with the right treatment.

CHRONIC NOT CONTROLLABLE–a long term condition which it is not possible to control with any right treatment.

CYCLICAL BUT UNEXPECTED - long periods with no symptoms but then can get symptoms for no apparent reason.

CYCLICAL BUT EXPECTED - long periods with no symptoms but symptoms recur at expected points, such as during menstruation[xxvii].

As IBS is a very individual illness[xxviii] it is possible for the presentation of symptoms to take on a number the above options, however there were some that are not accurate. The options that are NOT ACCURATE ARE:

- **That IBS is terminal – this is not true**
- **Chronic not curable – this is extremely unlikely**
- **Chronic not controllable – this is extremely unlikely**

New developments are being made all the time to cure / control IBS. In the mean time it has been shown that thinking positively about the cure / controlling of your symptoms actually can reduce the symptoms[xxix]! So if you have circled one of the three options listed above go back and look at the list and pick an option that is more positive, write this below:

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If you are still unsure what category your symptoms fit into, e.g. whether they are chronic or cyclic, try keeping a diary for a few weeks and see if you can spot any patterns. Can you think of any other things you can do? If so write them below:

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You may continue over the page if necessary.

Section 5 – Your beliefs about the consequences of your IBS

You may think that having IBS has a number of consequences (effects) on your life, this can include anything that you feel has happened since your developing IBS. This is going to be very individual as it will depend on your life experiences, symptoms and your interests. The consequences can be negative or they can be positive. They can be directly related to your symptoms or indirectly related. An example of a negative consequence is, not being able to go for long car journeys; an example of a positive consequence is having more time to read for pleasure. Next to the bullet points below list as many consequences as you can think of:

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You may continue over the page if necessary.

Action step 1 –Identifying positive consequences of your IBS

You will have now written a number of consequences of your IBS, some of which are probably positive, whilst others are negative. As thinking about positive thoughts is a good coping strategy[xxx] this section will focus on your positive thoughts regarding the consequences of having IBS. For some people it may be hard at first to think of positive things but it is really important for the improvement of your IBS to get out of a negative mind set, so really think about anything positive you can say that has happened as a result of developing IBS, for example making new friends, e.g. at a support group.
First look back at the points you made in the previous section and write below any positive comments you made there first, after this list any other positive things you think of.

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7).....

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You may continue over the page if necessary.

Action step 2 –Remembering positive consequences of your IBS

You should look back at these positive consequences whenever you are feeling unhappy because of your IBS. Even if you can't think of that many positive consequences now in the future things will arise which are positive and you should add these to the list.

Action step 3 –Rethinking negative consequences

In addition to the positive consequences of having IBS it is likely that some of the things you believe are negative consequences of IBS are either not actually a consequence of having IBS, or are things that can be make less problematic by taking simple steps. Below is a list of things that are NOT CONSEQUENCES of IBS. Look at the list below and put a tick near any point that you knew was not a consequence of having IBS. If there are any items of the list that you previously thought were consequences of IBS you should put a cross by these. You can now take comfort in the fact that these concerns are unnecessary. To make sure you remember the ones that you thought were consequences aren't write them out below on the dotted lines. For example if you thought Cancer was a possible consequence of having IBS you would write this on the dotted line.

NOT CONSEQUENCES of IBS

- **Cancer is NOT a consequence of IBS[xxxi]**
- **Crohns disease is NOT a consequence of IBS[xxxii]**
- **Colitis is NOT a consequence of IBS[xxxiii]**
- **Poor social support is not a necessary consequence of IBS[xxxiv]**

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MINIMISING CONSEQUENCES of IBS

In light of the information you have just been given you may have altered your view of the possible consequences of your IBS. However, there may be some things which you feel are negative consequences of your having IBS. If you no longer have any negative consequences in your mind then please skip the next section and go straight on to, SECTION 5. However, if there are still some things you consider to be negative consequences write these on the dotted lines below.

1).....

2).....

3).....

4).....

5).....

Action Step – 4 Actions to minimize these consequences

Even though some things may not be avoidable, in almost all cases it is possible to minimize the negative consequences. Below are some suggestions of possible consequences and action steps you could take to improve these. There are only a few listed as everyone's experience of IBS differs read the suggestions listed and tick any that match what you listed above.

Consequence – Financial burden
Possible Actions – Most over the counter medications are available on prescription so ask your GP. You are entitled to claim for disability allowance as IBS is recognised as a chronic condition, so find out how to apply for disability allowance, for example contact your local citizen's advice bureau. There are a number of jobs that can be conducted at home, and many employers are happy for people to work part time or on flexible hours, so speak to your Job Centre, or look in the local paper and see what options are available for you.

Consequence – Feeling a lack of support from family and friends
Possible Actions – Research is emerging to show that people are happy to discuss IBS symptoms and are happy to make concessions to help friends and family who suffer from IBS. However, many sufferers worry that discussing their IBS can be embarrassing. It is easy to get stressed and feel isolated because of this. However, this is a worry that is unnecessary so if you feel this way push the feelings to one side

and speak to a close friend or family member about how you are feeling. If you do not feel able to do this there are a number of other possible actions you could take such as joining an IBS self-help group, contacting the IBS network to speak to a specially trained nurse, or to be put in touch with a 'befriender'. Sometimes talking to someone impartial is also helpful so speaking to a counsellor about your worries is something you might find helpful.

<u>Consequence – Feeling that your quality of life has reduced</u>
Possible Actions – instead of dwelling on the things you cannot do that you could before think of all the things you are still able to do. Arrange things that you enjoy, such as inviting friends over to play board games, or taking up a hobby you can enjoy at home such as painting or craft making. The important thing is rather than focussing on negative aspects to think of the positive things that you can do instead.

By now you should be thinking of action steps you can take to minimise the consequences you have listed. Using the same scale as before where 1 indicates the action is very easy to do and 6 indicates that it is very hard to do. Write the name of the action on the dotted line above the scale. Circle the number that best applies to how easy it will be for you to make this change. Below the scale on the dotted line write any help that is needed for you to be able to achieve this behaviour. For example if you now believe a possible action step you could take to minimise the financial burden of paying for medications is to ask your GP to give you the medications on prescription make an action step talking to your GP about what over the counter medications, for example Imodium is available on prescription.

1) Consequence.....

Action step.....

/---------/---------/---------/---------/---------/---------/
1 2 3 4 5 6
v. easy v. hard

Comments.....

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2) Consequence.....

Action step.....

/---------/--------/--------/--------/--------/--------/

1 2 3 4 5 6

v. easy v. hard

Comments.....

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3) Consequence.....

Action step.....

/---------/--------/--------/--------/--------/--------/

1 2 3 4 5 6

v. easy v. hard

Comments.....

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4) Consequence.....

Action step.....

/---------/--------/--------/--------/--------/--------/

1 2 3 4 5 6

v. easy v. hard

Comments.....

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5) Consequence.....

Action step.....

/---------/--------/--------/--------/--------/--------/

1 2 3 4 5 6

v. easy v. hard

Comments.....

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6) Consequence.....

Action step.....

/---------/--------/--------/--------/--------/--------/

1 2 3 4 5 6

v. easy v. hard

Comments.....

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7) Consequence.....

Action step.....

/---------/--------/--------/--------/--------/--------/

1 2 3 4 5 6

v. easy v. hard

Comments.....

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You may continue over the page if necessary.

Section 6 – Ways of curing / controlling your IBS symptoms

For many sufferers the ultimate question is how can my symptoms be cured or controlled? Although it can sometimes seem like this is a difficult task people often tell me that they used to have IBS and that they no longer have it. Therefore it is possible to recover from IBS. However, as it is such an individual illness it is not as simple as providing a quick fix as what works for one person will not necessarily work for you. The important issue is not to get disheartened by this, and instead of comparing your IBS to somebody else think about your own experiences of IBS. As IBS fluctuates you will have periods when you feel largely fine, it is important when this is the case to enjoy feeling well and to use these positive thoughts when you are feeling unwell. It is likely that you already do certain things which make your IBS seem better. These can either be things you think (such as thinking calming thoughts in difficult situations) or these can be things you do (such as avoiding a particular type of food). There may be some things that are unique to you, but they work. Below write any thoughts or actions you take that help you to feel better.

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You may continue over the page if necessary.

Below are some suggestions for improving your IBS. The first section called GENERAL HELP lists suggestions that should be beneficial for all sufferers of IBS. The second section called SPECIFIC SYMPTOM HELP refers to things that are helpful depending on your symptoms of IBS at certain times. Look at the suggestions below and put a tick next the ones that you feel would be helpful for you, these might be things you have found helpful in the past or new things you would like to try.

GENERAL HELP

- **Thinking positively has been shown to improve IBS, so think positively and belief not only that your IBS is curable but that you are in control of your symptoms. So next time you are unwell, e.g. in severe pain, don't just give in to it, tell yourself that you can make it go away, think positively and you will see how much your symptoms improve both in the short term and the long term.[xxxv]**
- **Medications can improve some of the symptoms, but if a particular medication is not working for you don't feel that you have to take it without questioning. Speak to your GP and ask if there are any alternatives that can be suggested and try these instead.**
- **Alternative therapies can be beneficial. Why don't you go to a Chinese herbal clinic and ask then to suggest something to help your symptoms[xxxvi]**

- **<u>Reflexology, Chiropractic and Aromatherapy</u> have all been shown to be successful for some people and are readily available at most alternative clinics, so have a look in your local paper and see what is offered in your area[xxxvii]**
- **<u>Relaxation</u> is one of the most important things you can do to help your IBS. This can either take the form of learning how to meditate or gentle yoga, there are many books or videos available to teach you how,[xxxviii] or by relaxing by taking deep breaths, putting on calming music and allowing yourself time where you can forget all your worries. Relaxation is a very individual thing, and it really does not matter what you do as long as it is something that you enjoy.**
- **<u>Hypnosis</u> has also been found to be helpful for some people. This can be particularly helpful if you suffer from anxiety, or if your IBS is the result of a traumatic event in your past. The hypnosis can work by helping you to use techniques to relax you when you are feeling anxious, and can also be beneficial for helping teach you distraction techniques when you are in severe pain[xxxix]. Hypnosis might not be something that you want to do, but even without going to a hypnotist using distraction techniques can be very useful.**
- **There is a connection between the brain and the gut, known as the brain gut axis[xl] this is why even people who don't suffer from IBS can have an upset stomach or 'butterflies' when they are nervous. When you are experiencing symptoms of IBS, especially constipation and**

bloating and pain it is possible to immediately improve them by visualising that you are improving them. So next time you are in pain instead of thinking about how much it hurts take some calming breaths and imagine yourself releasing the pain and pushing it away.

- Cognitive Behaviour Therapy (CBT)[xli] has shown some benefits and many psychologists offer this as a course of treatment for a variety of illnesses. This type of therapy is focussed around changing negative thoughts and changing negative behaviours. Even if you don't want to go to a psychologist it is possible to practise basic CBT on your self. This can be as simple as some allowing yourself to get caught up in negative thoughts. Sometimes we can think about something stressful and we can't seem to let it go, this is especially problematic if you are finding it difficult to sleep. Get into practice of saying to yourself things like, "there is no point stressing over things I can't change", and "night time is for sleeping I can think about things again tomorrow". Once you let go of your stressors your symptoms should improve[xlii]. If you find it difficult to let go of stress by stopping negative thoughts distract yourself by doing something to take your mind off it, you may be surprised to see you symptoms ease up it your carry on as normal rather than concentrating on them.
- Food eliminations are one of the most often talked about ways of controlling IBS. Unfortunately because of this they are usually one of the most difficult ways of controlling IBS symptoms because of all the

conflicting advice. The best way of using food elimination or moderation is to listen to your own body. Other people might advise you to eat high fibre food, but if every time you do it makes you feel worse then listen to your own body and don't feel like you have to continue to eat it. You probably already have a good idea of what foods you can't eat, and know that sometimes a particular food will be OK, and that other times you won't be able to eat it, this is perfectly normal. If you want to get a better idea of what foods are making your symptoms worse keep a food diary[xliii] marking off whenever you have symptoms, you will then be able to look back and see if a particular food is making you feel worse most times you have it. Some general guidance for food is given below.

- <u>Finally Exercise –</u> Many people with IBS find it difficult to do exercise because of worry over being ill. The important thing to remember is that exercise can be going for a walk, cleaning the house, gardening; basically anything that gets your body active and a little out of breath. Exercise is really important as it has lots of positive effects at reducing stress levels, improving fitness and generally helping the body to function properly. If you have not exercised for a while it is important to build it up slowly. You might notice your symptoms getting a little worse to begin with, although this thought might put you off it is really important to push past it and think of feeling a little worse in

the short term as a concession to feeling a great deal better in the long term[xliv].

Action Step – 1 Which general help do you want to try?

Look back over the list of GENERAL HELP and pick up to three things that you would like to try in the next few weeks. You may think that all of the options seem good or that there are a few that you really feel drawn to. As you can't do them all at one and such a big list might seem daunting pick out up to three and list them below. Using the same scale as before where 1 indicates the action is very easy to do and 6 indicates that it is very hard to do. Write the name of the action on the dotted line above the scale. Circle the number that most applies to how easy it will be for you to make this change. Below the scale on the dotted line write any help that is needed for you to be able to achieve this behaviour. For example if you want to take up gentle yoga you might need to go any buy a tape.

1) General Help.....

   Action step.....

/---------/---------/---------/---------/---------/---------/

1 2 3 4 5 6

v. easy v. hard

Comments.....

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2) General Help.....

Action step.....

/---------/---------/---------/---------/---------/---------/
1 2 3 4 5 6
v. easy v. hard

Comments.....

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3) General Help.....

Action step.....

/---------/---------/---------/---------/---------/---------/
1 2 3 4 5 6
v. easy v. hard

Comments.....

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SPECIFIC SYMPTOM HELP

Sometimes when you have a specific symptom of IBS you need something more than a general help. Therefore below are some suggestions for dealing with specific symptoms. The suggestions should be effective both at reducing the frequency of these symptoms and also at helping them to reduce in severity when you are experiencing them[xlv]. Remember if a particular suggestion makes your symptom

worse and it does not improve after a couple of days listen to your body, a particular suggestion might not be the one for you.

Diarrhoea

Helpful:

- Black pepper
- Ginger
- Lavender
- Peppermint
- Rosemary

Avoid:

- Dairy
- Seeded Fruits

Constipation

Helpful:

- Black pepper
- Camomile
- Fennel
- Increase fibre intake
- Drink more fluid
- Increase exercise
- Bulking agents (like Bran)

Bloating and wind

Helpful:

- Basil
- Bergamot
- Black Pepper
- Camomile
- Clary Sage
- Fennel
- Ginger
- Juniper
- Lavender
- Peppermint
- Rosemary

Avoid:

- Gas producing vegetables, such as Brussels sprouts
- Fizzy Drinks

Pain

Helpful:

- Basil
- Bergamot
- Black pepper
- Juniper
- Rosemary

Look back over the specific symptom advice, are there any suggestions that you would like to try? There may be other things that you have found work for you that are not listed. Below write up to five things that you would like to try. Remember if introducing something new do it slowly at first and let your body get used to it, this is particularly true of the herbs and essential oils.

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You may continue over the page if necessary.

Thank you very much for filling in this intervention booklet I hope you found it helpful. If you have any comments that you would like to make then please write them below, detach this page and return it to me.

You may continue over the page if necessary.

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APPENDIX 24

LETTER AND INFORMATION SHEET TO IBS PARTICIPANTS FOR THE INTERVENTION RESEARCH

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Department of
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20 December 2006

Version 2 09/06/05 Q5/Q1602/53

UniS
Department of Psychology

IBS

DO YOU SUFFER FROM IBS?

(IRRITABLE BOWEL SYNDROME)

FRUSTRATED BY THE CURRENT TREATMENT OPTIONS?

WANT TO TEST A NEW TREATMENT THAT DOES NOT INVOLVE MEDICATION?

WANT TO GET A FREE SELF-HELP BOOKLET?

THEN TAKE PART IN AN INTERVENTION STUDY!

The research will take approximately 4 hours (spread over 5 months). There is no payment available. To take part you must have been diagnosed by a medical professional.

If you would like more information please contact Carly Jacobs
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Department of
Psychology

22 November 2005

Patient Information Sheet For IBS Participants

1. Study Title

Self Regulatory Model based intervention in IBS

2. Invitation Paragraph

You are being invited to take part in a research study. Before you decide if you would like to take part it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Contact me if there is anything that is unclear to you, or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

3. What is the purpose of the study?

Thank you for your interest in participating in this study. This study will investigate whether an intervention based on a psychological model relating to how you think and behave relating to your IBS affects the frequency of your IBS symptoms and quality of life. Research of this type is necessary to gain a better understanding of how to improve illness outcomes for sufferers. It will take up to four hours of your time spread over a period of five months (proposed duration of the study one year).

4. Why have I been chosen?

You have been chosen because you sufferer from IBS, with a confirmed diagnosis from a medical professional. You are one of approximately 100 patients participating in this study.

5. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form, which you will have a copy of. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the care you receive from the NHS.

6. What will happen to me if I take part?

Your involvement in this research will be for a total of four hours spread over a period of five months. There are a number of stages to this research which will be numbered below:

1. **Stage 1.** You will be sent two envelopes through the post one marked pre-intervention pack, and one marked post-intervention pack. You will also receive an intervention booklet. Firstly you need to fill in the pre-intervention pack. This needs to be completed in the order it is presented to you and *prior* to starting the 'IBS intervention booklet'. If you have taken part in my research previously you may recognise the style of questionnaires and the diary. Despite having filled them in previously they need to be filled in again this time to see if the intervention is successful. Once you have completed the pre-intervention pack it needs to be returned to the envelope and posted back to me. Once you have completed the pre-intervention pack you can then start the intervention. The first page of the booklet contains instructions for filling in the booklet, which you need to read before taking part. Once you have completed the booklet it is yours to keep, although if you would like to send me a photocopy with any comments you have you are very welcome. Once you have completed the booklet you need to fill in the questionnaires contained in the envelope marked post-intervention questionnaires. Once completed you need to return them to the envelope and post back to me. Postage is free post therefore please do not put stamps on the envelope.
2. **Stage 2.** Two months after I have received your completed pre and post intervention packs you will receive a pack containing questionnaires similar to those in the pre-intervention pack. This is necessary to assess the success of the intervention.

7. What do I have to do?

The research is designed to involve minimal disruption to your routine, and can be completed at a location convenient to you. There are no lifestyle restrictions and you can therefore continue to undertake all normal activities.

8. What is the procedure that is being tested?

The research is testing the usefulness of an intervention based on how you think and feel about issues relating to your illness.

9. What are the alternatives for treatment?

There are a number of alternative treatments available for IBS however, none so far have been found to have long-term success. For the purposes of this study you are not required to alter any other treatments you are currently receiving including medical care or any alternative treatments you are having. This intervention is designed to be administered in conjunction with you current treatments

10. What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks from participating in this study.

11. What are the possible benefits of taking part?

The results of this study may help future treatments of IBS, in addition you may experience some benefit. The first is that hopefully the intervention will improve your IBS, however this cannot be guaranteed. Secondly the information from this study may help in the future treatment of IBS, this is important as many sufferers report frustration at the current lack of knowledge concerning this illness. No previous research has investigated the usefulness of an intervention of this type and therefore it is important to establish its usefulness in order to see if it improves illness outcomes.

12. What if new information becomes available?

In the event of further contact being necessary, inclusion of your address on the consent form will allow for you to be contacted.

13. What happens when the research study stops?

When the research study stops you are not required to have any further involvement.

14. What if something goes wrong?

In the unlikely event you are harmed by taking part in this research, there are no special compensation arrangements, but standard university insurance cover is in place. If you are harmed due to someone's negligence, then you may have grounds for a legal action, but you may have to pay for it. Regardless of this if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the standard university complaints mechanisms should be available to you.

15. Will my taking part in this study be kept confidential?

Your doctor will not be informed of your participation in this study. All personal data will be anonymous and processed in the strictest of confidence and in accordance with the Data Protection Act (1988). By consenting to participate in this study you are indicating your agreement not to restrict the results of the study on the understanding that your anonymity is preserved. It is necessary for you to sign the consent form to indicate your consent, but this is the only place where your name will appear, all other data will be identified by coding only. It is essential that you include an identifying code word on the consent form, and the same

word on the questionnaires and the diary, this will allow for all of your data to be matched together. If you would like to be contacted in the event of any further information regarding this research becoming available, then please include a contact address on the consent form.

16. What happens to the results of the research study?

It is anticipated that the results of this study will be published. Participants should note that they will not be able to be identified in any publication. Publication may be in academic journals, in the journal of the IBS NETWORK, and on the IBS NETWORK's website. The findings may also be presented at academic conferences. The IBS NETWORK's website has no access restrictions and can therefore be accessed by the general public. Requests can also be made to myself the chief investigator for a summary of the research findings.

17. Who is organising and funding the research?

The research is funded by the University of Surrey.

18. Who has reviewed the study?

This study has been reviewed by the Berkshire Research Ethics Committee who raised no objections on ethical grounds.

17. Contact for further information

If you have any questions regarding any aspects of the study, or would like further information and advice please do not hesitate to contact me prior to the start of the study. The signing of the consent form indicates that you fully understand the study, and therefore if this is not the case please contact me prior to indicating your consent.

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APPENDIX 25

LETTER TO IBS PARTICIPANTS FOR TWO MONTHS POST INTERVENTION STAGE

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20 December 2006

Dear IBS study participant,

Please find enclosed the follow up pack to the intervention study:

Self Regulatory Model based intervention in IBS (05/Q1602/53).

which you kindly filled in the first stages of a two months ago. Please would you now fill in the information requested in these packs as without the follow up information I cannot assess the success of the intervention. You do you of course have the right to withdraw from the study at any time.

Thank you once again for your time, and please don't hesitate to contact me if you have any questions.

Carly Jacobs