

**THE ROLE OF AN ADVANCED NURSE
PRACTITIONER IN THE IDENTIFICATION AND
MANAGEMENT OF PATIENTS WITH SYMPTOMS OF
IRRITABLE BOWEL SYNDROME**

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CHAPTER ONE

Introduction

1.1 Background

Approximately 20% of the Western World's population is affected by irritable bowel syndrome (IBS) (Greenberg, Amitrone, & Galiczynski, 2002), yet it is a widely misunderstood problem that creates a high level of dissatisfaction amongst patients, GPs and gastroenterologists. It is a complex syndrome that can present with very debilitating symptoms. Patients with IBS symptoms generate a large, time consuming workload for general practitioners (GPs) and specialist medical practitioners, and their management incurs substantial costs to the work force, health sector, and to the individual patients themselves (Wilson, Roberts, Roalfe, Bridge & Singh, 2004). The symptomology of IBS is complex as many differential diagnoses share symptoms such as Crohn's disease, coeliac disease, ulcerative colitis, bowel cancer and endometriosis, to name a few.

In New Zealand, patients with IBS are managed by GPs and gastroenterologists. By contrast, in the USA nurse practitioners (NPs), who make up a considerable portion of Primary Health Care Providers (HCP)s, are more likely to manage these patients (Croghan & Heitkemper, 2005). In the USA and the UK there are specialist clinics for patients identified as having IBS. These clinics are either led by a dietitian or a specialist nurse.

This study examined the role of an advanced nurse practitioner in the identification, diagnosis and management of patients referred to an IBS nurse led clinic with symptoms of IBS as their primary problem. Items of interest were identification of the causes of symptoms, the effects of symptoms on quality of life (QOL), coping strategies of the patient, and patient satisfaction with care. These were measured by prospective data on two questionnaires given several months apart. In addition, some basic retrospective data were collected from a database of information on prior patients, to determine that the study subjects were representative of the IBS practice. The service offered by a specialist nurse practitioner gave busy GPs and specialists a service where they could refer patients, knowing more time at a nurse specialist level was available to these patients.

1.2 *Problems with Identification of IBS*

Irritable bowel syndrome is a functional bowel disorder with a variety of symptoms. The most common symptoms include constipation, faecal urgency, diarrhoea, abdominal pain and bloating, excessive wind, and a sense of incomplete evacuation. Patients need exhibit only a few of these symptoms as per identification criteria (see chapter 2; Talley, 2006) to be told they have IBS.

In order to identify IBS as the likely problem, health care professionals first eliminate other causes of symptoms and associated alarm features, for example, unexplained weight loss, haematochezia or malaena, as a number of differential diagnoses share the same symptoms, including inflammatory bowel disease (IBD) and bowel cancer. It is common practice to eliminate other disorders by pathological and endoscopic

tests, thus the “diagnosis” of IBS is essentially a diagnosis of elimination. Once any pathology has been eliminated, it is suggested further medical assistance is limited (Farup, Vandvik & Aabakken, 2005).

Understanding the symptom types and knowledge of IBS identification criteria can reduce unnecessary expensive and/or invasive tests. Currently a colonoscopy costs approximately NZ \$2,000, and a simple stool test for faecal calprotectin costs approximately NZ \$100.

Colorectal cancer probably crosses almost every person’s mind as New Zealand has one of the highest incidences of colorectal cancer in the world (New Zealand Guidelines Group, 2004). There are evidence based guidelines to help determine who requires colonoscopy. Patients with private insurance are usually able to access this procedure, but those whose needs are provided for by the public sector must meet certain criteria before being screened. The process and the waiting can be alarming for some identified with IBS, especially those who have encountered colorectal cancer in relatives. As a result patients require time and effort in alleviating their fears. Those who have been screened in the public sector and are identified with IBS often find themselves with few resources other than reassurance that they do not have a life threatening condition.

The benefits an advanced nurse practitioner (ANP) has, is the ability to spend time alleviating fear with education and validation. Further exploration via a long consultation often reveals other significant, but not life threatening contributors to triggers of symptoms. The nurse, as part of a team, is able to work with the patient

with assistance in addressing the source of the problem behind the symptoms. Often, subsequent referral on to the appropriate clinician is required such as a counsellor, dietitian, gastroenterologist or surgeon to treat the underlying cause of their symptoms. IBS is a syndrome of symptoms, the cause of these symptoms being the diagnosis, whether it be a food intolerance, stress, endometriosis, polycystic ovary syndrome (PCOS), or inflammatory bowel disease (IBD) in remission.

1.3 *Patients' Experiences of IBS*

When a patient is experiencing debilitating symptoms such as constant diarrhoea, abdominal pain and bloating, to be told there is nothing wrong can be as negative as one would perceive it to be positive. Unfortunately many patients' experiences have been negative or dismissive. Patient frustration and social isolation, as well as physicians' lack of knowledge and misinformation are significant issues for individuals with IBS (Bertram, Kurland, Lydick, Locke & Yawn, 2001; Lacy et al., 2006).

The perceptions and ability of patients to deal with IBS depends on how they have been informed of their diagnosis and the quality of explanations given about the syndrome (Dixon-Woods & Critchley, 2000). Patients have complained that GPs appear to have little time to adequately explain their symptoms, or to explore possible causes. Many patients have become depressed by being told there is nothing wrong, it's all in their head, or to go home and learn to live with it. This can create a vicious circle where the patient becomes depressed or anxious because of their symptoms, and symptoms worsen because the patient is depressed or anxious.

IBS patients frequently find QOL to be affected, with symptoms too embarrassing to allow them to socialise, or too troublesome to be able to enjoy themselves (Gerson et al., 2006). Frequent sick days affect employment and relationships may suffer. Family conflict may add to the intensity of symptoms reinforcing the vicious cycle. Many patients express frustration about the inability to control symptoms and identify triggers. IBS patients also relate to feeling less confident in their appearance and in their relationships with partners (Dancey, Hutton-Young, Moye & Devins, 2002). Patients often feel the syndrome controls their lives and leaves them socially isolated (Bertram et al., 2001), feeling frustrated and angry at the lack of compassion from colleagues, family and the health care community.

The use of a research questionnaire in this study explored QOL including relationships and self esteem, to investigate if time and education with the patient, and appropriate referral on contributed to better self esteem and self management of their symptoms. Time, empathy, and education are variables the nurse practitioner can readily access in a specialty clinic.

1.4 Medical Perspectives of IBS

Until recently IBS has been perceived by many health care professionals as a psychosomatic disorder, or featuring an element of psychiatric illness (Talley, Boyce & Jones, 1997). Comments from medical perspectives on IBS indicate IBS to be one of the most difficult health problems to treat (Lacy et al., 2006). As most health care

professionals, bar gastroenterologists, have had little education around the syndrome they often find it difficult to convince the patient that there is no disease process. Generally, GP appointments are fifteen minutes long, which is insufficient time in which to gather all related data in IBS. GPs readily admit that this amount of time does not permit proper exploration of symptoms beyond the immediate presenting concern, nor time to adequately explain the syndrome.

Gastroenterologists' time is expensive, and could be better used by those with complex medical issues. Many GPs in the UK referred to gastroenterologists because of uncertainty and patient dissatisfaction (Thompson, 1999). Up to fifty percent of referrals to gastroenterologists were for IBS (Wilson et al., 2006). Barclay (2007) identified a need for streamlined, effective management of IBS patients, as they comprise a large proportion of patients seen at gastroenterology clinics. This would impact favourably on the overall management of all gastro-intestinal diseases and the costs of IBS management.

According to Lacy et al., (2006) only thirty five percent of family practitioners knew either the Manning or Rome I or II criteria for identifying IBS. The presence of a specialist clinic provides a resource for GPs and gastroenterologists, not only for expediency of time, but also resources. Therefore with a need identified for patients and for clinicians the following question was asked.

1.5 *Research Question*

Does an advanced nurse practitioner led service improve the identification and ongoing management of patients with symptoms of IBS?

1.6 *Advanced Practice Nursing and IBS*

For the purposes of this study the term ‘advanced nurse practitioner’ (ANP) was used, as the researcher is practising at an advanced level of nursing as required for the position. The role requires an advanced level of knowledge in gastroenterology with colorectal and gynaecological experience. It is necessary to clarify that this is not to be confused with the dedicated title ‘Nurse Practitioner’ (NP) which requires further work experience and assessment by the Nursing Council of New Zealand. There are areas of overlap, however, identified in the requirements below with the exception of prescriptions of interventions and medicines.

According to the Ministry of Health (2002, p.1) the role of the Nurse Practitioner is to:

- “prevent unnecessary hospital admissions
- Target specific populations....emphasising health promotion and maintenance, and disease prevention
- Build on existing health services....
- Use different models of nursing care to lead or collaborate in health care
- Allows for the prescription of interventions and authorised medicines within a defined scope of practice”

As described above, the role of the ANP is ideally placed in order to identify individuals who have IBS, and to assist in the management of their symptoms reducing costs and improving quality of life.

1.7 *Significance of the Study*

Approximately twenty percent of the population have IBS but only about twenty five percent seek help (Williams et al, 2006). Even so it is one of the largest problems seen by gastroenterologists at a significant cost to the country.

This study was conducted to show there is a need for a specialised service for people with IBS that can be competently managed by an advanced nurse practitioner not only reducing the strain on the medical system, but also improving patient outcome, knowledge and satisfaction. By specialising, the nurse can provide holistic care at an advanced level of knowledge, and build a trust in the relationship with patients and doctors. By competent triaging the patient is referred to the appropriate resource, avoiding unnecessary procedures and potential hospital admissions.

Working within a team approach including a dietitian, counsellor, and other clinicians including the patient's own GP shows a collaborative approach, building on already existing services. The application of nursing models compliments the medical approach, and adds another dimension to the identification of causes behind symptoms, offering more holistic management strategies. GPs use the service often to

confirm their diagnosis and for help in patient management, thus saving expense and time in the public sector and for the patient.

There is frequent comment that a strong provider-patient relationship is necessary for the successful management of any illness. In the case of IBS this is especially true (Dixon-Woods & Critchley, 2000; Longstreth & Burchette, 2003). The complimentary role of a nurse practitioner with an advanced knowledge of IBS and related gastrointestinal conditions, sharing the load with GPs and gastroenterologists should result in a better resolution of identifying and managing those patients for whom an individual's GP has neither the time nor the resources to manage.

1.8 *Conclusion*

IBS is a complex syndrome. It is difficult to identify and requires large amounts of time and resources to manage. An advanced nurse practitioner in gastroenterology may be the solution to improved diagnosis and patient management, the purpose this study.

1.9 *Structure of the Thesis*

1.91 *Chapter 2: Literature review*

In chapter two a review of the literature is presented. Topics related to IBS epidemiology, aetiology, management, physician, and patient views of care are presented. The role of an advanced nurse practitioner and implications for nurses is

discussed. Additional information around the economic impact of IBS and outcomes are also covered.

1.92 *Chapter 3: Methodology*

Chapter three includes the design, methodology and data analysis for the study using a quantitative approach. Definition of variables and a discussion of the limitations of the study are also presented.

1.93 *Chapter 4: Results*

Chapter four presents comparisons between the study group and a retrospective group of IBS patients. This was to establish the study group as representative of IBS patients seen in this practice. Results of the study group are then presented.

1.94 *Chapter 5: Discussion*

Chapter five includes the discussion of this work and how it relates to the current literature. It attempts to answer some of the questions related to the similarities and differences found in this group compared to findings in the literature.

1.95 *Chapter 6: Conclusion*

This chapter forms the conclusions formulated across the study which are shared, and recommendations for future research are presented.

CHAPTER TWO

Literature Review

2.1 *Introduction*

Irritable bowel syndrome (IBS) has been a difficult functional problem for physicians and patients alike. For many years it has been treated as a psychosomatic disorder that had little understanding, there being a knowledge deficit identified amongst general practitioners (Longstreth & Burchette, 2003). The literature describes how patients often feel dismissed, their symptoms not taken seriously.

Over the last few years researchers have found different explanations for symptoms that suggest it often has organic origins, as well as finding links between childhood trauma and a gut response (Blanchard, Keefer, Payne, Turner & Galovski, 2002; Grundy & Schemann, 2006; Olbe, 2008). IBS is a multifactorial concern, the literature continually changing and refining the identity and definitions of IBS. Because of this patients not only need time taken with them but expert knowledge to tease out all variables.

This chapter presents an extensive, computer assisted, review of the literature.

Databases were searched through Ovid to Medline, Embase and Pubmed. Key words used to select specific topics relevant for this study were “irritable bowel syndrome” with AND, or OR and terms such as “identification and management”, “causes”, “quality of life”, “feelings”, “attitudes” “risk factors” “perceptions”, “childhood”, “abuse”, “prevalence”, “underlying factors”, “gut dysbiosis”, “social impact”, “nurse practitioner” and “nurse-led clinics”.

The literature chosen for review was sorted into several sections for clarity, the first section exploring literature on the identification of symptomology and different manifestations of symptoms. The second section looks at the variety of underlying factors responsible for symptoms of irritable bowel syndrome. This is followed by defining the nature of the impact IBS has on individuals and the wider community. Included in this section was perceptions of the attitudes of health care providers, and vice versa. Next, current management strategies are discussed as is the role of an advanced nurse practitioner in health care. Finally the perceived needs of the community and the benefits for gastroenterologists and general practitioners are presented.

2.2 *Identification of irritable bowel syndrome and its characteristics*

A variety of terms have been used in the past to describe IBS, such as “spastic colon” or “mucous colitis”, the latter being described in 1892 by Sir William Osler who identified the syndrome as ‘tubular casts, with mucus, debris and ‘intestinal sand’. (Greenberg, Amitrone & Galicznsky, 2002). Both spastic colon and mucous colitis are terms that have still been used in some surveys (Halder et al., 2007).

Identification of IBS is complex as characteristics of IBS share those of other disease processes such as bowel cancer, Coeliac disease and inflammatory bowel disease. IBS is a group of symptoms, varying between individuals, although many share symptoms in common. Common symptoms include an irregular bowel habit with either

diarrhoea, constipation or both, abdominal bloating and excessive wind, abdominal pain, and a sense of incomplete evacuation.

Because IBS symptoms are reflected in differential diagnoses, identification tools have been created by various gastroenterologists (Mearin et al., 2001). Manning was the first to develop an identification tool in 1978 (table 1), other gastroenterologists such as Talley followed (Hatlebakk & Hatlebakk, 2004). Over time these tools evolved, with the emergence of new theories, changing the criteria (Farup et al, 2005).

The Rome criteria, versions I, II and III, were designed by gastroenterologists who met in Rome to create a tool for a more precise means of identifying functional gastrointestinal disorders when all possible differential diagnoses were eliminated (Farup et al., 2005). Manning criteria (Figure 1), and Rome II criteria (Figure 2) are similar, however Manning criteria included abdominal distension (Cash & Chey, 2004). None of the Rome criteria included bloating, which is surprising considering 75% IBS patients complain of bloating and distension (Lea & Whorwell, 2005).

Mearin et al., (2001) found Rome II criteria to have a stricter application than both Manning and Rome I, which reduced the number of potential IBS patients in a study by using Rome II as opposed to Manning or Rome I. Manning criteria are found in figure 1. Rome II criteria are found in figure 2.

Figure 1.

The Manning Criteria for Identification of Irritable Bowel Syndrome.

- Visible abdominal distension
- Relief of pain with bowel movement
- More frequent bowel movement with the onset of pain
- Loose stools at the onset of pain
- Passage of mucus per rectum
- Feeling of incomplete evacuation

(Hatlebakk & Hatlebakk, p.736, 2004)

It is interesting to note that constipation does not feature in the Manning criteria, neither is it specified as to how many of the listed symptoms are needed to meet the criteria for a diagnosis of IBS.

Figure 2.

The Rome II Identification Criteria for Irritable Bowel Syndrome

At least 12 weeks, which need not be consecutive, in the preceding 12 months, of abdominal discomfort or pain that has 2 of 3 features:

1. Relieved with defaecation; and/or
2. Onset associated with a change in frequency of stool; and/or
3. Onset associated with a change in form (appearance) of stool

Supportive (non essential) symptoms of the irritable bowel syndrome

1. Fewer than 3 bowel movements a week
2. More than 3 bowel movements a day
3. Hard or lumpy stools
4. Loose or watery stools
5. Straining during a bowel movement
6. Urgency

(Hatlebakk & Hatlebakk, p.737, 2004)

More recently the Rome III criteria was established. Rome III criteria are more succinct, being a greater than three month history of abdominal discomfort or pain for at least three days per month, that is relieved by defaecation, and associated with changes in stool appearance and frequency (Talley, 2006).

2.2.1. IBS subtypes

There are several subtypes of IBS. The most featured ones are constipation predominant IBS (C-IBS), diarrhoea predominant IBS (D-IBS) or an alternating pattern of constipation and diarrhoea, than can be interspersed with normal motions, or with each other (Drossman et al., 2005). This is known as alternating IBS (A-IBS). Mearin et al., (2006) found that C-IBS was the most predominant subtype, but the more severe cases were D-IBS. Those who complained the most about abdominal pain were the A-IBS type. Individual perceptions of what constitutes diarrhoea or constipation vary enormously. This factor needs careful consideration when a history is taken before investigations or consideration of treatment options.

The classification of IBS into subtypes made it easy to instantly picture a patient's symptoms, but as the boundaries change and other symptoms are seen as part of IBS, other subtypes either exist, or will be created. A classic example is the recent recognition of the post infectious subtype. IBS developing after an acute infection is well documented, being identified as 'post infective' IBS, or PI-IBS (Azpiroz et al., 2007). Although this could be labelled as a subtype on its own this subtype crosses all other groups, but is more often seen in A or D-IBS. This subtype is more about the initial onset, than current symptoms. Co- morbidities are frequent across all IBS subtypes, but C-IBS and A- IBS have a higher incidence than D-IBS (Mearin, et al., 2006). Non digestive system symptoms such as headache, fatigue, stress and anxiety, backache, were present in about fifty percent of patients. Of the non IBS control group, digestive tract symptoms, heartburn and dyspepsia were the most frequently reported.

There are suggestions that a group without constipation or diarrhoea exist, identified as pain predominant IBS or P-IBS.

Identifying features of the different groups suggest different underlying pathophysiology, for an example D-IBS has often been associated with stress or anxiety, or linked to a post-infective cause (Greenberg et al., 2002; Gwee et al., 1999; Mayer, Tillisch & Bradesi, 2006). PI-IBS clearly suggests pathophysiological features as evidenced by inflammatory cells seen in the rectal mucosa (Quigley, 2007).

2.2.2 A diagnosis of exclusion

The aims of identification criteria that has evolved over the years are to facilitate defining which way to investigate symptoms. These guidelines help to avoid unnecessary and potentially expensive testing (Croghan & Heitkemper, 2005). Other disease processes share the same symptoms which, in reality, mean that investigations are needed to exclude differential diagnoses. This is why IBS has historically been known as a diagnosis of exclusion. Those more invasive or expensive investigations are only needed if there are potential 'red flags', or alarm features (Hatlebakk & Hatlebakk, 2004).

Diagnostic tests are required to exclude organic diseases with similar symptoms, and to confirm identification of IBS to the clinician and patient (Cash & Chey, 2004).

Patient age and family history affect what type of testing is done, for example colonoscopy is mandatory for persons over fifty with recent onset of symptoms or

earlier if there is a strong family history of organic gastrointestinal disease or colorectal cancer. Laboratory testing should suffice in the absence of any alarm features (Croghan & Heitkemper, 2005; Cash & Chey, 2004; Hatlebakk & Hatlebakk, 2004). These tests include a complete blood count (CBC), serum chemistries and thyroid function. Coeliac antibodies provide useful information in determining if further examination is needed to identify coeliac sprue. Stools should be examined for occult blood, ova and parasites. Unless specific symptoms or abnormalities become apparent prudence is needed in avoiding the use of limited and expensive diagnostic resources. Faecal calprotectin, although a relatively expensive test, is very useful in discriminating between IBS and inflammatory bowel disease (IBD). Faecal calprotectin is a diagnostic marker of inflammation (Gearry, Barclay, Florkowski, George & Walmsley, 2005). It is also an accurate predictor of relapse in IBD, where, according to Quigley (2005), IBD in remission can be IBS; or subclinical.

Major pathophysiological mechanisms of IBS involve dysregulation of gut motility and visceral hypersensitivity which results in an altered gut-brain axis (Harris & Chang, 2006). Visceral hypersensitivity was proposed as a biological marker of patients with IBS, as ninety four percent of IBS patients in a rectal distension study had reduced pain thresholds in comparison to control subjects (Azpiroz et al., 2007; Heitkemper & Jarrett, 2005). This has also been found in other functional disorders; the mechanisms behind this are not fully understood (Azpiroz et al., 2007). Visceral hypersensitivity to distension is well documented with several possible explanations which include the primary afferent neurons to the spinal cord and brain (Quigley, 2006), as a sympathetic response to deep visceral pain caused by bowel endometriosis (Griffiths, Koutsouridou & Penketh, 2007).

With even the best diagnostic tests in the world an accurate diagnosis of any condition requires a thorough history. The process of comprehensive history taking and the evaluation of alarm features has the potential to improve accurate diagnosis, thus avoiding unnecessary diagnostic studies (Hammer, Eslick, Howell, Altiparmak & Talley, 2004). Other conditions can co-exist, but not be the focus of the patient's problems. Because of the concurrence of other functional disorders IBS would often be missed as patients presented to other specialists with overlapping symptoms (Talley, 2006). This fundamental factor was illustrated by Hatlebakk & Hatlebakk (2004) who found it common for patients with IBS to concomitantly have another functional disorder such as functional dyspepsia, pelvic pain, sleep disorders or fibromyalgia. Cole, Rothman, Cabral, Zhang and Farraye (2006), observed a close relation of IBS with fibromyalgia, migraine, and depression. Fatigue is also often associated with IBS (Bjornsson, Simren, Olsson & Chapman, 2004). IBS patients were 60% more likely to have one or more of these disorders than those without IBS.

The only identifiable pathological features of IBS appear to be a dysregulation of gut motility and visceral hypersensitivity. Despite modern technology the reasons for this are largely unknown, although many theories are being developed. These studies suggest that despite the large amount of research around IBS, it is still often described as a diagnosis, where this term belongs to the cause of IBS symptoms. As IBS is a syndrome of symptoms it is the cause of the symptoms that needs identification if there is any real hope of finding a more effective way to treat the patient. A thorough history is required to identify underlying causes of symptoms and alarm features. The

presence of alarm features, often known as red flags, indicate a need for further investigation.

2.3 *Alternate Diagnoses, or Differential Diagnosis*

Abdominal pain and an altered bowel habit represent many differential diagnoses which can challenge differentiating between IBS and serious, potentially life threatening conditions (Holten, Wetherington & Bankston, 2003). (Figure 3). Whitehead et al., (2006b) suggested identification of ‘red flags’ such as unintentional weight loss, blood noticed with or in stools, or nocturnal symptoms. Onset of symptoms around or after age 50, should alert the clinician to consider more invasive diagnostic testing such as colonoscopy. Certain ‘red flags’ have been used to eliminate IBD or other sinister diseases, but some patients can have IBS concurrently with other bowel disorders (Bradesi, McRoberts, Anton & Mayer, 2003).

Figure 3.

Differential Diagnosis of Irritable Bowel Syndrome

<i>Inflammatory bowel disease</i>	<i>Endocrine disorders</i>	<i>Intestinal pseudo obstruction</i>
	Hypo/hyperthyroidism	
	Diabetes	Scleroderma
<i>Infections</i>	Addison's disease	
Parasitic	Polycystic ovary syndrome	<i>Psychiatric disorders</i>
Viral	Endocrine tumours (rare)	Depression
Bacterial and opportunistic	Gastrinoma	Anxiety
	Carcinoid	Somatisation syndrome
<i>Malabsorption syndromes</i>		
Coeliac disease	<i>Colorectal carcinoma</i>	
Pancreatic insufficiency	Adenocarcinoma	
Lactose intolerance	Villous adenoma	
<i>Medications</i>		
Laxatives		
Constipating medications		

(Holten, Wetherington & Bankston, p. 2159, 2003)

IBD can be misdiagnosed as IBS for some time due to similarity of symptoms. The age of a person can, in itself almost be perceived as a red flag, as onset of IBD is often as a young adult (Rodriguez, Gonzalez-Perez, Johansson, & Wallander, 2005). It is usually only when 'red flags' emerge that lead to further investigations. The concept of IBS as a diagnosis of exclusion is constantly being challenged with goal posts continually changing as more evidence identifies causes of symptoms. Overlapping borders are demonstrated when inflammatory disorders become 'subclinical'. IBD in remission exhibits the same symptoms as D-IBS (Quigley, 2005). There is a possible parallel here with asthma and IBS, but whether they are linked is not clear. Azpiroz et al., (2007) described asthma as an analogy by describing the gut being subject to numerous insults, as do the airways in asthma. Insults lead to inflammation, however gut tissues manage to repair themselves so that macroscopically there is little or no evidence of damage.

Olbe (2008) suggested there is a link between IBS and IBD by means of both having an increased permeability in the intestinal mucosa triggered by an oral-pharyngeal bacterium. Bradesi et al., (2003) found both IBS and IBD to have positive feedback loops developing in response to stress between the gut and the brain. Chronic stress affects the immune system's tolerance to indigenous microflora. These similarities may mean that patients with IBD are identified with IBS for some time before they are correctly diagnosed (Miura, 2007).

The different symptom subtypes can assist in diagnostic choices (Holten, Wetherington & Bankston, 2003). Diarrhoea predominant symptoms lead more to diagnoses of IBD, malabsorption syndromes, infections, and diverticular disease.

Symptoms of diverticular disease may be difficult to distinguish from those of IBS (Petruzziello, Iacopini, Shah & Costamagna, 2006), as patients experience visceral hypersensitivity in response to a physiological stimuli, such as food or stress. This hypersensitivity is not found in diverticular disease when the disease is in remission, or when the patient is asymptomatic. Causes of diverticulosis are remarkably similar to those of some types of IBS, particularly the interaction between colonic dysmotility and intestinal microflora. Low grade mucosal inflammation, sensitised primary afferent neurones in the submucosal layer and changes in motility are factors now well recognised in IBS (Petruzziello et al., 2006).

An overlap with chronic pelvic pain was identified in thirty five percent of women with IBS (Heitkemper & Jarrett, 2005; Quigley, 2006), with a heightened awareness of smooth muscle reactivity as in urinary and gynaecological symptoms being common. Endometriosis and other pelvic conditions can also cause symptoms of IBS. Endometriosis has been reported as being frequently misdiagnosed as IBS or pelvic inflammatory disease (Seaman, Ballard, Wright & de Vries, 2008; Yantiss, Clement & Young, 2001). Bowel endometriosis is often missed (Ferrero, Camerini, Ragni and Remorgida 2008), where intestinal endometriotic nodules are responsible for gastrointestinal symptoms. It cannot be identified on physical examination (Remorgida, Ferrero, Fulcheri, Ragni & Martin, 2007), therefore an imaging modality is required. The most frequent site of endometriosis involving the bowel is the sigmoid colon (Remorgida et al., 2007). The symptoms that mimic IBS include constipation, diarrhoea, bloating and wind, with symptoms typically being relieved by defaecation. Griffiths, et al., (2007), have suggested that common IBS symptoms may be predictors of rectovaginal endometriosis. Talley and Martin (2006) suggest

that common IBS symptoms can co-exist with gynaecological symptoms, which can be a clinical indicator for further investigation.

Other physiological disorders not identified in figure 3 that involve symptoms sometimes thought to be IBS are related to pelvic floor disorders. Faecal incontinence (Nygaard et al., 2008) has been identified as affecting nine percent of a national survey population, where twenty three point seven percent of women have at least one pelvic floor disorder. Many patients thought to have C- IBS in fact have defaecation disturbances, with feelings of incomplete evacuation, and tenesmus (a chronic urge to defaecate), constipation, and a need to digitally assist evacuation (Vermeulen et al., 2004). Obstructive defaecation is often confused with IBS, and is commonly caused by a rectocele (Finco et al., 2007). A study by Palmer, Lockley, Palmer and Kulinskaya (2002) found the majority of patients with IBS symptoms who had ano-rectal problems, such as rectocele, fissures, mucosal prolapse or haemorrhoids, had their IBS symptoms disappear after intervention or surgical correction of these problems.

Uncommon differential diagnoses should not be forgotten, some being difficult to manage, such as adhesive enteropathy (Talley & Martin, 2006). Others are chronic intestinal pseudo-obstruction and chronic mesenteric ischaemia, where abdominal pain in the latter often occurs after a meal, gradually resolving over one to three hours. These symptoms occur in IBS, but not as severely, with other concurrent symptoms such as bloating and wind, often relieved on defaecation.

According to El-Serag, Pilgrim and Schoenfeld (2004), once identification of IBS was made, fewer than five percent were diagnosed with another organic disorder. More recent research has challenged the accuracy of such claims as new evidence has shown that disorders once identified as IBS are now known to be an organic disorder. A classic historical example is coeliac disease, which has similar symptoms, and a high prevalence. Until recently coeliac disease was believed to be a functional disorder. A study of a group of IBS patients who had identified immunological markers for potential coeliac disease, but were not clinically classified as coeliac disease on endoscopic biopsy, found six months of gluten free diet normalised those values (Hatlebakk & Hatlebakk, 2004). Talley (2006) suggested that as coeliac disease presented with the same symptoms as IBS in the absence of alarm symptoms, presenting patients should be tested, typically using the serum tissue transglutaminase (TTg) test which is an accurate indicator of coeliac disease.

Intolerance to specific food ingredients such as lactose, sorbitol and fructose (Heitkemper & Jarrett, 2005), is associated with diarrhoea and abdominal bloating and discomfort. Fructans, which are oligosaccharides and polysaccharides of fructose units, can also induce the same symptoms, on their own, or as an additional substrate to fructose (Shepherd & Gibson, 2006). Identification and removal of foods containing these substances, for example refined wheat, a major source of fructans, has seen substantial improvement in diarrhoea, bloating and discomfort.

Many documents relate to identification of IBS, but it is identifying the cause of the symptoms of IBS that is the true diagnosis. According to Talley (2006), this paradigm shift in identification showed the term 'functional' no longer applies to IBS,

although there is a long way to go, as changing our thinking is still in its infancy. A classic example identified by Lacy et al., (2006), found many clinicians were more likely to associate IBS with depression or anxiety, or an injury of some type to either the enteric or the autonomic nervous system. As there are a number of associated disease processes which are the diagnoses behind IBS symptoms it is important to obtain a good history and investigate for a potential differential diagnosis. Examples are diseases such as endometriosis, inflammatory bowel disease and colorectal cancer, or a physiological problem such as a rectocele, or post haemorrhoid surgery. As such, each patient regardless should be investigated for underlying causes. The major focus of any investigation is to look for the underlying factors behind the symptoms. This can be another disease process that, when treated, relieve the patient of their IBS symptoms.

2.4 *Underlying Factors*

2.4.1 *The role of infection*

Almost quarter of IBS cases occur after an acute gut infection (Bose & Farthing, 2001; Talley, 2006). They suggested the acute inflammation in the mucosa associated with infection induced a chronic visceral hypersensitivity and changes in the visceral afferent pathway. Bradesi et al., (2003), discussed altered gut immune function in those patients who had gastroenteritis or parasitic infection. There may be a genetic predisposition to inflammatory dysregulation in a subset of IBS patients. Preliminary evidence has suggested there is reduced production of cytokines with IBS patients in comparison with healthy controls. Persistent antigenic exposure to pathogens such as *Blastocystis hominis* was found to activate an immune response, where patients with

IBS showed elevated IgG antibody levels to *B. Hominis* as compared to asymptomatic controls (Stark, Marriott, Ellis & Harkness, 2007). They suggested there may be a genetic predisposition to inflammatory dysregulation in a subset of IBS patients. Preliminary evidence has suggested there is a reduced production of cytokines in comparison with healthy controls. Those who have had an acute diarrhoea are fourteen times more likely to develop IBS than the general population (Stark et al., 2007), with changes lasting more than a year after the initial infection resolved.

The type of IBS following an acute infection, PI-IBS, showed changes in gut motility, epithelial function and an increase in enterochromaffin cells (EC). An increase in substance P (SP), 5-HT and calcitonin gene related peptide (CGRP), all associated with an inflammatory response, were found in both the terminal ileum and rectosigmoid regions in patients with both PI-IBS and D-IBS (Azpiroz, et al., 2007). This evidence was supported by Quigley (2005) who demonstrated a persistent increase in enteroendocrine cells (also known as enterochromaffin), T-lymphocytes and gut permeability in patients with post dysenteric IBS.

Stark et al., (2007) found in a group of IBS patients, peri-ganglionic lymphocytic infiltration on full thickness biopsy in the region of the myenteric plexus. This was in the presence of normal mucosa. Increased intraepithelial lymphocytes and mucosal inflammation suggest a link between inflammation of the enteric nervous system and mucosal inflammation, leading to gut dysmotility. In a study that involved a group of IBS patients, those with reported normal histology showed microscopic evidence of inflammation by increased intraepithelial lymphocytes, and increased CD3 and CD25 cells within the lamina propria. This is said to show evidence of activation of the

immune response, however the inflammatory response hypothesis in IBS is still in very early stages (Quigley, 2006).

There was a link between the number of mast cells found close to the enteric nerves and the intensity of IBS symptoms. Mast cells and lymphocytes were found close to the nerve trunks in IBS patients (Bose & Farthing, 2001). Persisting chronic inflammatory cells in the rectal mucosa were found in patients whose onset of IBS followed a gastrointestinal infection (Quigley, 2007). Intriguing evidence was also found by Quigley, linking infection and inflammation in chronic intestinal pseudo-obstruction (CIP), which is associated with other chronic motility syndromes, such as achalasia, also linked with an infectious aetiology.

Gwee (2005) found intraepithelial lymphocytes and T-lymphocytes on rectosigmoid biopsies of patients with a history of PI-IBS, evidence that the pathogenesis of IBS is underpinned by an inflammatory process. Talley, (2006) related to evidence of changes in peripheral cytokines in IBS that are also seen in IBD, as well as abnormal interleukin ratios, suggesting that IBS may no longer be a diagnosis of exclusion. That is, there may be more underlying factors contributing to symptoms than is already now being recognised.

The use of antibiotics has been implicated in an increased risk of IBS. Quigley (2007) suggested that the 'privileged child' syndrome, where there is not only easier access to antibiotics, but also a reduced exposure to common pathogens found in less hygienic areas which contribute to natural immunity increased susceptibility to IBS. It was suggested that the use of antibiotics interfered in the balance of normal gut

flora, and thus contributed to a gut dysbiosis. This may be due to a “dysfunctional interaction between the indigenous flora and the intestinal mucosa” (p.5) leading to an immune reaction in the gut mucosa like IBD.

The post infectious, or post dysenteric IBS theory was initially postulated in 1994, but has taken over a decade to become accepted (Quigley, 2007). There is some thought, and debate, about the use of antibiotics, or probiotics to remedy this imbalance.

According to Jones (2004), one in five patients with IBS, related onset to an enteric infection. However, Howell, Talley, Quine and Poulton (2004) suggested patients tend to underreport any previous infection. Their reasoning was, that some have a desperate need to have their symptoms explained, and given an official ‘disease’ status. This classically represents the differing opinions amongst clinicians.

Patients often recall during consultation, an event or illness that possibly triggered their IBS symptoms. What makes the person more susceptible to the resultant ongoing inflammatory response is still not known, though some suggest it is a genetic trait. It is possible that the brain-gut relationship is involved, particularly if there has been some life changing, traumatic event that could weaken the individual’s response and inhibit full recovery of the gut. The role of serotonin and its production in response to infection or inflammation may also relate to the brain-gut relationship.

2.4.2 *The role of serotonin*

The role of neurotransmitters in the gut is a relatively new concept. Researchers, such as Harris and Chang (2006), have explored the action of neurotransmitters in the absence of activation of inhibitory pain mechanisms in the gut by the central nervous system. Serotonin dysregulation is now receiving recognition as serotonin plays an important part in regulation of peristaltic reflex and relaying sensory information to the brain (Talley, 2006).

According to Azpiroz et al., (2007), recent researchers claimed that IBS is a disorder of serotonin, suggesting that plasma levels of 5-HT are often elevated in patients with IBS. Different studies in post-infectious IBS and non post infectious IBS showed significantly increased numbers of 5-HT cells on rectal biopsy, suggesting that prior infection need not be the only key factor to serotonin levels. 5-HT has historically been associated with the central nervous system (CNS) because of its role in depression, anxiety and other CNS functions (Mawe, Coates & Moses, 2006). As it has been found that 5-HT maintains normal gut function and gut-brain communication (Grundy & Schemann, 2006), studies have focussed on the 5-HT 3 receptors for diarrhoea predominant and 5-HT 4 receptors for constipation predominant IBS symptoms.

The enteric nervous system (ENS) has almost every neurotransmitter and associated receptors, making it the most complex component in the peripheral nervous system (Mawe et al., 2006). More than 80% of the body's serotonin is produced and stored in the EC cells in the intestinal tract, and is released in response to mucosal

stimulation (Azpiroz et al., 2007; Mayer et al., 2006). A wide range of stimulants cause serotonin to be released from the EC cells, for example, bacterial toxins, glucose and adrenergic and cholinergic receptor stimulation (Spiller, 2005). Patients who develop post infectious IBS often have lymphocytosis and an increase in numbers of enterochromaffin (EC) cells releasing serotonin. Serotonin acts on the various 5-HT receptors in the lamina propria acting on afferent neurons and on pre and post synaptic 5-HT receptors (Spiller). These afferent nerves are responsible for transmitting signals for satiety, pain and discomfort and other digestive system functions (Mawe et al., 2006). These signals can equally be terminated by the selective serotonin reuptake transporter, (SERT), for which Mawe et al., suggested the use of selective serotonin reuptake inhibitors (SSRIs) such as fluoxetine and citalopram to counter inappropriate reuptake of 5-HT.

Jarrett et al., (2007) described a SERT genotype that is a likely risk for depressive episodes, supporting a biopsychosocial model of IBS. They suggested the psychosocial environment may play a part in both susceptibility and outcome. Mawe et al., (2006) have suggested the probability that a SERT gene exists considering IBS patients often appear to have a genetic predisposition.

The concept that serotonin is a major factor in IBS is now strong as the response to various serotonergic agents, such as tegaserod and cilansetron lent support to this theory (Talley, 2004). Unfortunately these drugs are no longer available due to serious adverse reactions (Talley, 2003), including ischaemic colitis, severe constipation and death.

Drugs aimed at the brain-gut axis have, in the past, been sedatives and anti-anxiolytics, often because of the perceptions that a high percentage of patients have an anxiety disorder (Mayer et al., 2006). Currently there is more research exploring the beneficial actions of antidepressants, often tricyclic antidepressants, (TCAs) on both neuropathic and visceral pain. As constipation can occur as an adverse effect (Brunton, Parker, Blumental & Buxton, 2008) this can be of benefit to patients with D-IBS.

Serotonin is now recognised as playing an integral part on the regulation of gut motility and sensation, which opens up room for discussion about the role anxieties and psychological issues play in impacting on gut function. Differing thought processes about the gut-brain relationship can now either be challenged or confirmed. This supports the suggestion there is a pathological explanation of IBS symptoms related to serotonin production. Psychological and psychosocial factors possibly contribute to this puzzle by stimulating serotonin production as a stressor, or if the excess production of serotonin heightens an anxiety/stress response.

2.4.3 The role of psychological and psychosocial influences

Irritable bowel syndrome has historically been thought to be a psychosomatic disorder (Heitkemper, Carter, Ameen, Olden & Chang, 2002). Stress and diet were the most frequently reported factors exacerbating symptoms (Croghan & Heitkemper, 2005).

At the turn of the nineteenth century, medical practitioners described patients with IBS as hysterical, hypochondriacal, self centred, depressed, with symptoms of

nervous diarrhoea (Greenberg et al., 2002). The nineteenth century physician William Osler who described IBS as mucous colitis, suggested this mainly occurred in young women with psychiatric disorders. This view was accepted for nearly a century (Jones, 2004).

An interesting idea was postulated by Greenberg et al., (2002) that patients who were depressed had decreased motility of their gut, while those who were anxious or agitated were prone to increased motility. This thought was echoed by Grundy and Schemann (2006) who reported a growing body of literature supporting the evidence that depression or anxiety and other changes in CNS function dramatically affected the gut, leading to inflammatory changes. It was observed that, while stress levels may correlate with intensity of symptoms, stress or other psychosocial factors are not the cause of the syndrome (Greenberg et al., 2002). Psychological stress has been shown to activate sensitised cells which induced a chronic inflammatory effect on visceral afferents (Bose & Farthing, 2001).

Theories about the brain-gut axis have been around for some time, although the brain-gut axis has not been adequately described. Grundy and Schemann (2006) identified that the ENS is linked to the CNS by afferent and efferent pathways, yet there is coordinated reflex function independent of the CNS in sensory and motor neurons. Mayer, et al., (2006) described the way in which the digestive processes are regulated by brain-gut interactions. There are still many aspects to this process not completely understood. It is felt, however, that in IBS there is a disturbance in the interactions of the gut lumen, the mucosa, the ENS and the CNS. This leads to altered motility, sensations and immune function.

The enteric nervous system is thought to be monitored and modulated by the CNS, though this is an unconscious process (Nabiloff, Frese & Rapgay, 2008). Continual communication between the CNS and the gastrointestinal (GI) tract is needed for coordination of gut function, and it is thought that vagal visceral afferent input plays an important role in diverse functions such as emotion, pain, satiety and the immune response (Mayer et al., 2006). This brain- gut axis sheds new light into understanding the interface between stress, emotion, pain, and IBS, even though the ENS has its own reflex system. As well as dealing with life stressors, the experience of a visceral sensation that is known to lead to more problems only serves to heighten the anxiety experience (Nabiloff et al., 2008). For example, the fear of not being able to make it to the toilet in time for patients with urgency and diarrhoea is unbearable, and is socially disruptive (Payne, 2004). This can become self-perpetuating with the slightest abdominal twinge increasing the anxiety, which can ultimately lead to pre-occupation with the fear of soiling themselves, with consequential social isolation, shame, and poor quality of life.

An early study by Gwee et al., (1999) suggested that psychological disturbances were more common in IBS patients than those without, but did not look at the possibility that either stress or anxiety possibly resulted from developing IBS itself. They used a control group without IBS for their study but did not test this group with psychometric studies, or use a group of patients without IBS who had high life anxiety scores, or hypochondriasis. Hertig, Cain, Jarrett, Burr and Heitkemper (2007), and Motzer, Hertig, Jarrett and Heitkemper (2003) suggested it remained unclear as to whether psychological distress causes IBS, or IBS causes psychological distress. It is known

that stress exacerbates symptoms in IBS, in particular the severity of abdominal pain, but does not alter bowel pattern symptoms. Bray, Nicol, Penman and Ford (2006), found that most IBS patients understood the concept of mind-body relationships and welcomed opportunities to explore any psychosocial links with their symptoms. These findings thereby discredit any suggestions that IBS patients were only committed to a somatic reason behind their symptoms. Creed et al., (2008) found patients with high somatisation patterns responded well to psychotherapy, a finding they did not expect, which suggests that patients were keen to improve.

Williams et al., (2006) found that patients who had IBS for more than two years were more likely to have some degree of psychological impairment than those who were subsequently found to not have IBS. They found that those IBS patients who sought medical care experienced IBS as affecting their social and physical functioning in comparison to those with IBS who did not seek medical care. Therefore it can be suggested the degree of suffering experienced by a person with IBS is relative to the individual experience of symptoms. There are theories that perceptions of the longevity of illness are related to the ability to cope. Rutter & Rutter, (2002) found that those who felt they had little control over their life dominating illness related to the belief that their illness would last a long time. Conversely, those who believed their symptoms would not last reported finding positive support, seeking rejection of illness status.

Chitkara, van Tilburg, Blois-Martin and Whitehead (2008) suggested that increased severity in IBS symptoms in women was associated with lower perceived social competence, whereas with men with IBS, symptom severity was more associated with

lower perceived athletic competence. This could be construed to mean there is a gender difference in priorities in life in which the prominence of IBS is perceived differently.

Gerson et al., (2006) argued that relationships within the family unit are related to an individual's ability towards a favourable health outcome. Criticism by the spouse was often associated with an increase in symptomology. They suggested that IBS is frequently associated with a familial systemic process; psychosocial repercussions often occurring in the presence of a biomedical event. Family malfunctions are major risk factors of systemic health concerns. Childhood traumatic events such as physical or sexual abuse can predispose an individual to an increased predisposition of a functional disorder (Chitkara et al., 2008). Other childhood events play a just as important role. Patients who had either an unsatisfactory relationship with parents, parental deprivation, or death of a parent, had the same gut response as those who had been abused. Payne (2004) found a high proportion of both men and women with IBS reporting sexual abuse as a child. Early life adversity was linked to IBS symptoms (Lackner, Gudleski & Blanchard, 2004).

A study of adolescents with chronic pelvic pain found there was a prevalence of prior physical and sexual abuse in women with IBS as compared to women with organic disorders (Blanchard et al., 2002; Greenberg et al., 2002; Song & Advincula, 2005). Childhood abuse was known to result in long term outcomes of IBS (Springer, Sheridan, Kuo & Carnes, 2003). The majority of reports were regarding young females reporting sexual and physical abuse under the age of fourteen years. Those abused as a child were more likely to be abused as an adult. Other forms of abuse

featured in IBS studies on self blame and self silencing (Ali et al., 2000), such as emotional abuse, psychological maltreatment and nonphysical aggression.

There is much literature about the role of either psychological, physical or sexual abuse and IBS. More patients with IBS than any other physical illness reported sexual abuse in both childhood and adulthood (Salmon, Skaife & Rhodes, 2003).

Other studies showed a high proportion of both men and women with IBS reported childhood sexual abuse (Payne, 2004), showing figures as high as thirty three percent of women and around twenty percent of men reporting abuse either as a child or an adult. Young and Quigley (1997) were among the earlier writers to associate sexual abuse among women and IBS symptoms.

A relationship was identified by Lackner et al., (2006) between severity of abuse and severity of symptoms. They used a tool in their study that actively asked blunt questions such as “has anyone touched the sex organs of your body...?” (p317). Their study identified twenty seven percent of patients reported abuse; physical or sexual, or both, where Ringel et al., (2004) reported up to fifty percent of patients attending gastroenterology clinics for any complaint, reported physical or sexual abuse.

Springer et al., (2003) discussed the fact that childhood sexual abuse was present in twenty two percent of women, and encouraged health care professionals in the use of non threatening questions. Springer et al indicated that primary and subspeciality physicians need to be able to recognise and acknowledge child abuse as a trigger of chronic conditions such as IBS, fibromyalgia, and chronic fatigue syndrome.

Chitkara et al., (2008) suggested that childhood trauma such as physical or sexual

abuse led to a predisposition for hyperreactivity to stress, which manifests as IBS or other functional disorders.

Any suggestion that patients who had been severely abused had lower thresholds for pain, urgency, or coping mechanisms, has been disproved in a study by Ringel et al., (2004) where these people were found to have high threshold and tolerance of pain. This was explained by use of a dissociative response, screening out painful stimuli. Such a suggestion is entirely feasible given that Salmon et al., (2004) linked dissociation with recalled childhood sexual abuse and somatisation.

The relationship between the CNS and the ENS is still largely a mystery, but it is now well documented that the gut-brain relationship is necessary for the coordination of visceral function. Stressors, such as anxiety affect this relationship, and factors such as childhood abuse or a dysfunctional family life contribute to the way in which a person is able to cope with stress. Unfortunately this relationship can lead to stress if the gut is hyperresponsive, which can lead to a self-perpetuating cycle of fear and response, disrupting an individual's life. This was historically seen as a psychological hysteria affecting mainly women. Apart from the anxiety associated with symptoms other stressors, such as a dysfunctional family life and spouse criticism affect symptoms. A history of childhood abuse has been associated with IBS and contributes to the way in which the person as an adult is able to cope with stress. How a person perceives their gut problem affects their coping skills as well, for instance, a belief that the illness will be short-lived is associated with better coping mechanisms.

2.4.4 The role of socioeconomic status

Studies by Howell et al., (2004, 2005) were conducted on a cohort of people born in Dunedin, New Zealand between April 1972 and March 1973. This population group is described as primarily white. No account of ethnic backgrounds are available. Although they describe in their methodology (2005) a means for identifying the socioeconomic status in this cohort, the data were not included in the analysis. There is no clear way of knowing whether socioeconomic status had an impact on IBS.

According to Howell et al., (2004), the way an individual responded to stress resulted from their socialisation experiences. In the upper classes of society self regulation in competence and coping may have taught the child to internalise stress, instead of responding to the adrenergic ‘fight or flight’ response in aggression and risk taking. This privileged child syndrome has driven home a link between socioeconomic status and functional disorders. The more affluence experienced in childhood the more likely the odds of developing IBS (Howell et al.), therefore, an independent risk factor for developing IBS was having an affluent upbringing in childhood. Howell et al., reported that IBS like symptoms, and/or recurrent abdominal pain occurred more in children whose parents identified one or some characteristics of either competitiveness, high achievement, perfectionism, strong willed, and moralistic in their personalities. While these characteristics are more frequently identified with middle to upper class families there are always exceptions. The 2005 study by Howell, Poulton and Talley (2005), found the relationship between recurrent abdominal pain in childhood and adult IBS was only found in a group of children

aged between nine and eleven. It could be conceived that this is an important formational time for children in developing socialisation skills and peer bonding.

The relationship between economic status and IBS is not clearly understood, however some characteristics associated with a higher economic status may play a role. There was documented evidence of a relationship between a high academic performance and IBS (Jarrett et al., 2007). In a research project undertaken by Jarrett et al., (2007), sixty two percent of participants with IBS had completed tertiary education. Other researchers found over a quarter of IBS patients to have a university degree (Mearin et al., 2006; Williams et al., 2006). Donker, Foets and Spreeuwenberg (1999), did not reach the same conclusion. Their study suggested that patients with IBS tended to have a lower level of education and experienced generalised poor health in non colonic symptoms.

Chitkara et al., (2008) reported that there was possibly an explanation for an affluent childhood and adult IBS. An hypothesis was that factors associated with the lower socioeconomic society are not experienced, such as over crowded living conditions. Therefore the immune system is not as highly developed, a 'hygiene hypothesis' being promoted. This links in to the privileged child syndrome mentioned by Quigley (2007), where easy access to antibiotics can predispose the individual toward developing a gut dysbiosis leading to IBS.

Howell et al., (2004) continued, however, to discuss the fact that most gastrointestinal infections occur in the so called "lower class" group of the population, and that few studies have investigated this association. Hospital admission data noted children

with gastroenteritis more commonly came from the lower socio-economic group.

Minocha, Johnson, Abel & Wigington (2006), found the prevalence of IBS to be more common in younger, poorer patients, and in older, church-going adults. The correlation of the latter is not known. There was a trend among divorced patients as well, possibly highlighting the stress factor.

IBS is beginning to become more prevalent in countries that previously did not eat Western foods such as cereals and dairy products, which are now being advertised as healthy eating in these countries. (Gwee, 2005). What does seem obvious is that the Western way of life has some kind of impact. IBS symptoms, and lactose intolerance are steadily on the increase. Intolerance to certain foods is a major contributor to symptoms of IBS, such as fructans and fructose, the former being found in highly refined carbohydrates and in artificially sweetened foods or drinks (Shepherd, Parker, Muir & Gibson, 2008). Access to these foods is now much easier in non Western countries, therefore there must be a link between types of foods, as well as the type of stress associated with a Western lifestyle.

No studies have been found on New Zealand Maori and IBS. There are few studies found on culture and IBS, other than those noted in a literature review by Kolowski, Talley and Boyce (2001), which tabled a study undertaken on Native African Medical students, a Singapore study on their residents, and another comparing Hispanic and non Hispanic employees. All other studies are generally Western countries, though Minocha et al (2006) described other ethnicities in these countries, such as Black Americans, Hispanic and other coloured races have the same numbers of IBS patients as Caucasian. A Chinese study by Dong, Dinggou, Xiaxing and Hanming (2005)

found a prevalence of IBS of 13.25% among adolescents across China. They identified IBS as relating to psychological factors and family conditions. An unhealthy exterior environment, poor diet and inadequate protection from inclemental weather were also thought to contribute.

Higher and lower socioeconomic groups have different reasons for stress, and whether IBS is seen more in the higher socioeconomic group, or the lower, remains to be seen. Perhaps the relationship between childhood socialisation skills combined with factors arising in the childhood home, stressors and expectations are more related to IBS than socioeconomic status. Different stressors create the same outcome. It would be plausible to correlate fatty, highly processed foods with IBS, as well as traumatic events, which know no barriers to socioeconomic status.

2.4.4.1 Summary of underlying factors

There is a multitude of factors that influence symptoms of IBS. Anxiety and stress, trauma and abuse, antibiotics and economic status are some identified factors. More recent papers look to underlying pathology as the cause of symptoms causing a gut dysbiosis, which is one of the more credible causes of IBS (Talley, 2006). The identification of inflammatory markers found in rectosigmoid biopsies in IBS patients suggest an inflammatory process (Bose & Farthing, 2001). The neurotransmitter serotonin, is thought to play a regulatory role in gut function and gut-brain communication (Grundy & Schemann, 2006). Stimulants, such as bacterial toxins affect serotonin levels. Thus, the increasing evidence of a link between serotonin and psychological disturbances associated with IBS encourage lateral thinking.

2.5 Predictors of Health Care Seeking

So far no definitive predictors of the evolution of IBS have been identified, and there is little evidence on how patients improve in symptom severity (Mearin, et al., 2006). Individuals respond differently, despite classification into one of the subtypes. Heterogeneity best describes the myriad of data relating to IBS subtypes and clinical outcomes. A study by Halder et al., (2007) described frustration about the ability to accurately predict the outcome of IBS, finding that symptoms moved between different functional disorders. Patterns do emerge however, such as a history of abuse (Kolowski et al., 2001). Psychological morbidity and personality traits also are thought to influence health care seeking.

Poor quality of life can depend on the attitude, psychosocial state and support systems of the individual as well as coexisting conditions (Patrick, Drossman, Frederick, Dicesare & Puder, 1998), and thus could be identified as a predictor of IBS. These factors can drive the individual to seek out health care, as poor quality of life is also associated with symptom severity. An important factor in health care seeking behaviours is symptom severity (Kolowski et al., 2001). Predictors of symptom severity include the belief that something is seriously wrong with the body (Spiegel, Strickland, Naliboff, Mayer and Chang 2008). Severity of symptoms and anxiety about the potential serious nature of IBS symptoms such as fear of cancer have been identified by Kolowski et al., (2001) as determinants of health care seeking in eighty five percent of IBS patients. Williams et al., (2006) found that among females, significant predictors of health care seeking behaviour were having 'disabled' as an

employment status, and fear that their symptoms are related to cancer or other major illness. Men sought help only when their abdominal pain score was equal or greater than four out of a possible five on a pain score, as well as being unemployed with a disability.

Although approximately twenty percent of the population have IBS, the majority of these people do not seek help. Williams et al., (2006) found only twenty five percent of people with IBS sought treatment, yet IBS is the largest health concern seen by gastroenterologists, costing the USA about \$1.4 billion annually. Not all studies agree on why IBS patients present for help (Kolowski et al., 2001). The most obvious reason for an initial consult would be for diagnosis of their complaint and symptom relief. Some studies show women to be more frequent attenders than men for IBS symptoms. At least eighty percent of all IBS patients are women (Kolowski et al., 2001). It was postulated that women are more likely to pay attention to repeated symptoms. Williams et al., (2006) however, found that health care seeking was the same between females and males with IBS symptoms, but females were more likely to be given a diagnosis of IBS. Abdominal pain and discomfort and seeking treatment for symptoms because of dissatisfaction with previous treatments were the main reasons for health care seeking. It was suggested by Payne (2004) that men were more embarrassed and more reluctant to seek help when the issue was so private, where women were more concerned about losing control of their symptoms, as well as feeling anxious about outward appearances, feeling clean and smelling nice. Women tend to seek help from fear of a sinister disease or because of social disruption, while men seek help for both severity of abdominal pain, or the impact on athletic performance.

It was believed in the past that psychological factors or psychiatric disorders were the triggers behind IBS, however this is now controversial. For instance it was thought that while psychological distress did not cause IBS, it did lead patients to seek help for their symptoms (Talley et al., 1997), but they found that this cause, along with that of abuse, was associated with any type of medical care sought. Abdominal pain was found to be an important predictor of health care seeking.

In order to curb the heavy costs associated with frequent attending by IBS patients it was suggested that physicians need to consider the patient from a broader psychosocial context. Kolowski et al., (2001) also suggested that physicians can play a key part in modifying health care seeking behaviour, if they are able to understand the patient's beliefs and anxieties, as well as cognition and expectations of illness. Patients with IBS symptoms require time to provide a detailed history. Patients, in a study by Hayes (2006), preferred to seek help from a Nurse Practitioner for this very reason.

IBS is a unique experience for each individual, and while patients are continually being compartmentalised into a subtype or classification, no study has been able to confidently predict outcomes, or provide real determinates of health care seeking. Much research is being done on identifying underlying causes that refute some of the psychosomatic theories. IBS was thought to be associated with health care seeking behaviour, and although research is showing otherwise, a few clinicians still hold to this view to some degree. There are, no doubt, some people for whom there is a need to frequently see the doctor for one reason or the other. Whether that is mainly IBS

symptoms that drive health care seeking is a contentious issue. It is still not known whether IBS is the result of stress or anxiety, or the trigger of stress and/or anxiety. The impact this has on individuals, on families, and on the economy is significant.

2.6 Prevalence of IBS and the impact on economics

IBS exists across all age groups (Minocha et al., 2006), however there is a greater prevalence reported in the younger adult which can impact on the economy.

IBS affects the individual through increased visits to the health care provider, lost days at work, diagnostic testing, and prescriptions or over the counter remedies (Heitkemper et al., 2002). IBS is responsible for significant indirect and direct costs to both patients and society and is considered to be a costly disorder (Cash & Chey, 2004).

A study by Barbazet et al., (2002) examining the same cohort studied by Howell et al., (2004, 2005) used the Manning criteria for identification of IBS. Barbazet et al., found 18.8% met the criteria with two or more symptoms (See Figure 1). This prevalence was similar to other studies in the USA and the UK. Their findings included a preponderance of females, suggesting that the population of IBS patients in NZ is similar to those of the USA and UK.

IBS is one of the more common reasons for visiting a General Practitioner (GP) or consulting a gastroenterologist which accounts for 2.5 to 3.5 million physician visits in the UK and USA per year. The high proportion of patients referred on to specialist care generates a high workload at both specialist and general practitioner levels,

incurring substantial costs to the work force, health sector, and the individual (Wilson et al, 2004). Gastroenterologists spend almost half their time caring for those with a functional gut disorder, such as IBS and chronic dyspepsia (Halder et al., 2007). A study by Akehurst et al., (2002) found that IBS patients cost the NHS in the UK significantly more dollars per person than a control group. This related to having more time off work, with a subsequent considerably lower quality of life (Donker et al.,1999). On the other hand, Le Pen et al., (2004) found patients avoided taking time off work, with an attitude of tolerating symptoms as much as possible rather than interfere with work.

There was a higher use of health care resources by patients with IBS, spending almost double than those without bowel symptoms. They also observed more frequent consultation with alternative healers, spending a significant amount of money on alternative treatments. This was perceived as a burden as alternative treatments are not covered by insurance companies. Alternative therapies also have the potential to jeopardise a patient's health with the risk of interaction with some prescribed medications.

A literature review by Inadomi, Fennerty and Bjorkman (2003) showed there was a substantial economic impact resulting from not only those that sought health care, but also those sufferers that didn't seek help. There was a loss of productivity in the workplace by patients often taking sick days. Patients reported IBS to affect their work productivity and quality (Bertram, Kurland, Lydick, Locke, & Yawn, 2001). Often this was due to the large amount of time in the toilet, and days off because of cramping and diarrhoea.

According to the New Zealand 'NatMedCa' study conducted by the Ministry of Health (2004) digestive complaints were identified as a reason for consultation in 6.0 % of those attending private GP, and 9.3% in those attending a non-profit practice. IBS was not specifically addressed in this study.

Major impairments in health status and quality of life associated with functional gastrointestinal disorders have implications on the economy and health policies around the globe. A study by Levy et al., (2001) found that the cost of care for IBS patients was higher for both gastro-intestinal (GI) and non GI related problems, than the general population. It was estimated that indirect costs to the economy of \$10-20 billion from work absenteeism and decreased productivity in the USA is related to IBS symptoms alone (Cash & Chey, 2004).

Other studies also showed increased work absenteeism and higher physician visits (Patrick, Drossman, Frederick, Dicesare & Puder, 1998). The prevalence of people with IBS symptoms who do not seek medical aid does not appear to have been well researched, the impact on their lives, as well as employment, sick leave, and quality of life for families are not known (Wilson et al., 2004). It was found, however, in a survey by Hungin, Chang, Locke, Dennis and Barghout (2005), that IBS patients spent more days in bed and had more time off work than non IBS patients. Minocha et al, (2006), suggested little had been written on age and quality of life. They investigated these factors and found that younger people were more affected in quality of life than older people, who possibly had existing coping skills developed from other co-existing health concerns. As younger people make up a significant

proportion of the workforce, this can have a significant impact on the economy. Females were more likely to have a reduced quality of life than males (Simren, Abrahamsson, Svedlund & Bjornsson, 2001), where fatigue was ranked as one of the more troublesome symptoms. Fatigue was one of the most common symptoms for time off work. The other was diarrhoea, patients sometimes experiencing discrimination in the workforce being perceived as dirty (Kennedy, Robinson & Rogers, 2003). Patients found it embarrassing trying to describe IBS and why they couldn't come to work.

There does not appear to be any literature available that directly addresses the economic impact of IBS in New Zealand. One could hypothesise that it is similar to those in other Western cultures. A study by Bindman, Forrest, Britt, Crampton and Majeed (2007), found that the types and frequencies of health concerns seen in primary health care are the same in Australia, New Zealand and the United States of America.

According to the "Everybody.co.nz" website (2008), which provides information on the New Zealand health care system; patients pay an average of \$50 per visit to their GP unless they are a beneficiary card holder. According to Crampton, Jatrana, Lay-Yee and Davis (2007), patients visit their GPs on an average of 6.6 times per annum. No data are reported on IBS visits to GPs, therefore it is difficult to calculate the cost to the patient or the government for these visits.

Frequent visits to GPs and alternative therapists becomes expensive, as does the cost of medications and herbal remedies. According to the Pharmac website (2009),

patients spend \$30 per month alone on loperamide and hyoscine butylbromide. Pharmac have quoted an estimate of \$1,210,336 spent for the year ending June 2009 on loperamide alone. The majority of patients needing loperamide will be IBD and IBS patients. Add the cheapest probiotic at \$33 per bottle, and other herbal remedies, the costs per month quickly escalate. Laxative costs add up as well, particularly if enemas are required, a fleet phosphate enema costing \$2.50 each.

Private health insurance policies vary, and comprehensive policies still do not cover alternative health care providers, including nurse specialists. If a person wishes to seek consultation with a private gastroenterologist this can cost anywhere up to \$300 for an initial consult.

There are a number of factors to consider when exploring the individual or the collective cost on the health care system and the family of IBS. For example, the support structure around the individual, the financial, or socio-economic position of the individual, the relationship they have with their health care provider, and the individual's own beliefs and attitudes. Differing opinions result from examining different perspectives.

Major responsibility for how the patient is perceived and treated falls to the primary health care provider. Considering that most primary care physicians have less consult time, the ability to understand and explore patient cognition, beliefs, and anxieties is compromised. Physicians have been reported to have less of an understanding of the intricacies of IBS, and patient perceptions often are that they are not being heard, or that they are considered neurotic.

2.7 *Physicians' Attitudes*

IBS is largely identified by exclusion of differential diagnoses. This, and the absence of a well defined physiological cause for symptoms may lead physicians to perceive that IBS is a non – significant, or trivial condition not worth their attention. The lack of diagnostic and treatment guidelines may lead the physician to feel ill-equipped and inadequate when dealing with patients with IBS symptoms Bertram et al., (2001).

Different attitudes and management strategies may exist among GPs, where Casiday, Hungin, Cornford, de Wit and Blell (2009) reported a wide gap in GP knowledge on causes of IBS.

How physicians, or family practitioners/GPs actually evaluate and treat patients with IBS has not been widely studied, but Longstreth and Burchette (2003) found GPs manage more IBS patients than gastroenterologists. What research has been conducted shows that physicians with different levels of training use widely different approaches to diagnostic testing and treatment strategies (Lacy et al., 2006). The respective specialty groups, Gastroenterology, Internal Medicine, and Family Practice, also showed different attitudes toward identification and management of IBS. Gastroenterology physicians (GI) were more likely to link IBS with physical or sexual abuse, infection, or a learned behaviour.

Charapata and Mertz (2006) found physician's knowledge of identification criteria of IBS, such as the Manning, or Rome II criteria, was less than fifty percent. It was discussed that the use of "diagnosis by exclusion" method led to unnecessary

diagnostic work ups and excessive use of health care resources. They also found that IBS patients frequently have unnecessary surgical procedures performed. The recommendation was that surgical specialists, as well as physicians be more familiar with identification criteria such as the Manning or Rome II or III criteria. Longstreth & Burchette (2003) found that a minority (thirty five percent) of physicians were able to identify the Manning, or Rome criteria for identifying IBS, and fewer than fifty percent were able to identify a group of typical IBS symptoms. Clinicians appeared to be unaware or ignorant of the current consensus criteria for identifying IBS (Casiday et al., 2009; Charapata & Mertz, 2006; Levy et al., 2001). Family physicians were found to have limited understanding about chronic functional syndromes, including chronic fatigue syndrome or functional dyspepsia, where they admitted they were not taught about these conditions in medical school (Chew-Graham, Cahill, Dowrick, Wearden & Peters, 2008). It was identified in Lacy et al., (2006) that these limitations are added to by the fact that most literature around research and IBS is mostly found in gastroenterology and other related specialist journals, and not often in the types of journals published for general medicine.

A frustrating aspect for physicians in trying to manage patients with IBS is the lack of evidence to suggest the outcome of their disorder/syndrome. The inability to predict how IBS will manifest must feel challenging to any doctor (Halder et al., 2007). IBS has been rated as the most difficult of chronic pain syndromes for which satisfactory relief can be achieved (Lacy et al., 2006; Longstreth & Burchette 2003). The amount of time a family physician has per patient is generally insufficient for these patients, and the focus is often on managing the presenting complaint rather than an holistic approach.

There is frequent comment that a strong doctor-patient relationship is necessary for any success in management of IBS symptoms (Dixon-Woods & Critchley, 2000; Donker et al., 1999; Longstreth & Burchette, 2003), but patients' experiences have often been negative or dismissive. How an individual feels when told they most likely have IBS depends on the way they have been told, what explanations are given about the syndrome, and how they are delivered (Dixon-Woods & Critchley, 2000). A patient would find it hard when the GP feels he has to convince the patient they only have a psychosomatic illness (Casiday et al., 2009). Donker et al., (1999) noted that many GPs tend to try and treat patients themselves rather than refer on, but that better understanding of the syndrome with guidelines and training in IBS may result in better outcomes. Surveys show that many primary health care providers do not adequately listen to their patients' agendas, and do not address their fears and concerns failing to address the impact IBS has on their lives. (Spiegel et al., 2008).

Considering women comprise approximately eighty percent of the IBS population, gender bias is likely (Hamberg, Risberg & Johansson, 2004), where physicians tend to interpret symptoms as psychosocial in women, and are more likely to interpret men's symptoms as organic. Payne (2004) suggests that women's experiences of IBS is different to that of men, particularly in how symptoms impact on daily life. This may possibly impact on how patients are managed, from both a biological and a gender role perspective. Whitehead et al., (2006a), identified that patients diagnosed with IBS by their health care provider as compared to other diagnoses, were more likely to be younger females. Williams, et al (2006) found that females, rather than males,

were more likely to be diagnosed with IBS, despite the fact that more males were more likely to seek help for abdominal symptoms.

Irrespective of the fact that more information is emerging on the changing face of IBS, Lacy et al., (2006), reported that the majority of clinicians; which include Internal Medicine physicians, Family Practice physicians, and Gastroenterologists; reported that the most common causes of IBS symptoms were anxiety and depression. Other causes were injury to the enteric nervous system, the autonomic nervous system, or cause unknown. Studies exist that discuss physicians' attitudes, knowledge, and practices around IBS (Dixon-Woods & Critchley, 2000; Lacy et al., 2006; Longstreth & Burchette, 2003), but little has been written regarding stigma (Dancey et al., 2002). According to Dixon-Woods & Critchley, (2000), and Heitkemper et al., (2002), patients were labeled as being 'bad', or 'good' patients. 'Bad' patients were those who didn't accept the diagnosis. Doctors suggested they were seeking a more serious diagnosis, and became defensive when it was suggested it could be psychological. 'Good' patients were those who were relieved to have a non serious diagnosis and had finally been given an explanation for their symptoms. Casiday et al., (2009) described the frustration some GPs expressed when patients did not accept there was no organic nature to their illness; that they were in denial. The belief by GPs that there is a strong somatic element with IBS patients is borne out by a dismissive attitude by some toward self help groups. This is said to be because patients would dwell on their symptoms and make attempts to treat very difficult (Casiday et al., 2009).

There are medical practitioners who feel the cause of symptoms is psychological which often leads to patient labelling. Nurses are as much a part of this scenario, hence it is important that nurses examine their attitudes and knowledge base before developing and maintaining supportive care. Consequently the behaviour of some nurses makes this study applicable to nurses as well (Dancey et al., 2002; Smith, 2006). Physicians may be frustrated by the lack of hard core evidence, and an inadequate knowledge base on how to manage their patients. How patients perceive their GP, and patient experiences, impacts on their quality of life.

2.8 *Patients' Perceptions of Health Care Providers*

Until recently there were no evidence based guidelines for specific treatments for IBS, (Bertram et al., 2001). There has been frustration at the inability to control symptoms and disappointment in the lack of understanding and empathy by colleagues, family and physicians, which led to anger and disappointment. Consequently many patients have felt very alone.

All too frequently, women with IBS feel that doctors think their symptoms manifest from a psychological issue (Heitkemper et al., 2002). Despite the differing opinions some were still happy to be under the care of their GP, although frustration from absence of pathology found themselves challenged in their own belief of self.

Some women thought that doctors were more likely to take men's complaints seriously while being more dismissive of women. There is a general perception by patients that when nothing organic is found to explain symptoms of syndromes like

chronic fatigue and irritable bowel, they are all too quickly put on antidepressants, which, to them, suggests their symptoms are interpreted as a psychological problem (Chew-Graham et al., 2008; Hamberg et al., 2004). Payne (2004) felt that women in particular felt that GPs or other HCPs did not take their symptoms or complaints seriously. Neither are they given adequate education. Additionally, the perception is there is no time spent explaining what is happening (Motzer et al., 2003).

Those who found it hard to accept that nothing was wrong found themselves labelled as 'neurotic', and felt that their fears were ridiculed (Dixon-Woods & Critchley, 2000). People with IBS often experience negative attitudes toward them as there is no quantifiable abnormality to 'prove' their disability. The general consensus (Bertram et al., 2001), was that patients did not find their primary health care physician to be of value with identifying and managing their IBS symptoms. Overall there was a feeling of lack of empathy, frustration about the lack of treatment options, and their experiences not being validated. It was felt that it was paramount that doctors were educated on how severely IBS impacts on a patient's life (Bertram et al., (2001), who also describe patients with other functional disorders experiencing the same frustrations.

It is little wonder that IBS patients feel stigmatised and discriminated against when it is documented in the literature that some gastroenterologists' views tend to be perjorative, and some GPs can be dismissive. Longstreth & Burchette (2003) confirm this in naming GP attitudes toward IBS patients to be negative, and that patients are labelled as good or bad patients by their primary health care provider (Heitkemper et al., 2002).

Patients have often felt misunderstood or dismissed by members of the medical community, in particular women, who perceive that they are wasting a doctor's time. The most frequent impression made on an IBS patient is that their problem is psychosomatic. They are often all too aware of the judgemental attitudes of some healthcare providers. This is not surprising given that the language in some of the literature reflects comments made by patients. The relationship they have with their HCP has the potential to affect the quality of life and the symptom severity of patients, a strong patient-provider relationship needed to facilitate any kind of recovery process.

2.9 *Quality of Life and Symptom Severity*

Illness intrusiveness impacts significantly on quality of life (QOL), where Dancey et al., (2002) found this to impact more on men than women. It was suggested that it could be because men either had less effective coping strategies than women, or that it disrupted their lifestyle more. Patterns of socialisation in our society may explain this difference where historically women needing to stay at home was less of an issue than a man, therefore it was perceived that men did not cope so well with an illness.

Individuals respond differently, for example patients who believe their illness is relatively short-lived had a more positive view to seeking help (Rutter & Rutter, 2002). Poor QOL can depend on the attitude, psychosocial state and support systems of the individual as well as coexisting conditions. (Patrick et al., 1998). Disease concern was found to predict overall health related QOL according to Spiegel et al., (2008).

Patients who felt there was something seriously wrong rated their symptoms as more severe than those who did not share those concerns. These patients also reported poorer QOL and health satisfaction (Rutter & Rutter, 2002).

IBS patients often experience a significant reduction in QOL (Lacy et al., 2006; Motzer et al., 2003), which can be reflected in relationships, an ability to learn, and to function at work. Bray et al., (2006) found quality of life as reported by IBS patients to be similar to those with other patients with long term chronic illnesses. It has been suggested that many IBS patients were more than willing to address any psychological dimension to their symptoms, and accept the mind-body concept. Bray et al., (2006) also identified the fact that extraintestinal causes related to more time off work than IBS symptoms, which has been found in other literature.

Gerson et al., (2006) suggested that IBS was often associated with stress and anxiety, and that family relationships had an inverse effect on the ability to cope. Conflict within the family was associated with an increased symptom score. If physicians were focussing on the absence of pathological findings while the patient is experiencing lack of family support there was a much reduced chance of relieving the patient's distress.

The age group of the patient is also possibly another factor in reported severity of QOL, where Motzer et al., (2003) found QOL to be lower in women aged between eighteen and forty nine. This is a key period in terms of building relationships, family and socialising. The ability to socialise was significantly impaired in younger patients

with IBS (Minocha et al., 2006) where the unpredictability of their symptoms could often find them in physical discomfort or feeling embarrassed (Talley, 2004).

Day to day QOL is affected in patients in many ways. Work productivity is decreased, (Bertram et al., 2001), and an individual's social life is also often affected. This can lead to people socially isolating themselves (Dancey et al., 2002). Flatulence and borborygmi are usually perceived as socially undesirable, and individuals fear stigmatisation. This also affects relationships, particularly for women who feel that symptoms make them less attractive. Women were more likely to be embarrassed by their symptoms, concerned that they didn't smell nice, that IBS symptoms might impact on their outward appearance, and were afraid of losing control of bodily functions (Payne, 2004). Meanwhile, men appeared to be less likely to seek help, being embarrassed and shamed by their symptoms, not wanting to waste health care resources.

So far, predictors of the evolution of IBS have yet to be adequately identified, and there is little evidence on how patients improve in symptom severity (Mearin, et al., 2006). Schoenfeld and Talley (2006) suggest that improvement in QOL in IBS patients needs to be measured more by reduction in symptoms as a primary endpoint, and by measuring specific symptoms as secondary endpoints.

Embarrassing symptoms can lead to withdrawal from society and family relationships can be affected. It is unclear to patients and clinicians as to which causes what, the 'chicken and egg' syndrome, as stress and symptoms go hand in hand. This provides

opportunities for nurses to offer holistic care that can help to unravel this puzzle and steer the individual toward the appropriate resource.

2.10 *Management of Irritable Bowel Syndrome*

Back in 1999 it was recommended that the best approach was patient education, with a basic explanation of the pathophysiology of IBS, and how the gut works (Paterson et al., 1999). Direct patient-physician communication was imperative.

Today, management of IBS focusses more on symptomatic relief by a variety of 1) medications, 2) psychological interventions including hypnotherapy, acupuncture, or 3) dietary manipulation. Medications target specific types of symptoms, such as an antidiarrhoeal agent, antispasmodics and antidepressants (Mearin, 2006).

The main antidiarrhoeal agent used is Loperamide. This is a synthetic opioid that reduces gut secretions and inhibits propulsive movements in the gut, allowing more reabsorption of water and electrolytes (Bryant & Knights, 2007). This reduces stool frequency and helps reduce urgency and borborygmi. Codeine is also available, but not recommended by some because of the risk of dependence (Talley, 2004). This is usually a discretionary matter between the physician and patient, who would determine the appropriate use of codeine. Bulking agents such as Psyllium husk, or Metamucil, are also used in diarrhoea to bulk up stool consistency (Bryant & Knights, 2007).

Lactulose and Macrogol (Movicol), both osmotic laxatives, are often first line treatments for constipation predominant IBS (Bryant & Knights, 2007). A high fluid intake is needed when taking any bulking agent or any laxative (Greenberg et al, 2002). This is especially so with Lactulose, commonly used in the elderly, which can also increase abdominal cramps, and is sometimes poorly tolerated (Talley, 2003). Others include stool softeners, and stimulant laxatives. There is some controversy regarding the efficacy of bulking agents in IBS, as they can increase bloating, though they do improve stool consistency (Lesbros-Pantoflickova, Michetti, Fraid, Beglinger & Blum, 2005).

A recent clinical trial looks promising, introducing a glucagon like peptide -1 (GLP-1) synthetically manufactured, identified as ROSE-101. GLP-1 is released after eating, stimulating insulin release, reducing gastric emptying and slowing intestinal motility (Hellstrom et al., 2008). IBS patients were found to have a significant reduction in post prandial abdominal pain, as well as relief on demand of episodic acute abdominal pain.

The success of antispasmodics is questionable (Mearin, 2006). There have been several trials which have had limited success with patients dropping out. There have been antispasmodics that had some success in the past, such as cimetropium bromide, pinaverium bromide, but due to adverse events these became unavailable.

Mebeverine, a smooth muscle relaxant, has been found superior to placebo (Talley, 2003), and peppermint oil has also been found to have antispasmodic properties.

Wind and bloating has been successfully relieved in some patients by the use of peppermint oil (Bryant & Knights, 2007), though if the enteric coating isn't secure it

can reflux from relaxation of the lower oesophageal sphincter. Shen and Nahas (2009) reported on a placebo controlled study where seventy five percent of patients who took four peppermint oil capsules a day for four weeks had a significant improvement in symptoms compared to thirty eight percent on placebo.

There is interest in the theory that small intestinal bacterial overgrowth (SIBO) may be responsible for IBS symptoms, and antibiotics aimed at treating this have been trialled. For example Rifaximin (not yet available in New Zealand), has minimal systemic absorption (Lacy, 2007) and is well tolerated. This antibiotic showed an overall improvement in symptoms in comparison to placebo.

SSRI's may have the most benefit in constipation predominant IBS as they increase oro-caecal transit time (Talley, 2003). In the last few years, serotonergic agents that treated both diarrhoea and constipation were developed (Spiller, 2005). Tegaserod, which is a 5-HT₄ agonist was used for constipation with good effect, as were Cilansetron and Alosetron, 5HT₃ antagonists, useful for diarrhoea (Jones, 2004). Unfortunately both these medications have had some severe adverse reactions that now either limit their use, or are not currently available (Harris & Chang, 2006).

Probiotics have come to the fore in recent times. Diarrhoea can result from use of antibiotics, as well as from a gastrointestinal infection, altering the balance of bacteria in the gut (Goosens., 2003). Benefits from probiotics have been shown in reducing antibiotic associated diarrhoea and post infectious IBS, however not everyone responds well. Kajander, Hatakka, Poussa, Farkkila & Korpela (2005) found that while there was a positive reduction in symptoms of IBS with the use of a probiotic

mixture, QOL did not improve. The study group completed a symptom diary every month, and a quality of life questionnaire at half way and end point. Other studies show positive results with different strains of probiotics, for example *Bifidobacterium infantis* reduced flatulence, bloating and abdominal pain (Harris & Chang, 2006).

The role of psychotherapy is still unclear (Creed et al., 2005), however patients with a history of abuse responded well to psychotherapy, possibly because their perceptions of pain was altered. Their recommendation is that psychological intervention be used in patients with severe IBS who have not responded to other treatments. This will only work, however if psychotherapy is available, as not all clinics have a multidisciplinary team. Other factors need to be considered with psychotherapy, such as patient preference, the cost of therapy sessions, and the abilities and availability of the therapist (Shen & Nahas, 2009). No one really understands the enteric nervous system and the gut-brain axis. Coping strategies and QOL could well be improved though if psychological intervention changed a patient's belief structure Naliboff et al., (2008).

Several different psychotherapy approaches were discussed by Naliboff et al., (2008), where cognitive behavioural therapy was one of the more popular approaches. Other approaches included brief psychodynamic psychotherapy, hypnotherapy, meditation, and an acceptance and commitment theory. Psychological treatments which emphasised stress management, self empowerment and positive coping skills have been proven to be efficacious. Creed et al., (2008), found patients with severe symptoms who also somatised, responded highly to either psychotherapy or paroxetine. They identified the fact that these patients were more likely to be seen in

secondary, rather than primary care clinics. Both tricyclic antidepressants and SSRIs have been used to some benefit over the years. A systematic review by Ford, Talley, Schoenfeld, Quigley & Moayyedi (2008) showed these to be still effective in the treatment of IBS. They suggested the reasons they are effective is still unclear. Tricyclics have central analgesic actions as well as an anticholinergic effect (Talley, 2004). This would be of benefit to some degree with diarrhoea predominant IBS.

Hypnotherapy, in the form of gut directed hypnotherapy (GDH) was reported 20 years ago in the management of IBS (Wilson, Madison, Roberts, Greenfield & Singh, 2006). Various studies have shown improvement through GDH, though Wilson et al., in their systematic review of studies on GDH, found significant fault with the trials. However, the investigations of GDH suggest that existing treatment centres are achieving good results. Smith (2005) found patients had a high anxiety level related to uncertainty of diagnosis, and severity of symptoms. Hypnotherapy resulted in significant improvement in both anxiety and depression. It was suggested that this worked well as a complimentary management strategy with specialist gastrointestinal nurses. This was because nurses were more aware of patients' responses and that the nursing support itself is able to reduce anxiety. Sanders, Blanchard and Sykes (2007) found a modest improvement in symptoms with patients who self administered treatments found through the reading of a self help book. There was, however, no improvement in QOL.

Dietary manipulation has been a recommended management strategy as many patients have found particular foods to trigger symptoms. Dietary literature is now exploring the mono, oligo and disaccharide groups of carbohydrates (Burden, 2001; Shepherd &

Gibson, 2006). These are fructans, closely linked to fructose. As they are not digested they can rapidly ferment in the bowel causing abdominal symptoms, such as bloating and pain. Fructose malabsorption can be reasonably common, and is not restricted to people with IBS, though the response is stronger in patients with IBS (Shepherd et al., 2008).

The development of an IBS “school” was a successful intervention utilising different key clinicians each session (Ringstrom, Storsrud, Lundqvist, Westman & Simren, 2009). Patients benefitted from key inputs from specialists such as a gastroenterologist, dietitian, physiotherapist, psychologist and nurse specialist, where information and education was successful within the multidisciplinary approach.

Over time there seems to have been few changes in treatment or management of IBS symptoms other than alternative therapies such as herbal remedies, hypnotherapy and acupuncture (Shen & Nahas, 2009). These are all seen as actions of treating the symptoms of the patient. Paterson et al., (1999) identified that patients needed to be listened to, having symptoms and experiences validated, as well as educating and reinforcing management strategies tailored to the individual. These are key factors today. No matter how many drugs one can offer a patient, the attitude of the practitioner consulted by the patient is going to impact enormously on the patient’s ability to improve and cope. This includes the ability of the practitioner to convey to the patient the role they need to take in overcoming their illness. Management by a specialist nurse offers a unique resource that should be accessible to all. The role of a specialist nurse in gastroenterology is different to the role of a doctor and brings a variety of skills that is not limited to focussing on IBS.

2.11 *Advanced Nursing Practice and Gastroenterology*

There are numerous titles for a nurse who is practising at an advanced level. These include clinical nurse specialist, Nurse Practitioner (NP), advanced nursing practitioner (ANP), advanced practice nurse (APN), nurse educator, Nurse Consultant, Certified Nurse Anaesthetist and Certified Nurse Midwife. (Dyson, 1997; Laperriere, 2008; Norton & Kamm, 2002). Qualified Nurse Practitioners are specially licensed nurses practising autonomously, who have now begun to prove their efficacy and worth in health care. This is a protected title in New Zealand, identifying a particular kind of nurse who has a Master's Degree, met competencies and assessment criteria as set by Nursing Council, and has had a minimum of four to five years experience in advanced nursing in a particular area of expertise (Ministry of Health, 2002).

Slowly the medical profession is realising that the NP role is a complimentary rather than a threatening role. In the UK it is becoming more recognised that the boundaries separating nurses from doctors and pharmacists are becoming less clear as the need for services that are driven by patient need is more obvious (Mayberry & Mayberry, 2003).

Not all medical practitioners support an NP role. A study by Cheung, Dove, Lervy, Russell and Williams, (2002) found that many GPs were in support of a specialist gastrointestinal nurse role for supporting shared care, but the reasons were more task oriented, such as arranging appointments, accessibility for advice and reducing medical workload. Mayberry and Mayberry (2003), on the other hand, described the

range of interventions, including counselling, that a gastroenterology NP should be able to do. These include the ability to take a history, perform a relevant physical exam, perform appropriate investigations which includes endoscopy, prescribe, and give advice and counsel on management and prognosis. They insist that the different philosophical approach by an NP brings both benefits and limitations. Traditional borders were blurred, but nursing expertise continues to potentially provide more comprehensive care. There was a risk involved where it was expected that a nurse would take on roles that were traditionally medical (Dyson, 1997), however this has brought about some unique nursing roles such as diabetes nurse specialists, wound care nurse specialists and stoma care nurse specialists.

As a considerable number of patients seen by gastroenterologists have a functional disorder such as IBS or functional dyspepsia, Norton and Kamm (2002), identified a need for a nurse specialised in gastroenterology to care for these patients. They suggested that medical models of care are inappropriate for these patients.

Heitkemper and Bond (2004) investigated the value of clinical nurse specialists delivering cognitive behavioural interventions to patients with IBS. They found significant improvement in symptoms and QOL in patients irrespective of the number of sessions.

Patients are generally very satisfied with care given by NPs and have expressed confidence in their expertise (Hayes, 2007). A study involving NPs in gastroenterology showed increased patient satisfaction, increased cost savings, lower hospitalisation rates or length of time in hospital and a decrease in the number of emergency department visits (Hillier, 2001). Cheung., (2002) felt that shared care

with a gastrointestinal NP would enhance the management, and increase empowerment of patients in taking responsibility for their care. Nurses are in an ideal position to empower and encourage autonomy and creativity in individuals and groups with a common goal toward health (Laperriere, 2008).

Fellow nurses need to support those who take on the challenges of advanced nursing practice. According to Morcom, Dunn and Luxford (2004) collegial support of a nurse specialist contributed to the success of the development of an NP role in colorectal cancer screening performing flexible sigmoidoscopies. There was a sporadic start to the service while GPs became acquainted with the service, but referrals soon increased, and private gastroenterologists soon recognised the benefits of the time spent by the NP in educating and reassuring the patient. Maruthachalam, Stoker, Nicholson and Horgan (2006), also studied the benefits of nurse led flexible sigmoidoscopies which not only saved money, but led on to colorectal nurse specialists who treated conditions such as anal fissures and haemorrhoids. This is very much a part of services offered in the United Kingdom now, most likely due to the strain on the National Health scheme. This indicates that, in the UK, if there is a need and nurses can competently and safely do it, then it is an acceptable practice. The use of specialist nurses in the United Kingdom has seen a decrease in clinic visits because of the focus on assessing coping skills and teaching self management in IBD and IBS instead of the paternalistic 'illness service' (Norton & Kamm, 2002).

These days, with easy access to information, the patient is now better informed and less tolerant of waiting lists and inadequate answers (Norton & Kamm, 2002). The increasing range of specialist nurses and nurse practitioners in Europe and the USA is

well suited to meet the needs of both patient and physician. In fact, in the UK nurse endoscopists perform gastroscopies and colonoscopies.

The USA system of NPs appears to fulfill an increasingly important role in providing healthcare, patients reporting total satisfaction and trust in the advice and care given by the NP (Hayes, 2007). Communication is closely linked to patient satisfaction and is an integral component of any interpersonal relationships, as is trust and compassion (Redsell, Stokes, Jackson, Hastings & Baker, 2006). In countries where the NP role is still unfolding, such as in New Zealand and Australia, patients are still learning the difference in roles. The act of developing trust is an iterative process, which means that NPs and advanced practitioners need to be flexible and adaptable in their approach, bringing innovation within these new sets of constraints (Litchfield 1998)

There is a trend amongst some patients who are not satisfied with the treatment they receive from the medical profession to be drawn to alternative therapies. According to Norton and Kamm (2002), NPs and advanced practitioners can be placed between the two, providing holistic care from the nursing model that is different to the medical model. This way, the needs of the patient are able to be met. Because of the increasing use of alternative medicine it is important that nurse specialists at whatever level, are familiar with the range of options. There is an abundance of 'natural remedies' available that are promoted for bowel care, and in particular IBS. There is a safety issue here with potential drug interactions as well as unknown effects on the bowel (Bryant & Knights, 2007). This is where the ANP and NP knowledge and expertise is vital. The ANP cannot prescribe, but must have a good grounding in

pharmacology to improve safety in management of patients. The ANP must have advanced theoretical qualifications and critical thinking skills (Dyson, 1997). The NP can improve on current management strategies of IBS patients, by being able to prescribe appropriate medications. The current restrictions on prescribing can be overcome through collaboration and consultation with gastroenterologists and other specialists. It is anticipated that many restrictions will be lifted in the next three to five years. (Snell, Robinson & Perry, 2009).

It has been identified that a patient is able to change their health-seeking behaviour when the HCP, (in this article, the physician) takes notice of their beliefs and anxieties and their knowledge, expectations and fears around their symptoms (Kolowski et al., 2001). The nursing approach is more of a partnership (Jonsdottir, Litchfield & Pharris, 2004) where insight and attention assists the patient in finding their own meaning of health. Key contributing factors to their health status are identified through working with the patient, and the appropriate approach to the patient's health predicament is made. This approach spells the difference between medicine and nursing. The Nurse Practitioner, an advanced nurse practitioner or nurse specialist all have key leadership roles that define the difference in patient management.

Spiegel et al (2008) identified the need for a balanced biopsychosocial history in order to appreciate the patient's perceptions of severity of illness, gastro-intestinal and extra-intestinal symptoms compounding their anxieties. Inquiring about family relationships is an approach all HCPs should be taking (Gerson et al, 2006) as the health of the relationship is important in treating the illness. Recognition of the psychological needs of the patient and implementation of therapy has its place as part

of the holistic approach which is ingrained in every nursing student. It is important to not forget the application of a nursing theoretical model such as Orem, Roy, or Watson (McCutcheon, 2004). By choosing a theoretical framework from which a nurse can base their practice will help clearly delineate the boundary between doctor and nurse. This is particularly relevant to an NP, as he/she has autonomy over their practice, and can intervene, and refer on as necessary.

In order to strive towards health, all aspects of the individual need exploring, and nurses spend time talking and educating their patients. Patient assessment is holistic, exploring family history and dynamics as well as past history, culture and health education (Morcom et al, 2004). Nursing theories have identified that health incorporates more than the absence of disease where the patient is a pathophysiological object (Jonsdottir., 2004). The success rate in treatment of children with chronic constipation by advanced nurse management in comparison to a doctor led clinic showed children improved much quicker with the nurse than the doctor (Burnett, Juszczak & Sullivan, 2004). The reason given for this was the different approach to treatment, where nurses focussed on the whole person and on education as compared to symptom identification and treatment.

The economic impact of IBS on the individual, the gastroenterologist and the GP has been well documented and the use of specialised nurses is recognised in countries such as the USA and the UK. Nurses are performing roles traditionally seen as medical, such as endoscopy and flexible sigmoidoscopy. The relationship between specialist nurses and patients is very different to those with a doctor as the nursing model operates uniquely and holistically. Patients are appreciative of nurse care,

especially when it means avoiding long waits in the public health sector. It will take time and hard work for such opportunities to occur in other countries where the NP role is not yet properly recognised by the medical fraternity. Given the opportunity and education, the large gap in IBS care can be competently managed by either an ANP or an NP, depending on the individual environment.

2.12 *Development of a Questionnaire*

Over the years a variety of questionnaires have been developed and validated for use in different studies. Many examine QOL, such as in Patrick et al., (1998) who created and validated the Irritable Bowel Syndrome- Quality of Life (IBS-QOL) tool.

Wiklund et al., (2003) developed a new questionnaire by expanding on an already existing questionnaire measuring gastrointestinal symptoms, in order to measure non physiological responses in IBS patients. A number of correlations between symptoms and activities were made. They refer to other questionnaires commonly used such as the Hospital Anxiety and Depression (HAD) scale, and the IBS-QOL, among others.

Francis, Morris & Whorwell, (1997) were possibly the first to develop a scoring system for severity of symptoms in IBS patients. Talley et al., (1995) had already developed a Bowel Symptom Questionnaire (BSQ) which was used for the measurement of chronic gastrointestinal disease in Australians. (Wong, Guyatt, Cook, Griffith, and Irvine, (1998) developed a questionnaire to measure QOL in IBS, when there were no specific questionnaires for IBS, as did Patrick et al., (1998), about the same time, although over the past few years more questionnaires have been developed that look at psychometric elements, and methodological tools for research.

Bengtsson, Ohlsson and Ulander (2007) identified a need for a tool that could translate how a patient feels into numbers, that was not too long. As a result they created the Visual Analogue Scale-IBS (VAS-IBS) in order to discern a clinical opinion of how a patient is feeling over a period of time.

Because IBS fluctuates in severity it is difficult to measure outcomes (Roalfe, Roberts & Wilson, 2008), yet the Rome committees (an International group of gastroenterologists) have repeatedly said that patient centered outcome should be the main assessment. It was suggested that satisfactory, or adequate relief is an acceptable outcome, but this relates generally to trials, not to ongoing management.

The VAS-IBS tool was created by Bengtsson et al., (2007) to measure response to therapy. Roalfe et al., (2008) commented that the VAS-IBS tool was only tested on women, and needs a wider application in clinical practice. Bengtsson et al created their own tool because they felt there were too many questions required in previously validated tools, overwhelming the patient. The VAS-IBS tool was designed for use in the clinical setting to assist the clinician in assessing an individual's response to therapy. The Bengtsson tool is too brief and non specific, therefore insufficient for use outside the consultation. The subjectivity of three of the five questions, especially the question "How do you rate your mental well-being over the past month?" (Bengtsson et al., 2007, p7), potentially restricts its applicability to other research. Tools designed to be patient friendly by its brevity are invariably used alongside several other questionnaires for the purposes of a particular study. Completion of multiple questionnaires defeats the purpose of brevity.

The 'satisfactory outcome' as suggested by the Rome committees was assessed by Whitehead et al., (2006a) who developed a questionnaire specifically for their study. Their findings were confounded by symptom severity at baseline and were subsequently challenged by Schoenfeld and Talley (2006) who suggested their primary endpoint should be assessed by improvement in IBS symptoms. The tool Whitehead et al., (2006a) created, was specifically designed for this study, though other previously validated questionnaires were also applied. Gerson et al., (2006) created their own unvalidated tool for their study, alongside previously validated questionnaires such as the 'quality of relationship inventory, (QRI)' and the Short Form-36 (SF-36), a validated scale of thirty six questions focussing on eight different health issues, ranging from physical functioning, through pain, mental health, to general health perceptions.

A significant number of tools appear to be generic rather than specifically related to IBS, for example, the HRQOL tool, SF-36, and the HAD scale. The BDQ the BSQ relate generally to bowel diseases and not specifically IBS. While all these instruments potentially have a place in capturing the essence of the impact of IBS on an individual, the actual effect on day to day coping, family life and quality of life is not adequately captured by these instruments. Generic tools miss specific elements of patient experiences in IBS. They are unlikely to detect important changes, especially if they are small (Wong et al., 1998). While it is wise to use previously validated tools for research, there are some areas of research that need specific tools. IBS is a complex disorder from which there are many approaches to study it, with no easy answer.

2.13 Conclusion

It has been stated that there are several faces to IBS with many different factors behind the syndrome. The effects on the individual, the community, and the health care system is large, financially, and from a QOL perspective. Patients do not cope well with being told there is nothing wrong with them while experiencing difficult symptoms, and many doctors become exasperated with repeat attenders who are not managing as was otherwise expected.

More recent studies indicate a paradigm shift in thinking on the causes of IBS symptoms. The recent studies on post infectious IBS, the role of serotonin and theories of underlying quiescent inflammation suggest more studies need to be conducted on identifying the causes of IBS symptoms and the treatment of those causes, rather than treating symptoms alone. Articles discuss the effects of stress, and its all too frequent precursor abuse, on the gut.

Treatment of symptoms appears to be the focus of some literature. A lot of research has gone into pharmacotherapy treatment for IBS looking at the role of SSRIs, TCAs, and other symptom specific drugs (Talley, 2003). Others explored the costs and economic impact (Cash & Chey, 2004), psychological and environmental issues (Bray et al, 2006; Gerson et al, 2006), and the brain-gut axis (Grundy & Schemann, 2006). Little research has been done on the response of patients to education and understanding with psychological input and dietary advice. Apart from a few studies the literature appears to be repeating itself.

Finally, various studies have explored the roles of an advanced nurse specialist and the nurse practitioner where it has been shown that nurses provide a more holistic approach to the individual. While for some patients this is an iterative learning curve to trust the expertise of the nurse, others value the time given and the total care of the individual rather than seeing only a disease process. As it can be extrapolated that there is an overlap of different pathophysiological triggers (Halder et al, 2007), management of patients with IBS is unique to each individual requiring dedicated time and resources. This study aims to show that a dedicated advanced nurse practitioner (as opposed to a licensed Nurse Practitioner) in IBS positively influences the outcomes and management of patients with symptoms of irritable bowel syndrome.

CHAPTER THREE

Methodology

3.1 *Introduction*

This chapter describes the study design, methodology, and data analysis. A two phase descriptive quantitative approach was used to answer the following research question.

Does an advanced nurse practitioner led service improve the identification and management of patients with symptoms of IBS?

3.2 *Research Design*

This descriptive, biphasal study was conducted in a cohort of patients attending a private Irritable Bowel Syndrome Service. Data collected from eighty one patients attending the IBS service between May 2005 and March 2008 was referred to as retrospective data or phase one. A research questionnaire was added for patients registering between April 2008 and November 2008. The number of patients recruited into phase two, (prospective data) was fifty five though after attrition the final number was forty five. The descriptive biphasic design was chosen as it was recommended as the best design for simple comparisons between variables (Polit & Beck, 2004). A biostatistician was consulted for assistance with study design and selection of variables.

The aim of phase I of the study was to describe selected characteristics of the patients seen at the IBS service. This was needed to help establish that the patients in phase II, the focus of this study, were representative of patients attending the service. The aim of phase II was to explore the research question by 1) identifying the diagnostic outcome of patients referred with IBS; and 2) comparing patient symptom severity, satisfaction, quality of life, and coping strategies before and after attending the IBS service. Demographics were gathered for comparison of phase I with phase II, and to promote context for other findings.

3.3 *Study Variables*

For the purpose of this study improved identification and improved management must be defined. Patients were referred with a provisional diagnosis of IBS, underlying causes generally unknown. Improved identification refers to the identification of an alternate diagnosis underlying the causes of symptoms, for example Crohn's disease, after consultation at the IBS service. Improved management means improved satisfaction with care, quality of life, and coping skills, and a reduction in the number and severity of symptoms.

3.4 *Instruments*

3.4.1 *Phase 1*

Phase 1 examined data gathered from eighty one patients referred to the service by GPs, specialists, or self referred, from May 2005 to March 2008. These patients had had a consultation with the ANP which included a full history, review of systems, and

family history. Inquiries are made regarding childhood and experiences because of the correlation of trauma in early years and IBS (Lackner et al., 2006). Relevant physical examination including rectal exam is performed, and blood and stool tests including faecal calprotectin (Gearry et al., 2005) and coeliac antibodies collected. Patients completed a food and symptom diary as well as the IBS questionnaire, and returned for a review consultation two weeks later where findings and management strategies were discussed, including referral on if needed. All patients were aged eighteen and over, and had met Rome II criteria for IBS. This data was gathered from a spreadsheet containing information from the clinic questionnaire. All data from the questionnaire has been kept, since inception of the service, on a spreadsheet in anticipation of reviewing practice. Additional data entered on the spreadsheet was the final outcome after consulting the IBS service. This included to which specialist they were referred, such as a gastroenterologist, colorectal surgeon, or to their GP with recommendations. This data included any identified alternate diagnosis.

The clinic questionnaire was designed to gather data on age and gender, different symptoms and different types of symptoms, defaecation patterns, along with pain and symptom severity scores. It was intended to ensure no critical information was missed at consultation and complement data already gathered. Any non IBS symptoms would be identified. Subjects were asked to tick boxes in this questionnaire relating to;

- 1) types of symptoms,
- 2) types of stool, and
- 3) frequency, consistency, and passage of stool.

(see appendix 1)

This data revealed how patients defined constipation or diarrhoea. Clarifying definitions with the patient during consultation ensured accurate classification of IBS subtypes (A-IBS, D-IBS, C-IBS & P-IBS). As this questionnaire was given to all patients attending the service, patients in phase II also completed this questionnaire from which their IBS subtype was identified.

3.4.2 *Reliability of phase I data*

Reliability of a tool is defined as the degree of consistency and dependability the tool has in the measurement of data for which it was designed (Polit & Beck, 2004). The questionnaire used in phase I had been in use for four years and has undergone minor refinements over that time. These refinements did not affect the constancy of data over the years. It has been reported to be easy to use by patients at home with no issues arising over patient understanding of the questions. Data supplied by completed questionnaires correlated with data given at initial consult indicating reliability. This tool was designed based on validated proformas used in IBS clinics in the United Kingdom and in consultation with a colorectal surgeon in the service. The only data used from this questionnaire in this study were age, gender, and IBS subtype.

All data from each questionnaire of every patient seen was transcribed onto a spreadsheet as soon as it was returned. The spreadsheet is anonymous, in that a number was assigned to each questionnaire before that data was entered on the spreadsheet. Additional data added to the end of the spreadsheet was done by cross identification of patient ID numbers with questionnaire numbers and data entered as

soon as outcome was known. As information was gathered from the spreadsheet only it was not easily identifiable. The only data obtained other than age gender and subtype, was an alternate diagnosis.

3.4.3 Phase II

Phase II of the study involved the completion of an IBS research questionnaire on two occasions, the first given at the initial consultation for patients to take home and complete. The second questionnaire, was sent to the patient at three months after their second consultation which took place two weeks after the first. This questionnaire was the same as the first but excluded demographic questions. Patients in phase II were those seen between April 2008 and November 2008. All patients were aged eighteen and over, and met Rome II criteria for identification of IBS. The questionnaire contained a section on demographics using official census questions as recommended by the Ethics Committee. Demographic data were excluded at the second data collection as it was unnecessary to collect twice. The questionnaires were divided into four sections. The first captured information on the number of IBS symptoms experienced, and descriptors of their experience, frequency and severity. The second section related to patient perceptions' management by their HCP of IBS. The third section related to impact of IBS on QOL, and the fourth section on coping strategies they may have developed.

3.4.4 Reliability and validity of phase II questionnaires

The IBS-PP was created with the assistance of the literature (Dancey, 2002; El-Serag et al., 2004; Kolowski et al., 2001; Patrick et al., 1998; Whitehead et al., 2006a; Wong et al., 1998), a gastroenterologist, and a colorectal surgeon at the study site. The use of extensive literature with experts in the field supported the validity of the instrument. According to Polit & Beck (2004), the validity is the degree to which the tool has measured what it was intended to measure.

The reliability of phase II questionnaires was assessed by the consistency with which patients responded to the both phase II questionnaires. Questions were phrased in the ‘ceiling/floor’ effect so that a negative response could mean “not at all” in one question, and “always” in another. This was to avoid a patient response of uniformly ticking down one side of the column. Responses were recoded floor-floor/ceiling-ceiling for analysis.

A pilot study using other staff, and pre study patient volunteers was conducted to evaluate the use of the tool and the ease of answering questions. No major refining was required, only one participant thought wording in one sentence may have been ambiguous. No changes were made as no other pilot study participants had any concerns.

3.5 *Study Subjects*

The study population in both phases were patients who had either been referred from a HCP, usually either their GP or another specialist, or self referred to the IBS service with a provisional diagnosis of IBS.

Inclusion criteria for phase I were:

- 1) The patient met Rome II criteria at initial consultation regardless of the outcome.
- 2) The patient had completed the IBS service questionnaire and had attended two consultations with the IBS nurse specialist.
- 3) The patient had to have attended the service prior to the commencement of phase II.

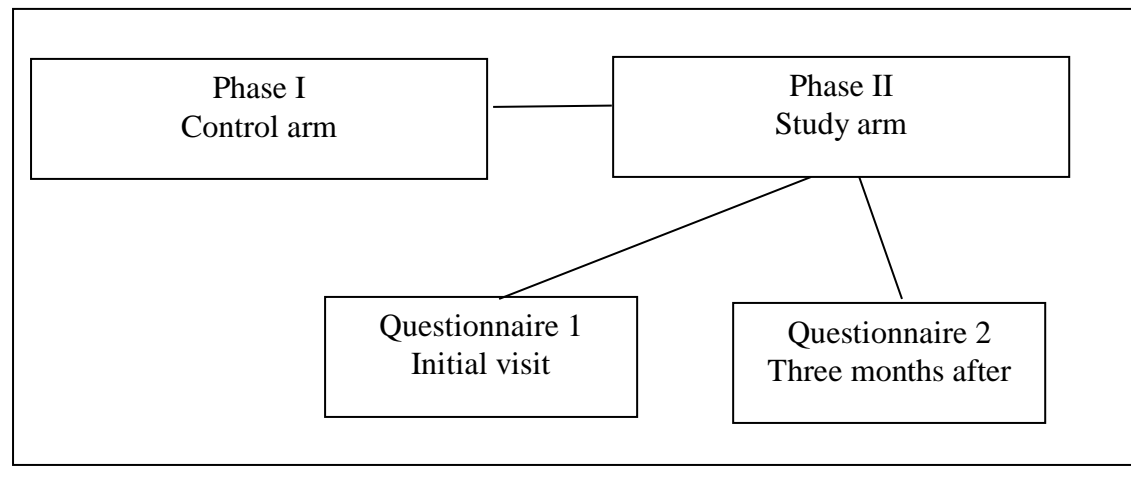
Inclusion criteria for phase II were

- 1) The patient met Rome II criteria at initial consult regardless of the outcome.
- 2) The patient needed to have completed the IBS service questionnaires and the first of the phase II questionnaires; by returning this was consent.
- 3) The patient needed to have completed and returned the second phase II questionnaire within three and a half months.

3.6 *study procedure*

Figure 4

Diagrammatic perspective of study procedure



All patients, in phase I, the retrospective arm, and phase II, the prospective arm, were seen by the researcher in an initial consultation and returned for a review consultation to discuss findings and outcomes. Referral to a dietitian, counsellor, or a medical or surgical specialist was recommended if necessary, and a management plan created for all patients irrespective of phase. All data from the patient IBS service clinic questionnaire was routinely entered onto a spreadsheet, identifiable only by a patient number. Relevant data for phase I was extracted from this spreadsheet for those first patients meeting study criteria.

Phase II patients were new patients presenting between April 2008 and November 2008 who attended initial consult and review as the same process as above. At initial consultation patients were given the first of the two phase II questionnaires accompanied by an explanation sheet about the research and were invited to participate. It was explained that completing and returning the questionnaire in the

supplied prepaid envelope implied consent. The patient was reassured that non participation would not affect care in any way. Patients were considered to have declined the invitation to participate if they did not return the questionnaire. Questionnaires returned by mail before the second consultation were numbered and filed. This ensured blinding of research participation to researcher who was also the care provider.

A second questionnaire containing the same questions, minus demographics, was sent to every patient who completed and returned the first questionnaire. This occurred three months after their second consult at the IBS service. The three month period allowed time for memory of responses in the first questionnaire to fade. To ensure a maximum return rate of the second questionnaires, one follow up telephone call was made to each subject within two weeks of mailing if there had been no response. Both phase II questionnaires were self completed by the patient at home.

3.7 *Ethics Committee Approval*

Application was made to the Ethics Committee in Christchurch. Both phases were approved by the Upper South A Ethics Committee, Christchurch, in March 2008. It was the Ethics' committee's recommendation that return of a completed questionnaire implied consent.

No patient was offered any incentive for completing either questionnaire. There was no difference in treatment of those who participated and those who didn't. As this is a

private clinic each patient pays a small fee for consultation. No one was offered a free consult.

3.8 *Maori Consultation*

Maori consultation was sought via Elizabeth Cunningham from the University Of Otago School Of Medicine, Christchurch Campus in February 2008, and assurance given that the number of Maori participating in the study would be reported to Maori Health Research. Assurance was given that there are no procedures or questions that could affect Maori cultural protocol.

3.9 *Confidentiality*

All data, both retrospective and prospective, was only identifiable via an assigned subject number. No patient could be identified by either information on the EXCEL spreadsheet, or the Phase II patient questionnaires. All raw data is contained in a password protected computer that is only able to be accessed by the researcher. Hard copy data is stored in a locked cupboard at the researcher's place of employment.

3.10 *Data Analysis*

3.10.1 *Phase I the control arm*

Phase I data was entered onto an EXCEL spreadsheet where descriptive statistics were applied. That is, frequency distributions, percentages or proportions, measures of central tendency and standard deviations were used to describe the subjects with

regard to age, gender, subtype of IBS, and alternate diagnosis. This data was later used to help determine the characteristics representative of the phase II study sample.

Comparisons between age, gender, IBS subtype variables, and alternate diagnosis were made using Chi square (χ^2) and t-test on data from phase I and phase II. This was to establish phase II subjects were representative of the typical patient presenting to the IBS service.

3.10.2 Phase II the study arm

A comparison of the data from time one and time two of Phase II was conducted. Raw data from both phase II questionnaires were entered onto an EXCEL spreadsheet and transferred to an SPSS file for analysis. The data were determined to be free of ceiling or floor effects. Descriptive statistics were applied to all Phase II data. That is, frequency distributions, percentages or proportions, measures of central tendency and standard deviations as indicated by data, described the subjects. Change over the three months on the four subscales were explored between subjects using two tailed t-tests.

2.3 Limitations of the Study

The sample size in phase II was small, with forty five participants. The target number of between fifty and eighty participants was set because this was a realistic estimate of the number of new patients referred in the set time frame. Fifty five patients were recruited, though only forty five completed the study. The small size of the patient

population studied makes it easier for type II statistical errors to occur. A larger sample size would give more strength to study results.

As there was only one clinic involved in the study, findings cannot be compared across groups, nor can findings be generalised beyond this practice. There are no other local specialist practices with which to compare, the literature being the only means of validation. Further research needs to be conducted in consultation with other nurse led clinics in similar disciplines.

The questionnaire used in this study was designed by the researcher based on other questionnaires in other studies, and has been minimally piloted. This may affect the reliability and validity of the tool and the data collected.

Factors such as not responding to some questions, nor allowing for total recovery from all symptoms of IBS, were not accounted for. There was no provision made in the prospective questionnaire for people who had become totally well. Several patients found that their symptoms totally disappeared after identification and treatment of the cause, but there was nowhere in the questionnaire for this to be documented. Patients identified with endometriosis became well, as did others identified with a specific diagnosis. Consequently some questions were not answered as they did not perceive them to be relevant. This would skew results either way. There was also no provision made in the questions for retired or widowed persons which meant they could not answer the questions relating to how their symptoms affected their work, or impacted on their relationship with their partners.

By patients completing their questionnaires at home some data was not entered, or was possibly entered incorrectly. Those with more than two questions missed from each section were not included in the analysis of that section, hence the different numbers in those three groups of data.

Some patients who were referred back to their GP with an alternate diagnosis discovered, such as a rectocele, may not have improved in symptoms, as the waiting period in the Public Sector is more than three months. Some of those whose symptoms were serious, such as one of the patients found to have bowel cancer, or those sent to the public sector with signs of IBD were lost to contact. The final outcome of some of these patients is not known.

Quality of life and coping strategies are subjective questions, so they are subject to placebo bias, therefore both questions are subject to respondent variability. What is severe for one person may be mild for another. There may have been patients recruited into the study who were eager to please. They may have erred on showing improvement in the second questionnaire, but this is difficult to quantify. The fact the researcher is the ANP whose key role was to identify concerns and manage IBS patients may have potentially caused a major error. She was known to the patients, and even though they were encouraged to be brutally honest it is inherent in human nature to please and not offend. It would have been more prudent to have had an independent person recruit participants who would have reassured participants that the researcher would not know who was a participant or not, even though the study was already blinded.

3.12 *Summary*

This chapter has outlined the design of the study, the methods used to gather data and the analytical approach taken. The main weaknesses in this study are that data was collected via a new questionnaire, and that there is no control or comparative group with which to compare. Chapter 4 will present the results of this study.

CHAPTER 4

Results

4.1 Introduction

The question “Does an advanced nurse practitioner led service improve the identification and management of patients with symptoms of IBS?”, was tested via a questionnaire given to a group of patients at initial consultation and at three months following. This group identified as “phase II” was compared with a control group of patients, “phase I”, to determine if phase II patients were representative of the typical practice population attending the IBS service. The phase I control group included all eighty one patients presenting to the IBS service between May 2005 and March 2008, for whom definitive data had been collected.

Fifty-five patients were recruited into phase II. Forty-five individuals in the prospective group completed both questionnaires. Of the eighteen percent who did not return the second questionnaires seventy percent were males. Only three females did not return the second questionnaire. Of those men who did not complete, fifty seven percent or four out seven were identified as having D-IBS. One other had A-IBS, the other two an alternate diagnosis, one being a hernia, the second, coeliac disease. These statistics were included in the data pertaining to IBS subtype and alternate diagnosis as this was known in the early stages of their consultations, and was not part of the analysis of comparative data. We had already compared these people in the demographics, and there was nothing unique about this population therefore we are confident that their missing data would not affect final results. An assumption was made that they did not represent a biased group.

4.2 Comparisons between Phase I group and Phase II group

Comparisons were made between the two groups on the following variables: age and gender, IBS subtype and the number of those identified with an alternate diagnosis. There was no significant difference in age, or gender between groups (see table 1).

Table 1

Comparisons between Phase I and Phase II in Age, Gender and IBS Subtype.

	Retrospective group	Prospective group	χ^2 (1) or	df	p. Value
	Group 1 n=81	Group 2 n=55	t-test (2)		
Mean age:	44.02	48.2	-1.27	134	0.203 (2)
Std dev	18.27	19.24			
Range	18-87	18-85			
No. males	23 (28%)	12 (22%)	0.741	1	0.389 (1)
A-IBS	21 (26%)	10 (18%)			
C-IBS	12 (15%)	9 (16%)			
D-IBS	17 (21%)	10 (18%)			
P-IBS	1 (1%)	2 (4%)			

(1) = χ^2 (2) = t-test

The proportions among IBS subtypes were similar, however there was a significant difference between phase I and phase II on alternate diagnoses. This will be discussed in chapter 5 (see tables 2 and 6).

Table 2

Alternate Diagnosis in phase I and phase II

	Retrospective group	Prospective group	χ^2	df	p. value
	Group 1	Group 2			
Alternate					
Diagnosis	30 (37%)	24 (43%)	2.259	1	0.016

4.3 PROSPECTIVE GROUP

Phase II Results

Fifty five people completed the first of the two questionnaires which contained demographic data. Thirteen percent identified themselves with another nationality, all but two being European or from the United Kingdom. One was from Sri Lanka, the other identified herself as New Zealand Chinese. That left eighty seven percent, all but one identified as New Zealand Caucasian, who called herself European New Zealand.

Twenty percent of study participants achieved National Certificate in Educational Achievement (NCEA) level one, which is equivalent to School Certificate, or year eleven at secondary school. Forty nine percent of study participants achieved either NCEA level 2 or 3, twenty two percent qualified with a Bachelor degree, and five percent with a Master's degree.

No one identified as unemployed. Three were on a sickness benefit, otherwise all were working or retired. Eleven percent were students, seven percent were self

employed, forty two percent were employees, six percent were on invalid/sickness benefit, twenty four percent were retired, four percent identified themselves as home makers, and six percent did not answer the question.

A paired sample t-test was conducted to evaluate the impact of the ANP led service on patient perceptions of health care, QOL, and coping strategies. A statistically significant difference was found on all variables except coping strategies from the questionnaire completed at initial consult and the questionnaire completed three months later. There was a statistically significant increase in patient satisfaction with the IBS ANP as compared to their initial HCP from their first questionnaire (M=29.46, SD=8.89) to the second, three months later (M=39.62, SD 4.81), $t(38) = -7.20$, $p < 0.001$. Results from the initial questionnaire compared to the questionnaire three months later also showed a statistically significant improvement in quality of life, the initial questionnaire (M=77.29, SD=18.39), and the later (M=88.64, SD=20.27), $t(41) = -3.83$, $p < 0.001$. There was no statistically significant difference in patient coping skills from the first questionnaire (M=40.48, SD=5.57) with the questionnaire three months later (M=40.41, SD=4.94), $t(38) = -.391$, $p 0.698$. There was a statistically significant decrease in symptom numbers from the initial questionnaire (M=3.89, SD=1.45) with the second questionnaire three months later (M=2.36, SD=1.17), $t(44) = 5.78$, $p < 0.001$.

A wilcoxon signed rank test revealed a statistically significant reduction in symptom severity at three months after consultation with the IBS ANP, $Z = -3.96$, $p < .001$. The same test was applied to symptom frequency, where at three months after consultation there was a statistically significant reduction. $Z = -4.43$, $p < .001$.

The confidence interval was ninety five percent (see table 4).

Table 3.

Comparisons of variables before and after consulting the IBS service using t-test

	Pre IBS service		3 months later		df	t-test	p value
	mean	SD	mean	SD			
1: Perceptions N=39	29.46	8.88	39.62	4.81	38	-7.20	<0.001
2: QOL N=42	77.29	18.39	88.64	20.27	41	-3.83	<0.001
3: Coping skills N=39	40.08	5.57	40.41	4.94	38	-.391	0.698
4: Symptom numbers N=45	3.89	1.45	2.36	1.17	44	5.78	<0.001

Table 4.

Comparisons of variables before and after consulting the IBS service using Wilcoxon signed rank test

	Pre IBS service	3 months later	Z score	p value
5: Symptom frequency	Mean 15.50	Mean 16.64	$Z = -3.96$	<0.001
6: Symptom severity	Mean 15.33	Mean 10.50	$Z = -4.43$	<0.001

Within these tables it is shown that all but coping skills are statistically significant.

Numbers vary in the three different variables; perceptions of the health care provider, QOL, and coping skills, because of non item response in several questionnaires. Questions relating to employment, and partner relationships were not answered by some. These people were found to be either retired, or widowed. Their responses were averaged with the averaged response in missing response categories.

Table 5

Alternate Diagnoses

	Retrospective N=81	Prospective N=55	BOTH
thyroid dysfunction	1	1	2
post haem.surgery	3	1	4
haemorrhoids	2	1	3
slow transit colon	2	1	3
rectocele	5	2	7
enteritis	2	1	3
IBD	6	4	10
myeloma	1		1
GERD	2	1	3
endometriosis	3	1	4
hernia	1	4	5
PCOS	1		1
bowel ca	1	1	2
fissures		2	2
Normal function		2	2
coeliac disease		1	1
sub acute bowel obstruction		1	1
TOTAL	30	24	54
PERCENTAGE	37%	43%	40%

4.4 Summary

This chapter has presented the findings of this study. There was no significant difference in age, gender and IBS subtype between the phase II study group, and the phase I control group. There was a significant difference between these two groups in the identification of alternative diagnoses with a larger percentage of alternative diagnoses found in phase II two. Apart from alternative diagnoses the study group was determined to be representative of the practice.

Demographics and academic status were described in group two. These data will be further discussed in chapter five. A significant improvement was found at three months in perceptions of the IBS service in comparison with their health care provider; QOL, and symptom number, frequency and severity. There was no significant improvement in coping strategies. The relevance of these findings are discussed in chapter five.

CHAPTER 5

Discussion

5.1 Introduction

This study examined the role of the advanced nurse practitioner in the identification and management of patients with symptoms of IBS. Results reported in chapter four showed a significant improvement in patient symptoms and severity and quality of life three months after attending the IBS service. Patients indicated that they felt less depressed, more satisfied, more listened to and better understood as a result of care by the ANP. Their coping skills, however, did not improve.

5.2 Patient Demographics

Both the gender ratio and mean age of the study group reflected those in the literature, as seen in Rutter and Rutter (2002), and Simren et al., (2001). The educational attainment level in the prospective group was also consistent with most studies (Jarrett et al., 2007; Mearin et al., 2006; Williams et al., 2006).

Demographics captured in phase II showed a tendency toward having a minimum of three years secondary schooling with forty nine percent having reported University entrance or NCEA level two and above. Only eighteen percent did not have a secondary school qualification. Twenty two percent had a Bachelor degree from university, others having a Masters degree, or certificates of trades. Williams et al., (2006) reported twenty six percent with Bachelor's degree or higher, and Mearin et

al., (2006) found almost twenty three percent with University degrees. In the current study an unemployment rate of seven percent was noted which differed from Rutter and Rutter (2002), who had a twenty six percent unemployment rate.

Reasons behind a correlation between IBS and a high level of education are not clear. (Chitkara et al., 2008; Jarrett et al., 2007) suggested the effects of affluence, a higher socio-economic status in childhood, higher education and easier access to antibiotics can have a negative effect on the development of the immune system. A possible explanation of a higher educational level and a lower unemployment population in our study group may relate to the population used in this study attending a fee for service private practice service. Patients need to have some element of exposure to, or understanding of, the private health care sector. Many patients in this study did not have private medical insurance, but were able to afford the fee charged.

5.3 IBS Subtypes

IBS subtypes, (A-IBS, C-IBS and D-IBS) were similar in proportions between phase I and phase II participants. Initially it appeared that another sub-type needed to be considered, identified as pain predominant IBS (P-IBS), who did not have either constipation or diarrhoea. However, all but three were eventually identified with an alternate diagnosis. This may mean that such a group does not exist.

Percentages of patients in each of the subtypes in this study are similar to those of other researchers. Williams et al., (2006) identified thirty nine percent with D-IBS, sixteen percent with C-IBS, and forty five percent with A-IBS. This compares with

our study population where thirty two percent had D-IBS, twenty six percent were identified with C-IBS, and thirty eight percent with were identified with A-IBS. The number of patients in our study with C-IBS was higher than that of Williams et al. we can't explain this, however proportions of different subtypes may vary in different populations.

5.4 Alternate Diagnosis

The number of patients with an alternate diagnosis in phase II (forty three percent) was greater than those in phase I (thirty seven percent). Why there is a difference between these groups is a mystery. It could be postulated that the refinement of the service over the last three years and the changes in thinking around IBS as a diagnosis has meant a higher detection rate of an alternate diagnosis. Phase I patients were more likely to have been referred by specialists who had already excluded alternate diagnoses, thus diluting the patient numbers that were referred by GPs or self referred who may have been misdiagnosed. It could also be suggested that more trust was shown by GPs who referred patients on earlier than they might otherwise done. It could also be pure coincidence that more people with a differential diagnosis presented during this period.

Forty percent of all patients involved in the study were identified as having, or potentially having an alternate diagnosis. Some of these patients had a diagnosis that is not usually a differential diagnosis of IBS such as hernia. One man had a previously dismissed incisional hernia that was interfering with his bowel function. Another had a hiatus hernia identified on gastroscopy which was performed at the same time as colonoscopy because of upper GI symptoms. There was an inguinal hernia

concurrently found, the cause of bloating and pelvic pain, but was not, in fact, the cause of his IBS symptoms. One patient referred for D-IBS symptoms also had upper GI symptoms and was found to have oesophagitis and early ulceration. Treatment with Proton pump inhibitors relieved both his upper GI and D-IBS symptoms. Two patients were found to have colorectal cancer following investigation for abnormal pathology results.

The largest group of alternate diagnoses were those identified with IBD, (seven percent), most commonly Crohn's disease. Some patients identified with IBD reported they paid frequent visits to the GP for ongoing symptoms of IBS; it was not until they presented to the IBS service that previously undetected pathological changes were found. These changes were shown when blood and stool tests were repeated, where inflammatory markers and a subsequent colonoscopy revealed IBD. This scenario is reflected in comments by Miura (2007), who identified the fact that patients are frequently reported to have IBS before IBD is diagnosed, and that some people are misdiagnosed with IBS for some considerable time. Earlier, these patients would have had subtle inflammatory changes, where changes in peripheral cytokines suggest a pre-macroscopic inflammatory state (Talley, 2006). These thoughts are supported by Bradesi et al, (2003) and Olbe (2008), who described an inflammatory process, via increased permeability of the intestinal mucosa as a common denominator in IBS and IBD. Altered gut permeability, altered gut motility and the effect of life stressors on symptoms also link IBS and IBD together. Some patients with IBS, have been found to have signs of immune activation in the gut, and we also know that IBD can be put into relapse by emotional factors (Bradesi, 2003; Miura, 2007; Quigley, 2005). It is known that many patients with IBD who are in remission

exhibit symptoms of IBS. Their bowels react irritably to certain foods or stressors, showing some apparent convergence (Quigley, 2005).

A number of patients, both in the prospective group and the retrospective group were found to have ano-rectal abnormalities; those that are known to have been treated have recovered well. Diagnoses such as rectocele, haemorrhoids or fissures corresponded with findings of Palmer et al., (2002), who described ano-rectal problems as a major cause of IBS, with symptoms resolving after treatment. Two such cases were fissures in the study group. One recovered after simple education on how to clean the fissure, which spontaneously healed. The other required a fissurectomy. Palmer et al., (2002) postulated that even though abnormalities such as haemorrhoids, various types of pelvic prolapse, or fissures are known as common causes of obstructive defaecation, they cause IBS symptoms, which used to be thought of as co-incidental. These physiological problems are stimulants for the abnormal reflex contractility of the bowel found in symptoms of IBS. The surgical repair of the pelvic floor to correct a rectocele can alleviate symptoms of obstructive defaecation or chronic constipation which mimic C-IBS (Finco et al., 2007) suggesting that IBS has some origins in a pathophysiological cause, rather than existing as an entity. Other origins are organic such as endometriosis.

We found endometriosis to be the cause of IBS symptoms in 2 of our female patients in the last 12 months. They became symptom free when their endometriosis was excised suggesting that the trigger of their IBS symptoms was the endometriotic lesions. Endometriosis is known to cause irritable bowel symptoms (Remorgida et al.,2007), including constipation, diarrhoea, abdominal pain, wind and bloating.

Conversely, Yantiss et al., (2001) suggested that IBS is a differential diagnosis of endometriosis. Symptoms that caused suspicion in our patients were diarrhoea related to menstruation, with a tendency to constipation mid cycle. Bowel symptoms that coincide with periods is a clinical clue according to Talley and Martin (2006), however, they say that in some people symptoms can be independent of their cycle. Symptoms relating to menstrual cycle have historically been identified as IBS, but are in fact symptoms of bowel involved endometriosis. Williams et al., (2004) do not necessarily agree that endometriosis is associated with IBS, but do confirm an association between IBS and chronic pelvic pain and a history of abuse.

The number of study patients found to have another cause of symptoms other than what is traditionally known as IBS possibly shows that the way we perceive IBS may be too narrow. In a review of the literature El-Serag et al., (2004) reported alternative organic disorders in people initially 'diagnosed' with IBS. Examples were gastric ulcers, carcinomas and thyroid disorders, extending the range of differential diagnoses for IBS. People can be diagnosed according to Rome Criteria, yet have an underlying treatable problem. This challenges the validity of the Rome criteria as it currently stands for some people.

Many of the study patients reported onset of symptoms after an enteritis, some other major illness, travel, or a heavy course of antibiotics. Post infectious IBS can develop after an enteritis has occurred and caused a colitis, which heals, but symptoms remain (Quigley, 2007). Changes in gut flora may have more of an effect on microscopic inflammatory changes than has previously been thought, where lymphocytic colitis and IBS have more in common.

The age of a patient presenting with symptoms can alert to the possibility of a differential diagnosis. We found most of our patients identified with IBD to be young adults. This is consistent with the literature (Rodriguez et al., 2005). Although IBS can present at any age, onset in later life needed to be investigated (Croghan & Heitkemper, 2005) to screen for bowel cancer as well as other diseases. It was through colonoscopy for one of our study patients that a serious rectal cancer was found.

5.5 *Attrition within the Prospective Group*

Data gathered within the prospective group related to forty-five (82%) patients who completed the first and the second questionnaire. This represents a loss of ten subjects between questionnaires one and two. There may be a group of people who could not, for a variety of reasons, re-visit the questionnaire. They may have been those for whom little progress was made, or were unhappy with the service. Those who had an alternate diagnosis made may have considered themselves ineligible, and decided not to continue to participate. The fact that seventy percent of those who did not complete were male is interesting. Whether this is a gender issue, and that women are more likely to comply than men remains to be seen. Women are more likely than men to report negative experiences with their GP. As they will not have encountered this at the IBS service they may have been more inclined to participate (Payne, 2004).

5.6 Patient Satisfaction

Findings of patient satisfaction with the IBS ANP were significantly higher than with their initial health care provider. These findings on patient satisfaction are not surprising. It is well documented that patients, in particular women, feel they are not taken seriously by their health care provider regarding their IBS symptoms. Neither were they given adequate explanation of, or information on the condition (Heitkemper et al., 2002; Motzer et al., 2003). According to Hayes (2007) patients are more satisfied with care provided by a NP, especially with regards to communication. A group of IBS patients studied by Bertram et al., (2001) made suggestions on improving patient – physician interactions. It was felt more education on IBS at time of diagnosis would be very helpful.

A key reason for study participants' dissatisfaction with their health care provider identified in the phase II questionnaire was the fear that something serious could be wrong, which was not being addressed. Many felt insufficient time was spent with them, and that they were a nuisance to their health care provider. Most patients though, were quick to say their doctor was a good doctor; however they did not feel their stories were validated. There is evidence in the literature (Spiegel et al., 2008) that doctors do not do well in addressing a patient's fears and concerns over disease-specific fears. Fear that something serious is wrong is an important predictor of health care seeking behaviour (Williams et al., 2006), and this is possibly why some patients eventually present at the IBS service, through GP referral, or self referral.

Many patients in our study voiced a feeling of being dismissed by the doctor. They felt they were perceived as hypochondriacal, nothing serious was wrong with them. It was all in their head, even though the doctor did not actually say so. This was the experience of patients in Heitkemper et al., (2002), when they repeatedly visited for the same symptomology. It is little wonder that patients do not feel supported by the medical fraternity when research is pointed toward being able to accurately stratify patients, finding it difficult as illness severity relies upon symptomatic reporting instead of biological markers (Spiegel et al., 2008). Instead of listening to a patient's story, doctors are trichotomising a patient's symptoms into mild, moderate, or severe.

Dixon-Woods & Critchley (2000) described some GP views that IBS patients were very stressed, neurotic middle aged women that are worriers, labelled as "anally retentive people who think a lot about their health and bowels" (p. 109). Anecdotal comments from a few patients in this study confirmed this, but they were in the minority. There are still some in the medical profession who felt IBS patients were overreacting to bodily sensations (Rutter and Rutter, 2002), and the problem was purely psychological. The response by some study patients possibly reflects this in the question asking if they felt they were a nuisance to their HCP. GPs were found to focus on stress and family issues when dealing with IBS, and have generally found IBS difficult to treat, some believing anxiety and depression to be the only cause (Casiday et al., 2009; Lacy et al., 2006), despite recent findings that dispute this belief. Those attitudes have no doubt improved over the last few years as the growing body of research done is filtering through the medical world. Comments from local GPs and referrals from specialists to dietitians suggest food intolerances

have become the latest theory behind IBS. Fructans intolerance in particular is being researched (Shepherd et al., 2008).

Longstreth and Burchette (2003) found generally that GP level of knowledge about the syndrome was limited. This knowledge gap between real life practice and current research illustrates a need for the literature to be accessed by GPs (Casiday et al., 2009). It is suggested that many doctors generally lack the time to update on the changing face of IBS. Nor do they have enough time to spend with these patients, and understanding of their symptomology, coping strategies and quality of life was very limited. As Longstreth and Burchette (p. 670) state, “An effective physician-patient interaction is crucial”, in relation to GPs caring for IBS patients. Bertram et al., (2001) suggested that physicians be educated on how IBS patients are affected in their daily lives, as empathic care is an essential part of therapy. GPs themselves, however, felt they went to great lengths to validate the patient’s experiences and misery as well as trying hard to convince them there was nothing wrong to treat (Casiday et al., 2009). That, perhaps is part of the issue. The patient is more concerned about understanding the pathophysiology of the problem and what can be done to help treat the causes of symptoms. Time spent with the study patients were a key factor in patient satisfaction, as it is in the time arena that patients can voice their fears, and doctors, or other health care professionals can allay them.

It is not intended to paint GPs in a negative light. In busy practices they are restricted by time, and by the amount of detail needed to specialise in IBS. They cannot specialise in every disease or disorder. The advantage the ANP has is the specialised study at an advanced level of knowledge on IBS. For this reason many GPs use the

service as a resource, welcoming assessment of patients who are often difficult to treat.

Patient satisfaction with the diagnostic outcome after visiting the IBS service was higher. Reasons, as indicated by specific questions addressed were, because they felt listened to, they felt their symptoms were improving, they were feeling less depressed, and less scared something serious was being missed. Quality and quantity of time, education and appropriate referral on may also have contributed. A comment made by Redsell et al., (2006) was that nurses made more time for patients, and were more compassionate. Many patients attending the IBS service had expressed feelings of frustration at the lack of empathy and caring from their friends and families, which is not uncommon (Bertram et al., 2001). As indicated by the first questionnaire, patients found IBS to intrude significantly on their lives, and while this may have improved after involvement with the IBS service, there was still a sense of intrusiveness, and often a feeling of stigma, in how patients perceived their quality of life. As described by Dancey et al., (2002), the burden of IBS was no different from those with more serious diagnoses despite it being considered less severe than other chronic conditions. It could feel worse for IBS patients, as sometimes a diagnosis of an actual disease process will inevitably have some definitive treatment, where, when treated, they think they would feel a lot better. As one patient put it “A diagnosis without a remedy; that’s not very useful” (Casiday et al., 2009, p.38).

Patients with an inflammatory bowel disease preferred to relate to a nurse specialist rather than the consultant (Read and Mayberry, 2000). Patients generally chose the nurse specialist because more time was given to listen, to provide education and to be

available generally. The knowledge that there is a nurse specialist in their particular health problem probably contributed to the ability to trust that person. Among some of our study participants, education about bodily function and the role of different organs was all that was needed to improve patient symptoms as the patient had misguided and ill informed ideas about their body. Education is a key factor in managing patients with a health concern, as is reassurance (Croghan & Heitkemper, 2005). Mayberry and Mayberry (2003) reported that patients were more satisfied in consulting with a Nurse Practitioner as they were able to understand and to receive education and advice that is informative and achievable. This may be an explanation behind the patient satisfaction score being higher for the advanced nurse practitioner than for their initial health care provider.

It needs to be remembered that patients do not always prefer a nurse as their sole provider of care. Trust in their GP or main health care provider is critical. It would be prudent not to presume that because a patient was unhappy with their GP's handling of IBS symptoms, they distrust their management of other health concerns. This is borne out in comments made by Redsell et al., (2006), where even though patients thought nurses were more compassionate, and had more time to spend with them, they preferred to trust the experience of the doctor or specialist if they perceived their ill health as being serious. They would not necessarily believe the reassurances of a nurse. Cheung et al., (2002) discussed the fact that many participants, in a study examining the role of nurses and general practitioners, preferred to see the doctor rather than the nurse if they felt their problem was serious, and would require a higher level of knowledge and judgement. On the other hand, if it was relatively minor or straightforward the nurse was preferred.

5.7 *Quality of Life*

Quality of life, rather than pain severity or duration, is often the main reason patients seek help (Wilson et al, 2004). There was quite a discrepancy between the number of symptoms and QOL in some patients. Some individual scores recorded only three symptoms, yet quality of life was poor. Others recorded up to seven different IBS symptoms, but their quality of life score was high. A similar finding was reported by Whitehead et al., (2006a) where patients with mild symptoms were less likely to report satisfactory relief than those with severe symptoms. Severity of symptoms may be related to patient fears (Spiegel et al., 2008) which would be an important topic for future research, as some study participants improved in quality of life when they were better informed about their health concerns.

Evaluation of QOL and symptom severity in patients with IBS has been the focus of several studies (Bertram et al., 2001; Dancey et al., 2002; Gerson et al., 2006; Motzer et al., 2003). There is little data, however, on improvement following attendance at a clinic. More studies focussed on improvement after drug treatment (Talley, 2003; Harris & Chang, 2006) or looked for underlying factors behind the syndrome (Azpiroz et al., 2007; Stark et al., 2007).

This study showed improvements in QOL. The only treatments we offered were 1) 'over the counter' (OTC) remedies available at the chemist or health food store; 2) nursing interventions of education with explanation of their symptoms; 3) referral on to a dietitian, counsellor, or another specialist. Sanders et al., (2007) found there was

an improvement in symptoms and quality of life in patients who were given a self administered treatment plan. This was via a treatment book, patients learned not only what occurred within their body, but also in identifying situations, feelings and foods that influence their IBS. Cognitive behavioural therapy was the mechanism behind this. This was the premise by which the service operated, from working with the patient on a management strategy with the understanding that it is work they need to do as well. Williams et al., (2006) described how patients are more able to accept the fact that psychological issues may be behind their symptoms and are more likely to accept psychological help. While this was the case for many patients, recommendations for interventions were tailored for each individual, as interventions were aimed at the cause of the symptoms as much as was possible rather than symptom relief alone. Often a combination of interventions were recommended.

The study results regarding quality of life and perceptions of symptom severity did show the subjectivity of trying to measure one's quality of life. Data that showed reduction in symptoms could reflect the fact that either treatment or interventional strategies were working, or that perceptions of severity were reduced after consultation, investigation and education by the ANP, the dietitian or the counsellor. Again, how patients perceive their illness affects their quality of life. Gerson et al., (2006) reported patients who attributed their symptoms to physiological factors experienced more severe symptomology. By specialised exploration of symptoms and pathological testing, with validation of their experiences, education and referral on to the appropriate resource, our patients were more likely to improve in quality of life.

Quality of life data gathered in the questionnaires described how patients felt about their ability to socialise, exercise, and perceptions of self. Findings in the first questionnaire mirrored comments in Bertram et al., (2001), who commented that many patients felt alone, socially isolated, and unable to dine out. Although there was improvement in the second questionnaire there were still some patients for whom these variables did not improve. These findings support a need identified by Spiegel et al., (2008) where it was felt IBS patients should complete a health related QOL questionnaire at initial consultation to assist the health care provider in their approach to treatment.

The economic impact of IBS on QOL is often quite significant. The fact that there were only three (six percent) patients on a sickness benefit does not reflect the enormous effect patients' symptoms have on their ability to work. Though work was affected, patients generally managed, with less time off work than would be expected. This may be a reflection of the socio-economic status of many of our patients. Their work ethic and type of work they did would possibly affect this finding. Similarly, Le Pen et al., (2004) found the average number of absences from work among IBS patients to be low. This contradicts the findings of Akehurst et al., (2002) who reported that IBS patients had more time off work and a greater utilisation of the health care system.

Regardless of socioeconomic status patients' QOL related to how they perceived their illness, and to the level of information and education that was given about their health. Although our study population was from a middle to upper class of socioeconomic background, these fundamental elements still apply. Measuring patients' QOL is very

subjective and dependent on many variables. High stressors, family issues, and past traumas affect the ability to improve. Patients who improve more easily than others are generally those who have grasped the concept that they have to work to become well. It is possible this message given to our patients early on in their care produced the noted improvement.

5.8 *Coping Strategies*

The study showed that coping strategies did not change significantly over the three months. Few studies have examined coping skills in both functional and organic bowel disorders (Seres et al., 2008). The recognition of IBS patients' self-care strategies and how they perceive themselves has not been widely studied (Kennedy et al., 2003). However, IBS patients were reported to be not so different in coping skills from those with IBD, although QOL was significantly poorer (Kolowski et al., 2001; Seres et al., 2008). The difference between IBS and IBD was that tangible treatment was perceived to be available for IBD, but not for IBS. Why it is that coping skills are similar, but QOL is not, is a puzzle. This is good reason for further research to be carried out on the coping strategies of patients with IBS.

Traumatic events in childhood such as abuse, parental deprivation and major traumatic events predispose the individual toward the development of IBS (Chitkara et al., 2008; Croghan & Heitkemper, 2005). Significantly fewer coping skills, with more severe symptoms were reported in traumatised persons. One would expect it would take considerable time for any symptom improvement to occur (Chitkara et al., 2008; Kolowski et al., 2001; Talley et al., 1997). The relationship between childhood

trauma and coping skills, quality of life, or symptom severity, was not specifically studied amongst our participants. It is unknown whether any study patients had childhood trauma.

Psychological pain, and stressful environments are detrimental to recovery from symptoms, and as Gerson et al., (2006) found, the continuing chronic symptoms of IBS can have a negative effect on relationships. Some patients had indicated in their questionnaires that their relationships with partners were affected by their bowels and they felt their partner was fed up with their symptoms. The resulting conflict in relationships often destabilised the person's own ability to acknowledge the complexities of a mind-body illness. The ability to cope is significantly lessened in the absence of relational support.

Measuring coping strategies would have shown more accurate results if we had linked patients' attitudes and beliefs about their symptoms with coping strategies, and with satisfaction in health as mentioned in (Rutter & Rutter, 2002). Cognitive factors and levels of social isolation contribute to an individual's ability to cope. The topic of coping strategies needs further research to see how people manage, so as to define and develop strategies to assist others. There is always the possibility some of our study patients may have already developed strong coping mechanisms, as they have lived with symptoms for a long time. Therefore there was possibly little room for improvement.

5.9 Symptom Improvement

Symptom improvement was significant ($p < 0.001$) in terms of the number of symptoms patients reported which dropped from an average of 3.9 symptoms to two after three months, as well as the frequency and severity of symptoms. This would be expected since QOL and patient satisfaction had improved.

A variety of factors affects or influences IBS symptoms. Disease related fears impacted on severity of symptoms (Seres et al., 2008; Spiegel et al., 2008). A number of patients scored highly on the Likert scale to the question “I am scared something more serious has been missed” in the first questionnaire. The second questionnaire three months later showed a significant reduction in that fear. An explanation for this could be the time taken in our patient consultations with assessment, education and instruction, as well as interventions by clinicians, all contributed to symptom improvement.

Listening to the patient contributed to the overall wellbeing of the patient. After discussing the effect stress has on the body, and the brain-gut relationship we found the majority of patients were only too happy to identify with this and work with a counsellor if needed. This finding is confirmed by Bray et al., (2006) who demonstrated that it is a myth to believe IBS patients somatise, disputing findings of Gwee et al., (1999), and Salmon et al., (2002), who suggest that anxiety, neuroticism and somatisation predict the development of IBS, though Gwee et al., (1999) did suggest that psychological factors can predict improvement as well as decline.

Many patients fear cancer (Bertram et al., 2001). This was a fear frequently expressed by our patients, and it was anticipated that the time spent in consultation including physical examination, pathology testing, and education provided some reassurance. Heitkemper et al., (2002) confirm this in describing greater improvement in patient symptoms when the patient was in a trusting and therapeutic relationship with their health care provider, whether that be a physician or nurse.

Articles written on the effects of stress levels (Hertig et al., 2007), identified less improvement of IBS symptoms if high levels of psychological distress remained. An interesting finding of theirs was a higher stress level experienced in women with alternating constipation and diarrhoea based IBS. A high proportion of women in our study group; seventeen percent were identified with A-IBS. No correlational studies could be found examining relationships between QOL and symptom frequency/severity or the IBS subtypes, and none were done in our study.

Few articles could be found that discussed symptom improvement after intervention in a similar manner to our study, though comparisons using various drug or alternative therapies abound. A study on the prevalence of IBS, symptom patterns and impact, reported that IBS patients seldom report improvement in symptoms (Hungin et al., 2005). The treatments described were largely various medications for symptom relief, and used only in periods of relapse, as often the syndrome was described as intermittent. This was not our experience, where not only was there an improvement in the number of symptoms and severity, but treatment options were aimed at the cause, such as stress management or dietary interventions.

Whitehead et al., (2006a) found that the more severe a patient's symptoms were on enrolment in his study, the larger the reduction in symptom severity after six months of standard treatment. Our study patients were similar in that they presented to the clinic for help when symptoms were more severe. The same phenomenon of improvement in symptom severity was found, though we did not specifically explore and compare individual symptom severity with improvement.

Mearin et al., (2006) also found that those with severe symptoms and poor QOL were more likely to improve after standard treatment for the different symptoms in patients being monitored. In Mearin's study the patients had the benefit of frequent involvement with personal medical care. Perhaps that is why their patients and our patients improved. This phenomenon could be explained by the fact that patients knew they were being monitored and had easy access to a specialist IBS team, possibly creating a placebo effect. It is the validation of their experiences that seems to be a critical factor we have found in communication with our patients.

We measured only the number of symptoms in both questionnaires, not noting which were the more frequent symptoms to improve. Mearin et al., (2006) found abdominal pain/discomfort and bloating to have improved more than other symptoms, at follow up four months after initial consultation. There was no further improvement at twelve months from actual diary data, though approximately half the patients and half the clinicians thought there was. Does this mean that only patients' perceptions improve? Though this is subjective data, it could mean that patients had better control over their symptoms.

Gerson et al., (2006) suggested there are limitations to studies if patients self report on symptoms at home, suggesting psychological distress could influence the severity and frequency of symptoms. This distress could come from relationship or family conflict. As distress is related to the severity and frequency of symptoms this is relevant to any study. Interventions can not claim to make any difference except for those that work on the cause of distress. If stressors resolve, and the patient is able to break the gut-brain relationship, symptoms can also resolve. Heitkemper and Bond (2004) used specialist nurses in mental health to work with patients with IBS and found that symptoms were greatly reduced and quality of life much improved after several sessions with the nurse on stress management. This reflects the work of this study's IBS clinic where not only is time spent with the IBS ANP, but those needing stress management reported significant improvement following several sessions with the counsellor.

The recommendations of the Rome Committee are that any trial relating to IBS therapy should measure global subjective improvement in IBS symptoms (Schoenfeld & Talley, 2006). Their recommendations were that such studies also need to use a previously validated questionnaire. This relates to the present study in that an unvalidated questionnaire was used. The rationale behind this was that patients would be flooded with too many questions if we used the different tools that would be needed to cover our question. Therefore the questionnaire was inspired by combinations of other already validated questionnaires, (Akehurst et al., 2002; Lackner et al., 2006; Patrick et al., 1998; Roalfe et al., 2008 Simren et al., 2001 & Wong et al., 1998). The questions in our study are closely linked to the philosophical

approach of Bengtsson et al., (2007), who found there were too many questions required if you relied on previously validated tools, where patients did not comply because they were overwhelmed.

5.10 Management

As described in chapter three this is a nurse led, protocol driven service. Apart from the initial consultation with the IBS specialist nurse, the approach to patient management is of a multidisciplinary nature. Patient management protocols are often used by advanced practice nurses in gastroenterology (Hillier, 2001), developed in collaboration with other consultants. Each of our patients is discussed with one of the medical/surgical specialists to confirm findings and diagnoses.

The plan of action, potential interventions and general conversation ensue involving education on what is normal and clarification of terminology. For example, many patients differ in their interpretation and meaning of the word “constipation”. The act of listening and validating patient symptoms has often meant patients become more aware of triggers and are prepared to work at ways of avoiding them (Paterson et al., 1999).

Patients would return in two weeks by which time all laboratory results would have returned. All patients completed a food and symptom diary which was analysed for potential triggers of symptoms. As Paterson et al., (1999) identified, the very act of completing a diary is a first step in cognitive behaviour therapy as, on occasion, patients have been able to self identify causes of their symptoms. A classic example

is the discovery that sugarless gum, diet coke, and other artificially sweetened foods caused a lot of problems. Conversation would focus on changes that need to be made with encouragement of the patient to self manage their rehabilitation, and, where necessary, recommend referral to a dietitian. Certain over the counter remedies such as a particular peppermint oil capsule, or certain brands of probiotics, anti-diarrhoeal agents, and laxatives may be offered at this point if they hadn't already been done so at initial consultation.

Referral to other specialists depended on the nature of the patient's symptoms and laboratory results. For example, patients with elevated inflammatory markers were referred on to a gastroenterologist. A few patients were diagnosed with Crohn's disease or some other IBD. If ano-rectal problems were revealed (Palmer et al., 2002), a consultation with a colorectal surgeon was recommended.

A number of patients were referred to both the dietitian and the counsellor. This is because there was no clear cut line that indicated it was all dietary, or all stress and anxiety related. Patients were generally very happy to work with both specialists, with positive results as the outcome. As discussed earlier in this chapter, patients were more satisfied with diagnostic outcomes from the IBS ANP than from their initial HCP. This relates to their ongoing management as well. Hayes (2007) found patients of NPs in the USA to be very satisfied with their care by the NP, with comments of trust and confidence in her. The way in which patients were able to communicate with the nurse with an ability to speak their mind showed a different kind of relationship to that of their GP. Our anecdotal experience is that patients relax and do not feel so over-awed or disempowered as they do when consulting a

medical practitioner. Management strategies were from the nursing holistic and educational perspectives, and patients had more time that was able to be given to them than was possible by their GP. Morcom et al., (2004) described the difficulties encountered by some patients where they not only felt afraid of the doctor, but did not feel at ease during a procedure, issues such as anxiety, lack of privacy and sensitivity, and explanations or feedback at the time causing distress.

Time is a key factor in managing patients. It is a matter of how one suggests psychological intervention when it is perceived that this may be an appropriate avenue of ongoing management. Part of the relationship between the patient and the IBS nurse is building an ability to have an in depth discussion about their symptoms, their feelings and the relationship between emotional conflicts and symptoms (Naliboff et al., 2008). This then feeds into the ability of the patient to recognise that psychological assistance would be valuable. As Creed et al., (2008) describe, patients in secondary care are the more severe IBS patients, where psychological intervention is most likely to benefit. This has been corroborated by comments from our patients who have spent considerable time with the counsellor to whom they are referred, and are very happy with the outcomes.

A multidisciplinary approach appears to work the best. Patients that have been referred to the counsellor and/or the dietitian have anecdotally reported feeling better. While we did not specifically measure the results of the input by the dietitian and the counsellor, benefits are noted by the improvement in symptoms and quality of life. The development of an IBS school described by Ringstrom et al., (2009) reflects the importance of education and input from different disciplines. Their approach would

be worth developing, as it not only gives credibility to the patient's experiences, but provides them with information with the benefit of meeting others in similar circumstances. As Ringstrom et al., (2009) describe, several sessions are needed over a period of time. Therapeutic relationships would develop, and patients would learn from each other as well.

There are a number of potential negative aspects to the running of the service.

The main issue is financial accessibility of the IBS service for some people, and, just as important is affordable access to specialist referral which cannot be assured as there is no equivalent service in the public system. As it is a nurse led service, it is not covered by insurance companies. Again, patients may not wish to be referred on to the dietitian or counsellor as there is another cost factor. This has been encountered on occasion, especially with the elderly, or university students.

5.11 *The Role of the Advanced Nurse Practitioner*

Blurred boundaries currently exist where nurses are taking on many skills traditionally thought of as belonging to doctors (Mayberry & Mayberry, 2003), for example the first assist role in surgery. The ANP operates from a different model of care and enquiry from the medical model of care. This is not to confuse the ANP with the dedicated title of NP, although the boundaries are close. Within the gastroenterology/colorectal areas of care, many nurses operate as specialists, such as stoma therapists, IBD nurse specialists, and now, nurse endoscopists, in the UK and USA only (Norton, & Kamm, 2002).

ANPs, of whom the largest group are clinical nurse specialists, have contributed to the community not only in their care, but in cost effectiveness, especially in the reduction of hospitalisations and emergency department visits (Hillier, 2001). The researcher, in this instance, is functioning as an ANP, which is the same as a clinical nurse specialist. An ANP or nurse specialist in gastroenterology is able to save time for busy gastroenterologists in assessment, management and education of patients. This is the key role of the researcher as described earlier. As IBS patients comprise a large number of patients for gastroenterologists, it would seem valuable to have a dedicated ANP attend to these people in a manner that meets both patient and doctor needs. This very role is described by Heitkemper and Bond (2004), where clinical nurse specialists trained in stress management worked with patients with IBS. Their success was easily measurable even if a patient had only one session. This role though, was only described as an intervention, not a consultative or investigatory position.

There is much merit in the ability of an ANP to consult, investigate, and refer, to complement the role of the doctor (Mayberry & Mayberry, 2003). The role of this nurse is to bring a different philosophical approach. There is partnership in an interaction between nurse and patient which allows the patient to fully express their concerns (Jonsdottir et al., 2004). While this is not yet an NP role, there are similarities in the role of the IBS service's nurse. This nurse coordinating the IBS service is the first point of call for patients referred to the service. As discussed in Hillier (2001) becoming an ANP involves an advanced level of education with clinical supervision, becoming an expert in this field. This is described by Morcom et al., (2004), who added that collegial support by nursing peers and networking

contributed to the establishment of a new NP led service in flexible sigmoidoscopy. As the nurse is not an NP ordering of investigative tests, plans of action and intervention, and referral to other health professionals, are under the supervision of a clinician. Confirmation of the diagnosis of underlying pathology, or the type of IBS, is also made by a clinician. This is necessary in order to practice within the nurse's current scope of practice.

The difference in this role is that a key approach is nursing interventions, where nursing involves more than identification and management of disease. Jean Watson's theory of human caring provides grounding in a nursing approach that is particularly suited to IBS (McCutcheon, 2004). By entering the caring-healing relationship with a patient it is more likely the patient will develop trust and reveal sometimes vital information that can make all the difference in management strategies. This is particularly relevant in the nurse researcher's role when a patient reveals childhood abuse when consulting about a very personal and embarrassing topic. This approach, while investigating and planning management strategies, provides physical, psychological and emotional support to a patient. Listening, acknowledging and validating the patient's experiences assist in guiding the individual to the appropriate resource. A major part in this role is to empower the patient to actively become involved in their own management of symptoms (Laperriere, 2008), and thus can begin to take responsibility for their own healthcare (Norton & Kamm, 2002).

In addition to direct patient care the ANP is able to refer as well as consult, and collaborate with other health care providers, including GPs, within their scope of practice. It is the patient's own GP that is first contacted if any abnormalities are

found, or suspicious alarm features show. There are a number of primary health care physicians who already refer to the IBS ANP, wanting help with diagnosis and management of their patients. This indicates an increasing willingness by doctors to recognise that nurses can attain specialist expertise (Mayberry & Mayberry, 2003).

Rapidly advancing changes have occurred within the UK and USA, with nurses being trained in endoscopy (Norton & Kamm, 2002). Nurses perform flexible sigmoidoscopies in the UK, as well as banding haemorrhoids and treating anal fissures (Maruthachalam et al., 2006). There are particular advantages for a nurse specialist in IBS to have competent training in some investigatory procedures such as anoscopy, rigid and flexible sigmoidoscopies. This will enable the IBS nurse specialist to identify more accurately conditions and abnormalities such as haemorrhoids, fistulae and fissures, or other anorectic problems.

An ideal feature for New Zealand would be that nurses specialise in IBS and other functional disorders to assist GPs and consultants in the identification and appropriate management of these patients. It is a disadvantage that this service is currently only available in the private sector, thus denying a large proportion of the population who are not comfortable or familiar with the private sector, or cannot afford to pay for care. District Health Boards would benefit through employment of a specialist nurse, as gastroenterology clinics would have more space freed for other patients. Nurses are by both training and their very nature, information givers, therefore whether it be informed consent, or an explanation of the nature of their ill health, patients are more likely to give agreement, or understand the process (Mayberry & Mayberry, 2003).

5.12 Recommendations for Further Research

While there is the occasional study coming from Australia, very little has been researched in New Zealand. There was no data found on IBS and Maori, and the implications for the different ethnic groups in New Zealand are not known. Spurious theories can be applied that relate to Caucasian New Zealanders, but not to other groups. Research needs to be done among Maori to identify the incidence of IBS and its effect on quality of life, and potential impact among whanau.

Comparative studies with other centres are needed to see if findings of this study are reproducible. This will mean searching in the UK and the USA. Collaboration with other nurse specialists and NPs working in gastroenterology is vital.

Studies examining the relationships between fear and symptom severity or frequency, and combinations of other variables may lead to better management strategies. For example, coping skills in patients with IBS and IBD were not so different, but examining this in relation to IBS subtypes may give some indications for future treatment options. Correlational studies between symptom severity, or quality of life and IBS subtypes may provide more insight into a patient's perspectives and needs.

The financial impact of IBS on New Zealand's economy has not been studied. This would be a suitable project to accompany this study as it would show if there would be a financial benefit to the health sector to engage such nurses. The aim would be to assist people by reducing the number of visits to health care facilities and reducing time off work.

5.13 *Summary*

Time and communication affect the way patients perceive their health care provider whether it is their GP or an ANP. All too frequently patients are heard to complain about the medical profession being unsympathetic (Dixon-Woods & Critchley, 2000), and doctors are often perceived to be intolerant of patients with IBS.

Patients reported greater satisfaction in dealing with the ANP than with their health care provider. They also reported an improvement in quality of life, and a reduction in the severity and the number of symptoms. Coping strategies did not improve however, and this may be because the questions were not easily understood, or perceptions of coping were already high.

There was a significant improvement in the number, severity and frequency of symptoms which possibly relates to improved quality of life, and the fact that their concerns and fears were validated. Patients also had expert assistance from specialists to whom they were referred on such as the dietitian and the counsellor. The literature supported the findings that validation of patients' experiences and education assisted in improvement in overall wellbeing.

CHAPTER SIX

Conclusion

This study suggests that an ANP can make a significant difference in the identification and management of patients with symptoms of IBS. A key role of the ANP is to coordinate therapeutic interventions by referring patients to appropriate resources allied to the service such as the dietitian and the counsellor. Initial contact with the patient involves applying an advanced nursing model when taking a detailed history. Talking about bowel function and gut disturbances can be embarrassing for some people, symptoms being very personal, especially when they need to be descriptive in detail. The necessary physical exam that is part of the consultation can be rather undignified (McCutcheon, 2004).

Time and communication are important factors in working with IBS patients, where time is disadvantaged in the medical world. Patients with IBS symptoms are frequently afraid of more serious diseases. Despite the fact the GP has reassured them, they are often not believed. Validating a person's fear is already halfway to healing (McCutcheon, 2004). It is important that specialist nurses promote their role so that they are not seen as cheaper options in health care (Read & Mayberry, 2000), as there is much nurses can do to compliment the role of the doctor. The specialist nurse not only has a deeper knowledge of the patient's illness, but can also interact with the patient at a different level and provide the patient with continuity of care if that option is available. The advanced nursing model is different to that of the medical model, thus it should be perceived as complementary, rather than threatening, to the medical profession.

The identification of alternate diagnoses is not so surprising in that there is more and more literature identifying underlying causes of IBS symptoms. Examples are, when non specific findings of microscopic inflammation have been found in some IBS patients (Bradesi et al, 2003), ano-rectal conditions causing IBS symptoms (Palmer et al, 2002), endometriosis identified as causing IBS symptoms (Seaman et al, 2008) and IBD patients more likely to have been diagnosed with IBS before correct diagnosis of IBD (Miura, 2007). Access to specialised information on IBS is not easily available to GPs. The advantages the IBS service nurse has are time, expert knowledge, and information on identification of causes and needed interventions. Disadvantages within this service are that the patient has already been referred by the GP, and may well be expecting that the nurse is the ultimate resource. It may be disillusioning if it is suggested that they are referred on.

There appear to be no nurse-led clinics or services found in Australasia. The success of the existing service and other similar services in the UK and USA show a definite need for such services in New Zealand. The researcher has received numerous phone calls and emails from around the country looking for help or asking if such a service exists in their location. This group of people need proper care and due recognition that their symptoms are valid and real. Whatever help can be given should be done. It is disappointing that our District Health Boards do not appear to have the financial resources to put into an illness that prevents people from working, severely affecting their quality of life. The cost to society is most likely very significant in terms of sick leave, unemployment, and the use of medical and surgical services.

As Laperriere (2008, p 392) puts it, “While health can be an individual issue for privileged, middle class people, for most people health is a social issue”. This encompasses the way many IBS patients feel actually, regardless of socioeconomic status.

The use of specialist nurses in gastroenterology in New Zealand, in particular working with functional disorders would not only free specialists up for managing organic disorders, but be a resource for busy GPs. This study supports such a role and identifies areas for future study for nurse specialists. It is envisaged that other nurses will be encouraged to pursue specialist study and create similar nurse specialist scenarios.

It is important to our community to disseminate findings of this study as many IBS patients would benefit from such a service. As well, many GPs and other health care practitioners do not know that a specialist service exists for patients with irritable bowel syndrome. An IBS support group has recently commenced with attendees highly enthusiastic

Further dissemination of findings is planned in applications for publication in appropriate medical and nursing journals, as well as giving presentations at conferences, and to other audiences. It is planned that further research will eventuate from these findings and that there will be specialised resources available for all IBS patients.

REFERENCES

- Akehurst, R.L., Brazier, J.E., Mathers, N., O'Keefe, C., Kaltenthaler, E., Morgan, A., Platts, M., Walters, S. (2002). Health related quality of life and cost impact of irritable bowel syndrome in a UK primary care setting. *Pharmacoeconomics*, 20(7), 455-462.
- Ali, A., Toner, B.B., Stuckless, N., Gallop, R., Diamont, N.E., Gould, M.I. & Vidins, E.I. (2000). Emotional abuse, self-blame, and self-silencing in women with irritable bowel syndrome. *Psychometric Medicine*, 62(1), 76-82.
- Azpiroz, F., Bouin, M., Camilleri, M., Mayer, E.A., Poitras, P., Serra, J. & Spiller, R.C. (2007). Mechanisms of hypersensitivity in IBS and functional disorders. *Neurogastroenterology and Motility*, 19(suppl. 1), 62-88.
- Barbazet, G., Pouton, R., Milne, B., Howell, S., Fawcett, P. & Talley, N. (2002). Prevalence and correlates of irritable bowel symptoms in a New Zealand birth cohort. *The New Zealand Medical Journal*, 115(1164), 1-8.
- Barclay, L. (2007). New guidelines for treatment of irritable bowel syndrome in adults. *Gut*, online. May 8, 2007. via Medscape Medical News.

- Bengtsson, M., Ohlsson, B. & Ulander, K. (2007). Development and psychometric testing of the visual analogue scale for irritable bowel syndrome. *BMC Gastroenterology*. Retrieved May 22, 2008, from <http://www.medscape.com/viewarticle/559749>
- Bertram, S., Kurland, M., Lydick, E., Locke, G.R., & Yawn, B.P. (2001). The patient's perspective of irritable bowel syndrome. *The Journal of Family Practice*, 50(6), 521-525.
- Bindman, A.B., Forrest, C.B., Britt, H., Crampton, P. & Majeed A. (2007). Diagnostic scope of and exposure to primary care physicians in Australia, New Zealand and the United States: cross sectional analysis of results from three national surveys. *British Medical Journal Online*. Retrieved October 1, 2009, from www.bmj.com/cgi/reprint/334/7606/1261
- Bjornsson, E, M., Simren, M., Olsson, R. & Chapman, R.W. (2004), Fatigue in patients with primary sclerosing cholangitis. *Scandinavian Journal of Gastroenterology*, (10), 961-968.
- Blanchard, E.B., Keefer, L., Payne, A., Turner, S.M. & Galovski, T.E. (2002). Early abuse, psychiatric diagnoses and irritable bowel syndrome. *Behaviour, Research and Therapy*, 40, 289-298.
- Bose, M. & Farthing, M. J. G. (2001). Irritable bowel syndrome: new horizons in pathophysiology and treatment. *British Journal of Surgery*, 88, 1425-1426.

- Bradesi, S., McRoberts, J.A., Anton, P A. & Mayer, E.A. (2003). Inflammatory bowel disease and inflammatory bowel syndrome: Separate or unified? *Current Opinion in Gastroenterology*, 19(4), 336-342.
- Bray, B.D., Nicol, F., Penman, I.D. & Ford, M.J. (2006). Symptom interpretation and quality of life in patients with irritable bowel syndrome. *British Journal of General Practice*. 56, 122-126.
- Brunton, L., Parker, K., Blumenthal, D. & Buxton, I. (2008). *Goodman & Gilman's Manual of Pharmacology and Therapeutics*. New York. McGraw Hill Medical.
- Bryant, B. & Knights, K. (2007). *Pharmacology for Health Professionals. 2nd ed.* Marrickville, NSW Australia. Mosby, Elsevier.
- Burden, S. (2001). Dietary treatment of irritable bowel syndrome: current evidence and guidelines for future practice. *The British Dietetic Association*, 14, 231-241.
- Burnett, C.A., Juszczak, E., & Sullivan, P.B. (2004). Nurse management of intractable functional constipation: a randomised controlled trial. *Archives of Disease in Childhood*, 89, 717-722.

Cash, B.D. & Chey, W.D. (2004). Irritable bowel syndrome – an evidence-based approach to diagnosis. *Alimentary Pharmacology and Therapeutics*, 19(12), 1235-1245.

Casiday, R.E., Hungin, A.P.S., Cornford, C.S., de Wit, N.J. & Blell, M.T. (2009). GPs' explanatory models for irritable bowel syndrome: a mismatch with patient models? *Family Practice*, 26, 34-39.

Charapata, C. & Mertz, H. (2006). Physician knowledge of Rome symptom criteria for irritable bowel syndrome is poor among non-gastroenterologists. *Neurogastroenterology and Motility*, 18, 211-216.

Chew-Graham, C.A., Cahill, G., Dowrick, C., Wearden, A. & Peters, S. (2008). Using multiple sources of knowledge to reach clinical understanding of chronic fatigue syndrome. *Annals of Family Medicine*, 6(4), 340-348.

Cheung, W.Y., Dove, J., Lervy, B., Russell, I.T. & Williams, J.G. (2002). Shared care in gastroenterology: GPs' views of open access to out-patient follow-up for patients with inflammatory bowel disease. *Family Practice*, 19(1), 53-56.

Chitkara, D.K., van Tilburg, M.A.L., Blois-Martin, N. & Whitehead, W.E. (2008). Early life risk factors that contribute to irritable bowel syndrome in adults: A systematic review. *American Journal of Gastroenterology*, 103, 765-774.

CMPMedica NZ Ltd. (2008). New Zealand Health Care System-what you might pay for health care. Retrieved September 17, 2009 from

<http://www.everybody.co.nz/page-Oa4164ca-3942>

Cole, J. A., Rothman, K.J., Cabral, H.J., Zhang, Y., & Farraye, F.A. (2006).

Migraine, fibromyalgia, and depression among people with IBS: a prevalence study. *BMC Gastroenterology*, 6(26); Retrieved February 6, 2008, from

<http://www.biomedcentral.com/1471-230X/6/26>

Crampton, P., Jatrana, S., Lay-Yee., R & Davis, P. (2007). Exposure to primary medical care in New Zealand: number and duration of general practitioner visits. *Journal of New Zealand Medical Association*, 120(1256). Retrieved October 13, 2009 from www.nzmj.com/120-1256/2582/

Creed, F., Guthrie, E., Ratcliffe, J., Fernandes, L., Rigby, C., Tomenson, B., Read, N. & Thompson, D.G. (2005). Reported sexual abuse predicts impaired functioning but a good response to psychological treatments in patients with severe irritable bowel syndrome. *American Psychosomatic Society*. 67(3), 490-499.

Creed, F., Tomenson, B., Guthrie, E., Ratcliffe, J., Fernandes, L., Read, N., Palmer, S. & Thompson, D.G. (2008). The relationship between somatisation and outcome on patients with severe irritable bowel syndrome. *Journal of Psychosomatic Research*, 64, 613-620.

Croghan, A. & Heitkemper, M. M. (2005). Recognising and managing patients with irritable bowel syndrome. *Journal of the American Academy of Nurse Practitioners*, 17(2), 51-59.

Dancey, C.P., Hutton-Young, S.A., Moye, S., Devins, G.M. (2002). Perceived stigma, illness intrusiveness and quality of life in men and women with irritable bowel syndrome. *Psychology, Health & Medicine*, 7(4), 381-394.

Dixon-Woods, M., & Critchley, S. (2000). Medical and lay views of irritable bowel syndrome. *Family Practice*, 17(2), 108-113.

Donker, G.A., Foets, M. & Spreeuwenberg, P. (1999). Patients with irritable bowel syndrome: health status and use of health care services. *British Journal of General Practice*, 49, 787-792.

Dong, L., Dingguo, L., Xiaxing, X. & Hanming, L. (2005). An epidemiological study of irritable bowel syndrome in adolescents in children in China: A school based study. *Pediatrics*, 116(37), 393-396.

Drossman, D.A., Morris, C.B., Hu, Y., Toner, B.B., Diamant, N., Leserman, J., Shetzline, M., Dalton, C. & Bangdiwala, S.I. (2005). A prospective assessment of bowel habit in irritable bowel syndrome in women: Defining an alternator. *Gastroenterology*, 128(3), 580-589.

- Dyson, L. (1997). Advanced nursing roles: their worth in nursing. *Professional Nurse*, 12(10), 728-732.
- El-Serag, H. B., Pilgrim, P. & Schoenfeld, P. (2004). Systematic review: natural History of irritable bowel syndrome. *Alimentary Pharmacology and Therapeutics*, 19(8), 861-870.
- Farup, P.G., Vandvik, P.O. & Aabakken, L. (2005). How useful are the Rome II criteria for identification of upper gastrointestinal disorders in general practice? *Scandinavian Journal of Gastroenterology*, 40, 1284-1289.
- Ferrero, S., Camerini, G., Ragni, N. & Remorgida, V. (2008). Endometriosis and irritable bowel syndrome: co-morbidity or misdiagnosis? *An International Journal of Obstetrics and Gynaecology*, 116(1), 129-129.
- Finco, C., Savastano, S., Luongo, B., Vecchiato, M., Gasparini, G. & Merigliano, S. (2007). Colpocystodefecography in obstructed defecation: is it really useful to the surgeon? Correlating clinical and radiological findings in surgery for obstructed defecation. *The Association of Coloproctology of Great Britain and Ireland. Colorectal Disease*, 10, 446-452.
- Ford, A.C., Talley, N.J., Schoenfeld, P.S., Quigley, E.M.M. & Moayyedi, P. (2008). Efficacy of antidepressants and psychological therapies in irritable bowel syndrome: systematic review and meta-analysis. *Gut*, 58, 367-378.

- Francis, C.Y., Morris, J. & Whorwell, P.J. (1997). The irritable bowel severity scoring system: A simple method of monitoring irritable bowel syndrome and its progress. *Alimentary Pharmacology and Therapeutics*, 11, 395-402.
- Gearry, R., Barclay, M., Florkowski, C., George, P. & Walmsley, T. (2005). Faecal calprotectin: the case for a novel non-invasive way of assessing intestinal inflammation. *The New Zealand Medical Journal*, 118(1214), 1-7.
- Gerson, M-J., Gerson, C.D., Awad, R.A., Dancey, C., Poitras, P., Porcelli, P. & Sperber, A.D. (2006). An international study of irritable bowel syndrome: Family relationships and mind-body attributions. *Social Science & Medicine*, 62(11), 2838-2847.
- Goosens, D., Jonkers, D., Stobberingh, E., van der Bogaard, A., Russel, M. & Stockbrugger, R. (2003). Probiotics in gastroenterology: Indications and future perspectives. *Scandinavian Journal of Gastroenterology* (Suppl. 239).
- Greenberg, M.R., Amitrone, H. & Galiczynski, E.M. (2002). A contemporary review of irritable bowel syndrome. *Physician Assistant*, 26(8), 26-35.
- Griffiths, A.N., Koutsouridou, R.N. & Penketh, R.J. (2007). Predicting the presences of rectovaginal endometriosis from the clinical history: A retrospective observational study. *Journal of Obstetrics and Gynaecology*, 27(5), 493-495.

- Grundy, D. & Schemann. (2006). Enteric nervous system. *Current Opinion in Gastroenterology*, 22(2), 102-110.
- Gwee, K.A. (2005). Irritable bowel syndrome in developing countries – a disorder of civilisation or colonisation. *Neurogastroenterology and Motility*, 17(3), 317-324.
- Gwee, K-A., Leong, Y-L., Graham, C., McKendrick, M.W., Collins, S.M., Walters, S.J., Underwood, J.E., Read, N.W. (1999). The role of psychological and biological factors in postinfective gut dysfunction, *Gut*, 44(3), 400-406.
- Halder, S. L. S., Locke, G.R., Scleck, C.D., Zinsmeister, A.R., Melton, L.J. & Talley, N.J. (2007). Natural history of functional gastrointestinal disorders: A 12 year longitudinal population-based study. *Gastroenterology*, 133(3), 799-807.
- Hamberg, K., Risberg, G. & Johansson, E.E. (2004). Male and female physicians show different patterns of gender bias: A paper-case study of management of irritable bowel syndrome. *Scandinavian Journal of Public Health*, 32, 144-152.
- Hammer, J., Eslick, G.D., Howell, S.C., Altiparmak, E., Talley, N.J. (2004). Diagnostic yield of alarm features in irritable bowel syndrome and functional Dyspepsia. *Gut*, 53, 666-672.

- Harris, L.A. & Chang, L. (2006). Irritable bowel syndrome: new and emerging therapies. *Current Opinion in Gastroenterology*, 22(2), 128-135.
- Hatlebakk, J.G. & Hatlebakk, M.V. (2004). Diagnostic approach to suspected irritable bowel syndrome. *Best Practice & Research Clinical Gastroenterology*, 18(4), 735-746.
- Hayes, E. (2007). Nurse practitioners and managed care: patient satisfaction and intention to adhere to nurse practitioner plan of care. *Journal of the Academy of Nurse Practitioners*, 19(8), 418-425.
- Heitkemper, M. M. & Bond, E.F. (2004). Clinical nurse specialists: state of the profession and challenges ahead. *Clinical Nurse Specialists*, 18(3), 135-140.
- Heitkemper, M., Carter, E., Ameen, V., Olden, K & Cheng, L. (2002). Women with Irritable bowel syndrome. Differences in patients' and physicians' perceptions. *Gastroenterology Nursing*, 25(5), 192-202.
- Heitkemper, M. & Jarrett, M. (2005). Overlapping conditions in women with irritable bowel syndrome. *Urological Nursing*, 25(1), 25-31.

Hellstrom, P.M., Hein, J., Bytzer, P., Bjornssons, E., Kristensen, J. & Schambye, H.

(2008). Clinical trial: the glucagon-like peptide-1 analogue ROSE-010 for management of acute pain in patients with irritable bowel syndrome: a randomized, placebo-controlled, double-blind study. *Alimentary Pharmacology and Therapeutics*, 29, 198-206.

Hertig, V.L., Cain, K.C., Jarrett, M.E., Burr, R.L. & Heitkemper, M.M.

(2007) Daily stress and gastrointestinal symptoms in women with irritable bowel syndrome. *Nursing Research*, 56(5), 399-406.

Hillier, A. (2001). The advanced practice nurse in gastroenterology: Identifying and

comparing care interactions of Nurse Practitioners and Clinical Nurse Specialists. *Gastroenterology Nursing*, 24(5), 239-245.

Holten, K.B, Wetherington A. & Bankston, L. (2003). Diagnosing the patient with

abdominal pain and altered bowel habits: is it irritable bowel syndrome? *American Family Physician*, 67(10), 2157-2162.

Howell, S., Talley, N.J., Quine, S. & Poulton, R. (2004). The irritable bowel

syndrome has its origins in the childhood socioeconomic environment. *American Journal of Gastroenterology*, 99, 1572-1578.

Howell, S., Poulton, R. & Talley, N.J. (2005). The natural history of childhood

abdominal pain and its association with adult irritable bowel syndrome: Birth-cohort study. *American Journal of Gastroenterology*, 100, 2071-2078.

- Hungin, A.P.S., Chang, L., Locke, G.R., Dennis, E.H. & Barghout, V. (2005). Irritable bowel in the United States: Prevalence, symptom patterns and impact. *Alimentary Pharmacology and Therapeutics*, 21(11), 1365-1375.
- Inadomi, J.M., Fennerty, M.B. & Bjorkman, D. (2003). The economic impact of irritable bowel syndrome. *Alimentary Pharmacology and Therapeutics*, 18(7), 671-682.
- Jarrett, M.E., Kohen, R., Cain, K.C., Burr, R.L., Poppe, A., Navaja, P & Heitkemper, M.M. (2007). Relationship of SERT polymorphisms to depressive and anxiety symptoms in irritable bowel syndrome. *Biological Research Nursing*, 9(2), 161-169.
- Jonsdottir, H., Litchfield, M. & Pharris, M.D. (2004). The relational core of nursing practice as partnership. *Journal of Advanced Nursing*; 47(3), 241-250.
- Jones, R. (2004). Irritable bowel syndrome: management of expectations and disease. *British Journal of General Practice*, 54(504), 490-491.
- Kajander, K., Hatakka, K., Poussa, T., Farkkila, M. & Korpela, R. (2005). A probiotic mixture alleviates symptoms in irritable bowel syndrome patients: A controlled 6-month intervention. *Alimentary and Pharmacology and Therapeutics*, 22(5), 387-394.

Kolowski, N.A., Talley, N.J. & Boyce, P.M. (2001). Predictors of health care seeking for irritable bowel syndrome and non ulcer dyspepsia: A critical review of the literature on symptom and psychosocial factors. *The American Journal of Gastroenterology*, 96(5), 1340-1349.

Kennedy, A., Robinson, A. & Rogers, A. (2003). Incorporating patients' views and experiences of life with IBS in the development of an evidence based self-help guidebook. *Patient Education and Counseling*, 50, 303-310.

Lackner, J.M., Gudleski, G.D. & Blanchard, E.B. (2004). Beyond abuse: the association among parenting style, abdominal pain, and somatization in IBS patients. *Behaviour Research and Therapy*, 42, 41-56.

Lackner, J.M., Gudleski, G.D., Zack, M.A., Katz, L.A., Powell, C., Krasner, S., Holmes, E. & Dorscheimer, K. (2006). Measuring Health-related quality of life in patients with irritable bowel syndrome: can less be more? *Psychosomatic Medicine*, 68(2), 312-320.

Lacy, B.E. (2007). Latest from the literature in IBS and chronic constipation: January 2007. *Medscape Gastroenterology* 01/19/2007. View article at www.medscape.com/viewarticle/548916

- Lacy, B.E., Rosemore, J., Robertson, D., Corbin, D.A., Grau, M. & Crowell, M.D. (2006). Physicians' attitudes and practices in the evaluation and treatment of irritable bowel syndrome. *Scandinavian Journal of Gastroenterology*, 41, 892-902.
- Laperriere, H. (2008). Developing professional autonomy in advanced nursing practice: the critical analysis of sociopolitical variables. *International Journal of Nursing Practice*, 18, 391-397.
- Lea, R. & Whorwell, P.J. (2005). Expert commentary – bloating, distension and the irritable bowel syndrome. *Medscape General Medicine*, 7(1), 1-6.
- Le Pen, C., Ruszniewski, P., Gaudin, A-F., Amouretti, M., Bommelaer, G., Frexinos, J., Poynard, T., Maurel, F., Priol, G. & Bertin, C. (2004). The burden of cost of French patients suffering from irritable bowel syndrome. *Scandinavian Journal of Gastroenterology*, 39(4), 336-343.
- Lesbros-Pantoflickova, D., Michetti, P., Fried, M., Beglinger, C. & Blum, A.L. (2004). Meta-Analysis: The treatment of irritable bowel syndrome. *Alimentary Pharmacology and Therapeutics*. 20(11), 1253-1269.
- Levy, R.L., Von Korff, M., Whitehead, W.E., Stang, P., Saunders, K., Jhingran, P., Barghout, V. & Feld, A.D. (2001). Costs of care for irritable bowel syndrome patients in a health maintenance organisation. *The American Journal of Gastroenterology*, 96(11), 3122-3129.

- Litchfield, M. (1998). The scope of advanced nursing practice. *Nursing Praxis in New Zealand*, 13(3), 13-24.
- Longstreth, G.F., & Burchette, R. J. (2003). Family practitioners' attitudes and knowledge about irritable bowel syndrome. Effect of a trial of physician education. *Family Practice* 20(4), 670-674.
- Maruthachalam, K., Stoker, E., Nicholson, G. & Horgan, A.F. (2006). Nurse led flexible sigmoidoscopy in primary care- the first thousand patients. *Colorectal Disease*, 8, 557-562.
- Mawe, G.M., Coates, M.D. & Moses, P.L. (2006). Review article: Intestinal serotonin signalling in irritable bowel syndrome. *Alimentary Pharmacology and Therapeutics*. 23(8), 1067-1076
- Mayberry, M.K. & Mayberry, J.F. (2003). The status of nurse practitioners in gastroenterology. *Clinical Medicine*, 3(1), 37-41.
- Mayer, E.A., Tillisch, K. & Bradesi, S. (2006). Modulation of the brain-gut axis as a therapeutic approach in gastrointestinal disease. *Alimentary Pharmacology and Therapeutics*, 24(6), 919-933.
- McCutcheon, T. (2004). Statement on nursing. A personal perspective. *Gastroenterology Nursing*, 27(5), 226-229.

Mearin, F. (2006). Pharmacological treatment of the irritable bowel syndrome and other functional disorders. *Digestion*. 73(suppl. 1), 28-37.

Mearin, F., Badia, X., Balboa, A., Baro, E., Caldwell, E., Cucula, M., Diaz-Rubio, M., Fueyo, A., Ponce, J., Roset, M. & Talley, N.J. (2001). Irritable bowel syndrome prevalence varies enormously depending on the employed diagnostic criteria: Comparison of Rome II versus previous criteria in a general population. *Scandinavian Journal of Gastroenterology*. 36(11), 1155-1161.

Mearin, F., Badia, X., Balboa, A., Benavent, J., Caballero, A.M. , Dominguez-Munoz, E., Garrigues, V., Pique, J.M., Roset, M., Cucala, M & Figueras, M. (2006). Predictive factors of irritable bowel syndrome improvement: 1-year prospective evaluation in 400 patients. *Alimentary Pharmacology and Therapeutics*; 23(6), 815-826.

Ministry of Health. (2002). *Nurse Practitioners in New Zealand*. Wellington, New Zealand. Ministry of Health. Available from www.moh.govt.nz

Ministry of Health. (2004). Family doctors: methodology and description of the activity of private General Practitioners. *The National Primary Medical Care Survey (NatMedCa) 2001/02*. Report 1.

- Ministry of Health. (2004). Primary Health Care in community-governed non profits: The work of doctors and nurses. *The National Primary Medical Care Survey (NatMedCa) 2001/02. Report 2.*
- Minocha, A., Johnson, W.D., Abell, T.L. & Wigington, W.C. (2006). Prevalence, sociodemography, and quality of life of older versus younger patients with irritable bowel syndrome: a population based study. *Digestive Diseases and Sciences, 51(3)*, 446-453.
- Miura, S. (2007). Inflammatory bowel disease (IBD) versus irritable bowel syndrome (IBS): are there any overlaps? Exploring their interrelationships. *Journal of Gastroenterology, 42(suppl. XVII)*, 28-28.
- Morcom, J., Dunn, S.V. & Luxford, Y. (2004). Establishing an Australian Nurse Practitioner led colorectal cancer screening clinic. *Gastroenterology Nursing, 28(1)*, 33-42.
- Motzer, S.A., Hertig, V., Jarrett, M. & Heitkemper, M.M. (2003). Sense of coherence and quality of life in women with and without irritable bowel syndrome. *Nursing Research, 52(5)*, 329-337.
- Nabiloff, B.D., Frese, M.P. & Rapgay, L. (2008). Mind/body psychological treatments for irritable bowel syndrome, *eCAM. 5(1)*, 41-50.

New Zealand Guidelines Group. (2004). *Surveillance and management of groups at increased risk of colorectal cancer*. Author, Wellington, New Zealand.

Norton, C. & Kamm, M.A. (2002). Specialist nurses in gastroenterology. *Journal of the Royal Society of Medicine*, 95(7), 331-335.

Nygaard, I., Barber, M.D., Burgio, K.L., Kenton, K., Meikle, S., Schaffer, J., Spino, C., Whitehead, W.E., Wu, J. & Brody, D.J. (2008). Prevalence of symptomatic pelvic floor disorders in US women. *Journal of the American Medical Association*, 300(11), 1311-1316.

Olbe, L. (2008). Concept of Crohn's disease being conditioned by four main components, and irritable bowel syndrome being an incomplete Crohn's disease. *Scandinavian Journal of Gastroenterology*, 43, 234-241.

Palmer, B.V., Lockley, W.J., Palmer, R.B. & Kulinskaya, E. (2002). Improvement in irritable bowel syndrome following ano-rectal surgery. *International Journal of Colorectal Disease*, 17, 402-411.

Paterson, W.G., Thompson, W.G., Vanner, S.J., Faloon, T.R., Rosser, W.W., Birtwhistle, R.W., Morse, J.L. & Touzel, T.A. (1999). Recommendations for the management of irritable bowel syndrome in family practice. *Canadian Medical Association Journal*, 161(2), 154-160.

- Patrick, D.L., Drossman, D.A., Frederick, I.O., Dicesare, J., & Puder, K. (1998).
Quality of life in persons with irritable bowel syndrome. Development and
validation of a new measure. *Digestive Diseases and Sciences*, 43(2),
400-411.
- Payne, S. (2004). Sex, gender and irritable bowel syndrome: Making the connections.
Gender Medicine, 1(1), 18-28.
- Petruzzello, L., Iacopini, F., Bulajic, M., Shah, S. & Costamagna, G. (2006).
Review article: Uncomplicated diverticular disease of the colon. *Alimentary
Pharmacology and Therapeutics*, 23(10), 1379-1391.
- Pharmac. NZ. (2009). Alimentary tract and metabolism. Page 25. Pharmaceutical
Schedule. Retrieved September 26 from
www.pharmac.govt.nz/patients/Schedule?code=A01
- Pharmac. NZ. (2009). Pharmaceutical suppliers: multi product tender consultation.
Retrieved October 14 from www.pharmac.co.nz/2009/08/21/2009-08
- Polit, D.E. & Beck, C.T. (2004). *Nursing Research. Principles and Methods*,
7th ed. Philadelphia: Lippincott, Williams & Wilkins.
- Quigley, E.M.M. (2005). Irritable bowel syndrome and inflammatory bowel disease:
interrelated diseases? *Chinese Journal of Digestive Diseases*, 6, 122-132.

- Quigley, E.M.M. (2006). Non-erosive reflux disease, functional heartburn and gastroesophageal reflux disease; insights into pathophysiology and clinical presentation. *Chinese Journal of Digestive Diseases*, 7, 186-190.
- Quigley, E.M.M. (2007). Bacterial flora in irritable bowel syndrome: role in pathophysiology; implications for management. *Journal of Digestive Diseases*, 8, 2-7.
- Read, A.M. & Mayberry, J.F. (2000). Doctor or nurse? The patients' choice. *Postgraduate Medicine*, 76, 212-214.
- Redsell, S., Stokes, T., Jackson, C., Hastings, A. & Baker, R. (2006). Patients' accounts of differences in nurses' and general practitioners' roles in primary care. *Journal of Advanced Nursing*, 57(2), 172-180.
- Remorgida, V., Ferrer, S., Fulcheri, E., Ragni, N. & Martin, D.C. (2007). Bowel endometriosis: presentation, diagnosis and treatment. *Obstetrical and Gynecological Survey*, 62(7), 461-470.
- Ringel, Y., Whitehead, W.E., Toner, B.B., Diamant, N.E., Hu, Y., Jia, H., Bangdiwala, S.I. & Drossman, D.A. (2004). Sexual and physical abuse are not associated with rectal hypersensitivity in patients with irritable bowel syndrome. *Gut*, 53, 838-842.

- Ringstrom, G., Storsrud, S., Lundqvist, S., Westman, B. & Simren, M. (2009).
Development of an educational intervention for patients with irritable bowel
syndrome (IBS) – a pilot study. *BMC Gastroenterology*. 9(10). Retrieved
April 24, 2009, from www.biomedcentral.com/1471-230X/9/10
- Roalfe, A.K., Roberts, L.M. & Wilson, S. (2008). Evaluation of the Birmingham IBS
symptom questionnaire. *British Medical Council of Gastroenterology*, 8(30).
Retrieved October 15, 2008 from www.biomedcentral.com/1471-230X/8/30
- Rodriguez, L.A.G., Gonzalez-Perez, A., Johansson, S. & Wallander, M.-A. (2005).
Risk factors for inflammatory bowel disease in the general population.
Alimentary Pharmacology and Therapeutics. 22(4), 309-315.
- Rutter, C.L. & Rutter, D.R. (2002). Illness representation, coping and outcome in
irritable bowel syndrome. *British Journal of Health Psychology*, 7, 377-391.
- Salmon, P., Skaife, K. & Rhodes, J. (2003). Abuse, dissociation, and somatisation in
irritable bowel syndrome: Towards an explanatory model. *Journal of
Behavioural Medicine*, 26(1), 1-18.
- Sanders, K.A., Blanchard, E.B. & Sykes, M.A. (2007). Preliminary study of a self-
administered treatment for irritable bowel syndrome: Comparison to a wait list
control group. *Applied Psychophysiological Biofeedback*, 32, 111-119.

- Schoenfeld, P. & Talley, N.J. (2006). Editorial: Measuring successful treatment of irritable bowel syndrome: Is “satisfactory relief” enough? *American Journal of Gastroenterology*, *101*, 1066-1068.
- Seaman, H.E., Ballard, K.D., Wright, J.T. & de Vries. (2008). Endometriosis and its coexistence with irritable bowel syndrome and pelvic inflammatory disease: findings from a national case-control study – Part 2. *An International Journal of Obstetrics and Gynaecology*, *115*, 1392-1396.
- Seres, G., Kovaks, Z., Kovaks, A., Kerekgyarto, O., Sardi, K., Demeter, P., Meszaros, E. & Tury, F. (2008). Different associations of health related quality of life with pain, psychological distress and coping strategies in patients with irritable bowel syndrome and inflammatory bowel disorder. *Journal of Clinical Psychology in Medical Settings*, *15*, 287-295.
- Shen, Y.A. & Nahas, R. (2009). Complementary and alternative medicine for treatment of irritable bowel syndrome. *Canadian Family Physician*. *55*, 143-148.
- Shepherd, S.J. & Gibson, P.R. (2006). Fructose malabsorption and symptoms of irritable bowel syndrome: Guidelines for effective dietary management. *Journal of the American Dietetic Association*, *106*, 1631-1639.

- Shepherd, S.J., Parker, F.C., Muir, J.G. & Gibson, P.R. (2008). Dietary triggers of abdominal symptoms in patients with irritable bowel syndrome: Randomised placebo-controlled evidence. *Clinical Gastroenterology and Hepatology*, 6(7), 766-771.
- Simren, M., Abrahamsson, H., Svedlund, J. & Björnsson, E.S. (2001). Quality of life in patients with irritable bowel syndrome seen in referral centres versus primary care: The impact of gender and predominant bowel pattern. *Scandinavian Journal of Gastroenterology*, 36(5), 545-552.
- Smith, G.D. (2006). Effect of nurse-led gut-directed hypnotherapy upon health-related quality of life in patients with irritable bowel syndrome. *Journal of Clinical Nursing*, 15, 678-684.
- Snell, H., Robinson, J. & Perry, V. (2009). Towards a New Zealand medicines strategy: on behalf of the Nurse Practitioners of New Zealand (NPNZ). Retrieved October 2nd 2009 from http://www.nurse.org.nz/nurse_practitioner/subm_health_strategy.html
- Song, A.H. & Advincula, A.P. (2005). Mini review. Adolescent chronic pelvic pain. *Journal of Pediatric and Adolescent Gynecology*, 18, 371-377.
- Spiegel, B., Strickland, A., Naliboff, B.D., Mayer, E.A. & Chang, L. (2008). Predictors of patient-assessed illness severity in irritable bowel syndrome. *American Journal of Gastroenterology*, 103, 2536-2543.

- Spiller, R.C. (2005). Rationale for the use of serotonin-modulating agents in the management of IBS and chronic constipation. *Medscape Gastroenterology*, 7(2), 1-8
- Springer, K.W., Sheridan, J., Kuo, D. & Carnes, M. (2003). The long-term health outcomes of childhood abuse. An overview and a call to action. *Journal of Internal Medicine*, 18(10), 864-870.
- Stark, D., van Hal, S., Marriott, D., Ellis, J. & Harkness, J. (2007). Irritable bowel syndrome: A review on the role of intestinal protozoa and the importance of their detection and diagnosis. *International Journal for Parasitology*, 37, 11-20.
- Talley, N. (2003). Evaluation of drug treatment in irritable bowel syndrome. *British Journal of Clinical Pharmacology*, 56, 362-369.
- Talley, N. (2004). Irritable bowel syndrome remains a difficult condition to manage. *Drug Benefit Trends*, 16(6), 313-322.
- Talley, N. (2006). Irritable bowel syndrome. *Internal Medicine Journal*, 36, 724-728.
- Talley, N., Boyce, P.M. & Jones, M. (1997). Predictors of health care seeking for irritable bowel syndrome: a population based study. *Gut*, 41, 394-398.

- Talley, N. & Martin, C.J. (2006). *Clinical Gastroenterology. A practical problem-based approach*. Sydney, Churchill Livingstone, Elsevier.
- Vermeulen, J., Lange, J.F., Sikkenk, A.C. & van der Harst, E. (2005). Anterolateral rectopexy for correction of rectoceles leads to good anatomical but poor functional results. *Technical Coloproctology*, 9, 35-41.
- Whitehead, W.E., Palsson, O.S., Levy, R.L., Feld, A.D., Von Korff, M. & Turner, M. (2006a). Reports of “satisfactory relief” by IBS patients receiving usual medical care are confounded by baseline symptom severity and do not accurately reflect symptom improvement. *American Journal of Gastroenterology*, 101, 1057-1065.
- Whitehead, W.E., Palsson, O.S., Feld, A.D., Levy, R.L., Von Korff, M., Turner, M.J. & Drossman, D.A. (2006b). Utility of red flag symptom exclusions in the diagnosis of irritable bowel syndrome. *Alimentary Pharmacology and Therapeutics*, 24(1), 137-146.
- Wiklund, I.K., Fullerton, S., Hawkey, C.J., Jones, R.H., Longstreth, G.F., Mayer, E.A., Peacock, R.A., Wilson, I.K. & Naesdal, J. (2003). An irritable bowel syndrome-specific symptom questionnaire: Development and validation. *Scandinavian journal of Gastroenterology*, 38(9), 947-954.

- Williams, R.E., Black, C.L., Kim, H, -Y., Andrews, E.B., Mangel, A.W., Buda, J.J. & Cook, S.F. (2006). Determinants of healthcare-seeking behaviour among subjects with irritable bowel syndrome. *Alimentary Pharmacology and Therapeutics*, 23(11), 1667-1675.
- Williams, R.E., Hartmann, K.E., Sandler, R.S., Miller, W.C. & Steege, J.F. (2004). Prevalence and characteristics of irritable bowel syndrome among women with chronic pelvic pain. *The American College of Obstetricians and gynecologists*, 104(3), 452-458.
- Wilson, S., Maddison, T., Roberts, L., Greenfield, S. & Singh, S. (2006). Systematic review: the effectiveness of hypnotherapy in the management of irritable bowel syndrome. *Alimentary Pharmacology and Therapeutics*, 24, 769-780.
- Wilson, S., Roberts, L., Roalfe, A., Bridge, P. & Singh, S. (2004). Prevalence of irritable bowel syndrome: a community survey. *British Journal of General Practice*, 54, 495-502.
- Wong, E., Guyatt, G.H., Cook, D.J., Griffith, L.E. & Irvine, J. (1998). Development of a questionnaire to measure quality of life in patients with irritable bowel syndrome. *European Journal of Surgery*, 164, suppl 583: 50-56.

Yantiss, R.K., Clement, P.B. & Young, R.H. (2001). Endometriosis of the intestinal tract. A study of 44 cases of a disease that may cause diverse challenges in clinical and pathologic evaluation. *The American Journal of Surgical Pathology*, 25(4), 445-454.

Young, R.L. & Quigley, E.M.M. (1997). Chronic abdominal pain in women: Cost conscious ways to avoid diagnostic errors. *Consultant*, June 1997; 1489-1500.

26 March 2008

Judy Moore
Oxford Clinic
P O Box 3932
Christchurch

Dear Judy Moore,

The role of an advanced Nurse Practitioner in the management of patients with Irritable Bowel Syndrome

Investigators: J Moore, MJ Gagan, R Perry

Ethics ref: URA/08/02/EXP

The above study has been given ethical approval by the Chairperson and Deputy Chairperson of the Upper South A Regional Ethics Committee.

Approved Documents

Information sheet and consent form dated 22 February 2008

Questionnaire dated 22 February 2008

Progress Reports

The study is approved until **31 October 2009**. The Chairperson will review the approved application annually and notify the Investigator if they withdraw approval. It is the Investigator's responsibility to forward a progress report prior to ethical review of the project in March 2009. The report form is available on <http://www.newhealth.govt.nz/ethicscommittees>. Please note that failure to provide a progress report may result in the withdrawal of ethical approval. A final report is also required at the conclusion of the study.

Amendments

It is also a condition of approval that the Committee is advised if the study does not commence, or is altered in any way, including all documentation eg advertisements, letters to prospective participants.

Please quote the above ethics committee reference number in all correspondence.

It should be noted that Ethics Committee approval does not imply any resource commitment or administrative facilitation by any healthcare provider within whose facility the research is to be carried out. The organisation may specify their own processes regarding notification or approval.

We wish you well with your study.

Yours sincerely

Alieke Dierckx

Upper South A Regional Ethics Committee Administrator

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IRRITABLE BOWEL SYNDROME QUESTIONNAIRE

Irritable bowel syndrome is a common and debilitating problem that affects a large proportion of the population. It is a gastro-intestinal disorder that can manifest itself in a number of ways with different groups of symptoms.

This questionnaire is comprehensive so we can gather as much information about you as we can in order to find the best way to treat you. Please take the time to complete this with as much information you can give us.

All information provided will be kept confidential.

Name _____ Date of Birth ____/____/____

ID no (office use only) _____ GP _____

1. Below are a number of medical symptoms. Please tick boxes relating to problems you have been experiencing. You may tick as many boxes as is necessary.

- | | |
|--|--|
| 1. <input type="checkbox"/> Irregular bowel habit | 2. <input type="checkbox"/> Diarrhoea |
| 3. <input type="checkbox"/> Constipation | 4. <input type="checkbox"/> Abdominal pain/discomfort |
| 5. <input type="checkbox"/> Wind | 6. <input type="checkbox"/> Unable to control wind |
| 7. <input type="checkbox"/> Abdominal bloating | 8. <input type="checkbox"/> Feeling of pressure in rectum |
| 9. <input type="checkbox"/> Rectal prolapse (rectum falling out) | 10. <input type="checkbox"/> Feeling a sense of incomplete emptying after a bowel motion |
| 11. <input type="checkbox"/> Anal irritation | 12. <input type="checkbox"/> Indigestion |
| 13. <input type="checkbox"/> Mouth ulcers | 14. <input type="checkbox"/> Fatigue |

1.1 Which symptom bothers you most? Use the number next to the symptom (choose only one)

2. When did your bowel symptoms start?

1. less than 3 months ago
2. between 3 months and 2 years
3. more than 2 years

Title: IBS Questionnaire	Review Date: 01 05 10 Version: 2	Document File name: Q:\Patient Information Intus\IBS\IBS Questionnaire.doc	Page 1 of 8
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The role of an Advanced Nurse Practitioner in identification and management of patients with Irritable Bowel Syndrome.

INFORMATION SHEET

You are invited to participate in a study looking at the role of an advanced nurse practitioner in helping people identify the causes of their symptoms of Irritable Bowel Syndrome (IBS) and providing the best possible management plan. All patients attending the service between March and November 2008 will be invited to participate, anticipating participation from between 50 and 80 patients.

Researcher:

Judy Moore, IBS nurse specialist, who is currently undertaking a clinical masters programme that is recognised by the Nursing Council of New Zealand as training for Nurse Practitioner. This course of study is supervised through the Post Graduate Department of Nursing Studies, Christchurch School of Medicine, University of Otago.

Background:

IBS is a set of symptoms affecting almost 20% of the population, of whom most are women. It is characterised by an altered bowel habit for more than 3 months with abdominal pain or discomfort, and possibly diarrhoea, constipation, or both. It has been traditionally seen as a functional disorder, that is, there is no disease identified with the syndrome. It does not lead to other illnesses, or cause mortality. However, many people live with debilitating symptoms and find it hard to understand that nothing wrong can be found.

There is no public health system designed to care for patients with IBS. Busy General Practitioners (GPs) cannot spend the considerable time needed to eliminate possible causes of symptoms in patients who present with symptoms of IBS. Specialist clinics run by nurses and dietitians exist in the UK and USA, and provide an outlet for GPs and Gastroenterologists. A nurse practitioner can ease this load, and spend more time with the patient exploring the person as a whole.

Often other health problems have been identified as the cause of IBS symptoms and these people have been referred to a more appropriate specialist to treat that disease.

What is involved for me?

You will be sent/given 2 questionnaires, the first will be sent on confirmation of your initial appointment before your first visit. Questions are aimed at how you felt before you visited the IBS service. The second will be sent 3 months after your visit. The only requirement we ask of you is that you complete the questionnaires to the best of your ability and honestly. We also ask that if there is any question you are not comfortable in answering, you do not have to. By completing the first questionnaire and sending it back, this implies consent. Therefore we will contact you 2 weeks after sending you the second questionnaire if you have not returned it to remind you to do so.

What if I don't want to be identified?

This questionnaire is totally anonymous. The researcher will only be gathering your data by a number, and will not be intentionally identifying you with a questionnaire. Again, if you are not comfortable with this project, you are in no way obliged to do so. Your care and confidentiality will not be compromised in any way.

What if I decide I don't want to participate?

It doesn't matter. The study is entirely voluntary. If you decide not to take part, this will not affect your future health care. You can withdraw from the study at any time. If you have any questions or concerns, please contact me at the address below or the clinical manager at Intus, Oxford Clinic.

What are the potential benefits of the study?

That a dedicated service is recognised and available to all people with symptoms of IBS. This service is a resource for doctors and patients alike, providing information, assistance and care in identification and management of their symptoms. It is anticipated that a support group will be generated from this service, and that patients nationwide have access to specialist advice. The outcomes of the study will be published in nursing and medical journals, aimed at providing information for health professionals.

What if I have concerns about my rights?

If you have any questions or concerns about your rights as a participant in this research study you can contact an independent health and disability advocate. This is a free service provided under the Health and Disability Commissioner Act.
Telephone: (NZ wide) 0800 555 050
Free Fax (NZ wide) 0800 2787 7678 (0800 2 SUPPORT)
Email (NZ wide): advocacy@hdc.org.nz

Will I be able to know the outcome?

You will be sent a copy of the outcome of the study unless you indicate you don't want it.

This study has been approved by the Upper South A Regional Ethics Committee.

Thank you for reading this letter of information.

Judy Moore
Researcher.

Intus, Oxford Clinic
P.O. Box 3932
Christchurch
Ph. 03 3637085
Fax. 03 3791558
Email: judy.moore@oxfordclinic.co.nz

The role of an advanced nurse practitioner in management of patients with Irritable Bowel Syndrome

IBS service research questionnaire ID no. _____

Dear participant, thank you for agreeing to be a part of this research project. Please only tick one box per question unless specifically asked to tick more than one. You do not have to answer all the questions if you do not wish to.

First questionnaire

1. Demographics

- a. age _____
- b. male female

2. Ethnicity.

Which ethnic group do you belong to? Tick all that apply.

- 2.1 New Zealand Caucasian 2.2 Maori 2.3 Samoan
- 2.4 Cook Island Maori 2.5 Tongan 2.6 Niuean 2.7 Chinese
- 2.8 New Zealand Chinese 2.9 Indian 2.10 Caucasian South African
- 2.11 Other, _____ please specify

3. Marital/cohabitation status (tick all that apply)

- 3.1 Never married 3.2 Married/de facto 3.3 Divorced/Separated
- 3.4 Single/divorced/separated/widowed, but in a relationship
- 3.5 Living with friends/family 3.6 Widowed and living with friends/family
- 3.6 Widowed and alone 3.7 Living alone

4. Education

What is your highest secondary school qualification?

4.1 None

4.2 NZ school certificate in one or more subjects or NCEA level 1

4.3 NZ Sixth form certificate in one or more subjects, or NCEA level 2

4.3 NZ University Entrance

4.4 NZ A or B Bursary, Scholarship, or NCEA level 3

4.5 Other secondary school qualification from overseas

4A. Apart from secondary school do you have another qualification?

(don't count incomplete qualifications or those that took less than 3 months of full time study to get)

Yes

No

4.6

If yes, please state your highest qualification and main subject.

5. Employment

What is your current employment status?

5.1 Student 5.2 Self employed 5.3 Employee 5.4 Unemployed

5.5 Looking for work 5.6 Invalid/sickness benefit 5.7 Retired

5.8 Temporarily laid off 5.9 Home maker 5.10 Maternity leave

5.11 Other (please state)

.....

6. Section one. Symptoms and severity

6. How long ago were you told you have IBS?

6.1 within last 3 months 6.2 3 months – 1 year ago 6.3 more than a year ago

6.4 Over the last month what have been your most dominant bowel symptoms? (Tick all those that apply)

- a. Abdominal pain
- b. Abdominal bloating and discomfort
- c. Constipation
- d. Diarrhoea
- e. Constipation and diarrhoea
- f. Urgency – need to get to toilet for a motion straight away
- g. Sense of incomplete evacuation – feeling you haven't finished

7. How often do you experience your symptoms?

7.1 Daily 7.2 Several times a week 7.3 Several times a month
7.4 Regularly with menstrual periods 7.5 Several times a year

8. How severe do you rate your symptoms, 1 2 3 4 5
1 being very mild to 5 being very severe

9. If one symptom could be miraculously cured immediately, which one would you choose?

_____ (only put down one symptom)

10. How did you find out about the IBS service?

10.1 Doctor 10.2 Friend 10.3 Family 10.4 Internet 10.5 Phone book

10.6 Other (please state) _____

Section II. Being told, and perceptions of the health care provider before you came to the IBS clinic. (A health care provider can be your family GP, naturopath, herbalist, local nurse, pharmacist, or any recognised professional you ask for help relating to health)

	<i>Not at all</i>			<i>Always</i>	
	1.	2.	3.	4.	5.
11. Did your health care provider explain IBS to you in a way you could understand?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. How satisfied were you with the diagnosis?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. Was adequate time spent with you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Did you feel there is something else wrong?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
15. Did you feel you were listened to?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I felt I could make an appointment with my health care provider anytime for my bowel problems.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. Did you feel that you were a nuisance to your health care provider?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I felt more depressed after my diagnosis.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I am scared something serious has been missed	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. What type of health care provider identified IBS as the cause of your symptoms?					
<input type="checkbox"/> GP	<input type="checkbox"/> nurse	<input type="checkbox"/> pharmacist	<input type="checkbox"/> naturopath/herbalist		
<input type="checkbox"/> Other _____					
20.1. Was anything prescribed for you?	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No	
21. Were you offered referral on to someone else for help?	<input type="checkbox"/>	Yes	<input type="checkbox"/>	No	
21.1 If yes, what sort of help?	_____				

Quality of life – how symptoms affect you	<i>Not at all</i>			<i>Always</i>	
	1.	2.	3.	4.	5.
22. My bowel symptoms limit my social activities	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I still go out despite my bowel symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. My work is affected by my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. Because of my symptoms I have more time off work	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. I manage at work despite my bowel symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. I am embarrassed by my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. I can't exercise because of my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
29. I get less done around home because of my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
30. I can't go out at night because of my bowels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
31. My relationship with my partner is affected by my bowels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
					not applicable <input type="checkbox"/>
32. I feel my partner is fed up with my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
					not applicable <input type="checkbox"/>
33. My symptoms stop me from enjoying sex	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
					not applicable <input type="checkbox"/>
34. I can't eat what I want because of my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
35. If I watch what I eat I have better control over my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

	<i>Not at all</i>			<i>Always</i>	
	1.	2.	3.	4.	5.
36. Since my symptoms started I feel more depressed.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
37. I have to be near a toilet when I am out	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
38. I don't like the way I look because of my bowel problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
39. I feel unclean because of my bowels	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
40. My friends see me as much as they did before my bowel problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
41. My clothes don't fit me anymore	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
42. I am scared my symptoms will get worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
43. I feel others are irritated with me because I have bowel problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
44. I am angry that I have bowel problems	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
45. I don't feel other people understand what it is like	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Coping mechanisms	<i>Not at all</i>					<i>Always</i>
	1.	2.	3.	4.	5.	
46.I like to try and relax	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
47.I try to exercise when I feel able	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
48.I am willing to try any way of getting relief	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
49.I keep busy so as to not focus on my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
50.I find resting alleviates my symptoms	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
51.I need friends around me to cope	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
52.I joke about my bowels to my friends and family	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
53.My partner is very supportive	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	Not applicable					<input type="checkbox"/>
54. I have found the person I have been referred to very helpful.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
55. I am able to gain relief from advice given	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
56. I am interested in helping others with the same problem	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Date questionnaire completed: _____

Thank You