HITTING BELOW THE BELT:
A PHENOMENOLOGICAL EXPLORATION OF THE ADULT'S EXPERIENCE OF
LIVING WITH IRRITABLE BOWEL SYNDROME

by

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ABSTRACT

The purpose of this study was to gain a fuller understanding of the adult’s experience of living with irritable bowel syndrome (IBS) from his or her perspective. Four adults, recruited through an IBS support group, were interviewed using Colaizzi’s method of phenomenological inquiry. Analysis of the data revealed 9 themes which identified the symptomatological characteristics of the participants; the trajectory of the disorder; seeking professional help - medical doctors, psychologists, and alternative practitioners; the psychologic impact of IBS; the impact of IBS on relationships with others; the impact of IBS on daily life; and making meaning. Together, these themes revealed that IBS encompassed all realms of the participants lives: the emotional, social, physical, spiritual, intellectual and financial. The participants, nevertheless, refused to put their lives on hold, but rather, got on with life.
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Henry F. Hilliard
1925 - 1996

I Will Remember You Forever
CHAPTER 1: INTRODUCTION

Background and Significance of the Problem

Prevalence and the Reporting of Irritable Bowel Syndrome

Affecting 15% to 25% of the general population in developed countries, irritable bowel syndrome is a digestive disorder of enormous proportion (Collins, 1988; Dancey & Backhouse, 1993; Drossman, Thompson, & Whitehead, 1992; Hogston, 1993). It is the most prevalent disorder in the spectrum of functional gastrointestinal complaints (Drossman et al.) and surprisingly, is second only to the common cold as the leading cause of absenteeism from work (Almy, 1967).

Consequently, the costs associated with this disorder are considerable, both to the patient with IBS and to North American health care systems (Drossman et al., 1992). People with IBS account for 25% to 60% of total referrals to gastroenterologists (Habal, 1990; Hogston, 1993; Talley, 1994) and comprise a large proportion of the general practitioners's practice (Drossman et al.). In the United States, three million visits to physicians and more than two million medications are prescribed each year for this digestive disorder (National Center for Health Statistics, 1981; Sandler, 1990).

Despite these proportions, most people experiencing the symptoms of IBS never seek health care for these complaints. Only one in three persons with this condition actually see a physician for this disorder, and these individuals are usually "young, white, and female" (Drossman et al., 1992, p. 175). Of these individuals, at least half seek health care for their symptoms before the age of 35. Psychosocial variables and biological susceptibilities often precipitate their seeking medical attention (Drossman et al.).

It is unfortunate, however, that due to the taboo surrounding toiletting habits in
Western society, and to the embarrassing nature of this disorder, most people remain ignorant as to the existence of this remarkably prevalent syndrome. It is this investigator's intent to help dispel some of the ignorance surrounding this insidious affliction.

**Symptomatology of Irritable Bowel Syndrome**

Irritable bowel syndrome (IBS) is a chronic gastrointestinal disorder characterized by altered bowel habits and varying degrees of abdominal pain (Dancey & Backhouse, 1993; Thompson, 1991). Individuals suffer from diarrhoea, constipation, or a combination of both (Schaefer, 1986). Characteristic of this disorder is an urgency associated with defeacation; the passage of ribbon-like or pellet stools; tenesmus (the sense of incomplete evacuation of faeces); the passage of mucous; pain associated with eating; more frequent loose stools or hard stools with the onset of pain; and the relief of pain with defeacation (Drossman, Thompson, & Whitehead, 1992; M. A. Eastwood, J. Eastwood, & Ford, 1987; Kellow & Langeluddecke, 1989; Read, 1987). Other symptoms include bloating, flatulence, borborygmi (rumbling in the bowels), rectal pain, belching, early satiety (the sense of being full), and dyspepsia (indigestion). Less common symptoms include faecal incontinence, nausea, heartburn, and esophagitis (acid reflux). Symptoms which may be associated with, but are not specific to IBS, include dysmenorrhea (painful menstruation), dyspareunia (painful coitus experienced by the woman), dysuria (painful urination), and urinary frequency (Cann, 1987; Dancey & Backhouse, 1993; Eastwood et al., 1987; Kellow & Langeluddecke, 1989).

**Etiology of Irritable Bowel Syndrome**

Irritable bowel syndrome is a "functional" disorder, in that it is characterized by the absence of organic pathology - its symptoms cannot be explained by biochemical or
structural abnormalities (Drossman, Thompson, & Whitehead, 1992; Latimer, 1983). It has no known cause and no effective long-lasting cure. It has been postulated, however, that IBS may be related to stress, food allergies, antibiotics, a diet deficient in fibre, gastrointestinal infection, bile acid malabsorption, chronic alcohol abuse, and abnormalities in GI secretions and peristalsis (Eastwood et al., 1987; Kellow & Langeluddecke, 1989; Schaefer, 1986; Spollett, 1989).

Diagnosis of Irritable Bowel Syndrome

In 1990, consensus guidelines for the diagnoses of 21 functional gastrointestinal disorders were developed by a multinational committee of clinician-researchers (Drossman, Thompson, et al. 1990). The committee was formed out of the need to establish reliable methods of diagnosis which were based on existing clinical and epidemiological data. Included among these functional disorders was irritable bowel syndrome:

Symptom criteria for irritable bowel -
Continuous or recurrent symptoms for at least three months of:
1. abdominal pain or discomfort, relieved with defecation, or associated with a change in frequency or consistency of stool; and
2. an irregular (varying) pattern of defecation at least 25% of the time (three

---

1At the 1988 Rome International Congress, irritable bowel syndrome was defined as "A functional gastrointestinal disorder attributed to the intestines and associated with symptoms of: (a) abdominal pain, and/or (b) disturbed defeacation, and/or (c) bloatedness or distention" (Thompson, Dotevall, Drossman, Heaton, & Kruis, 1989, pp. 92-95). While many researchers still use the Rome criteria for selecting participants with irritable bowel syndrome, these criteria have since been expanded and improved upon by the multinational committee described above.

2For the complete classification of irritable bowel syndrome as developed by Drossman, Thompson, et al. (1990), please see Appendix A.

3The committee recognizes that some [researchers] may require abdominal pain as an essential criterion, and others may not. The decision to permit either categories 1 or 2 will be left to the [researcher].
or more of):
(i) altered stool frequency;
(ii) altered stool form (hard or loose/watery stool);
(iii) altered stool passage (straining or urgency, feeling of incomplete evacuation);
(iv) passage of mucus;
(v) bloating or feeling of abdominal distention.
(Drossman, Thompson, et al., 1990, pp. 165-166)

The committee placed special emphasis on the importance of using "symptom-based criteria with a minimum of diagnostic studies" for the diagnosis of IBS (Drossman, Thompson, et al., 1990, p. 159).

At present, there are no available tests for making a definite diagnosis of IBS (Spollett, 1989). Rather, the diagnosis for irritable bowel syndrome is one of exclusion (Davol, 1986; Habal, 1990). Emphasis must be placed on the selection criteria as outlined above, as well as a thorough history and physical exam to rule out the possibility of organic disease, enzyme deficiency, or parasites (Dancey & Backhouse, 1993). Exacerbations of IBS with stress, and pain associated with eating, can contribute to the medical practitioner's confidence in the diagnosis (Drossman, Thompson, & Whitehead, 1992).

**Predisposing Factors**

Although irritable bowel syndrome is a functional disorder with no known cause, there are a number of factors which appear to predispose or to make one more susceptible to incurring this digestive disorder.

**Gender**

• Women are two to three times more likely to incur IBS than men (Habal, 1990; Schuster, 1991; Spollett, 1989).

**Race**

• IBS is five times more likely to affect whites than blacks (Schuster, 1991).
Age

• The onset of this digestive disorder typically occurs between the ages of 30 and 40, although 33% of IBS patients can trace these gastrointestinal symptoms back to childhood (Spollett, 1989).

• The prevalence of irritable bowel syndrome is highest among those aged 45 to 64 years (Schuster, 1991).

Familial Relationship

• Irritable bowel syndrome has a familial link as high as 33% (Whorwell, McCallum, Greed, & Roberts, 1986).

Childhood Abuse

• Fifty-three percent of female patients with a functional bowel disorder report a childhood history of physical or sexual abuse, compared to 37% of patients with organic gastrointestinal diagnoses (Drossman, Leserman, Jr., et al., 1990).

Childhood Parental Loss

• Lowman, Drossman, Cramer, and McKee (1987) reported that in patients with IBS, there was an increased frequency of death or loss of a parent during childhood.

• Hill and Blendis (1967) found that for 33% of their IBS patients, death of a parent precipitated IBS.

• Hislop (1979) reported that 31% of IBS patients had lost a parent through death, separation, or divorce before the age of 15. In addition, Hislop found that 61% of IBS patients reported unsatisfactory relationships with their parents.

Epidemiology of Irritable Bowel Syndrome

Irritable bowel syndrome is a worldwide problem. Its prevalence and proportions vary according to nationality, gender, race, and region:
• Studies from several Western countries in Europe and North America indicate that 15% to 25% of the general population are afflicted with IBS (Bommelaer et al., 1986; Drossman, Sandler, McKee, & Lovitz, 1982; Thompson, 1986; Thompson & Heaton, 1980; Welch, Hillman, & Pomare, 1985).

• In the upper Midwest of the United States, 17% of adults aged 30 to 64 suffer from this digestive disorder (Talley, Zinsmeister, VanDyke, & Melton, 1991).

• In North America, IBS is two to three times more prevalent in women than in men (Habal, 1990; Schuster, 1991; Spollett, 1989), and is five times less likely to affect blacks than whites (Schuster, 1991).

• For blacks in South Africa, this digestive disorder is more common in urban than in rural populations (Segal & Walker, 1984).

• In China, the prevalence of IBS appears to be equal or slightly greater than in the West, as is the tendency to seek medical consultation (cited in Drossman & Thompson, 1992; cited in Wingate, 1991).

• In Southeast Asia, irritable bowel syndrome is less common than in the West (Danivat, Tankeyoon, & Sriratanaban, 1988).

• In India and Sri Lanka, male patients predominate those seeking health care for IBS, (Mendis, Wijesiriwardena, Sheriff, & Dharmadasa, 1982; Pimparkar, 1970) whereas in Western countries, 75% to 80% of those seeking medical consultation for this condition are female (Fielding, 1977; Harvey, Salih, & Read, 1983; Thompson, 1984). This finding suggests that economic or cultural factors influence health care use by those with this digestive disorder.

Purpose of the Study and Problem Statement

Recent studies on the role of psychologic interventions for the management of IBS
have demonstrated counselling to be an extremely effective treatment strategy (Bennett & Wilkinson, 1985; Blanchard & Schwartz, 1987; Greene & Blanchard, 1994; Guthrie, Creed, Dawson, & Tomenson, 1991; Harvey, Hinton, & Gunary, 1989; Lynch & Zamble, 1989; Neff & Blanchard, 1987; Svedlund, Sjödin, Ottosson, & Dotevall, 1983; Whorwell, 1989; Whorwell, Prior, & Faragher, 1984), yet few counsellors know what irritable bowel syndrome is, let alone how to validate, inform, support and counsel people suffering from this condition.

Counsellors need information concerning the physical and psychologic implications associated with this bowel disorder if they are to provide effective treatment strategies. Without this knowledge, the counsellor’s potential to be ineffective, or even damaging to these clients, is considerable.

To be able to work effectively with clients who have IBS, the counsellor must understand what the individual’s experience is like in the context of everyday living. An empathic understanding of the client’s frame of reference is imperative to establishing a good therapist-client relationship. This relationship is critical for effective counselling to take place (Goldstein and Higginbotham, 1991).

Bearing this in mind, the purpose of this study was to explore and describe the experience of the adult who is living with irritable bowel syndrome. To accomplish this end, the investigator asked the following research question: "What is the lived experience of the adult who has been medically diagnosed as having irritable bowel syndrome?"

**Definition of Terms**

Following are the definitions of a number of key terms which were used in this study.
Irritable Bowel Syndrome (IBS): A digestive disorder characterized by altered bowel habits and varying degrees of abdominal pain. Individuals typically suffer from diarrhoea, constipation, or a combination of both. Other symptoms may include bloating, rectal flatulence, belching, indigestion (dyspepsia), the sense of being full, rumbling in the bowels (borborygmi) and faecal incontinence. This disorder of the gastrointestinal tract has no known cause and no effective long-lasting cure. Irritable bowel syndrome is a "functional" disorder, in that it is characterized by the absence of organic pathology.

Phenomenological: A qualitative research methodology which focuses specifically on the human experience as it is lived. The researcher uses unstructured, collaborative interviews in order to derive information of the meaning of an experience for an individual. Through these interviews the researcher strives to develop an empathic understanding of the individual's frame of reference. Data is derived from the perspective of the participant who is being interviewed. The researcher looks for emerging themes, constructing a "picture" which takes shape as more information is collected and examined.

Participant or Co-Researcher (CR): In keeping with the phenomenological research design, the terms "participant" and "co-researcher" have been used in place of the word "subject," in that the researcher perceives each participant as a partner or co-researcher in the investigative endeavour.

Lived Experience: The participant's experience of living with irritable bowel syndrome from his or her own perspective.

Protocol: The plan of a research endeavour or treatment. The participants' transcribed interviews are also called protocols.
Psychologic: The medical term for "psychological."

Investigator: The author and conductor of this phenomenological research inquiry.

Assumptions

The following assumptions are imperative to the phenomenological approach to qualitative research (Liebelt, 1993). It was assumed that each participant or co-researcher had a desire to share his/her experience of living with irritable bowel syndrome. Furthermore, the assumption was taken that each individual's views portrayed reality for that participant, and that this reality was described as accurately as possible. Finally, it was assumed that while no individual's lived experience is the same, themes would emerge which were common to all of the participants' descriptions of living with irritable bowel syndrome.

Limitations

There are a number of factors which limit the generalizability of a phenomenological study. These limitations are largely due to the small size of the sample and to the purposive, nonprobability sampling strategies of recruitment. They are also due to the specificity of the selection criteria and the recruitment procedures utilized to obtain participants, as outlined in Chapter 3. Consequently, the lived experiences of the individuals participating in this study may not be representative of those adults with IBS who: (1) do not belong to "The IBS Support Group," (2) would not volunteer for a study of this nature, (3) have IBS but have not sought medical attention for this condition, (4) suffer from either a very mild or very severe case of IBS, and (5) do not understand or are not able to communicate in spoken English.

Even within the specialized subgroup used for the study, each individual's lived experience was described from the context of personal meaning. This meaning has been
shaped from personal, interpersonal and cultural reactions to living with this digestive disorder (Liebelt, 1993). Thus, the lived experience of these participants may be different from those members who are from significantly different social and cultural systems.

The purpose of this study is not to generalize its findings to everyone with IBS, but to gain an understanding of the lived experience of a particular specialized subgroup of the population. Consequently, rather than being a detriment, the limited generalizability described above adds considerable validity to the study, or more specifically, adequacy to the qualitative inquiry (please see Chapter 3). It is hoped that this study will generate further studies, both qualitative and quantitative, on what it is like to live with irritable bowel syndrome.

Summary

Counselling has been demonstrated to be an effective treatment strategy for the management of IBS. It is therefore important for counsellors working with this population to understand what life is like for individuals with IBS, so that appropriate information, support and encouragement can be provided for clients seeking help in coping with this digestive disorder. Bearing this in mind, the purpose of this study, as discussed in this chapter, was to explore and describe the experience of the adult who is living with irritable bowel syndrome. To accomplish this end, the following research question was asked: "What is the lived experience of the adult who has been medically diagnosed as having irritable bowel syndrome?"

This chapter discussed the background and significance of IBS. The prevalence, symptomatology, etiology, diagnosis, predisposing factors and epidemiology of this remarkably prevalent bowel disorder were presented. Definitions of significant terms
used throughout this manuscript were delineated, as were assumptions imperative to the phenomenological approach. This chapter concluded with a discussion of the limitations inherent in this study. These limitations, which revolved around the limited generalizability of the study, added considerable validity and adequacy to the qualitative inquiry.

In Chapter 2, selected literature relevant to the phenomenon under investigation is examined. Also presented is an introduction to the advantages of the phenomenological approach for investigating the experience and meaning of living with irritable bowel syndrome. Further discussion of the phenomenological research method and a description of how this design was applied is the focus of Chapter 3. Chapter 4 presents the study's findings and an interpretation of the data. And finally, in Chapter 5, the findings of this investigation are discussed, as are the ramifications for future research and the implications for counselling those with irritable bowel syndrome.
CHAPTER 2: LITERATURE REVIEW

Introduction

In order to facilitate further understanding regarding the adult’s subjective experience of living with irritable bowel syndrome, this chapter will present a review of the literature thought to be relevant to the phenomenon under investigation. The investigator will begin by presenting psychologic factors pertaining to IBS. Next, a number of studies which have been conducted concerning various psychologic treatment modalities will be reviewed. Thirdly, a critique of the current medical treatments will be presented, as will a brief look at medical treatment directions for the future. Following this, medical case studies of individuals with IBS will be delineated, and finally, two studies related to the experience of living with this digestive disorder will be examined. This chapter will conclude with the advantages of using the phenomenological approach to study the experience and meaning of living with irritable bowel syndrome.

Psychologic Considerations of Irritable Bowel Syndrome

Psychopathology and its Association With IBS

In 1871, DaCosta, who is credited with the earliest description of irritable bowel syndrome, noted this phenomenon’s association with symptoms of psychologic distress (cited in Whitehead & Crowell, 1991). During this century, many investigations of the psychologic aspects of IBS appear to have confirmed this association (Drossman et al., 1982; Narducci, Snape, Battle, London, & Cohen, 1985; Richter, Obrecht, Bradley, Young, & Anderson, 1986; Varis, 1987; Waxman, 1988; Whitehead, Crowell, Robinson, Heller, & Schuster, 1992): Seventy to 80% of patients with IBS display abnormal scores on psychometric tests (Liss, Alpers, & Woodruff, Jr., 1973; Whitehead, Enck, & Schuster, 1989; Whitehead, Engel, & Schuster, 1980; Young, Alpers, Norland, &
Woodruff, Jr., 1976), and when psychiatric interviews are used instead of psychometric inventories to assess psychopathology in IBS patients, as many as 100% receive a psychiatric diagnosis (Latimer et al., 1981). Stressful life events exacerbate symptoms in more than half of medical clinic IBS patients, and 50% of patients with IBS report that the first occurrence of their symptoms followed a period of psychologic stress (Chaudhary & Truelove, 1962; Hislop, 1971; Waller, 1971).

Whitehead and Crowell (1991) state:

The association of psychologic symptoms with IBS is so strong and has been so consistently observed that many view the IBS as a psychiatric disorder (Latimer et al., 1981; Waxman, 1988). However, recent studies of persons who have IBS but have not yet consulted a physician have forced a reassessment of the role of psychologic factors in this disorder. (p. 249)

Three well-designed studies (Drossman et al., 1988; Drossman, Sandler, McKee, & Lovitzet, 1982; Whitehead, Bosmajian, Zonderman, Costa, & Schuster, 1988) marked a turning point in the acumen of the role of psychologic factors in the onset and maintenance of irritable bowel syndrome.

In a 1982 community survey conducted by Drossman et al., the researchers discovered that the majority of those who reported symptom profiles consistent with IBS also reported a disinclination to seek medical attention. Previous research on the psychologic factors associated with IBS had consistently found a high incidence of psychologic abnormalities, primarily anxiety and depression, in patients with IBS when studied in a clinical setting (Bailey, Jr., Stewart, Jr., & McCallum, 1991). These

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studies, by investigating only IBS patients, had not sampled a truly representative IBS population.

Based on these findings, Drossman et al. (1988) and Whitehead et al. (1988) decided to compare people with IBS from the community, who had not yet sought medical attention, to IBS clinic attenders. The researchers found that those subjects from the community who had not consulted a physician about their IBS exhibited no more psychologic disturbance than the normal population (Drossman et al., 1988; Whitehead et al.). In other words, those who exhibited IBS symptomatology, but had not yet consulted a doctor, were psychologically normal. This finding suggests that psychologic distress does not cause IBS, but rather, influences the decision to seek treatment.

Assessing Psychologic Disturbance in IBS Clinic Attenders

At first glance, the Drossman et al. (1988) and Whitehead et al. (1988) studies suggest that neither maladaptive personality traits nor psychologic symptom status are truly representative of those with IBS, and that previous findings were the result of a self-selection sampling bias (Bailey, Jr. et al., 1991). On closer examination, it becomes apparent from their test scores that the IBS clinic attenders in the Drossman et al. and Whitehead et al. studies displayed, at most, only moderate levels of psychologic distress or dysfunction.

In the study by Drossman and colleagues (1988), the Minnesota Multiphasic Personality Inventory (MMPI) was used to make psychologic comparisons between IBS patients, IBS nonpatients, and normal controls. Although the IBS patients displayed higher scores on measures of hypochondriasis, depression, hysteria, psychasthenia and schizophrenia than nonpatients and normal controls, their scores failed to exceed the
clinical caseness cutoff score of 70. In other words, the IBS patients' scores were in the normal range.

In the study by Whitehead and colleagues (1988), the researchers used the Hopkins Symptom Checklist (SCL-90-R) to measure psychologic distress among IBS clinic attenders. Due to the properties of this psychometric instrument, the test scale elevations for the IBS patients were at the clinical caseness cutoff score of 63. Bailey, Jr. and colleagues (1991) state:

The low threshold for "caseness" using the SCL-90-R reflects its purpose as a screening device designed to detect current, point-in-time psychologic distress with a low false-negative rate. Accordingly, the standard time reference for which patients are instructed to estimate the intensity of the subjective distress caused by a set of 90 psychopathologic symptoms is made explicit in the test instructions, the "past 7 days including today." (p. 344)

As might be expected, subjects with IBS who came to the clinic that week for medical help were presumably experiencing an IBS flare-up, and thus, at the time of testing, reported acute, but moderate, psychologic distress. Subjects who remained in the community with IBS, however, were probably not experiencing an active flare-up at the time of testing, and accordingly, had minimal test score elevations (Bailey, Jr. et al., 1991).

Both the Drossman et al. (1988) and Whitehead et al. (1988) studies support the discovery that IBS patients display, at most, only slight levels of psychologic distress.

**Psychiatric Dysfunction and the Development of IBS**

The Whitehead and colleagues (1988) study also compared those subjects with IBS to those with lactose malabsorption. Except in rare cases, lactose malabsorption is due to a hereditary deficiency of the lactase enzyme, resulting in lifelong symptoms of

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abdominal pain, bloating, and altered bowel habits, symptoms which are indistinguishable from IBS (Whitehead & Crowell, 1991). The researchers found that those subjects from the community with either lactose malabsorption or IBS reported no more symptoms of psychologic distress than the asymptomatic normals. But surprisingly, both the medical patients with lactose malabsorption and the medical patients with IBS shared similar elevated levels of psychologic distress. From this one can draw three conclusions: (a) psychologic distress does not cause IBS, (b) chronic bowel symptoms do not cause psychologic distress, and (c) individuals with bowel symptoms share similar results on psychometric inventories regardless of whether their bowel symptoms are caused by IBS, a functional disorder, or by a hereditary deficiency in the lactase enzyme.

Although a large proportion of IBS patients have moderately elevated scores on psychometric inventories, there is no pattern of psychologic symptoms unique to patients with this diagnosis (Whitehead and Crowell, 1991). In the study conducted by Whitehead and colleagues (1988) the researchers used the Hopkins Symptom Checklist to evaluate IBS clinic attenders. The clinic attenders displayed elevated scores on a variety of scales, including depression, anxiety, somatization, interpersonal sensitivity and hostility. These results are typical of findings from other studies found in the literature (Whitehead, Engel, & Schuster, 1980; Wise, Cooper, & Ahmed, 1982). Studies that have employed the MMPI to identify psychologic distress among IBS clinic attenders generally reveal slight elevations on the "psychosomatic triad" scales of depression, hysteria, and hypochondriasis (Drossman et al., 1988; West, 1970). Depression, hysteria, and hypochondriasis, however, are also frequently associated with chronic pain syndromes and psychosomatic disorders (Whitehead & Crowell, 1991). Thus, these
profiles are not unique to IBS clinic attenders.

A similar pattern of nonspecificity is found in standardized psychiatric interviews used to screen for psychiatric disorders in IBS patients (Liss, Alpers, & Woodruff, Jr., 1973; Latimer et al., 1981; Whitehead, Holtkotter, et al., 1990; Young, Alpers, Norland, & Woodruff, Jr., 1976). From these studies emerges is a higher prevalence of major depression and somatization or hypochondriasis in IBS patients as compared to IBS nonpatients and asymptomatic controls. Also common is generalized anxiety, but the prevalence of this latter diagnosis is not different from that in the general community (Robins et al., 1984).

Although these findings appear to show some specificity, many IBS patients receive psychiatric diagnoses other than depression or hypochondriasis (Whitehead & Crowell, 1991). Furthermore, depression and hypochondriasis are common among patients with other medical conditions such as headache and fibromyositis. Moreover, in the Whitehead et al. (1988) study, the researchers found that the prevalence of psychiatric diagnosis was similar for both patients with lactose malabsorption and patients with IBS. These findings support the contention that psychiatric symptoms do not cause IBS, but predispose persons who have bowel symptoms to seek medical attention (Drossman et al., 1988; Whitehead et al., 1988).

**Restrictive Diagnostic Criteria Versus Vague Diagnostic Criteria**

In many of the early studies that show a strong association between psychopathology and IBS, the diagnostic selection criteria were vague (Whitehead & Crowell, 1991). These criteria consisted of the presence of abdominal pain and altered bowel habits, with no objective evidence for an alternative diagnosis. Thus, these studies included many subjects with somatization disorder which resulted in the overestimation
of the association between psychopathology and IBS (Whitehead & Schuster, 1985).

In the study conducted by Whitehead and colleagues (1988), the researchers compared subjects diagnosed with functional bowel disorder, based on the vague criteria of abdominal pain and altered bowel habits, to subjects who met the restrictive diagnostic criteria for IBS based on the work of Manning, Thompson, Heaton, and Morris (1978). Among the medical clinic patients, both groups showed elevated levels of psychologic distress.

Of the groups recruited from the community who had not consulted a physician about their bowel symptoms, those who met only the vague criteria for functional bowel disorder showed more psychologic symptoms than those with IBS and the asymptomatic controls. Neuroticism was significantly associated with the vague complaint of abdominal pain. When this abdominal pain was reported to be associated with a change in stool consistency or frequency, and relieved by defeacation (the restrictive IBS diagnostic criteria), the association with measures of neuroticism disappeared. These results support the inference that those meeting the restrictive diagnostic criteria for IBS differ psychologically from those diagnosed by the vague criterion of abdominal pain.

Whitehead and Crowell (1991) maintain that future studies should use subjects meeting the restrictive diagnostic criteria developed and recommended by Drossman, Thompson, and colleagues (1990).

Psychologic Stress and the Exacerbation of Gastrointestinal Symptoms

It was stated earlier in this chapter that "Stressful life events exacerbate

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*The restrictive diagnostic criteria for IBS based on the work of Manning et al. (1978) parallels the definitive diagnostic criteria later developed by Drossman, Thompson, Talley, Funch-Jensen, Jenssens, and Whitehead (1990). The latter criteria were detailed in Chapter 1 of this thesis.*
symptoms in more than half of medical clinic IBS patients" (p. 13). It is important to note that psychologic stress can affect bowel function even among healthy subjects, producing gastrointestinal symptoms indistinguishable from those of IBS (Drossman, Thompson, et al., 1990). Stress does, however, affect bowel function to a greater extent among those with IBS, in much the same way that stress triggers and exacerbates migraine headaches among those predisposed to them.

**Learned Illness Behaviour and the Utilization of Health Care**

The minority of people with IBS who do become patients for this disorder tend towards a pattern of multiple somatic complaints and overutilization of health care services (Drossman et al., 1988; Keeling & Fielding, 1975; Sandler, Drossman, Nathan, & McKee, 1984; Whitehead, Cheskin, et al., 1990; Whitehead, Winget, Fedoravicius, Wooley, & Blackwell, 1982). This pattern is collectively referred to as "illness behaviour" (Whitehead & Crowell, 1991). One hypothesis about the origin of this tendency maintains that children learn illness behaviour (a) by how their parents respond to the child's symptoms of illness, and (b) through the modelling that occurs when the parents, themselves, are sick (Lowman, Drossman, Cramer, & McKee, 1987; Whitehead et al., 1982). Whitehead and Crowell (1991), in a review of the literature on learned illness behaviour, state:

These studies suggest that a pattern of childhood social learning contributes to the development of illness behavior in general and that a preoccupation with gastrointestinal symptoms such as those involved in functional bowel disorders may be learned when parents respond specifically to bowel complaints to a greater extent than they respond to other types of somatic complaints. (p. 257)

Ultimately, it is the interaction between psychosocial factors combined with the intensity of somatic distress, specifically pain and diarrhoea, that determines the illness experience and who will seek health care (Drossman et al., 1988).
Summary of Psychologic Considerations of Irritable Bowel Syndrome

Among patients suffering from acute IBS, a slight level of psychologic distress has been reported through the use of self-rating or other subjective reports of psychopathology. The variability among clinic attenders, however, is significant, and for a subset of these patients the intensity and nature of the psychologic distress is marked, and thereby warrants aggressive intervention (Bailey, Jr. et al., 1991). Clearly, medical treatments that target IBS alone with the assumption that psychosocial problems will spontaneously resolve themselves are inadequate (Bailey, Jr. et al., 1991; Drossman et al., 1982). Providing quality health care requires acknowledging and addressing the accompanying psychosocial problems that clearly contribute to the seeking of medical attention.

Psychologic Treatment of Irritable Bowel Syndrome

Antidepressant Medications

About one third of IBS patients who meet the criteria for any psychiatric diagnosis are suffering from major depression (Whitehead et al., 1989), and many IBS patients who do not receive a psychiatric diagnosis display elevated depression levels (Whitehead & Crowell, 1991). Consequently, antidepressants were among the earliest drugs investigated for the treatment of IBS.

Hislop (1979) in a study involving 67 IBS patients, reported that 73% of them had depressive disorders. Using an uncontrolled trial, he gave amitriptyline (an antidepressant) to 56 of these patients. Twenty-nine of the subjects became symptom-free, and 16 showed distinct improvement. Subsequent trials, using a double-blind procedure, verify the worth of antidepressants for at least some of the symptoms of IBS (Whitehead & Crowell, 1991).
Myren, Lovland, Larssen, and Larsen (1984), in the largest and most definitive study involving 428 IBS patients, compared different doses and dosing schedules of trimipramine (another antidepressant) to a placebo. At a dose of 50 mg either divided or at bedtime, trimipramine reduced nausea, abdominal pain, and reflux symptoms more than the placebo. It, however, did not have any effect on stool frequency.

Greenbaum, Mayle, and Vanegeren (1987), in a double-blind, crossover trial, compared desipramine (an antidepressant), 150 mg at night; atropine, 1.2 mg also at night; and placebo. In the diarrhoea-predominant group, self-reported symptoms of abdominal pain and diarrhoea were significantly lower when they received desipramine. The constipation-predominant group showed no significant benefit from this drug. Earlier, Heefner, Wilder, and Wilson (1978) had failed to find a drug-placebo difference for desipramine, 150 mg, on symptoms of stool frequency and abdominal pain. These earlier researchers, however, did not divide their diarrhoea-predominant patients from their constipation-predominant patients, which may have contributed to the discrepant outcomes.

It appears then, that tricyclic antidepressants in doses appropriate for the control of depression are effective for the abdominal pain and diarrhoea associated with diarrhoea-predominant IBS. They do not, however, appear to be effective in constipation-predominant IBS. At present, it is not known whether the benefits of these drugs in some IBS sufferers are due to their antidepressant actions or to their anticholinergic activity (Whitehead & Crowell, 1991).

**Psychotherapy**

A wide variety of psychologic treatments have been shown to be highly effective in alleviating or eradicating the symptoms of irritable bowel syndrome. These
psychologic interventions can be classified into four categories: (a) short-term dynamic psychotherapy, (b) hypnotherapy, (c) multicomponent behavioural or cognitive-behavioural treatment, and (d) cognitive therapy.

**Short-Term Dynamic Psychotherapy**

Svendlund, Sjödin, Ottosson, and Dotevall (1983) were the first to conduct a controlled study on the effects of psychotherapy as it pertains to IBS. They recruited 101 of 119 consecutive patients with chronic IBS. Both the control group and the active treatment group received standard medical therapy. The latter group also received an average of 7.4, hour long, "dynamically-oriented psychotherapy" (p. 589) sessions, over a 3 month period. These sessions concentrated on the association of stressful life events to bowel symptoms and on teaching new ways of coping with problems in the context of a supportive therapist-patient relationship. The active treatment group was superior to controls in that they displayed significantly greater reductions in abdominal pain and in a composite measure of abdominal dysfunction. The last index summed together symptoms of diarrhoea (eg. loose, frequent stools) with symptoms of constipation (eg. hard, infrequent stools). Psychologic symptoms of depression and anxiety also improved more in psychotherapy patients than in control patients. The improvements in both psychologic and somatic symptoms were well maintained at a follow-up 1 year after the study.

A similar study was conducted by Guthrie, Creed, Dawson, and Tonenson (1991). The authors recruited 102 consecutive IBS patients from a gastroenterology clinic. These patients all had symptoms for at least 1 year, and medical treatment in the form of bulking agents and antispasmodics for a minimum of 6 months had failed to provide relief. While both groups still received standard medical treatment, the active treatment
group was randomly selected to receive seven sessions of short-term dynamic psychotherapy based on the "conversational method" developed by Goldberg, Hobson, & Maguire (1984). Conversational therapy consists of a series of conversations between patient and psychiatrist that focus on current problems, as opposed to childhood, traumatic events. This therapy emphasizes the feelings associated with these current problems, the aim being to help the patient learn more adaptive ways of coping with the feelings through discussions with a sympathetic, nonjudgemental therapist. The active treatment group showed significantly greater reductions in anxiety and depression, and in somatic symptoms of abdominal pain, diarrhoea and bloating. Constipation associated symptoms, such as hard and infrequent stools, did not change with therapy. At 1-year follow-up, treatment gains were well maintained. This study replicates the results of Svendlund et al. (1983), but extends their study by providing a more detailed analysis of the types of gastrointestinal symptoms that are responsive to brief therapy.

Based on the above studies, it appears that focused, short-term dynamic psychotherapy, coupled with routine medical care, is superior to routine medical care alone.

There have been only two studies which have examined the effectiveness of short-term dynamic group psychotherapy in treating IBS, and both were uncontrolled. In these studies, Lammert and Ratner (1986) and Wise, Cooper, and Ahmed (1982) conducted didactic group sessions which educated patients about the hypothesized causes of IBS symptoms. The researchers also advocated progressive muscle relaxation exercises to reduce stress. In both studies, these protocols were reported to be associated with significant reductions in psychologic symptoms and with a modest 30% reduction in bowel symptoms. The reduction in bowel symptoms, however, is difficult to evaluate in
the absence of a control group as this decrease could have been achieved by placebo (Whitehead & Schuster, 1985).

**Hypnotherapy**

Whorwell, Prior, and Faragher (1984) randomly selected 30 patients with severe refractory IBS to participate in their study comparing hypnotherapy to a control condition. The active treatment group received hypnotherapy, provided in seven half-hour sessions over a 3 month period, whereas the control group received a placebo and spent the same amount of time discussing symptoms and the possible contributing role of emotional arousal and stressful life events. Hypnosis involved giving the subjects instructions to relax and to control intestinal smooth muscles. These subjects also received daily practice of autohypnosis using a tape recorder. The group receiving hypnotherapy showed significantly greater reductions in altered bowel habits, abdominal pain, and abdominal distention by the end of treatment, compared with controls. At follow-up 1 year later, treatment gains were well maintained, but additional sessions of hypnosis had been provided every 3 months during this year.

Whorwell (1989) extended the sample to over 200 patients and reported an overall success rate of 85%. Whorwell found that patients with clinically significant psychopathological findings or who were over 50 years of age were less likely to show a favourable response to hypnotherapy.

Harvey, Hinton, Gunary, and Barry (1989) replicated the findings of Whorwell and colleagues (1984). They compared individual hypnotherapy to group hypnotherapy treatment protocols. Subjects participated in five sessions over 8 weeks. The hypnotherapy emphasized warmth (especially of the abdominal area), relaxation, and control of the GI tract. The researchers noted improvements in 61% of the patients.
The individual and group hypnotherapy protocols were found to be equally effective. Based on the above studies, brief hypnotherapy coupled with regular home practice of autohypnotic exercises has been shown to be an effective treatment strategy for IBS.

**Multicomponent Behavioural or Cognitive-Behavioural Therapy**

Bennett and Wilkinson (1985) conducted the first controlled study of multicomponent cognitive-behavioral therapy for IBS. The researchers compared medical treatment alone to psychologic treatment alone in newly diagnosed patients. The medical treatment consisted of a combination of a bulking agent, a smooth muscle relaxant (anticholinergic), and an antidepressant/tranquillizer. In the psychologic intervention the subjects received: (a) education to correct misconceptions about bowel physiology, (b) progressive muscle relaxation training to teach subjects to relax more quickly for the purpose of controlling reactions to stress, and (c) instruction on how to change habitual thoughts and attitudes that might contribute to stress. Both the medical and psychologic treatment protocols reduced bowel symptoms to an equal extent, but the psychologic treatment also reduced the amount of anxiety that patients experienced. Bennett and Wilkinson (1985) did not do a follow-up study.

Blanchard and Schwarz (1987), and Neff and Blanchard (1987) evaluated a cognitive-behavioural treatment package that combined progressive muscle relaxation training, biofeedback training (to learn to warm the hands as a relaxation technique), and cognitive coping skills training (training in how to modify habitual ways of thinking so as to reduce stress). They compared patients in active treatment to patients who were waiting to begin treatment for a time period equivalent to the treatment. Patients who received the treatment package improved significantly more than patients waiting for
treatment - 64% of treated patients reported at least a 50% reduction in bowel symptoms. Neff and Blanchard's results were well maintained at a 2-year follow-up (Blanchard, Schwarz, & Neff, 1988).

Lynch and Zamble (1989) investigated a similar approach to the cognitive-behavioural treatment of IBS. They compared subjects given a multicomponent treatment package immediately after a pretest assessment, to a control group who did a waiting period followed by a second assessment before treatment. Their multicomponent treatment package contained relaxation training, cognitive training designed to enable subjects to control stress-producing cognitions, and assertiveness training. Treated patients showed significantly larger reductions in a composite index of bowel symptoms than did the control patients waiting for treatment. Therapeutic gains were well maintained at a 5-month follow-up after the end of treatment.

Blanchard, Schwarz, and colleagues (1992) did two controlled evaluations of a multicomponent psychologic treatment for irritable bowel syndrome. The researchers compared (a) multicomponent treatment to a psychologic attention-placebo condition, and (b) multicomponent treatment to a symptom monitoring control. While the multicomponent treatment package was superior to assessment-only or symptom monitoring controls, it was not superior to the attention-placebo control. Fifty-four percent of the multicomponent group were clinically improved versus 47% of those in the attention-placebo category. Thus, there was no significant difference between those from the multicomponent group and those in the attention-placebo group at the end of treatment.

Multicomponent behavioural or cognitive-behavioural therapy has been shown to be superior to symptom monitoring and assessment-only controls on various measures of
psychologic distress and gastrointestinal symptoms (Blanchard & Malamood, 1996). Additionally, the replicability of this treatment is encouraging. It is unfortunate that this therapy, however, is no more effective than the attention-placebo condition.

**Cognitive Therapy**

Two recent studies point out the advantage of a purely cognitive therapy approach for the treatment of irritable bowel syndrome.

In the first, Greene and Blanchard (1994) randomly assigned subjects to either intensive, individualized cognitive therapy (10 sessions over 8 weeks), or to 8 weeks of daily gastrointestinal symptom monitoring. At post treatment, 80% of the cognitive therapy group showed significant improvement, including significant advantages in the reduction of diarrhoea, constipation, abdominal pain and tenderness, belching, bloating, flatulence, and nausea, as well as depression and anxiety. These symptom reductions correlated significantly with increases in positive, and reductions in negative, automatic thoughts. Only 10% of the monitoring group showed clinically significant improvements. These results held up well at a 3-month follow-up.

In the second study, Payne and Blanchard (1995) replicated and extended the above findings. Subjects were randomly assigned to one of three treatment protocols: (a) cognitive therapy, (b) a self-help support group for IBS, or (c) a symptom monitoring waiting-list control. Each of the protocols lasted approximately 8 weeks. Cognitive therapy was superior to both protocols, with 75% of subjects showing significant clinical improvement. These subjects demonstrated statistically significant improvements in GI symptoms and on psychologic measures of depression and anxiety. Three-month follow-up revealed further numerical improvements, with 83% of the cognitive therapy group clinically improved. For the IBS support group, a modest 25% of subjects showed a
significant improvement in GI symptoms, compared with only 18% at 3-month follow-up. There were no significant reductions in psychologic test scores for the IBS support group both at post treatment and at the 3-month follow-up.

Cognitive therapy has yielded stronger and more consistent results than any other psychologic treatment. While controlled trials have displayed each of the four categories of therapy to be superior to assessment-only or symptom monitoring controls, only cognitive therapy and hypnotherapy have been demonstrated to be superior to an attention-placebo control (Blanchard & Malamood, 1996).

**Psychologic Treatment Issues**

**Long-Term Maintenance**

Psychologic treatments result in relatively long-term, enduring improvements. In the two previously described trials which employed short-term dynamic psychotherapy (Svendlund et al., 1983, Guthrie et al., 1991) results were well maintained at 1-year follow-ups on the basis of mail surveys or global ratings.

Similarly, hypnotherapy has also produced enduring results. In the Whorwell, Prior, and Faragher (1984) study, treatment gains were well maintained at a 1-year follow-up, but additional sessions of hypnosis had been provided every 3 months during the year.

Multicomponent behavioural or cognitive-behavioural therapy has also shown long-term effectiveness. Neff and Blanchard’s (1987) results were well maintained at a 2-year follow-up conducted by Blanchard, Schwarz, and Neff (1988), and at a 4-year follow-up conducted by Schwarz, Taylor, Scharff, and Blanchard (1990). In the previously described study by Lynch and Zamble (1989), therapeutic gains were well maintained at 5-month follow-up.
Cognitive therapy has also produced therapeutic maintenance. In the Payne and Blanchard study (1995), improvements were well maintained at 3 months. In the Greene and Blanchard study (1994), not only were the treatment gains maintained after 3 months, but the results revealed further numerical improvements.

**Cost Effectiveness**

A perusal of the literature produced no literature on the cost-effectiveness of psychologic treatments for the management of IBS. Most psychologic regimes, however, are brief, varying from 5 to 12 sessions, with some requiring occasional periodic booster treatments to maintain therapeutic gains (Blanchard & Malamood, 1996).

**Prediction of Treatment Outcome**

While the picture is still a bit unclear, researchers are beginning to provide guidance on the indications for different forms of psychologic treatment. Research has revealed that different outcomes exist for different psychologic treatment regimes.

**Short-term dynamic psychotherapy.** Guthrie and colleagues, in their 1991 study, reported that brief psychotherapy was more effective in patients with significant symptoms of psychologic distress and in patients with bowel symptoms of pain and diarrhoea. Specifically, the initial presence of anxiety or depression, diarrhoea, abdominal pain exacerbated by stress, and a shorter duration of the disorder were associated with good treatment outcomes.

**Hypnotherapy.** Whorwell, Prior, and Colgan (1987) found that patients over 50 years of age were less amenable to treatment with hypnosis than those with intractable abdominal pain. Similarly, Whorwell (1989) reported that subjects over 50 and persons with more severe psychopathological findings were less responsive to hypnotic treatment.

Harvey and colleagues (1989), in their study involving individual and group
hypnotherapy in the treatment of refractory irritable bowel syndrome, also reported that
greater initial psychologic disturbance was associated with poor outcome.

**Multicomponent or cognitive-behavioural therapy.** Blanchard, Schwarz, Neff,
and Gerardi (1988) conducted a prediction of treatment outcome study. Using
multicomponent behavioural treatment, they found that elevated scores on the Trait
Anxiety of the State-Trait Anxiety Inventory (Spielberger, Gorsuch, & Lushene, 1970)
were associated with poor outcome.

In 1992, Blanchard, Scharff, and colleagues, using the same multicomponent
behavioural treatment, found that meeting the DSM-3 (3rd ed., rev.; American
Psychiatric Association, 1987) diagnostic criteria for one or more psychiatric disorders
was associated with poorer outcome. The majority of these comorbid diagnoses were
anxiety disorders, especially generalized anxiety disorder.

**Cognitive therapy.** In two independent studies, Greene and Blanchard (1994) and
Payne and Blanchard (1995) found cognitive therapy to be extremely effective for
patients with significant symptoms of psychologic distress. For example, in the Greene
and Blanchard study (1994), 90% of each subsample met the DSM-III-R diagnostic
criteria for at least one Axis I diagnosis; and of these, 66% were diagnosed with
generalized anxiety disorder (GAD). Cognitive therapy resulted in significant advantages
for the reduction of constipation, diarrhoea, abdominal pain and tenderness, bloating,
belching, flatulence, and nausea, as well as depression and anxiety.

**Summary of the Psychologic Treatment Literature**

Most patients who consult internists about bowel symptoms have significant levels
of depression and anxiety, and they tend to notice and worry about somatic complaints
more when they experience these dysphoric affects (Whitehead & Crowell, 1991).
Psychologic treatments that reduce the patients' level of psychologic distress frequently reduce the severity and frequency of complaints about bowel symptoms.

Tricyclic antidepressants may be tried as they have been shown to be superior to placebo for the management of abdominal pain and diarrhoea. They, however, are ineffective for the treatment of constipation-predominant IBS.

Several investigations on various psychotherapeutic treatments have demonstrated them to be extremely effective for the management of IBS. A variety of psychologic interventions, including short-term dynamic psychotherapy, hypnotherapy, multicomponent behavioural or cognitive-behavioural therapy, and cognitive therapy, have produced significant reductions in both bowel symptoms and psychologic symptoms in patients with IBS. The predominant focus in these treatment modalities is an "emphasis on current problems and on the development of ways of coping with stressful situations" (Whitehead & Crowell, 1991, p. 263).

Cognitive therapy has been shown to be especially effective, with at least 75% of patients responding well. While each class of treatment has been shown to be superior to symptom-monitoring or assessment-only controls, only hypnotherapy and cognitive therapy have proven to be superior to attention-placebo control. Cognitive therapy has a number of advantages over hypnotherapy, however, in that it does not have the moral implications that may be associated with hypnotherapy, nor does one have to worry about the hypnotizability of the patient. Furthermore, hypnotherapy is contraindicated for those over 50 years of age and those with significant psychopathology.

Medical Treatment of Irritable Bowel Syndrome

Pharmaceutical Treatment

Currently, the medical and pharmaceutical treatment options for patients with
IBS are inadequate\(^7\), as no pharmacological treatments have been shown to be consistently effective (Klein, 1988). The three classes of drugs which are routinely prescribed are bulking agents, antispasmodics, and tricyclic antidepressants.

**Bulking Agents, Antispasmodics, and Tricyclic Antidepressants**

Bulking agents, such as wheat bran or bulk laxatives, may help alleviate constipation (Read, 1993), but aside from having little effect on other symptoms, they tend to make pain and abdominal distention worse.

Antispasmodics may be useful in some patients with IBS, but side effects are common, particularly with anticholinergic agents, and few studies have shown antispasmodics to have any overall efficacy (Klein, 1988; Read, 1993).

Tricyclic antidepressants may help some patients. They have been shown to be superior to placebo for the management of abdominal pain and diarrhoea, but not constipation.

**Loperamide (Imodium)**

Unlike some of the above pharmaceutical treatments, Loperamide (Imodium) produces no side effects and has no addictive potential (Hovdenak, 1987; Read, 1993). Loperamide is an over-the-counter drug which has proven effective as a symptomatic treatment for some patients with IBS.

Lavö, Stenstam and Nielsen (1987) conducted a double-blind, placebo controlled study using 21 IBS patients whose main symptom was diarrhoea. Subjective overall response, stool consistency, pain, urgency, frequency, flatulence, borborygmi and painful

\(^7\)Two new drugs, Dicetel (a calcium channel antagonist) and Modulon (a motility regulator), are definite improvements over existing IBS medications. While 30% with IBS notice some benefit from the use of these drugs, Modulon appears to be more effective than Dicetel. Of the drugs currently available for the treatment of IBS, only Loperamide is superior to Dicetel and Modulon (F. H. Anderson, personal communication, April 18, 1998).
propulsions were studied over a 13 week treatment period. A significant advantage for those using Loperamide was found for stool consistency (p < 0.001), pain (p < 0.02) and urgency (p < 0.05). Subjective overall response was also significantly better in the Loperamide group. Self-tritation of dose and administration of a single nightly dose were efficient and safe.

Hovdenak (1987) also investigated the effects of Loperamide in a double-blind, placebo controlled study using 60 patients with irritable bowel syndrome. Active treatment was given in low dosage (4 mg nocte). For patients in the painless diarrhoea group, there was a highly consistent improvement in stool consistency and frequency. For those with alternating bowel habits and abdominal pain, there was also a statistically significant improvement in stool frequency and consistency, as well as significantly fewer painful days during Loperamide treatment. Patients with alternating bowel habits and no pain experienced no symptomatic improvement, and patients who were constipation-predominant generally felt worse on Loperamide. Patients encountered no side effects. Hovdenak (1987) concluded that Loperamide can be considered an alternative, symptomatic treatment in some IBS patients whose main symptoms are painless diarrhoea or alternating bowel habits associated with pain.

In summation, Loperamide is fairly effective for patients in the painless diarrhoea group and for those with alternating bowel habits and abdominal pain. For patients with alternating bowel habits and no pain, Loperamide is generally ineffective, and patients who are constipation-predominant generally feel worse on Loperamide.

Summary of the Medical Treatment Literature

At present, there are no universally agreed upon medical treatments for irritable bowel syndrome as current options are inadequate (Blanchard & Malamood, 1996; Read,
1993). Most patients with IBS are prescribed drugs to relieve predominant symptoms, and while these drugs may have some utility, they do not address the underlying mechanisms of IBS.

While Loperamide is effective as a symptomatic treatment for some patients with IBS, Read (1993) argues that what is needed is a treatment that attacks the mechanism of the condition itself, and not just the symptoms. Read states that different types of symptoms may require different therapies. Based on the emerging alternative concept of the irritable bowel syndrome, as "a manifestation of altered afferent mechanisms within different parts of the gut" (p. 323), Read asserts that radically new treatment strategies are needed. Some of these may include "receptor antagonists" for serotonin (5HT3), opiate analogues (Loperamide), antihistamines and mast cell stabilizers, somatostatin analogues, and substance antagonists. It is unfortunate that the effectiveness of these compounds cannot, at this present time, be evaluated. Read states "In the absence of a clear delineation of mechanisms underlying visceral hypersensitivity and associated motor reflex disturbances we currently do not have generally agreed-upon physiological markers which can be used to monitor the response of these therapies" (p. 323).

Psychologic Treatment Versus Standard Medical Treatment

Over the past 14 years, several controlled investigations of psychologic treatment for irritable bowel syndrome have been conducted (for a recent summary, see Blanchard, 1993). All of these have proven superior to medical management alone (Bennett & Wilkinson, 1985; Guthrie et al. 1991; Svendlund et al., 1983). Four of these studies directly compared psychologic treatment to medical treatment.

Bennett and Wilkinson (1985) compared a combination of bulking agents, antispasmodics, and antidepressants to their multicomponent behavioural treatment.
Both treatments led to reductions in altered bowel habits and abdominal pain. Only the psychologic treatment resulted in greater trait anxiety reduction.

In a second study, Shaw and colleagues (1991) randomized patients to one of two treatment protocols. The first protocol was a stress management program, which consisted of relaxation training emphasizing breathing exercises, exploration of the association of stress and GI symptoms, and education about normal bowel function. This group attended a median of six sessions over a 6 month period. The second group received three capsules per day of Colpermin, an antispasmodic. Patient global ratings at a 6-month follow-up were used to assess the two treatment protocols. Of the stress management group, 67% improved, experiencing a greater reduction in overall severity and frequency of IBS attacks, whereas in the Colpermin group, only 18% experienced symptom reduction.

The third study comparing psychologic versus medical treatment was done by Corney, Stanton, Newell, Clare, and Fairclough (1991). The first group received multicomponent behavioural treatment, which consisted of pain management and bowel habit training, coupled with education on normal bowel functioning and what appear to be various cognitive treatment procedures. The second group received routine medical care: bulking agents, antispasmodics, and dietary counselling. Assessment was done by symptom diary ratings. The multicomponent treatment was superior to routine medical care for reduction of constipation, stomach pain, headache, and irritability. Both groups experienced an overall reduction in psychiatric symptoms over the 9 month study period.

Finally, in the Guthrie et al. study (1991) mentioned above, the authors recruited 102 patients who all had symptoms for at least 1 year, and medical treatment for a minimum of 6 months had failed to provide relief. The active treatment group received
psychotherapy, relaxation training, and standard medical treatment, while the control group received only standard medical treatment. Assessment was done by gastroenterologist and patient ratings. At 3 months, the active treatment group showed significantly greater reductions than the controls in both dysphoric mood and in somatic symptoms of abdominal pain and diarrhoea. Symptoms associated with constipation changed little.

It appears then, that various forms of psychologic treatment, particularly those employing behavioural or cognitive procedures, are superior to both bulking agents and antispasmodics.

Unfortunately, there have been no controlled studies comparing psychologic treatments to the tricyclic antidepressants. Unlike antidepressants, however, psychologic treatments have no reported side effects.

**Living with Irritable Bowel Syndrome**

**Medical Case Studies**

While a number of medical "case studies" have been published on irritable bowel syndrome (Bennett, 1989; Cooper, 1980; The IBS Iceberg, 1992), none of them shed light on the experience of living with this digestive disorder. These accounts tend to be anecdotal and focus on the symptomology of the experience, rather than on the meaning or the experience of living with irritable bowel syndrome.

**Lived Experience Studies**

Surprisingly, a comprehensive review of the literature produced only two studies which looked at the human experience of living with this phenomenon (Corney & Stanton, 1990; Dancey & Backhouse, 1993). Both investigations were conducted in Britain.
Corney and Stanton (1990)

In the first study Corney and Stanton (1990) recruited 42 outpatients from two London hospitals who were diagnosed with IBS. Each patient was given a semi-structured interview covering demographic data, recent medical history, medical treatment, medication, and family history of illness. In addition, each patient’s psychologic state was measured by the Clinical Interview Schedule (CIS). The CIS measures depression, phobias, anxiety, somatic symptoms, disturbances of memory, concentration and sleep, obsessional and compulsive thoughts, and depersonalization and behaviour. Subjects were then asked to fill out the General Health Questionnaire (GHQ). This instrument was designed to predict whether an individual would be diagnosed as having "psychiatric ill-health" if examined by a psychiatrist working in an outpatient clinic. Following this, subjects were given the Social Problem Questionnaire; an instrument which measures the presence or absence of social problems in the areas of housing, employment, finance, social contacts, marriage and family, and other domestic relationships. Three rating scales were then administered, their purpose being to measure the severity, frequency and duration of pain experienced by each patient in the last month. Subjects then completed a number of rating scales which measured avoidance of various activities, both when symptoms were present and absent. Finally, patients participating in this study completed visual analogue scales, rating the severity of symptoms over the last seven days.

Corney and Stanton (1990) found that of the patients who took part in their study, over 40% were impaired by their IBS in the areas of work, socializing, travel, sexual intercourse, domestic and leisure activities, eating certain foods and eating with others. Women were more disabled by their physical symptoms than men, being more
likely to avoid sexual intercourse, socializing, going to work, domestic activities, and specific foods. Avoidance of these activities, with the exception of the latter, was less frequent when the symptoms of IBS were absent.

There are a number of limitations associated with this study. The researchers used hospital patients as subjects, so the results are not generalizable to other, more prevalent IBS populations. Furthermore, the quantitative design of the research instruments did not allow for the respondents to indicate their feelings, and at times, their beliefs (Dancey & Backhouse, 1993). Moreover, this study goes into no detail regarding its findings. For example, why is sexual intercourse avoided by many with IBS, and why are women's sex lives more affected by this condition than men's?

These limitations are addressed in the following study.

Dancey and Backhouse (1993)

In their 1993 study, Dancey and Backhouse looked at the "psychological and practical consequences of living with IBS" (p. 1444). Rather than obtaining only quantitative data regarding the lived experience of IBS, the authors designed their questionnaire to obtain both quantitative and qualitative information. Many of the participants also included letters with their completed questionnaires, adding considerably to the qualitative component of the study.

Instead of using patients for subjects, as in the Corney and Stanton (1990) study, this study obtained its participants from the IBS Network, a self-help organization started in 1990 for people with IBS. The researchers sent questionnaires to 200 members of this organization, chosen at random, and received 148 questionnaires back, representing a 74% response rate.

The results obtained were as follows: Fifty-nine percent of the participants
suffered from diarrhoea, 54% from constipation, 73% from lower abdominal pain, 67% from abdominal distention, 63% from flatulence, and 39% experienced nausea. Less common symptoms included rectal pain (42%), upper abdominal pain (39%), indigestion (36%), and burping (27%). Most of the participants suffered from more than three of the above symptoms. Of this sample, 5% were unable to work due to their IBS, and 16% admitted to faecal incontinence.

Following is a brief look at the various areas of life reported to be affected by IBS.

**The hidden problem.** Dancey and Backhouse (1993) found that most of their participants did not talk to anyone else about their IBS, and some made great efforts not to let anyone else know: "I have not told anyone, even the man I've lived with for 15 years" (Daisy, p. 1445). "IBS and its symptoms are thought to be funny or 'not quite nice' by many people, and so we have to suffer silently" (Glenda, p. 1445).

The authors attribute this reluctance to tell others to the taboo surrounding bowel and toileting habits in western society. They state that while IBS is a remarkably common digestive disorder, many people, upon finding out about the existence of the IBS Network, declared "I thought I was the only one" (p. 1445). The authors conclude by stating that while "coming out" as an IBS sufferer is very difficult, it is very important for these individuals to be able to talk about what is happening to them, as it alleviates much of the anxiety and fear associated with this disorder and its symptoms.

**Effects of IBS on employment.** As noted above, 5% of the participants were unable to work due to their IBS. Of the 63% of subjects who were employed, IBS proved to be a considerable concern. Lateness was a problem, as travel to work was often difficult. Stopping to use the washroom, sometimes many times, meant that
sufferers could not get to work on time. Secondly, people often lost time from work. Seventy-four percent of the participants who worked took time off due to IBS, missing from between 1 and 210 days. Thirdly, most of the employed participants tried to hide their IBS from their employers.

It's difficult, now, at work with people noticing... at work I have to hold or suppress the symptoms, which makes it worse, or keep going to the toilet. I am worried about how I can hold a job down in this condition. It's becoming increasingly difficult for me to hide the symptoms. (Sheila, p. 1446)

Furthermore, respondents often felt that IBS had damaged their promotion prospects:

Career promotion has twice been put on one side as I was unable to fulfil the obligations of the posts offered, because of IBS. If working as a team, you cannot expect your colleagues to cover or carry you for long periods. (p. 1446)

Sex and relationships. Forty-six percent of the respondents in this study stated that IBS directly affected their sex lives. Irritable bowel syndrome can sometimes make sex painful. At other times, the symptoms associated with IBS can take away all desire for sexual intimacy: "Regrettably, I've never had the chance to find out if IBS would make sex painful for me. Apart from embarrassment, it often makes you feel too ill to care for the opposite sex" (Andrea, p. 1446). Embarrassment was also reported as a deterrent to sex: "I worry that I might pass wind during intercourse. I was brought up to believe that passing wind just wasn't the thing to do and I get very embarrassed about it" (Judy, p. 1446).

Men were also affected in this area of their lives: "It makes it difficult to develop relationships with the opposite sex - what girl would want to go out with a man who daren't go out of reach of the loo? How can I be open with them about it?" (Henry, p. 1446.)

Respondents reported that IBS often causes a lot of tension and friction between
themselves and those with whom they live. Unless the family is particularly understanding, or suffer from IBS themselves, this is almost inevitable: "When the children were small, and my husband's workload permitted a family outing, it always, so it seemed, 'played up.' He would say, 'I knew this would happen' and I felt devastated" (Gail, p. 1446).

**Travel and leisure.** Nearly 70% of the respondents reported that IBS restricted travel. This included both long journeys and short, everyday excursions. "I need to find out where the toilets are before I travel anywhere" (Malcolm, p. 1446). Travelling abroad was particularly difficult, and for some sufferers, impossible. Leisure activities were also difficult; due to travel problems, eating difficulties (many respondents were on restricted diets), and the general feeling of malaise caused by this digestive disorder.

I don't have any leisure activities at all. I gave them all up. For 4 years I didn't go anywhere on holiday, or anywhere else, to a restaurant, didn't eat in the street, in case I couldn't find a loo, didn't visit anyone, stood at the back of the church where the loo was. In the cinema I have to sit in the end seat, in case. (p. 1446)

I only went to work, the village or stayed at home, and it was not much of a life. In desperation I even asked for my gut to be removed and a bag attached to let me live a better form of life - but it was greeted with horror by my doctor. (Rita p. 1446)

**Others are often unsympathetic.** The attitude of others can contribute to the suffering of the individual with IBS, and to the hiding of that suffering. Due to the fact that most people have experienced abdominal pain, diarrhoea, or constipation at some time in their lives, many have a tendency to believe that people with IBS are exaggerating their symptoms. Dancey and Backhouse (1993), state:

People are made to feel a nuisance by relatives and friends who do not understand why they have to visit the toilet six times before going out, why they feel that they cannot eat out anywhere, why they cannot travel on their own, why they continually turn down invitations, why they cannot stay overnight at someone else's house and why nothing can be planned. (p. 1446)
Many respondents who included letters with their completed questionnaires stated
that their partners became irritated with their bowel problems. This irritation
exacerbated the sufferer’s problems, making the symptoms far worse:

If we had visual signs like a broken leg, we would get much more sympathy from
those around us, instead of the same old phrase, "Oh, not another bad stomach.
It must be something you’ve eaten." If only it was that simple. (Judy, p. 1447)

Self-blame: Stress and lifestyle. Seventy-two percent of respondents stated that
stress made their IBS worse, and were trying to temper their lifestyles to reduce stress.
Commitments were cut to a minimum and many of the respondents tried to spend time
relaxing. Most reported that they exercised to further reduce stress.

Dancey and Backhouse (1993) note that most of their participants were told by
their doctors to avoid stress in some way. As a result, some of the individuals believed
that stress had caused their disorder, and "constantly blame[d] themselves for becoming
ill in the first place" (p. 1447). The researchers assert that the belief that stress causes
this digestive disorder is unfounded, as the cause of IBS is unknown.

Conversely, Dancey and Backhouse (1993) had many respondents who felt that
stress did not cause their IBS. Rather, the IBS, itself, caused their main source of stress:
having to cope with the pain, the loss of dignity, and the restrictions. They found that
while the use of relaxation techniques and attempts to reduce stress helped, they were
unlikely to prevent IBS from occurring. The authors maintain that while stress will
aggravate any disorder, the cause of IBS does not necessarily lie with its sufferers.

Self-blame: Eating habits. Seventy percent of the respondents in this study were
trying to ensure that they ate a healthy, balanced diet, being careful to consume plenty
of fruit and vegetables, and trying to avoid junk food. Fourteen percent of the
participants ate very restricted diets, hoping that their IBS would improve.
The authors of this study note that it is natural to believe that diarrhoea, constipation, abdominal pains and other digestive disorders are caused by faulty eating. Sixty-three percent of the participants said that they believed certain foods aggravated their digestive disorder. "the doctor said it was due to years of bad eating, which I consider impertinent and not true" (p. 1447).

Many sufferers of IBS, believing that the cause of their disorder is faulty eating habits, restricted their food intake. Dancey and Backhouse (1993) state:

It is important for sufferers to work out which sort of diet is best for them as an individual. A low-fibre, low-fat diet may work well for some people. Others may get relief from following gluten-free, or anti-candida diets, or trying an elimination diet to see if they are intolerant of certain foods (dairy products, wheat, citrus fruits, fatty foods are common offenders) but it is important that care is taken to make sure all nutritional requirements are met. (p. 1447)

**Medical investigations.** Over 25% of the respondents felt that their general practitioners did not understand their IBS problems and were not sympathetic. Many respondents attested that their doctor did not take their complaints seriously. Sheila declared that her doctor was "totally unsympathetic. [I was] treated with contempt, like a neurotic who ought to find a way of dealing better with life" (p. 1447). Another participant commented that she was treated "badly - given anti-depressant tablets and told it was all in my mind and to go away and sort myself out" (p. 1447). Still another said: "They were patronising - why don’t you go and have a holiday? Didn’t treat me with any urgency as though just because I didn’t have a recognized or terminal illness then I couldn’t be in much pain" (pp. 1447-1448).

Ninety-three percent of the respondents had been through the medical system, and had a wide range of tests: barium enema, sigmoidoscopy, barium meal, scans, blood tests, and others. All proved negative. When the doctors could not find any signs of parasites, enzyme deficiency or disease, patients were often told, "We can’t find anything
wrong with you" (p. 1448). Yet the patient remained worried, as this diagnosis was definitely at odds with his or her experience. The pain and symptoms remained. "His or her suffering was invalidated" (Dancey & Backhouse, 1993, p. 1447).

All of Dancey and Backhouse's (1993) participants said the treatment they received was inadequate. Approximately 50% said that they did not believe that the medical profession had done everything they could for them. When asked "What treatment do you think would have helped you the most?," no one cited new or better drugs. Rather, the participants wanted information about IBS and advice on how to cope with it. Respondents indicated that they felt they would have coped better with this condition had they been treated with greater sensitivity from members of the medical profession. They also specified that they wished they had been given more information about IBS, its possible causes, and its treatment. Many individuals said that they felt bad about taking up their physician's or the hospital's time.

Anxiety and depression. Patients who suffer from IBS and are still seeking medical help have demonstrated higher levels of depression and anxiety than other patients with similar symptoms but different disorders, such as Crohn's disease (Dancey & Backhouse, 1993). While researchers have speculated which comes first for the patient, depression or IBS, Dancey and Backhouse have chosen not to concern themselves with this quandary: "the patients tend to believe that their depression and anxiety are a result of living with IBS, and what concerns us is how their symptoms and feelings are managed by both the patients themselves and their carers" (p. 1448).

The authors state that the effects of living with such a chronic disorder are sometimes too much for the individuals involved: "I did become depressed and anxious largely due to IBS - not the other way round as my current GP imagined. I would go as
far as to say I think it played a part in our consequent divorce" (Gail, p. 144).

Thirty-nine percent of the participants in Dancey and Backhouse's (1993) study consulted a doctor for depression at some time in their lives. Thirty-five percent had felt more than "moderately anxious" in the past week. Dancey and Backhouse state that anxiety is common among those with IBS, particularly affecting those who frequently experience an urgent need to defaecate. This can occur with sufferers who have diarrhoea as well as constipation. Over 16% of the respondents in their study admitted to faecal incontinence. Worry as to whether one would make it to the toilet kept some participants bound to their homes.

Dancey and Backhouse (1993) state that depression, loss of confidence, and even panic attacks may follow those who feel isolated, unable to go anywhere unless a toilet is always immediately available. Individuals rarely reveal to their general practitioners or medical staff that they suffer from faecal incontinence. Thinking that they are the only ones, many suffer in silence, not knowing how to cope.

After a couple of narrow escapes on the Underground [rail network], when I had to ask to use the loos, I am now scared still to go on the Tube. The thought of getting stuck between stations acts as an instant enema, yet before I got IBS I travelled everywhere by Underground without giving it a second thought. (Julie, p. 1449)

I am 63 and very unhappy and frightened by what I've got - I can’t cope anymore. I've had blood tests, scans, enemas and X-rays and everyone keeps telling me there's nothing wrong. My doctor said it's my diet, but I don't know what he means... if there's any special food I ought to be taking, or leaving alone. I am at the end of my tether... I feel very frightened in case I've got something terrible. (p. 1449)

I am now an invalid - housebound as a result. Please help me, I am so depressed by my condition. I feel awful. Please help me soon as I cannot stand another year like this, I feel crippled and I am only 42. (p. 1449)

This study concluded with implications for nursing. Dancey and Backhouse (1993) stressed the importance of understanding, reassurance, and information on faecal
incontinence for helping those living with irritable bowel syndrome.

**Summary of the Lived Experience Studies**

Both the Corney and Stanton (1990) and the Dancey and Backhouse (1993) studies are tremendously noteworthy, as they are the only studies conducted which looked at the experience of living with irritable bowel syndrome.

The Corney and Stanton (1990) study was the first which investigated how it is like to live with IBS. The researchers investigated both the psychologic and practical consequences of living with this digestive disorder. Information regarding physical symptoms, and psychologic and social dysfunction were collected from 42 outpatients with IBS. It is unfortunate that the authors in this study did not go into much detail regarding their findings.

The Dancey and Backhouse (1993) study was much more descriptive and comprehensive than its predecessor, the Corney and Stanton (1990) study. Dancey and Backhouse went into much greater detail describing both the psychologic and practical consequences of living with IBS. Rather than obtaining only quantitative data relating to the experience of living with IBS, these researchers designed their questionnaire to obtain both quantitative and qualitative information. Furthermore, many of their participants included letters which added considerably to the qualitative component of their study. This study was groundbreaking, in that it is the only study which has provided detailed information on the meaning and experience of living with irritable bowel syndrome.

Both the Corney and Stanton (1990) and the Dancey and Backhouse (1993) studies employed questionnaires to obtain their data. The first study used a quantitative method, whereas the second utilized a quantitative and qualitative research design. Although there are a number of advantages to the use of questionnaires (Schumacher &
McMillan, 1993), these instruments are not without limitations.

First of all, because these studies relied predominantly on questionnaires to gather information, the researchers’ own preconceived ideas about the experience of living with irritable bowel syndrome dictated what questions would be asked. The obtained information could, therefore, be somewhat limited in breadth. Further limitations associated with using a questionnaire format will become apparent in the following section.

Introduction to the Study’s Methodology

In light of the paucity of data related to the adult’s experience of living with irritable bowel syndrome, and in order to shed more light on this experience than was possible in the above studies, the phenomenological method of research was chosen for this study.

Field and Morse (1985), in discussing the selection of a research methodology, state: "For each question, there is a best or most appropriate method, and selecting the method is the most important decision in the research process" (p. 29). Phenomenology was chosen because it lends itself particularly well to the purpose of this study - to explore and describe the experience of the adult who is living with irritable bowel syndrome.

The advantages of using a phenomenological research design are numerous (Pallikkathayil & Morgan, 1991). Of particular importance, is that, through phenomenology, one can derive the essence of the phenomenon, or the deepest understanding of the experience’s structure. A second advantage of phenomenology is the quantity of information one is able to gather through the use of the unstructured interview. A third advantage of this research design, is that through the use of the
unstructured interview, the researcher is able to gather valuable non-verbal and verbal information. Consequently, phenomenology has a definite advantage over purely written descriptions. A fourth advantage is the richness of data one is able to gather. According to Watson (1988), this method allows for recognition of the participant as an individual who is unique, with a unique set of experiences. A fifth advantage is that the researcher can use interpersonal and counselling skills to assist the participant in disclosing his or her lived experience. And finally, through this method, the researcher is able to gain insight into self. This, in turn, empowers him or her to respond with increased understanding when encountering this phenomenon in the future.

Summary

This chapter reviewed literature that was selected for the purpose of providing insight into the irritable bowel syndrome experience. Traditionally, irritable bowel syndrome has been viewed as a psychiatric disorder. More recent studies have shown that the majority of people with IBS do not seek health care for this condition, nor do they exhibit more psychologic disturbance than the normal population. This finding suggests that psychologic distress does not cause IBS, but rather, influences the decision to seek treatment.

For those patients who do seek medical attention for this digestive disorder, only moderate levels of psychologic distress are displayed, comparable, in fact, to those seeking medical attention for the hereditary condition of lactose malabsorption. The variability among clinic attenders, nevertheless, can be significant, and for a subset of these patients the intensity and nature of the psychologic distress is marked, warranting aggressive intervention.

Tricyclic antidepressants, particularly desipramine, have been shown to be
effective in treating abdominal pain and diarrhoea, but not constipation-predominant IBS. It is not known whether the benefits of these drugs are due to their antidepressant actions or to their anticholinergic activity.

Counselling or psychotherapy has been demonstrated to be highly effective in alleviating or eradicating the symptoms of irritable bowel syndrome. Short-term dynamic psychotherapy, hypnotherapy, multicomponent behavioural or cognitive-behavioural therapy, and cognitive therapy have all proven superior to medical management alone, with cognitive therapy yielding the strongest and most consistent results. Psychologic treatment is extremely cost effective and produces relatively long-term improvements.

Currently, the medical treatment options for patients with IBS are inadequate, as none of them have been shown to be consistently effective. Bulking agents, antispasmodics, and tricyclic antidepressants, while they may provide some relief, are often associated with unpleasant side effects. Recently, two new drugs, Dicetel and Modulon, have shown more promising results. With 30% of IBS patients noticing some benefit when taking these medications, these drugs are an improvement over the aforementioned pharmaceuticals. Loperamide, however, remains the most effective drug for the symptomatic treatment of IBS.

Loperamide (Imodium) has shown promising temporary results for the management of painless diarrhoea and for those with alternating bowel habits and abdominal pain. For patients with alternating bowel habits and no pain, Loperamide is generally ineffective. Individuals who are constipation-predominate generally feel worse on Loperamide. Loperamide produces no side effects and has no addictive potential.

The medical case study literature that is available is largely anecdotal in nature,
focusing on the symptomatology of the experience. It does not offer a portrayal of what living with irritable bowel syndrome might be like.

A comprehensive review of the literature produced only two studies which looked at the experience of living with irritable bowel syndrome. Corney and Stanton (1990) found that over 40% of the patients in their study were impaired by their IBS in the areas of work, socializing, travel, sexual intercourse, domestic and leisure activities, eating certain foods and eating with others. Dancey and Backhouse (1993), in their study designed to obtain both quantitative and qualitative information, identified the following themes: The Hidden Problem; Effects of IBS on Employment; Sex and Relationships; Travel and Leisure; Others are Often Unsympathetic; Self-Blame, Stress and Lifestyle; Self-Blame, Eating Habits; Medical Investigations; and Anxiety and Depression.

Finally, this chapter concluded with an introduction to the study's research methodology. The phenomenological approach was chosen because it lends itself particularly well to the purpose of the study - to gain a fuller understanding of the adult's experience of living with irritable bowel syndrome.
CHAPTER 3: METHODOLOGY

Introduction

In this chapter further discussion of the phenomenological approach, as it was applied to this research, is presented in relation to the selection and recruitment of the participants, data collection, and data analysis. Additionally, a brief description of the strategies used to promote scientific rigor or adequacy of the research will be provided. Finally, this chapter will conclude with a discussion of the ways in which the rights of the study's participants were protected.

Selection and Recruitment of Participants

In keeping with the phenomenological approach, the participants of this study were selected through purposive, or nonprobability sampling. The design used was sampling by case type, under which a combination of purposeful sampling strategies, typical-case sampling and concept/theory-based sampling, were used.

Selection Criteria

The following criteria were developed to select individuals best able to meet the objectives of the study.

Each participant was to:

1. have been in contact with an IBS support group;
2. be diagnosed by a gastroenterologist or qualified health care professional as having IBS;
3. meet the restrictive diagnostic criteria for IBS as developed by Drossman, Thompson, et al. (1990, p. 165):

Symptom criteria for irritable bowel -
Continuous or recurrent symptoms for at least three months of:

1. abdominal pain or discomfort, relieved with defeacation, or associated with a change in frequency or consistency of
2. an irregular (varying) pattern of defecation at least 25% of the time (three or more of):
   (i) altered stool frequency;
   (ii) altered stool form (hard or loose/watery stool);
   (iii) altered stool passage (straining or urgency, feeling of incomplete evacuation);
   (iv) passage of mucus;
   (v) bloating or feeling of abdominal distention;
4. have a "typical case" of IBS as opposed to either a severe or very mild case;
5. be an adult between the ages of 19 and 64;
6. have no co-existing psychologic or physical conditions which could adversely affect the individual's description and/or perception of what it is like to live with IBS. This includes other current or previous gastrointestinal diseases, as well as multisystem diseases such as diabetes;
7. have the ability to communicate, in spoken English, what is the experience of living with IBS;
8. have the desire to communicate what the lived experience of IBS is like.

Recruitment Procedure

Participants were recruited through a self-help support group for individuals with irritable bowel syndrome.

The investigator began by contacting the facilitator of the IBS Support Group by phone. After discussing with her the research proposal, the investigator was invited to

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8The committee recognizes that some [researchers] may require abdominal pain as an essential criterion, and others may not. The decision to permit either categories 1 or 2 will be left to the [researcher].
present her proposal at the next IBS meeting on November 1, 1994. The proposal was met with enthusiasm and every member who was present at this meeting expressed a desire to participate in the study. As not all members were there, and to protect their anonymity, the facilitator and one group member contacted the remaining members. After receiving permission, the investigator contacted these individuals by phone. Again, everyone expressed a desire to participate in the study.

Each prospective participant was screened using the selection criteria as outlined above. Those meeting the selection criteria read the Introductory Letter (see Appendix B) and then read and signed the Participant Consent Form (see Appendix C).

While it was hoped that there would be 14 participants, only 4 members met the selection criteria. As the investigator was employing Colaizzi's method of phenomenological analysis, 4 participants sufficed in meeting the objectives of this investigation.

**Characteristics of the Participants**

As mentioned above, 4 individuals consented to participate in this study. These participants, 1 male and 3 females, were all Caucasian and ranged in age from 36 to 53. All of the participants were married and had children living at home.

Each of the participants met the designated selection criteria. All had been diagnosed with IBS by a gastroenterologist and reported no significant diseases at the time of recruitment.

**Data Collection**

In this study, the investigator, in endeavouring to collect data true to the phenomenological perspective, perceived the participants as co-researchers or partners in the endeavour (Liebelt, 1993). Therefore, she related to them within the context of a
mutual and genuine "I-thou" relationship, as opposed to the traditional "I-it" association in which the subjects are at arms length and are objectively observed, examined and tested (Livingston, 1971). The interview, known more specifically as a qualitative interview, was largely unstructured in that the investigator acted as a participant-observer (Heppner, Kivlighan, Jr., & Wampold, 1992). This assisted the investigator in truly being "with" each participant, enabling her to begin to understand each individual's world.

**Bracketing and Horizontalization**

In conducting a phenomenological study, there are two major processes which the researcher uses in order to more fully understand the meaning that events have for participants (Heppner et al. 1992). The first process is called "bracketing" (Davis, 1978; Knaack, 1984; Omery, 1983; Pallikkathayil & Morgan, 1991).

Bracketing involves suspending prejudices and biases so the researcher can approach the qualitative interview in an open manner (Heppner et al., 1992). Knaack (1984) describes bracketing as setting aside one's own assumptions so as to not force the phenomena under investigation into a mold of preconception. The phenomena are to be met on their own terms. Peck (1978) states that bracketing involves "temporarily giving up one's self - putting one's self aside, so to speak - so as to make room for the incorporation of new material into the self" (p. 73). Denton (1980) notes that the process of bracketing is usually accomplished through asking oneself a number of intellectual questions regarding alternate ways of viewing phenomena.

The investigator's bias manifested itself in assuming that irritable bowel syndrome permeates all areas of the participants' lives - their relationships, work, diet, affect (anxiety and depression), leisure and travel. In order to approach the qualitative
interview and the data in an open manner, the investigator attempted to bracket or suspend these prejudices and biases.

The second process, horizontalization, involves treating every source of data as equal (Heppner et al., 1992). In other words, the researcher suspends any *a priori* presuppositions or preconceptions involving which participant's view will provide a more valid description of the phenomenon.

**The Interview Location**

Each of the 4 participants in this study were interviewed in their own residences. The decision to interview them in their homes was made for a number of reasons. First, it was thought that the participants would feel more secure and comfortable, allowing them to be more at ease when discussing their personal experiences. Second, it was surmised that privacy would be integral to the interview process, as it was thought that the participants would not want to discuss their bowel habits in a public meeting place. Third, should their IBS present itself, it was assumed that the participants would much prefer to be at home. Finally, the investigator anticipated that the participants may be reluctant to leave their homes as travelling to meet her could prove problematic should their irritable bowel syndrome become active.

**The Qualitative Interview**

After collecting demographic information, the investigator began the interaction by asking "Describe to me, as vividly as possible, what is it like to live with irritable bowel syndrome? What does the experience mean to you?" Interviews were collaborative, and for the most part, unstructured, which allowed the participants to discuss issues which they deemed relevant to living with irritable bowel syndrome. Each interview was audiotaped and lasted 1 1/2 to 2 1/2 hours.
Detailed field notes were made following each visit. The investigator documented observations related to the participant's affect, cognition, mood, and appearance. Of particular interest to the investigator was "how" the information was reported. In addition to the above, verbal information which was not audiotaped was documented. This included comments which the participant made either before or after the recorded interview. Finally, the investigator's feelings and thoughts in relation to her experience with each participant were noted. These detailed field notes, by becoming part of the data base, helped facilitate interpretation of the data.

**Data Analysis**

Each of the participant's recorded interactions was transcribed verbatim. These transcriptions were then subjected to a phenomenological analysis using the methodology developed by Colaizzi (1978):

1. The investigator read all of the participant's protocols in order to acquire a feel for them, to make sense out of them.

2. She then returned to each protocol and extracted significant statements; those phrases or sentences which pertained directly to the investigated phenomenon. These statements were then paraphrased.

3. Next, the investigator formulated meanings, or tried to spell out meanings from each significant statement. This was a difficult step. The investigator used creative insight, leaping from what the subjects said to what they meant, being careful never to sever the connection with the original description.

4. The investigator then repeated the above for the remaining three protocols. After completing this, she organized the aggregate formulated
meanings into clusters of themes, allowing for the emergence of themes common to all of the participant’s protocols. From some 600 pages of data analysis emerged 61 themes, which the investigator synthesised into nine thematic clusters.

a) Clusters were referred back to the original protocols in order to validate them. This was achieved by asking whether there was anything contained in the original protocols that was not accounted for in the thematic clusters, and whether the clusters proposed anything that was not in the original. As none of the thematic clusters were alien to the original protocols, a re-examination was unnecessary.

b) At this point, the investigator noted any discrepancies among and/or between the various clusters. While some of the themes appeared to be in contradiction, she proceeded with the solid conviction that what was logically inexplicable may be existentially real and valid. The investigator successfully resisted the temptation to ignore data or themes which didn't fit, or of "prematurely generating a theory which would merely conceptually-abstractly eliminate the discordant of [her] findings thus far" (Colaizzi, 1978, p. 61).

5. The investigator provided the results of the study in the form of an interpretive description of the adult’s experience of living with irritable bowel syndrome (please see Chapter 4).

6. In the summary of Chapter 4, the investigator "formulated the exhaustive
description of the investigated phenomenon in as unequivocal a statement of identification of its fundamental structure as possible" (Colaizzi, 1978, p. 61).

7. The investigator mailed each participant his or her respective protocol with the addition of the significant statements, paraphrases, and formulated meanings. Corrections, omissions, and clarifications were made. The investigator validated findings with the participant and clarified information, both through conversations and through notes written by the participant. This was done to insure that the data obtained from the participant was accurate, and that the investigator's interpretation of the data was correct. For the final step, the investigator interviewed the participants again in order to validate the themes which emerged from the data.

Scientific Adequacy of the Research

Important to qualitative research are the concepts of rigor and scientific adequacy of the inquiry. Adequacy of the qualitative inquiry is demonstrated when the research processes and outcomes are well grounded, relevant, cogent, justifiable, and meaningful (Hall & Stevens, 1991). Specifically, this standard is achieved when the researcher's description of the participants' reality corresponds to the reality the individuals perceive and experience, and when the processes of the study are appropriate to the research problem (Hall & Stevens, 1991). Sandelowski (1986), in discussing the standard of adequacy for qualitative research, proposed that Guba and Lincoln's (1981) criteria of credibility, fittingness, auditability and confirmability be employed to judge the rigor of this research method. The fourth criterion, confirmability, relates to neutrality -
freedom from bias in the research process and product. This criterion is met when credibility, fittingness, and auditability are established (Sandelowski, 1986).

Conclusions regarding the scientific adequacy of this research will not be available until participants and fellow colleagues have had an opportunity to provide feedback in relation to this study's findings.

**Credibility and Fittingness**

The criteria of credibility and fittingness are related to the truth value and applicability of qualitative findings (Beck, 1993; Liebelt, 1993; Sandelowski, 1986). Credibility is demonstrated when the researcher's description of the studied phenomenon is immediately recognized by the participants as being faithful or congruent to these individuals' own lived experience (Beck, 1993; Sandelowski, 1986). Also important is that other researchers find the analytical interpretations meaningful and recognize the "truth" value of these interpretations (Sandelowski, 1986).

Fittingness, the second criterion of scientific adequacy, is achieved when others reading the research findings conclude that the researcher's analytical interpretations are applicable to contexts outside of the study situation (Beck, 1993; Sandelowski, 1986).

The following strategies were employed to establish credibility and fittingness in the present study (Liebelt, 1993):

1. The selection criteria were adhered to as much as possible. This helped to ensure that the data was as representative as possible to the adult's experience of living with IBS.

2. Each participant was given the opportunity to correct and clarify their respective protocols, which contained significant statements, paraphrases, and formulated meanings. A final interview was then conducted with
each participant to validate the emergent thematic clusters and the investigator's interpretations of the data.

3. The investigator noted her reflections and personal feelings throughout the research process in an effort to prevent bias and remain self-aware when interpreting the data.

4. The investigator presented data from the protocols that demonstrated she had been "true" to the transcripts and had "not read in meanings that are not supported by textual evidence" (Benner, 1985, p. 11).

5. The investigator acquired validation from her thesis supervisor that interpretations of the data are supported by the text (Sandelowski, 1986).

Auditability

Related to the consistency of qualitative findings is the criterion of auditability (Liebelt, 1993; Sandelowski, 1986). Auditability is achieved for a study and its findings when another individual can follow clearly the thinking, methods and decisions used by the study's original researcher and can conclude that they are logical and appropriate (Sandelowski, 1986). Moreover, when another researcher is able to arrive at comparable or similar conclusions, given the original researcher's data and methodological perspective, auditability has been demonstrated (Sandelowski, 1986).

In this study, the investigator endeavoured to establish auditability throughout the text of this thesis, being careful to clearly describe and justify her decisions throughout the study's process. In addition, the investigator had her thesis supervisor examine her themes for agreement. Analytical interpretations were consistent and well founded in the phenomenological data obtained.
Ethical Considerations

From the genesis to beyond the completion of this study, the investigator strove to promote and protect the participants' rights to respect, dignity, anonymity, informed consent, confidentiality, and information.

Prior to data collection, approval for the study was obtained through the University of British Columbia's Behavioural Sciences Screening Committee for Research and Other Studies Involving Human Subjects. The investigator's proposed ethical standards were approved by the UBC Screening Committee and adhered to throughout this study.

To ensure that potential participants had the opportunity to make an informed decision regarding their participation in this study, each was asked to read the Introductory Letter and the Participant Consent Form before agreeing to partake in the study (see Appendices B and C).

Together, these letters outlined the purpose of the study, the title of the study, the nature of the participants' involvement, the rights of the participants, the investigator's name and telephone number, and her thesis supervisor's name and telephone number.

To further ensure informed consent, the investigator read these letters to the potential participants and answered any questions they had. The investigator emphasized that participation in the study was strictly voluntary and that the participant could refuse to answer any questions, request to have information removed from the audiotape, or withdraw from the study at any time. One participant requested to have a small part of her interview deleted as she felt it was too personal. The investigator also required that each participant provide written consent (see Appendix C) prior to the initial interview.
In order to maintain the participants' anonymity, the investigator coded the audiotapes and transcripts. Secondly, access to the audiotapes was limited to the investigator, the thesis supervisor, and the typists. And thirdly, the participants were informed that audiotapes and transcripts would be destroyed when all scholarly reports had been written.

Finally, to further promote each participant's right to information, the investigator will be giving each participant a copy of the completed thesis. The investigator will be presenting a synopsis of her thesis at the IBS Support Group meeting on May 5, 1998.

**Summary**

The purpose of this study was to gain a fuller understanding of the adult's experience of living with irritable bowel syndrome from his or her own perspective. Consequently, the methodology used was phenomenological, as this approach best facilitated a fuller and more complete exploration and description of the participants' lived experience.

Consistent with the phenomenological approach, purposive, nonprobability sampling was used to select 4 participants who were able to describe the experience of living with irritable bowel syndrome from their perspectives. The investigator conducted audiotaped interviews in the participants' homes, using predominantly unstructured, collaborative interviews to gain information. Using this format gave the investigator the advantage of being able to gather verbal as well as non-verbal details from the participant.

Each of the participant's recorded interactions were transcribed verbatim. The investigator then subjected them to a phenomenological analysis as prescribed by Colaizzi
(1978). Analysis of the data resulted in a description of the essential structure or meaning of the irritable bowel experience. It is this resultant description that is the topic of Chapter 4.
CHAPTER 4: FINDINGS AND INTERPRETATION

Introduction

Presented in this chapter are the findings of the research in the form of an interpretive description of the adult’s experience of living with irritable bowel syndrome. This description evolved as the investigator employed Colaizzi’s (1978) phenomenological method of data analysis to interpret the participants’ portrayals of their lived experiences. Thus, this description represents the collective experience of the study’s participants as understood by the investigator.

Experiencing Irritable Bowel Syndrome

The participants in this study reported that irritable bowel syndrome had profoundly impacted their lives: "It’s meant for me having to change, having to change my lifestyle around." "It’s debilitating both emotionally and physically, your life completely changes, the quality of my life is not the same as it was."

Following are nine thematic clusters, which combined, represent the essential meaning of the experience of living with irritable bowel syndrome as derived from this research.

Symptomatological Characteristics of the Participants

As mentioned previously, 4 individuals met the selection criteria and consented to participate in this study. These individuals, 1 man and 3 women, had all been diagnosed with irritable bowel syndrome by a gastroenterologist: The man was constipation-predominant, 1 woman was diarrhoea-predominant, and the remaining 2 women alternated between diarrhoea and constipation.

The frequency of the participants’ IBS flare-ups were as follows: The constipation-predominant man experienced one bad constipation bout per month with
flare-ups in between. The diarrhea-predominant woman suffered at least 25 out of 30 days from diarrhoea. The first woman with alternating bowel habits encountered 5 flare-ups per month, and the final woman with alternating bowel habits experienced IBS symptomatology 8 to 12 days per month when not taking medication.

Regardless of whether the individual was constipation or diarrhoea-predominant, or alternated between the two, a common picture emerged from the participants’ descriptions of the symptomatology associated with IBS: (a) abdominal pain - "The pain is incredible and you think at that moment that you must be dying because nothing can be this bad"; (b) abdominal bloating or distention - "if I didn’t know any better sometimes I’d think I’m about my fifth month of pregnancy. It’s like how can everything stretch that much with nothing in there except air"; (c) accelerated heart rate, sweating, and the inability to concentrate - "Your heart will start to pound" "I start sweating, getting hot, I can’t concentrate because I’m only thinking of the pain"; (d) urgency associated with defeacation - "It’s like an explosion. You have no control" "I’ve gotta go, I’ve gotta go"; (e) straining associated with defeacation - "I bear down all the time when I’m on the john"; (f) defeacation: loose, watery stool (diarrhoea) - "Five minutes and everything in your system can turn to water" and/or hard stool (constipation) - "I’m on the constipation side in a deep way.... the material’s hard"; (g) relief of abdominal pain with defeacation - "but once its out I feel okay"; and (h) intense exhaustion coupled with a feeling of being "drained" during the flare-up, and in some cases, for the rest of the day - "After the bowel sessions I am just absolutely tired, fatigued like you wouldn’t believe.... I’m wiped out."

Other symptomatology reported by all of the participants included rectal flatulence, abdominal tenderness, tenesmus (a sense of incomplete evacuation of faeces),
the passage of mucous, and an irregular pattern of defeacation.

In addition to the above, 2 women stated that menstruation exacerbated their irritable bowel syndrome: "Your hormones play tricks on you, you have the runs, you have cramping, it's like Double Jeopardy. It just hits you twice as hard."

Two women also reported experiencing backaches. Half of the participants disclosed that they had developed haemorrhoids as a result of their IBS.

Symptoms reported by only 1 participant included: borborygmi (rumbling in the bowels); dyspepsia (indigestion); esophagitis (acid reflux); headaches; nausea; light headedness, lack of appetite; and swollen face, hands, legs, and feet following acute diarrhoea.

None of the participants reported experiencing faecal incontinence.

**Trajectory of the Disorder**

At the time of this study, the participants had irritable bowel syndrome ranging from 8 to 33 years. The onset of this disorder occurred between the ages of 10 and 46, with the mean age being 19 1/2. The participants were diagnosed with IBS 3 to 26 years after this disorders' initial onset.

Initially, the participants' irritable bowel syndrome appeared to manifest itself as either a "nervous stomach" or a very mild case of IBS: "I mean, like I said, I would have my days but nothing that ever concerned me and made it impossible to manage and go on with my routine."

Two of the women were grateful they were in the initial stages of IBS when their children were small:

I'm just really thankful that I didn't have it like this when my kids were little, like when they were small because I think that would be awful. I know there's a lot of women that do have that and I just feel so sorry for them 'cause it must be horrible and I fortunately didn't have that.
Eventually, however, this insidious affliction intensified to the point that all of the participants sought medical attention.

Each of the participants suffered from chronic bowel symptoms. Additionally, all of the participants experienced a prolonged period during which time their IBS exacerbated. Two of the women lost considerable amounts of weight due to the severity of these prolonged exacerbations.

In time, however, the severity of the participants' symptomatology lessened, with one exception. At the time of this study, the diarrhoea-predominant woman was suffering from a prolonged exacerbation which she attributed to menopause: "Now is probably the worst I ever had it in my whole life."

Eventually, 3 of the 4 participants were able to alleviate their IBS through the use of medical treatment.

**Seeking Professional Help - Medical Doctors**

The participants went to a number of different doctors in an attempt to seek help for their irritable bowel symptoms. All went to their family physicians and were then referred to gastroenterologists. In addition, one participant went to an allergist, another went to an internist, and the third went to a proctologist.

**Doctors' Attitudes**

Regrettably, 2 of the female participants reported being patronized, discounted, and treated with contempt by the medical profession. While 1 woman had been treated with understanding and respect by her former gastroenterologist, her more recent doctors were condescending:

I wouldn't say that a lot of physicians take us seriously, take the problem that we have seriously..... Most of the gastroenterologists, if its Colitis or Crohn's, you have respect. If it's IBS, you're treated like your nuts and I really resent that.
The doctors, when I've gone to a specialist and what-not, almost treat me like I'm a child or an idiot or something and treat me like I don't have a brain in my head when they're talking to me. It's like, "There, there dear, calm down" type of thing and it's like, "Oh, get a life," you know.

A second woman had this to say:

I had one doctor like that. I could see he was angry with me. He didn't really express it so much, but it was just the look on his face. He sort of said to me "You better smarten up, or you could get, this could become really serious." Like I thought, "Well, okay, well you tell me how to do it."

In the above quotes, the doctors were insinuating that these women had psychological problems and were therefore to blame for causing, maintaining and exacerbating their IBS. These accusations will be addressed in the next chapter.

Conversely, the man was treated with understanding and respect by his doctors. His family physician was very helpful and empathic: "I went to my doctor over there and a female doctor. She was very, very good. I went to talk to her. I told her what I went through."

This participant also went to three gastroenterologists. The first doctor diagnosed him with IBS 20 years ago when he was still a child. While the participant does not remember a lot, he remembers being treated with compassion.

The second gastroenterologist was one of the doctors referred to in the above quotes. While this doctor had been condescending to the woman mentioned above, he treated the male participant with respect. This doctor, however, assumed a lot and did not give this participant a very thorough exam. In addition, this doctor was not very helpful.

The third gastroenterologist he saw was very supportive. Not only was the participant impressed by this doctor's expertise and thoroughness, but he also appreciated the fact that the doctor took time to answer his many questions. The
participant felt validated as this gastroenterologist treated him with both understanding and respect.

**Doctors' Lack of Information**

All of the women in this study expressed frustration because their doctors gave them little or no information regarding IBS:

My internist said that I would have to experiment with food and didn't tell me very much. I wanted to know more detail. "Tell me more, what can I eat, what can't I eat? Educate me a little bit on the symptoms. I know you know, but I don't know."

Under the previous heading, the doctor told the participant that she had better "smarten up" or her IBS could "become serious." This doctor, however, failed to tell her how to smarten up. As 1 woman stated: "None of them have the answers or solutions" "I don't think that the physicians know that much about it. But yet they are gastroenterologists. Why don't they know?"

Conversely, the man was given a lot of valuable information by both his gastroenterologist and his family physician:

[The doctor said] "Uh, do not take laxatives, the best thing to do.." She's the one who recommended to me the suppositories, didn't even know about them and also the Prodium and sure enough, those things helped me a lot. I think she was [more knowledgeable than the others]. I think she was a bit more open minded towards it.

**Diagnostic Procedures**

Each participant had been through the medical system and experienced a number of tests. These included sigmoidoscopy, colonoscopy, endoscopy, barium x-ray, and others. All proved negative.

One woman was referred to an allergist. She tested positive to an amazing variety of foods: "I'm pretty much allergic to almost everything." Her doctor attributed her IBS to food allergies.
A second woman was told by her internist that she had food intolerances. These intolerances were later identified by her naturopath. She, too, tested positive to an amazing variety of foods. This woman’s doctors believed her IBS was due to food intolerances.

**Therapeutic Modalities**

In an attempt to alleviate the symptoms associated with IBS, the participants used a myriad of pharmaceutical and other treatments: Buscopan, Colpermin, Demoral, Loperamide (Imodium), Lomotil, Modulon, Ovol, Fiorinal, Pepto-Bismal, Tylenol with Codeine, Librium (anti-depressant), Clonazepan (tranquilizer), glycerin suppositories, laxatives, Prodium (high fibre supplement), bran, fruit, vitamins, herbal supplements, and naturopathic medicinal aids.

A number of these treatments proved quite successful in reducing the symptomatology associated with IBS. All of the women reported Imodium to be effective for not only preventing, but in some cases reducing, their diarrhoea. In addition, the man who was constipation-predominant experienced some relief through the use of Prodium, a high fibre supplement, as well as Modulon, an antispasmodic. Furthermore, a woman with alternating bowel habits found tricyclic antidepressants to be quite effective for reducing her exacerbated symptoms some years ago.

Moreover, 3 out of 4 participants were able to significantly alleviate their IBS symptoms through the use of three specific modalities. In the first case, the constipation-predominant man relied on suppositories to ease the torment he experienced from this digestive disorder:

> And the glycerin suppositories, they do work. And I know you’re not supposed to use them very often, but at this extreme end of constipation, or chronic constipation, I find that if I use them constantly, it makes me go regularly every day, then the sessions are removed, reduced quite successfully.
The second participant, a woman with alternating bowel habits, also successfully reduced her IBS symptoms. She went from 3 months per year of continuous, severe bowel problems, rotating with two to three attacks per week for the rest of the year, to one or two flare-ups per month. She attributed this significant reduction in bowel symptoms to the use of "Nutribiotics," a natural antibacterial agent found in health food stores. She takes this medicinal aid three to four times per week, as needed.

The third significant reduction in symptoms began after the investigator finished her data collection. The woman who suffered from severe diarrhoea at least 25 out of 30 days now experiences these bowel symptoms only five to six times per month. She attributes this reduction of IBS symptomatology to her use of Imodium, which she takes every morning before work, and in the evening if she is going to night school.

While many of these treatments produced significant reductions in IBS symptomatology, not all pharmaceutical aids proved useful. In some cases, the negative side effects associated with the drug outweighed the benefits:

He put me on antidepressants and I remember sitting at my, I don't even remember how I got to work, but sitting at my computer and looking at it and going, "Okay, now what do I do?" I couldn't even remember how to turn the thing on and I took them for the time I was supposed to and it didn't do anything. It just made me feel like a space-cadet and your body was supposed to adjust to them after 3 weeks. I hated it. It was the most awful feeling in the whole world.... I must admit, I didn’t have the runs when I took it, but what a way to live not knowing what's up or down.

Furthermore, the drugs didn’t necessarily produce the same results in everyone, as evidenced by the divergent reactions noted above in relation to the antidepressants.

There is no miracle drug for us.... Many of us take the same medication, but they don’t seem to have come up with one that will help all of us.... So what works for one won't always work for the other.

So I’ve been taking care of myself for all these years with it and not self-diagnosing myself, but self medicating myself because each time you go to a different doctor they give you something else.... "We have this drug or that drug"
but they all work differently for people.

Finally, the participants maintained that these therapeutic aids were not permanent solutions. Rather, they were temporary coping devices. For example, 1 menopausal woman started taking estrogen. To her surprise, her IBS diarrhoea attacks went from at least 25 out of 30 days, to once or twice per month. This improvement was short lived, however, and due to the negative side affects associated with taking this hormone, she has discontinued its use. As stated by the participants:

Like the Imodium, like I relied on that Imodium for a while, "Oh, well, if I get that I'll take Imodium." That'll help it for awhile but that's just a band-aid solution, you know, and I've learned that I can't rely on that kind of, can't rely on anything. Yeah, it was like a band-aid solution and I knew it. I realized that, so I knew that it was going to come back if I wasn't careful.

I do take Imodium or Lomatil, whatever drug is at hand. Once it stops, then I will relax and then I feel like I have a little more control. But once it starts to wear off, the cramping will come back and then I will start to panic again because I know I've only controlled it for a short time or the drug has controlled it for a short time.

The best solution that I have right now for me to cope with it, and this is basically a coping, it's not a solution, is I use suppositories as a laxative. It opened my eyes to remedies, but again these are stop-gap measures. They're not permanent.

"But if there was some sort of medication that could calm it down with no side effects, it would be wonderful, until your body finally gets used to it and it doesn't happen anymore." "They'll work for a certain amount of time and then whatever we have seems to be stronger than a lot of the medication." "I've tried everything. I've tried laxatives, a lot of bran and all that stuff, but nothing where the result is permanent."

**Seeking Professional Help - Psychologists**

In Chapter 2, it was stated that "a wide variety of psychologic treatments have been shown to be highly effective in alleviating or eradicating the symptoms of irritable
bowel syndrome" (p. 20). These treatments include short-term dynamic psychotherapy, hypnotherapy, multicomponent or cognitive-behavioural therapy, and cognitive therapy. The predominant focus in all of these treatments is an emphasis on stress management.

**Stress Management**

All of the participants believed that stress exacerbated their IBS. Consequently, they believed that stress management would help them alleviate their IBS symptoms. Stress and the specific ways participants attempted to manage it will be discussed later in this chapter.

**Psychologic Treatment**

At the recommendation of her GP, 1 woman saw a psychologist who specialized in stress disorders. Like the treatment modalities discussed in Chapter 2, the psychologist used stress management for the control of IBS. Specifically, he employed relaxation techniques through the use of guided imagery and hypnosis:

So he does a tape and you sort of sit back and relax and he's got music in the background and then he's talking to you and he's telling you how to focus on what part of your body is giving you trouble and generally practising, I guess, relaxation as well.... He'll sort of give you visualizations, different things that you're supposed to visualize in your mind and I've found that that was good and I had a tape that I used to listen to like two, three, four times a day sometimes.... It did help. It didn't stop it, I don't think anything really stops it completely, but it did help. It sort of made me more in touch with [the] stress part and trying to just keep a sort of a calming effect and calm yourself down.

This woman saw the psychologist for about 3 years:

But it was just off and on 'cause it's very expensive and it's not covered by my husband's medical plan, so it's like $80 a session, so you can't afford to go too often. That's why you get the tape. You can take it home and listen to it and then, when you're ready to go back to see him again, he sort of leaves it up to you, in the beginning he might want to see you a little more often. As you get comfortable, then you sort of gauge how you want to do it, if you want to see him maybe every 6 months or whatever, but I haven't seen him for a couple of years and I still have the tape and I haven't listened to it for awhile I must say, but it's something I should really get back into again.
Seeking Professional Help - Alternative Practitioners

In a further attempt to seek help, the participants turned to alternative medicine.

Naturopaths

Two of the participants went to naturopaths with varying results. The first participant, a woman with alternating bowel habits, received considerable help. Not only did the naturopath give her the information that she needed about IBS, but he also pinpointed her food intolerances, provided her with diet restrictions, and gave her medication for her diarrhoea:

It was when I went to the naturopath that he started breaking everything down for me and I started understanding what was happening. Yeah, [he said my IBS was related to food intolerances].... He gave me some stuff to help my system to slow things down so that when I do start feeling like I’m getting it again... the diarrhoea is preventable I guess you could say. Uh, partially [preventable].

The second participant, also a woman with alternating bowel habits, was less successful in getting the help she needed:

I went to a naturopath a few years back and tried something that he gave me, but I didn’t have any success with it.... I don’t know what it was that he gave me, but I’d swear it tasted like scotch, scotch whisky.

Other Alternative Practitioners

The IBS support group regularly brought in various alternative practitioners in its quest to find help for its members. Some of these practitioners included a reflexologist, a herbalist, an iridologist, a health food store owner, and a reiki practitioner. Despite these specialists’ claims, none of the IBS sufferers received the help they so much needed:

We’re perfect prey for people who want to make a dollar off of us because we need help so badly. We’re looking for that miracle just like people with cancer or whatever the case may be. For us it’s just as bad, we’ve got to live with it.

One woman was adamant that these practitioners, were in fact, charlatan sharks who
attempted to prey on desperate people for the purpose of making money.

**Psychologic Impact of Irritable Bowel Syndrome**

The most salient feature of this study from a counselling perspective was the strong emotions that the experience of IBS elicited from the participants. These emotions included feelings of shame, fear, self-blame, guilt, anger, anxiety, depression, and loss of self-esteem.

**Shame**

Every woman in this study expressed feelings of profound shame in regards to her IBS symptomatology:

> When you are out somewhere, and you think that you might have to make a mad dash somewhere, just a horrible feeling comes over you. It's almost like a slope, like a little bit of death inside of you.... It's something that's so personal, and so humiliating, and so embarrassing that... when you're in a social situation, it [is] very difficult not to get upset.

The participants also disclosed that they felt socially unacceptable due to their IBS symptomatology. Consequently, they attempted to hide their bowel disorder from others: "If I don't have to [tell anyone] I usually won't."

Indicative of the shame they felt, the women reported that their IBS elicited unwanted attention: "It brings the worst attention to yourself because no one wants to know about somebody else's bathroom habits and having this, everybody knows, so there's nothing more embarrassing than this." "It automatically draws people's attention to you.... So you unintentionally bring attention to yourself and that's the last thing that I think any of us want to do."

I've gone through many a meeting with my stomach growling like crazy and people, they don't mean to snicker or laugh, but [they] can't help because somebody's saying something and all of the sudden you hear rawrawrawrawr. It's like, "oooooh," and then they all know it's you... and it's just making horrendous noise, really loud and squeaking away, squealing away... and they all look at you like, "Good God, what's going on there? Have you got E.T. in there
or something, or alien?"

One woman complained that her IBS affected her appearance and body image:

[A bloated stomach] causes a lot of discomfort along with embarrassment because women are supposed to project a... feminine type of appearance in today’s day and age and you’re supposed to be... svelte is a good word, and you can’t with IBS because you’ll always have a tummy.

"It’s humiliating. I feel they can see that my stomach’s swollen and they’re going 'God, look at that.' I’m a blimp or something."

All of the participants reported experiencing incredible flatulence: "Heaven help you if you ever pass gas in front of somebody. I, oh God, I wouldn’t want that, I wouldn’t want to imagine that. "But [gas is] a normal thing that goes along with this."

"Oh, [I have flatulence] all the time. "If I don’t go, then the gas builds up and I have flatulation like you wouldn’t believe." "Your [sexual] intimacy can be affected a bit by it too. Especially if, all of the sudden, you get this horrible gas in your stomach... at inappropriate times."

Another cause of shame was the inconceivable odour that was left after defeacation:

It’s indescribable as far as the repulsiveness of it. It’s disgusting, it’s sickening. It’s like your body is rotting at times because if anyone has ever been around a person who is deceased, it’s pretty comparable.... My son will walk in the house and go "Oh my God, who died." Just a phrase, but it’s as close as you can get....And I know in my own family, I’m sure as much as they love me, it takes a lot for them to come around, going "Oh my God, what did you eat?" I guess it’s undigested food and everything else, but I’d say... it’s a pretty close comparison [to the smell of my uncle’s rotting corpse] when you have a really bad attack. My only friend [is my dog] when I’m really sick. The animals can tolerate anything. They’re very forgiving. Your family will walk in, and go "Oh my God, let me outta here," so your family does put up with a lot, too, and your coworkers.

Two women in this study reported feeling "unclean" following their IBS attacks:

I have never felt so unclean in my whole life, no showers can take the odour away... even though the odour is no longer there, you can still smell no matter
how much you wash your hands and you still feel like you’re dirty. You have it on you, it’s just all over you.

Two of the women disclosed that they were worried about faecal incontinence: "I don’t know how I’d handle that. I don’t think that I’d go back. Oh God, I’d never go back wherever it happened."

Aside from producing shame, the possibility of faecal incontinence also produced fear. Fear and its association with faecal incontinence will be discussed in the following section.

Interestingly, while the male participant shared many of the above sentiments, such as the social unacceptability of IBS, he stated that at no time did he feel shame due to his bowel disorder: "I’ve never been ashamed of this and I’m not."

**Fear**

While none of the participants reported experiencing faecal incontinence, two woman and one man expressed fear over not being able to reach a toilet when they needed to defeacate. For the women, the fear was associated with faecal incontinence: "Your personality changes instantly. You get a feeling of panic and fear because you know you don’t have 5 minutes to find a washroom. You have seconds."

I’ve been lucky that I’ve been able to get myself from point A to point B, but I dread the time, I hope that it will never happen that I can’t, ’cause I’ve heard horror stories and I’m just lucky that it hasn’t quite happened.

While the women were afraid of faecal incontinence, the man’s fear was associated with the incredible pain he experienced if he delayed defeacation:

The pain is so severe, so acute that if I don’t do anything about it, I start sweating, getting hot, I can’t concentrate because I’m only thinking of the pain and then if I keep it longer I’m actually doubling over and it’s like, I gotta go, I gotta go.
Every woman expressed self-blame for incurring or exacerbating her IBS. While intellectually these women knew they were not responsible for "bringing on" this disorder, they still felt that somehow, they were to blame: "It's not a mental problem, but you do it to yourself. Yes you do because of the fear of what's happened before. [We] make whatever would trigger it within ourselves, trigger it."

And I've tried the herbs and the vitamins and I've done meditation, I'm doing medication and the exercise, I've done everything that they say you're supposed to do and yet I guess I find I blame myself that I'm not strong minded enough to get it under control. I think all of us tend to blame ourselves for having it, but we don't know what we're blaming ourselves about.

One woman, however, did eventually resolve this dichotomy. With time, she came to believe that she was not causing her IBS:

But it does tend to make you feel a little neurotic when you've got this, like, you think, "Oh my gosh. I'm always complaining, I'm always tired" and you've been to see the doctor more than you used to ever see a doctor before and you think, "They must all think I'm really a headcase here." That's the way you tend to think when you first get this thing and then you sort of have to realize that no, it's not something really that you're causing, it's just the way your body is, for whatever reason. Some people will get, they'll have a heart attack or they'll have a headache, for us it's right in the gut for some reason.

Likewise, the man in this study did not believe he was causing his IBS:

After learning more about it by reading and going through the self-help groups and everything else, by discussing with the doctors and realizing it's not just me, it's not psychological, it's not in my head, then it helps me out to cope with it.

Aside from experiencing self-blame, the women in this study also experienced feelings of guilt. Again, there appears to be a dichotomy here. For example, the woman quoted below is the same woman who stated: "But you do it to yourself."

If it's going out with [my husband] or if we're going somewhere, I can't handle a guilt trip and I can't feel bad about what's happening because it's not my fault. I'm not doing anything to bring this on that I know of. It's just happening, so I
can't sit there and feel guilty or worry that I'm spoiling something. If it's that important, go without me. And I feel bad that I have to miss something, but that's life.

In light of the above two quotes, the woman appears to be struggling with whether she brings the IBS upon herself, or whether this affliction happens randomly.

Again, while the women struggled with guilt over their IBS ruining or spoiling several occasions, the male participant did not experience this emotion.

**Anger**

The man in this study repeatedly voiced his annoyance in regards to his irritable bowel syndrome. "It's an annoyance, it is a distraction, an embarrassment sometimes, and it's a real pain, truly." "I would have to be there for like, 2, 3 hours with many visits to the john and that's annoying." "At that point I feel irritable in the sense that I've got to deal with it again. Not impatient, because I've learned the point where I gotta just let this thing happen." "I have been impatient before cause I'm going 'Oh, I gotta go, I gotta do this, I gotta do that,' it's an annoyance because I'm wasting time."

"It's an annoyance when I'm at a critical juncture, like when I'm at a meeting or something like that." "I get] annoyed, that's about it. Annoyed, and for a while there I was frustrated and not scared, but just nervous to go out."

Two women voiced their anger over IBS. The first expressed her anger as frustration or irritability: "That’s frustrating because I can’t do some of the things other people do. I can’t do as much." "I find that [IBS] affects my moods a lot, too. [I get] irritable."

The second woman also said that she found her IBS annoying. Moreover, she stated: "[When I’m having an attack] I feel pissed off. Yeah, I’m really mad that it’s happening. It’s like, 'Oh God, not again.'"
Anxiety

All of the participants expressed considerable anxiety over their bowel problems, particularly in relation to the shame and/or fear which they experienced: "There's anxiety and there's panic, and your heart will start beating a little faster." "If I'm constipated even, even for more than a day, if I'm 2 days in the going, then I know that when I do go it's going to be painful and that's the part where I get nervous."

More about anxiety will be delineated under the heading "Impact of Irritable Bowel Syndrome on Daily Life."

Depression

All of the female participants expressed feelings of depression in relation to their irritable bowel syndrome: "I get depressed sometimes, especially when the attack comes." "You're not depressed until it kicks in."

When I'm having a bout it really will still depress me. I tend to get that sort of hopeless feeling. That all comes under depression. Just a general unhappy state when you're having the bout... I usually get back on track again after it's all over and done with.

The man did not report experiencing depression.

Loss of Self-Esteem

All of the female participants expressed or intimated that their self-esteem had been diminished by their IBS. "You have no control. It takes everything away from you, your control, your self-esteem. It's so embarrassing." "I guess because this problem is so embarrassing, I don't want to bring any other embarrassment to myself. I guess because this is such an embarrassing thing, a knock down of self-esteem."

You'll be sitting there and you're not hungry, but your stomach will be growling and then someone will say real cutesy-like "No breaky today?" I feel like saying "No, I've got the trots." That's what I mean by self-esteem.

The man did not report loss of self-esteem.
Impact of Irritable Bowel Syndrome on Relationships With Others

As stated previously, the participants in this study believed that the symptomatology associated with their IBS was socially unacceptable, and therefore, it became a hidden problem. Participants were reluctant to confide in others about their bowel disorder, especially those they did not know well or who had not gained their trust.

The participants, however, did disclose their IBS to some, most notably their family, friends, and those they deemed necessary to tell. People's reactions were mixed, with some responding negatively and others positively. One woman, who reported only negative reactions from the few people she told, stated:

But [my husband] said to me one time, we were on a trip for a holiday and I... was making my little runs to the bathroom that day. I was having, not a bad day, but... I thought, "Well I better go" and he says "Well it's all in your head." Well, that didn't help. Yeah, 'cause that sort of thing doesn't happen all the time, but it did happen and it really upset me that he said that.

You have to wait until everything sort of settles down before you can even leave the door and so a lot of people aren't too patient with that. It's very hard for someone who doesn't have it to understand it.... They think it's probably something you're bringing on yourself. Another woman who suffered at least 25 out of 30 days from diarrhoea felt she had no choice but to tell others at work about her bowel disorder: "If I have to leave them suddenly, I don't want them to look at me like I'm crazy, it's just that nature's calling. 'I haven't got time to talk, goodbye.'... it's just too embarrassing." This participant's male co-workers responded to her IBS with humour:

I get teased a lot, but with this you have to have a sense of humour or it's just devastating. [At work] some of the fellows might write as I go walking by holding a piece of paper that says "10." That means I've walked past them ten times and so I have to go by their desks [to use the washroom].

Aside from her boss and co-workers, this woman confided in her family and in-
laws about her IBS. Her husband’s other relatives do not know she suffers from this bowel disorder.

The man experienced very positive reactions not only from family and friends, but acquaintances as well:

My kids are learning about it, and they know that dad’s on the john all the time and they ask me "Well, why am I on?" and I tell them.... so they’re supportive, they’re starting to learn. My parents know about this, my in-laws know about this, so whenever something happens... they just deal with it. They know that it’s happening so let me deal with the situation basically and so the support’s there, so it’s very good. So that helps psychologically in that regard.

Not always [do people know about my IBS], but if I do have something happen I’ll tell them. I’ll tell them a bit of history and I’ll tell them the situation.... And most of the people who I deal with are mature enough and intelligent enough to realize that people are people. [I never get "Everyone has occasional problems with their digestion, what’s your problem?"] not within my circle of friends and people I meet because they are well-educated and if I tell them why this is happening, and they go "Well I didn’t realize people had that" and then... [I will] sort of educate them.

I don’t think I ever got any sneers, maybe from kids at school, but that’s because they didn’t, I didn’t know what was going on and they’d go "[He’s] got gas, [he’s] got gas," that type of thing, so I’ve never really gotten it from adults.

A third woman stated: "Most of my close friends are aware of what’s wrong with me. They’re very supportive. I [told] my family, my extended family, and my friends. I have supportive family and friends."

Some of the people that I feel that I’ve developed a trust with, I’ll tell them a little bit, but I don’t tell them very much and when I tell them they’re going "Ooh, this is simply awful." I’m going "Yeah, it can be."

While there were many people who responded empathically to the participants’ IBS, no one understood like those who shared these bowel symptoms:

It’s hard for my husband’s side of the family, I think it would be a little more difficult for them to understand than say, my own mother because my mother has had problems of her own so she can kind of relate a little bit closer to what I’m going through. I think she knows how I feel and stuff.

But there’s people that do have the same condition. They’re the ones that know
exactly how you feel. If I know people, like I've talked to this one friend that was close by ... and she knows exactly how I feel and I know exactly what she's been through. You can say things and relate things to people that have had the same condition. It's things you can say, you can relate to them, that other's can't, not even people in your own family can understand.

The participants also found understanding from the members of the IBS support group. Not only did the group provide the participants with understanding, encouragement, support, and validation, but they helped to normalize the experience of IBS: "I just thought it was just me having this problem."

Some comments made by the participants about the IBS support group included:

From the group that I belong with, they're the most gentle people I've seen or met.... but they're the least judgemental, they don't have high expectations of anyone other than themselves and they don't seem to ask a lot of anybody.

Listening to the group it seems to affect people who are really busy, who have a lot more on their plate than the average person. It seems that these people, even though they have it, they're still trying to do a lot. It seems like they have really busy lives. They have jobs and some have hobbies and just things that keep them busy all the time.

That's what I like about our group... we can all talk quite freely and we have quite a good time talking about it sometimes, and there's been other times when people have been really upset because of what they're going through, so that's great for that part of it.

Not everyone, however, had a positive reaction to this support group.

Unfortunately, there's still a lot of doctors that don't agree with support groups. [Why that is] I have no idea. I guess they figure you dwell on it too much if you're going to support groups and therefore it becomes more of a problem for you if you're dwelling on it all the time. But I don't find that you're really dwelling on it so much as talking about it and realizing that other people are experiencing a lot of what you are and that you're not so isolated.

Research findings on the effectiveness of IBS support groups will be addressed in the following chapter.

**Impact of Irritable Bowel Syndrome on Daily Life**

The impact that IBS had on daily life was tremendous. As 1 woman lamented:
"No matter what you eat, no matter what you wear, no matter how much exercise you
do, you still can’t be like everybody else." This section will address a number of ways in
which this bowel disorder affected the participants’ lives. How the participants coped
with this disorder will also be discussed.

**Attack Triggers**

Three of the participants reported that there was "no rhyme or reason" as to
when their IBS symptomatology would manifest itself. "Whatever is taking over you
when you’re having this attack, whatever is bringing it on, it’s frightening because you
don’t have the control that you had 5 minutes ago and it’s an unexplainable thing."

Aside from these random attacks, all of the participants were able to identify
specific IBS "attack triggers." Regardless of whether the participant was constipation-
predominant, diarrhoea-predominant, or alternated between the two, these triggers fell
under four categories: getting up early and insomnia, confinement, stress, and
unsuitable diet.

**Getting up early and insomnia.** Because the participants’ IBS attacks generally
occurred first thing in the morning\(^9\), right after getting out of bed, the participants
adapted coping mechanisms so they could arrive on time for work or other morning
appointments:

Before I was taking suppositories I would wake up an hour earlier than I had to,
go in the washroom and sort of try to force it out, just work it out, but that
didn’t work very well and so I would have to go not knowing when I would have
a bowel movement.

Another participant, a homemaker, stated:

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\(^9\)Nocturnal diarrhoea is rare in irritable bowel syndrome (F. H. Anderson, personal
communication, April 17, 1998). Two women, however, reported that while their diarrhoea
happens more in the mornings, they do sometimes have cramping or diarrhoea during the
night.
If I'm going to be having a day when I'm going out and have a big day, I'll get up a little extra early, so I've got a couple of hours where I can get up and have my juice and get myself to where I know how I'm going to be.... Yeah, [if I have to be somewhere by 8:00, I get up at 5:30 and run for 2 hours.] That's true. Really early. I find if I'm getting up at 6:30 or so, I'm usually a little worse then, for whatever reason.

Another women heavily medicated herself so that she could get to work for morning meetings on time. She dreads meetings because she doesn’t like having attention directed to her nor does she like being confined due to her IBS:

I had a budget meeting on Monday and it was at 9:00 so that morning I was up at 5:00. I had taken Imodium by 7:00 and Buscopan and that got me through the meeting and by lunch time I had severe cramps because [of the] medication.... You do what you have to do to get through whatever you’re doing and then you deal [with] the side-effects afterwards, and then I won’t go anywhere. I’ll just go home and have a hot bath and go to bed.

Two of the women commented that lack of sleep exacerbated their IBS:

If I don't sleep as well I find I might have a bad day the next day. If my sleep is interrupted, or I don't get a good restful sleep, I find that has a certain effect on how I'm going to be.

I find that I have to get a good sleep. If I don’t have a rest, a good night’s sleep, I find that if I’m getting tired or it starts to act up, I slow right down. I learned what my limitations are.

Confinement. Three of the participants reported that they had a fear of being confined. This fear resulted not from claustrophobia as one may presume, but from the women’s fear of faecal incontinence and the man’s fear of incredible pain resulting from delayed defeacation. Consequently, these participants avoided any kind of confinement:

I think all of us joining the IBS group have that fear of being confined because we lose control of our bodies. Everything seems, from listening to other people, everything seems to move really quickly within us. It just seems that our bodies are jumping all over, or our nerves are, because we're panicking.

Public transportation also proved to be problem, as did travelling:

I mean, my worst nightmare would be travelling somewhere, being on a bus or being on an aeroplane or being somewhere maybe in a different country, where maybe you can’t get access to something, and it happening.
Bus rides are out. I’m very nervous about going on the bus, if it’s a long trip, I guess I’ll have to stop somewhere. If I’m going to work I’ll have to stop, get off the bus, and go find a gas station for a washroom. I remember one time I was on the bus, just dying to get off, but I’m thinking, "I’m close to the skytrain station. I’ll wait till [then] and get to the washroom" and when I do go, it’s very painful and I’m there for a long time.

I would never take a bus or anything like that anywhere.... Not a hope and a prayer. I won’t do it. I won’t do anything like that. Again, it’s being confined and certainly the horror stories of the things stopping and not going anywhere and the people stuck up there for 2 or 3 hours.

Being caught in a washroom line-up also caused fear:

You might be in a line-up which of course causes anyone, anyone who has our problem, panic because you can’t be the last guy, you have to be the first guy at the beginning of the line-up.

Sitting in from the aisle or sitting away from the exit where one didn’t have easy access to a washroom resulted in tremendous anxiety:

[My husband] went to a concert and he got tickets down on the floor... and I couldn’t go. I can’t stand the thought of being confined anywhere in a group or a concert or anywhere like that and not being able to get up and leave, even when [my husband] wants to go to hockey games.... he’s so happy and I’m going "Oh God, oh no." If it’s on the edge or if we go to a movie, I’ll sit on the outside. It’s almost like you feel safe. You feel like you’re in control and nothing will happen. Put me three seats over and I’ll be out of there in a flash. Your heart will start to pound and you’ll sweat. You’ll get a headache and the cramps will start and it’s like "Let me outta here!"

In fact, anywhere in which the person felt confined posed a problem:

I’ve had to leave classes, an exam. I know even if I go to the doctor’s for a medical checkup, the minute I don’t have my clothes on and am confined to that chair or that table, it’s game over. I have a dentist that knows not to put that rubber dam in my mouth because I’ll panic because he’s confined me. As soon as I know I’m confined, then I’ve told myself to go to the washroom.

Stress. As noted in Chapter 2, stress can affect bowel function even among those without a bowel disorder: "I find that some of my girlfriends are going 'I think I have what you have.' They don’t. It’s just stress related for them."

Chapter 2 also noted that stress affects bowel function to an even greater extent
among those with IBS. Accordingly, all of the participants reported that stress exacerbated their bowel disorder: "I think for me it's mainly stress." "If something stress-related or something happens, whether it be sad or happy, [it] can trigger the cramps." "But I know stress or happy occasions will trigger a lot." "Stress causes me to have a nervous stomach.... I have to go to the bathroom." "Definitely, [there are fluctuations with stress]." "The more pressure you have on you the more, the stronger of an attack I will have and I've found that for the rest of the people."

Interestingly, while stress in general exacerbated the women's IBS, the man noted that his body reacted differently depending on the type of stress:

I do find that if I'm in a nervous stress, like being in front of people or... in an interview... it's a different set of nerves for me. I find that makes me go which is the irony.... It's more like you have the butterflies in your stomach.... That's a nervous stomach but that ironically makes me want to go and that sort of helps. While "performance anxiety" regulated his bowels, stress induced tension exacerbated his constipation: "When you're tensed up, that's when it really starts to irritate the situation quite a bit, so that's kind of a funny experience for me."

As discussed in an earlier section, all of the participants recognized the value of stress reduction for the management of IBS. One participant went to see a psychologist who specialized in stress disorders. While the relaxation exercises he gave her were not a panacea for her IBS, they did help. Other successful attempts used by the participants to reduce stress included walking, hiking, aerobics, and cycling: "I try to do some exercise. I know what help[s] me is after supper I walk around the block. That helps me immensely."

What I've just been doing is trying not to let myself get upset and trying to keep the stress levels down and, just eating basically a healthy diet rather than a lot of junk food, and that seems to work for me.

Yes [it is affected by stress]. Yeah, I find that as soon as I start to feel stress or
pressure, one way that I have learned to deal with that is going for walks.... I've been doing a lot of walking and exercising. That's one way I've been dealing with a lot of stress... Stress does definitely affect me.

Not all attempts at stress management, however, were met with success:

But in trying to control it they say through exercise, through relaxation, you can when you're in that quiet environment, but put you in a stressful environment and you try to put what you know into practice, for some reason your body... whatever it is that's happening to you is way stronger than your mind at that time and it's really hard to get control.

Other people can learn to go with it and relax and I guess that's maybe a way to help us in some areas to get through this is to learn to relax.... I wish I was stronger willed to be able to redirect the thoughts, but I can't. Whatever you're supposed to do, I haven't learned how to do it.

"[Doctors] say "rest and no stress," well everything causes stress. I mean that's just a fairytale to think that you can't have stress in your life. You have it every day in one way or another."

**Unsuitable diet.** Diet also acted as an attack trigger. As noted earlier, 1 woman suffered from a myriad of food allergies while another had numerous food intolerances. Both of these conditions exacerbated the women's IBS symptoms. While the man had no known food allergies, he, too, was forced to endure a number of diet limitations. While the final woman had much more liberty with her diet, she also abided by certain diet constraints.

The following section will address specific diet restrictions.

**Diet Restrictions**

All of the participants ate restricted diets to avoid exacerbating their IBS. One woman found that eating a good, healthy diet, as opposed to "junk food," helped control her IBS. She also limited her coffee intake and avoided alcohol. Additionally, she monitored herself to watch for any problems: "For me it's generally just trying to keep an eye on what you're eating and see if you have any reactions."
The woman who was allergic to an amazing variety of foods stated: "No matter what I eat, it causes cramps and you don’t have a lot of choice in food." This woman was on a very strict diet as it was believed that her IBS was caused by allergies:

So, small meals four to six times a day, don’t eat after 7:00. Um, you have to have vegetables with bread. You’re only allowed to have one mint as far as candy, only once in a while. No salt, spices, or sugar, juices that are sugar free, no coffee, no onions, radishes, ginger, garlic, no gum, no candy, chocolates, raisins, peanuts, raw vegetables, breads with seeds, as little dairy as possible. [I can eat] rice cakes, brown bread, pita or bagel, potato, rice, chicken, turkey, eggs, bananas, vegetables, small amount of green peas, very small of broccoli, green salads, no coleslaw, only small amounts of oil and vinegar, angel food cake, a small piece of fish, sole, salmon, or halibut baked or grilled. These foods can be cooked in onions for flavour, just can’t eat the onions.

This same woman also attributed her IBS to stress:

If there’s any stress or any excitement that’s going to put me out with the public and stuff like that, then I have to really eat very bland foods because whatever’s taking place, I just won’t digest my food, and whatever I eat will, within a very short time, sometimes even 20 minutes it seems like, will just go through me.

The woman whose internist and naturopath believed that her IBS was due to food intolerances also ate a very restricted diet:

With my prognosis, if I keep my weight down, lose my weight, some of the weight that I’ve gained, my weight with the way I’ve been, if I keep my weight down and if I continue to experiment and follow the diet that has been suggested to me, plus some of the other areas that I’m learning about through reading and different resources, if I follow the right diet I’ll be okay.

"I’m learning that having more small meals, several small meals a day is supposed to be more helpful. I tried it and it worked."

This past year I was fine through July and August because I guess you could say my system was going through natural detoxification and when we went on holidays, I ate nothing but rice products. I stayed away from all the foods I knew that were wrong for me and I was fine through the summer, but I knew that I had to gain a bit of weight.

Because this woman’s diet was so restricted, she had problems disciplining herself to stay on it. As a result, her weight continually fluctuated and, understandably, she
became obsessed with food due to the deprivation she experienced.

The man, while he had no known food intolerances or allergies, also had to restrict his diet to avoid bowel problems. For example, course, rough food irritated his bowels:

I know about certain vegetables like corn, anything that's rough, I had a really bad session just last Halloween when I ate too many pumpkin seeds. I love pumpkin seeds, but I guess I chewed them too fast and they were still kind of rough and everything else. Boy, did I have a bad session. It just really irritated the bowels. Oh, it was awful.

The more mushier the better. If it's already pulverized, it's easier for me. Anything hard, some vegetables are very bad, like I said corn. Corn would not digest. I would have it coming out in the john. Meat is not really a problem, if I chew it properly it helps.

Other foods also caused problems:

I find that onions, anything like onions or beans, I was told by my doctor not to eat legumes, any kind of beans. That definitely can cause problems in terms of irritability.... It would basically be like a laxative type of thing, just kind of a weird way, but major gas and just be a bit of a nuisance.

Interestingly, spicy food, while it irritated his bowels, actually promoted his regularity:

Once in a while [I can eat hot foods]. Actually, it's a pleasure. I like to have a very spicy, szechuan type food. I love that, I love it with a pleasure, like I do hot wings. I do make them over here, but I don't think that affects me that much because, again, if I eat some the next day I could feel some sensation, but it wouldn't cause the constipation, I think and I would say it would probably help 'cause if you eat spicy foods, it gets irritated and may want to kick it out.

Finally, this man found that eating fatty food exacerbated his IBS. He has since restricted eating this kind of food which has resulted in a noticeable improvement.

**Social Restrictions**

All of the participants' social lives were restricted by their irritable bowel syndrome. For example, the woman with the food allergies experienced difficulties at her husband's large family dinners:

[My husband's] pretty good, except that I do know I have spoiled some occasions,
some holidays. A lot of times because I'm feeling okay and I'm getting ready to go somewhere, it might be to a family dinner because Chinese, we always have large family dinners and they eat, and they eat, and they eat and that's like 10 to 12 courses, well I can't do that.... I don't feel well. I can feel the cramping and he'll have to go without me.

It's a social get-together for Chinese people and the meals can last quite a long time. Because some of his family, like his mom and dad and sister, they know about it, but not the aunts and uncles and what-not, so it looks like I don't like what they're eating and it's not that at all. I can't eat it. It has ginger and garlic and spices and I'll be on the floor with cramps. I'll be in the washroom. I think in every Chinese restaurant we've ever gone to, I know where all the washrooms are. I can't eat spices like they do and salty gravies and things like that. I just can't eat it. It could be offensive once in a while. "[She's] on a diet again." No I'm not. I'm trying hard to stay the whole evening with them. And so I've spoiled a few occasions, not intentionally, and there have been times that [my husband] has had to go without me, but that's okay.

She also experienced difficulties going out to eat with people other than her husband's relatives:

Several times my husband and I have gone out to dinner with friends and I've tried to eat what they eat, and tried to fit in the way they do, and all I've ended up [doing] is sitting in the restaurant's washroom.

She also had to forgo many other social activities due to IBS. Some of those mentioned included going on holidays, visiting friends, going to concerts, the gym, the race track, movies, hockey games, and other occasions not specified.

The woman with food intolerances also experienced difficulties going to social gatherings involving food. She managed by bringing food she could eat or by eating beforehand.

My social life, it does affect your social life. It affects family life, for instance, when we go out for dinner with my family, to my husband's family or my parents, they know that I can't have some of the foods that they cook so sometimes I take my own food with me, depending on what they're having.... I'm okay. As long as the other family members, they seem to understand. And I'm fine with it as long as they're fine with it.

Got a few limitations. I mean you go to a social gathering where there's a group of people, a potluck or something like that, and you've got all these foods that you can't eat, so I always make a food that I can eat... so there'll be at least one
dish that I know that I can eat sometimes. And if I have enough time beforehand, I'll have a little something before we go out. So that's how I've learned to handle it. So, that's how I deal with that.

This woman's IBS affected her social life in areas other than those which involved food. Three of the areas mentioned included going to baseball games, going out for the day, and everyday excursions:

The other day we were supposed to go out... and my stomach was bothering me, so I waited a few extra minutes then I said, "I think I'm okay," but we didn't stay out for very long. We came back home. I knew we could come back home. We weren't going to be too far where we could come back home, so long as I know that, that's good.

The third woman reported that she was not able to participate with others the way she did before her IBS: "Because you can't always just pick up and go and participate in things the way you used to." People would get frustrated having to "wait on her bowels" before they could go out with her.

The man's social life appeared to be less affected by his IBS than the women's:

No, it hasn't affected me socially that much. A couple of times when I've went to a movie with my wife, and so I had to go to the washroom which is not so bad. Yeah, you blow your bucks on the movie, that does happen.

Activity Restrictions

All of the participants were faced with innumerable activity restrictions due to their irritable bowel syndrome. For example, the participants were forced to realize that due to their bowel disorder, they could no longer do everything they used to. They nevertheless, learned to cope with their limitations:

I feel like I'm limited. I can't do very much, and I'm trying to learn to accept that and realize that I can still lead a perfectly normal life. I just can't do as much as some other people can. I can't do as much.

For my family it's hard because I can't even do some of the easiest of housework when I'm in the middle of the attack. So my family last year had to help out a little bit doing housework and stuff, because I just couldn't do the heavy stuff.
But as far as living with the IBS, it took me awhile to accept it. It took me awhile to cope with it. I would say, it took me about 3 years to finally accept and realize I have this. I have limitations to how I can live with this condition.

Due to the unpredictability of his IBS, 1 participant became anxious to the point that he became incapacitated. Rather than going out and risking an attack, he would stay home. His resultant frustration acted as a catalyst to go out regardless of the risk:

For a while there I was frustrated and not scared, but just nervous to go out. I would be doing a little less things than I wanted to, to the point that I got so frustrated that I'm not doing those things I just go and do them. And if I get into a session, well, I just try to deal with it, cope with it when it happens.

Regrettably, the participants were no longer able to do anything on the spur of the moment, rather, they had to "wait on their bowels":

But generally for me, it's just the spontaneity, the looking forward to, there's a lot of joy that's gone out of my life since I've had this. Just to be able to get up and go and not have to worry about something that should be so natural.

"Spontaneity has gone out of my life. You can't do anything just at the spur of the moment. Travelling, anything that involves a change of your environment."

The participants, at times, were unable to avoid being late for work or other activities due to their IBS:

That's where I really think it affects me the most when I plan things, when I have to be at a certain point in time, at a certain location, and that's when I get nervous saying "Oh boy, if I have an attack then, it's going to really screw things up."

[During an attack] I can't make any decisions or anything. Whatever's happening just comes to a stop. If I have to go to work, I'm not going for that moment. I don't try to make quick decisions or anything like that because I can only deal with just what's happening. I can't deal with anything else, so it's a matter of putting everything else out of my mind, phoning them at work saying "I'm on my way."

"I gotta just let this thing happen. I can't go out, I just gotta let this thing happen. I'll be late to work or I'm not going to make this, I just gotta let this happen."

Unfortunately, the participants' irritable bowel syndrome sometimes made others
late:

There have been instances before we had kids where my wife was still working, we would carpool to work, but there would be mornings where I’d have an attack more often than not and we’re on the road and it happens and then I have to find a gas station, and go in there for a long period of time and I’m late to work and [my wife is] late to work and she’s trying to find an excuse to give. So that became very embarrassing.

The participants also experienced tremendous exhaustion during and after their IBS attacks. Consequently, at times they were forced to either curtail or cancel all activities: "It affects me physically. I get weak. I get tired... when I get the attack, all I want to do is sleep half the time."

’Cause it sort of blows everything. I know that if I’d have planned out my day and if I have a bad session I’m just exhausted and I can’t do anything. That really just sort of makes it frustrating you know.

In addition to the above, the participants had to guard against getting too tired, as fatigue exacerbated their disorder:

I’ve learned that when my activities get such that I’m so busy... I say "Sorry guys, but I’m taking it easy today." I feel like I’ve got to slow down and take it easy for a day or two, and that’s what I do. I’ve learned to say "No," to let my body tell me "You gotta take it easy for a day or two" and I find that after a couple of days of rest I’m fine. So that’s what I’ve learned to do.

The participants often felt very ill due to their IBS. Again, they sometimes had to either curtail or cancel their activities: "But it’s taken me a lot, it’s taken a lot to get me to the store. I’m not feeling very good, I maybe had diarrhoea all day." "I have to cut back on all my activities. I can’t commit to any activities outside the home when I’m sick like that." "If it’s something where I figure I’m having a really bad day or whatever, then I just don’t go out. I’ll cancel whatever plans I’ve made." "If it’s really bad... then that day is ruined for me." "You’re house-bound."

The participants went to great lengths to assure that they had easy and immediate access to the washroom should they need it:
When you do go out, you have to look around and you have to research, usually I research the areas before I go anywhere new. I don’t have time to go and ask people "Can you tell me where the washroom is?" I have to know beforehand so I very seldom go anywhere where I don’t know what’s involved in the area that I’m going to.... [So it’s] very embarrassing.... It certainly puts a damper on your day to day living.

Finally, some of the participants could not even leave their homes without first taking medication:

If you can’t take medication to control it you can’t leave your home. And it’s not agoraphobia or anything else like that. I mean, once the cramps stop, then you have no fear of doing anything. There’s no way you could [have a bowel movement] in a million years until it wears off and then once it does wear off then you’re in trouble. Unless you’re taking it on a regular basis you’re going to have to go to the washroom sooner or later. So you can’t take it forever and it’s frustrating to have to take medication to stop and then some of the other people in the group have to take medication to get themselves going again. I mean, what a lifestyle.

**Clothing Restrictions**

Clothing posed a problem for the participants due to their fluctuating waistlines:

"And if you’re sitting in a meeting and watching other people [with IBS], they start squirming 'cause you can tell their clothes are tight around their waist." "I can be getting dressed and what fit me yesterday won’t fit me today. My stomach’s swollen and you whole waist will grow another two sizes."

I have a perpetual swollen stomach and it’s embarrassing. You can’t put on a nice suit or something that’s form fitting. You always look for something that has elastic in the waist so that as your stomach expands, or your waistline expands, your clothes will too.

**Job Restrictions**

Regrettably, all of the participants reported having to make tremendous job sacrifices or allowances due to their IBS.

And I’m determined not to [quit my job]. I’ll take Imodium for the rest of my life if that’s what happened, it has to be. I mean, I don’t want to quit work or anything like that, I’ll do whatever it takes to continue working and functioning.
One of the participants, now a full-time homemaker, was forced to quit her job some years earlier due to IBS. The public nature of her job restricted her from using the washroom when she needed to. A second participant, also a homemaker, manages to work part-time despite her IBS by working out of her home - she has very flexible hours. The third participant, a former hair stylist who had to quit her occupation due to IBS, now works as a supervisor in an office. She has little contact with the public and a very understanding boss. If she does have an IBS attack, she is able to come in late or leave early, and make up the time later. The final participant works in a professional capacity. He has flex time, which allows him to come in late should he have an IBS flare-up. He is also able to take his work home.

**School Restrictions**

Two of the 4 participants commented on how their IBS affected them as students. The man stated:

> During my university days, fortunately, I wasn't so bad then. I guess not as much stress or a different type of stress, or whatever, but regardless of the reason of why it happens, I didn't have [constipation sessions] that much. During one test I had to be excused just for a little bit. Now I would get it during school, but luckily it didn't happen during that exam period.

Conversely, the woman had this to say:

> It stops you from doing a lot of things, even though your intentions are good and you'll say "No matter what, I'm going through with this," whether it'll be a presentation or attending a course downtown or a workshop.

"I'll try anything or try to do as much as I can. Whenever courses come up, I'll sign up for them and do them and take them. But I don't think people realize the price most of us pay."

The woman did pay a price. For example, class presentations proved to be particularly difficult for this participant:
For my BCIT course we got to do presentations and I was forced to, and my marks were high on that, but I don't think that anyone, unless they have IBS, knows what you have to go through to do it. It's just sickening, it's awful. It's humiliating because I could feel what's happening to me... I feel that they see that my stomach's swollen and they're going "God, look at that." I'm a blimp or something and so I always wear, if I ever have to go into a group where I know I am going to participate I'll wear the loosest jacket. And I'll make sure that I have Imodiumed myself up to the hilt or Lomotil or Buscopan, whatever I have on hand, but even though I've taken all that medication, I have yet not to have cramps while I'm doing a presentation or whatever I've been expected to do, but it's tough. It's really tough.

If you say "No I can't [do a presentation]" it's like you have to say "What don't you understand about the word 'no?' Get off my back, I can do what I can do and I can't do anymore. Give me time and I'll try, but for goodness sake, don't expect what I can't give right now." And the more the pressure you have on you the stronger of an attack I will have.

This woman's chronic diarrhoea also made her pay a price:

I've been downtown for workshops and I've taken some courses through BCIT. I always make sure I sit by the door. I've found that I'm always giving an explanation of why I don't want to be up at the front because you never know when it's going to hit.... I've had to leave classes, even an exam.... and if someone asks me to move over or something like that, I won't. Forget it. "You go over me and go on that side."... If I have to explain or apologize; I find I cause even more anxiety, so I just say "No" and don't explain.... [I] just make my answers very brief.

**Travel and Recreational Restrictions**

Travel and recreation proved to be real problems for all of the participants. One woman stated that she will travel, but not without a lot of concern and "what ifs." She takes Imodium when she goes on trips or holidays. She also takes Imodium before she goes socializing.

Another woman, who suffers from chronic diarrhoea, stated that she avoids travelling at all costs until her husband puts so much pressure on her that she feels she has to go. She will not go on the bus or skytrain, and catching the ferry or an aeroplane poses a real problem for her because of the wait involved before boarding. Going through customs also poses a problem for the same reason. When this woman goes
walking or hiking she brings toilet paper with her in the event that she gets diarrhoea and has to run behind a bush. In addition, while she exercises hard at home, she won't join a public gym:

I would be able to exercise with someone downstairs in my own home on the treadmill and work really hard at it and I would not have an attack, but if I had to go to a gym, where there's a whole bunch of people, for sure I would be in the washroom. I tried to join [a gym] and I had the runs all the time I went there and I joined their aerobics class and everything and that was cute; me trying hard not to pass gas while you're jumping around.

A third woman has to be very careful when she goes camping every summer, because up until this year, she got diarrhoea. She now watches her diet very carefully and avoids her food intolerances - foods which she knows will make her sick.

Finally, the man uses suppositories before and during his trips. This reduces his "sessions" considerably. If he does get into problems, he will let the person he's with know about his IBS, and use the washroom as needed: "Every other gas station I had to sort of stop and go and go and go." Despite his difficulties, he still goes camping, hiking, canoeing, biking, and cross country skiing, but not without precautions: Besides using suppositories, he often carries "an extra roll of toilet paper."

Making Meaning

All of the participants felt a need to make sense out of the experience of living with irritable bowel syndrome. The participants attempted to do this by developing theories as to the cause of their IBS, generating ideas as to what contributed to it, gathering as much information as they could about this bowel disorder, and finally, crying out for a cure.

First, each participant had a theory as to the origin of his or her bowel disorder. One woman believed that her IBS was caused mainly from stress. A second believed her bowel problems were the result of food intolerances, and noted that her symptoms were
exacerbated by stress. Still another woman attributed her IBS to both allergies and stress. The man had a number of different theories as to the cause of his bowel disorder:

I wish I knew exactly the reason of what causes it. I don’t know to be honest with you. I don’t know if it was stress, hormone-change, maturity, foods, I don’t know if I’m allergic to anything. [I’ve] never been tested for allergies yet. That’s one thing I really should investigate. I do have a stressful job where there’s a lot of pressure, but I don’t think it [is] just one thing that does it because there would be times when I’m in a non-stressful environment and yet I still get constipation.

Interestingly, the man also hypothesized that IBS may be due to an unidentified viral or bacterial infection, similar to that which was found to cause ulcers:

And I have a gut feeling that it is viral or bacterial, and my premises are strictly a guess. And what makes it more, in my opinion, more viable is that, that doctor in Australia who has diagnosed the ulcers.... And he’s proven that using antibiotic[s] to treat the symptoms, or the ulcer, works. Ulcers are not generated from acids, because there’s always acid in your stomach, but your immune system fails because of stress or whatever, and then a bacteria gets in, because some bacteria or viruses that will live in acid, get into your stomach wall and eat away at it. And he’s proven that a certain antibiotic will help the treatment. And if it happened in the ulcer in the stomach then there must be some bug, I’m not sure if it’s a bacteria or virus, I don’t know, I’m not a doctor, I’m not into microbiology, but if something exists in there, that would be something and if you can extrapolate from the ulcer approach to this, maybe towards a cure or something, something that you can at least work with.

I’ve got a funny suspicion that it could be some sort of bug that resides in the intestinal tract in the colon, down there somewhere and it is dormant for awhile and it grows and it dies and it grows and it dies for the peaks and the valleys. Basically when it peaks, you [have IBS symptoms].... What if one strain lived down there and it’s doing its bit and it just so happens that I am the host and my intestines are sensitive to that particular bug and I get a reaction to it. I’d expect something like that. It’s just an assumption. I wish, maybe I should go into microbiology and study it more.

While the above focused on the cause of IBS, the participants also discussed what they thought would contribute to this insidious disorder. The man and 1 woman theorized that being nervous or excitable might play a part in IBS: "I am a nervous person and always have been." "I sometimes eat fast. I have a tendency to talk fast, be excitable, I won’t say nervous, but just full of nerves, full of energy or very excitable
during whatever, I'm a very fast eater."

I'm just wondering if the lifestyle is causing that in terms of, I eat fast, it goes down quickly, not a chance to digest properly, could be part of the reason, I don't know, but that was since day one, since I was a kid.

One woman, who attributed her IBS to stress and diet, had her own theories as to what might contribute to IBS:

I don't think a lot of people today really feel secure [at] work or home because of the competition involved and I think that contributes to IBS because no one can be perfect and yet it seems to almost be turning into a perfect world.

I think today's day and age plays a great part in women having IBS. That's my own feelings. Obstacles, whether people related, work related, media related, the superficial myth that you have to be this superhuman woman, which is virtually impossible for anyone, anybody, any man, any woman, any boy or girl to live up to.

This woman also had her own theory about what safeguards people against IBS:

They're holding down a job. They don't have to come home and cook. They'll go out and go to the spa and do whatever they want to do or go shopping. When they come home, that's when dinner will be cooked. And these ladies don't have IBS. And these are women with children, too.... The ones who can come in and sit down and put their feet up tend to be a lot healthier than those who have to come in and start working the minute they come through the door. So maybe that's a contributing factor to women having IBS.

A second way in which the participants tried to make sense out of the experience of living with irritable bowel syndrome was by trying to learn as much as they could about this disorder. Consequently, they all displayed a hunger for information or knowledge in regards to their IBS. "When you've got something like this, you're reading and exploring all kinds of different things." In addition to reading books, the participants attended conferences on intestinal diseases and disorders, searched the Internet for information, talked to their doctors, joined intestinal research societies, subscribed to IBS newsletters, and became members of the IBS support group. Despite their quest for information, they still had a number of unanswered questions: "It's an
unexplainable thing that happens to you. I don’t understand it. And the group I belong to... we all have the same feelings. We don’t know why it’s happening. It’s very confusing." "But we all seem to have the same thing; fatigue, sweat, cramps, diarrhoea, bloating, gas, and a lot of pain. Unexplainable pain that is not caused by a disease." "I try to figure it out, 'Why, why?'" "Having this disorder, I don’t even know what they call this. Is this a disease, is it a disorder, what is it? Is it a mental problem? I mean what category do we fit under?"

Related to their thirst for information was their desperation to find a cure for IBS:

And if they say that’s psychological, so be it, but it still happens, so somebody stop it. I don’t think that we’re nuts as we’ve been portrayed a lot of times. And if that’s how our emotions, if that’s how our body deals with emotions, so be it. We still need help. I don’t care what causes it, if it’s our brain or endorphins, or whatever the case may be, we still need a cure for it. We still need good results. We need something to make it go away. Somebody, make it go away.

But unfortunately, there is no cure for IBS which is lastingly effective: "None of [the doctors] have the answers or solutions or do they profess to say that there’s been a lot of research done on it, on this problem to help us." "But I sure wish there was something that they would say: 'Oh yeah, we’re getting closer.'"

One participant, indicative of his frustration, stated:

So it’s not cancerous, which is kind of an irony. You’d think that if it’s cancerous, then maybe we could treat it with something, right? And that’s the most frustrating part, nothing I tried is permanent. I wish there was something that was specific and I could go for treatment and say, "Ah, yes, the treatment works."

Two women believed that even if a cure was found, their IBS would continue because their bodies’ were habituated to this bowel disorder. One woman, who attributed her IBS to stress, stated:
I don’t know if getting rid of stress would cure my IBS]. I just wonder at this point, your body’s got sort of to the stage where it’s going to do it regardless, because it’s gotten into that routine or maybe it’s just not going to work normally anymore, the way it used to. So I don’t know, but I don’t think we’ll ever really have that happen, unfortunately. I think that stress is always going to be a part of our life and it seems to be getting worse and worse.

The other women, who attributed her IBS to stress and diet, stated:

And yet the ones who have had to quit their job and be at home, they still continually have IBS. I don’t know, unless your body’s become so conditioned that it just can’t undo it immediately or in a couple of weeks.

So I don’t know if I’ve trained myself now, or what, but having it for this long my body is pretty well adjusted to having it. So it’s going to be a bit of an adjustment to undo what’s already been done that perhaps maybe could have been resolved many years ago, but they just didn’t have the knowledge.

One woman, in her need to make sense out of her experience of living with IBS, turned to her faith in God:

My church, my spiritual life, it helps me a lot. It helps me grow I think in that sense and because I am a Christian and I do have my faith, I think that helps me a lot. Yeah, it helps me to cope quite a bit.... Spiritual support, prayer from other brothers and sisters, it’s encouraging.... You take away your discouragement from your own circumstances and you feel more encouraged by focusing on others, on your faith... and that’s where I get my encouragement from, is through my faith.

Another woman turned to her faith in eastern healing:

So, something has got to be said between the mind and the body connection.... There’s therapists like Reiki practitioner[s] and sort of the power of channelling certain energies through your hand and working on the body that way. And then the oriental practitioners use one where they actually don’t even touch you. It’s just sort of done over your body and for some people it works. So it’s really hard to say what could work ’cause there’s probably something out there for everybody, you know, maybe acupuncture might work for somebody, so you tend to explore a lot of the different options.

Summary

This chapter presented the study’s findings in relation to the adult’s subjective experience of living with irritable bowel syndrome. The findings revealed that IBS profoundly impacted all areas of the participants’ lives: social, emotional, physical,
Within the first theme, the symptomatological characteristics of the participants were identified. Whether the individual was constipation-predominant, diarrhoea-predominant, or alternated between the two, the symptoms associated with IBS included abdominal pain; abdominal bloating or distention; accelerated heart rate, sweating and the inability to concentrate; urgency associated with defeacation; straining associated with defeacation; loose, watery stool (diarrhoea) and/or hard stool (constipation); relief of abdominal pain with defeacation; and intense exhaustion. Other symptoms experienced by everyone included rectal flatulence, abdominal tenderness, tenesmus (incomplete evacuation of faeces), the passage of mucous, and an irregular pattern of defeacation.

Within the second theme, the trajectory of the participants’ bowel disorder was outlined. Initially, their irritable bowel syndrome began as what appeared to be either a nervous stomach or a very mild case of IBS, neither of which concerned the participants. Eventually, however, this bowel disorder intensified to the point that all of the participants sought medical attention. In addition, all of the participants experienced a prolonged period during which time their IBS symptomatology exacerbated.

The third theme profiled seeking professional help - medical doctors. The first subheading addressed the doctors’ attitudes. It was found that while 2 of the women were patronized, discounted and treated with contempt by the medical profession, the man was treated with understanding and respect.

The next subheading outlined the women’s frustration over receiving little or no information in regards to their IBS from their doctors. In contrast, the man received valuable information from two of his doctors.
The third subheading addressed diagnostic procedures. These included sigmoidoscopy, colonoscopy, endoscopy, barium x-rays, and others. All proved negative. One woman was referred to an allergist. She tested positive to an amazing variety of foods. Another woman was told by her internist that she had a number of food intolerances. These intolerances were later identified by her naturopath.

The fourth subheading outlined therapeutic modalities. The women generally relied on Imodium while the man relied on suppositories to reduce symptoms. Surprisingly, 1 woman successfully reduced her IBS symptomatology through the use of "Nutribiotics," a natural antibacterial agent found in health food stores. While a number of drugs did prove useful, they were not without their limitations. In some cases the negative side effects of the drug outweighed the benefits. Furthermore, the drugs didn’t necessarily produce the same results in everyone. Finally, the participants maintained that these therapeutic aids were not permanent solutions, but rather, temporary coping devices.

The fourth theme profiled seeking professional help - psychologists. While only 1 participant went to see a psychologist, with beneficial results, all of the participants recognized the value of stress reduction for the management of IBS. They attempted various relaxation exercises and recreational activities in hopes of accomplishing this end.

The fifth theme also profiled seeking professional help, this time from alternative practitioners. Two women went to naturopaths with divergent results: One woman received considerable help while another received none.

In addition, the IBS support group brought in various alternative practitioners in its quest to find help for its members. Some of these included a reflexologist, a herbalist, an iridologist, a health food store owner, and a reiki practitioner. Despite their claims,
none of these specialists were able to help the IBS sufferers. One participant was adamant that these practitioners, were in fact, charlatan sharks who attempted to prey on desperate people for the purpose of making money.

Within the sixth theme, the psychologic impact of irritable bowel syndrome was identified. Emotions generated from the experience of living with this bowel disorder included shame, fear, self-blame, guilt, anger, anxiety, depression, and loss of self-esteem. While the women experienced these emotions, the man experienced only three: fear, anxiety, and anger.

Within the seventh theme, the impact irritable bowel syndrome had on relationships with others was discussed. All of the participants believed that the symptomatology associated with their bowel disorder was socially unacceptable. Therefore, they attempted to hide their IBS from others. The participants, however, did disclose their IBS to some, most notably their family, friends, and those they deemed necessary to tell. Others reactions were mixed, with some responding positively and others negatively. Among IBS sufferers, the reactions were always positive. Members from the IBS support group provided validation, support, understanding and encouragement. Surprisingly, 1 participant stated that a number of doctors do not agree with support groups.

Within the eighth theme, the impact that irritable bowel syndrome had on the participants’ daily lives was discussed. While the participants had random attacks of IBS, they also identified a number of specific things which exacerbated their IBS. These attack triggers included getting up early and insomnia, confinement, stress, and an unsuitable diet.

Specific diet restrictions were also identified. Two of the women, whose IBS was
attributed to food allergies or intolerances, ate very restricted diets. The third woman ate a healthy diet and monitored herself to watch for any reactions. She also limited her coffee intake and avoided alcohol. The man also watched what he ate, avoiding fatty foods, onions, and coarse, rough vegetables. Interestingly, beans acted as a laxative for this man, and eating spicy food promoted his regularity.

The participant's social lives were also hampered by IBS. Social gatherings involving food posed special problems for the women with food allergies or intolerances. Other social activities reported to be impaired included going on holidays, visiting friends, going to the gym, baseball and hockey games, concerts, movies, the race track, and other everyday excursions.

Activity restrictions were also discussed. The participants faced a number of physical limitations due to their IBS. Other constraints included the participants' loss of spontaneity; their inability, at times, to avoid being late; and the incapacitating anxiety which resulted from this bowel disorder. Also discussed were the participants' IBS produced exhaustion or illness which often forced them to curtail or cancel their activities; their need to have immediate access to a toilet; and some of the participants' inability to leave home without first taking medication.

Clothing also posed a problem for the participants due to their fluctuating waistlines and their desire to hide their bloated abdomens.

All of the participants were forced to make tremendous job sacrifices or allowances. One woman had to quit her job, another had to change jobs which involved retraining, a third woman works out of her home, and the man has flex time and is able to take his work home.

Two of the 4 participants commented on how their IBS had affected them as
students. The man stated that while he did have IBS during university, it was very mild. He had to be excused for a short period during only one exam.

In contrast, the woman student was forced to use a number of coping strategies. Her job required her to take various night school courses. Her chronic diarrhoea made it imperative that she sit on the aisle seat and near the exit so she had easy access to the toilet. Class presentations were particularly difficult for her because she needed to heavily medicate herself to avoid being "stuck" in the washroom. She also felt self-conscious and humiliated during presentations due to her swollen stomach. She, too, had to leave an exam to use the washroom.

The eighth subheading discussed travel and recreational pursuits. The participants went on holidays, trips, and day outings. They also went camping, hiking, canoeing, biking, walking, and cross country skiing. Participants used various coping mechanisms so that they could pursue these activities: bringing an extra roll of toilet paper, ingesting Imodium or other medication, using suppositories, and eating an extremely restricted diet.

Within the ninth and final theme, making meaning was described. This section explored how the participants attempted to make sense out of the experience of living with irritable bowel syndrome. The participants had theories as to the cause of their IBS: One woman attributed her IBS as mainly due to stress; another to both allergies and stress; and a third woman to food intolerances, but noted that stress exacerbated her IBS. The man stated that there was probably a number of factors which had caused his IBS. He also had an intriguing theory that IBS may be due to an unidentified viral or bacterial infection, similar to that which was found to cause ulcers.

Aside from stating what they believed to have caused their IBS, the participants
had a number of theories as to what contributed to it. These factors included: being an excitable or nervous person, insecurity due to today's competitive world, the myth that you have to be a superhuman woman, and working all the time with no time to relax. The factor which was stated to safeguard one against IBS was meeting one's own needs before meeting anyone else's.

A third way participants attempted to make sense out of their IBS experience was by trying to learn as much as they could about this disorder. Related to their thirst for knowledge was their desperation to find a cure for this affliction. Unfortunately, there is no cure which is lastingly effective. Two women believed that even if a cure was found, their IBS symptoms would continue due to their bodies' habituation.

Finally, 1 woman turned to her faith in God in her need to make sense out of the experience of living with irritable bowel syndrome. Another put her faith in eastern healing.
CHAPTER 5: DISCUSSION, IMPLICATIONS, AND CONCLUSION

Introduction

In this chapter the investigator will further explore some of the study's findings in relation to the adult's experience of living with irritable bowel syndrome. In particular, findings that pertain to the literature that was presented in Chapter 2 will be examined. Also presented will be the ramifications of the study for future research and the implications for counselling those with irritable bowel syndrome.

Discussion of the Results and Implications for Future Research

The purpose of this study was to gain an understanding of the experience of living with irritable bowel syndrome from the perspective of the adult. To accomplish this end, the present study asked the following research question: "What is the lived experience of the adult who has been medically diagnosed as having irritable bowel syndrome?"

In light of the above research question, the findings of this study reveal that irritable bowel syndrome profoundly impacts all realms of the participants' lives: the physical, intellectual, financial, emotional, social, and spiritual. Following is a more complete description of the ramifications associated with the experience of living with irritable bowel syndrome:

Physical Ramifications

The symptomatology associated with irritable bowel syndrome is enormously incapacitating. In the research reviewed in Chapter 2 of this thesis, Dancey and Backhouse (1993) sent questionnaires to 148 individuals from the IBS Network, a organization formed to help alleviate the distress and suffering of people diagnosed with irritable bowel syndrome. These respondents were reported to suffer from various
combinations of diarrhoea, constipation, lower abdominal pain, abdominal distention, flatulence, nausea, rectal pain, upper abdominal pain, indigestion, burping and faecal incontinence.

The present study is much more comprehensive in its portrayal of the participants' symptomatology. The 4 participants reported suffering from various combinations of diarrhoea, constipation, abdominal pain, abdominal bloating and distention, accelerated heart rate, sweating, the inability to concentrate, urgency associated with defeacation, straining associated with defeacation, relief of abdominal pain with defeacation, and intense exhaustion coupled with a feeling of being drained, often for the rest of the day. Other symptoms reported included rectal flatulence, abdominal tenderness, tenesmus (a sense of incomplete evacuation of faeces), the passage of mucous, an irregular pattern of defeacation, exacerbations with menstruation, backaches, haemorrhoids, borborygmi (rumbling in the bowels), dyspepsia (indigestion), esophagitis (acid reflux), headaches, nausea, light headedness, lack of appetite, and swollen face, hands, legs and feet following acute diarrhoea.

The symptoms not reported by the 4 participants which were reported in the Dancey and Backhouse (1993) study include rectal pain, upper abdominal pain, burping, and faecal incontinence.

Future studies on the experience of living with irritable bowel syndrome should use both a check-list and an open-ended design when identifying the symptomatology associated with this bowel disorder. Using both of these formats should result in a more comprehensive portrayal than may have been obtained from the above two studies.

**Intellectual Ramifications**

There were two major intellectual ramifications associated with the experience of
living with irritable bowel syndrome. First, the participants reported that during an IBS attack, they were unable to think. They were completely immersed in their pain and on getting to a toilet in time.

Second, the participants all displayed a hunger for information or knowledge in regards to their IBS. As a result, all of the participants were quite knowledgable about their bowel disorder and how to cope with it. Furthermore, they continually searched for new information. The participants wanted to know what caused irritable bowel syndrome, and above all, how to cure it.

The cause and cure for IBS, however, remain a mystery. To revisit Read (1993) who was cited in Chapter 2 of this thesis:

The current options for the treatment of the Irritable Bowel Syndrome are inadequate. These treatment strategies are based almost exclusively on the traditional concept of the "spastic colon," and are aimed at reducing excessive colonic motor activity. Different types of symptoms may require different therapies. Based on the emerging alternative concept of the Irritable Bowel Syndrome, as a manifestation of altered afferent mechanisms with different parts of the gut, radically new treatment strategies are [needed].... A major problem in the effectiveness of these compounds is our limited knowledge of these etiologies, mechanisms and treatment endpoints of the Irritable Bowel Syndrome. In the absence of a clear delineation of mechanisms underlying visceral hypersensitivity and associated motor reflex disturbances we currently do not have generally agreed-upon physiological markers which can be used to monitor the response of these therapies. (p. 323).

While it may be slow in coming due to the complexity of this disorder, it is hoped that one day soon, we will discover the cause and find the cure for irritable bowel syndrome.

Financial Ramifications

It was found that the experience of living with irritable bowel syndrome carried with it substantial financial implications, both to the medical services plan and to the sufferers, themselves.
The British Columbia Medical Services Plan (BCMSP) faced enormous expenditures as a result of this bowel disorder. Not only did the government pay for the participants' many doctors and their repeated visits, but it also paid for the myriad of tests necessary to rule out the possibility of organic disease, parasites, and enzyme deficiency. Even though the majority of people with IBS do not seek medical attention, with 15% to 25% of the population affected with this disorder, one must wonder how long our medical plan will survive in its present form.

The cost to the participants was also substantial. As stated by Almy (1967), this bowel disorder is second only to the common cold as the leading cause of absenteeism from work. Even more significant, is that in the Dancey and Backhouse (1993) study mentioned earlier, 5% of the 148 respondents were unable to work due to the severity of their symptoms. In the present study, 1 of the 4 participants was forced to quit her job. Another woman had to change her occupation. Consequently, she could no longer use her post-secondary education to earn a living but had to retrain.

The participants in this study saw a number of specialists who claimed to be able to cure their IBS. As no one was helped, 1 participant asserted that these practitioners were charlatan sharks: "We're perfect prey for people who want to make a dollar off of us because we need help so badly." Two of the participants went to naturopaths. One was helped immensely, the other saw no improvement.

Finally, all of the participants spent enormous amounts of money on pharmaceutical and/or other aids to ease some of the symptomatology associated with IBS. These drugs, however, had a number of limitations. First, the negative side effects of the drugs sometimes outweighed the benefits. Second, the drugs didn't necessarily produce the same results in everyone, and third, these aids were not permanent
solutions, but only temporary coping devices.

This study has demonstrated that having irritable bowel syndrome can result in considerable financial loss. Chapter 2 highlighted the effectiveness of counselling for the alleviation of IBS symptomatology, both physical and psychological. Counselling is extremely cost effective and has been shown to result in long-term improvements. Furthermore, psychological treatment has been demonstrated to be more effective than a purely medical approach. More about counselling will be presented later in this chapter.

**Emotional Ramifications**

One construct that came up repeatedly throughout Chapter 4 was stress and its relation to irritable bowel syndrome. So great were its effects that 2 of the participants maintained that stress was the cause of their IBS.

All of the participants in this study stated that stress exacerbated their bowel disorder. The research supports this contention as numerous studies have linked the exacerbation of irritable bowel syndrome to stress (Ford, Eastwood, & Eastwood, 1982; Narducci, Snape, Battle, London, & Cohen, 1985; Richter, Obrecht, Bradley, Young, & Anderson, 1986; Varis, 1987; Waxman, 1988; Whitehead, Crowell, Robinson, Heller, & Schuster, 1992). From this research it becomes apparent that reducing stress should result in a reduction of stress induced IBS symptomatology.

Another salient feature of this study from a counselling perspective was the strong emotions that the experience of living with IBS elicited from the participants. These emotions included shame, fear, self-blame, guilt, anger, anxiety, depression, and loss of self-esteem. While the women experienced these emotions, surprisingly, the man experienced only three: fear, anxiety, and anger. He did not feel shame, self-blame, guilt, depression or loss of self-esteem. Some possible explanations for this discrepancy
include: While stress induced headaches are socially acceptable, stress induced diarrhoea is not. These latter individuals are often presumed to be neurotic. Secondly, while western culture dictates that women remain very private about their "bodily functions," the opposite is often true for men. Thirdly, the man in this study works in a very prestigious professional capacity. Consequently, he may be treated with more respect than the average person. Fourthly, people reacted positively to the man’s IBS whether they were family, friends, or acquaintances. In contrast, the women in this study received varied reactions. Fifthly, the man’s doctors always treated him with respect and understanding. This stands in sharp contrast to how 2 of the women were treated. And finally, because we live in a male-dominated society, men are often treated with more respect than women. Consequently, a woman with bowel problems may be discounted and judged as neurotic and histrionic, whereas a man with this same disorder might be more likely to receive empathy.

Future research may want to extend the sample and compare the men’s and women’s emotional reactions to the experience of living with irritable bowel syndrome. An important component of this study would involve asking the participants to speculate why, or why not, they experienced these emotions.

**Social Ramifications**

The participants believed that sharing their feelings about their bowel disorder with the IBS support group was very beneficial. From this group they received validation and a sense of camaraderie. In Chapter 4 it was stated that a number of doctors "don’t agree with support groups," as it is believed that the participants dwell too much on their IBS, making it more of a problem. Payne and Blanchard (1995), in a controlled comparison of cognitive therapy and self-help IBS support groups, found that
at posttreatment, 25% from the support group protocol had clinically improved status, compared to 18% at the 3-month follow-up. While no significant reductions were seen in psychological test scores, the support group protocol did result in reductions in physiological symptoms. It appears then, that rather than being "a detriment," self-help IBS support groups are somewhat beneficial for the reduction of bowel symptoms. The efficacy of cognitive therapy will be discussed later in this chapter.

In Chapter 2, it was stated that IBS was originally seen as a psychiatric disorder. It is apparent from the participants' reports that a number of the doctors still hold this outdated view. What is of particular interest, however, is that the same doctors who treated the woman like a neurotic because she had IBS, treated the man with respect. As stated by the man: "I've heard from the ladies whose stories are, they go to the doctor who say[s] 'Well, it's in your head.'" One must wonder if this double standard is typical, or if it is an isolated incident perpetrated by these two gastroenterologists.

**Spiritual Ramifications**

While none of the literature reviewed in Chapter 2 addressed spiritual matters in relation to irritable bowel syndrome, 2 of the participants in the present study found encouragement and hope through their faith. One received comfort and the ability to cope through her faith in God, the other through her faith in eastern healing.

**Summary**

The results of this study demonstrated that irritable bowel syndrome profoundly affects all areas of the participant's lives: physical, intellectual, financial, emotional, social, and spiritual. The participants, however, are amazingly resilient and tenacious in the face of this debilitating bowel disorder. For rather than putting their lives on hold, they get on with life.
Implications for Counselling Those With Irritable Bowel Syndrome

The most salient feature of this study from a counselling perspective was the diversity of strong emotions which the experience of living with irritable bowel syndrome elicited from the participants. These emotions included shame, fear, self-blame, guilt, anger, anxiety, depression, and loss of self-esteem. Fortunately, there is much that a counsellor can do to help alleviate the IBS sufferer’s emotional distress.

The psychological management of IBS clients begins with establishing a good, client-therapist relationship. The first visit should set the stage (Whitehead & Crowell, 1991). Many of the IBS clients who come for help will have had a history of frustrating relationships with their doctors. Their physicians may have told them that no physical basis exists for their symptoms or that they are suffering from a psychological, rather than a medical, disorder (Whitehead & Crowell). This belief is unfounded, as the cause of IBS is unknown. Moreover, as was previously described in Chapter 2 of this manuscript, research has demonstrated that psychological distress does not cause irritable bowel syndrome (Drossman et al., 1988; Whitehead et al., 1988).

Unfortunately, as a result of this misinformation, many of the clients who are referred for counselling will be defensive or guarded during their initial visit. The counsellor should strive to be approachable and encourage clients to ask questions and discuss any concerns. Interest, understanding, and compassion, shown by the counsellor, should inspire confidence and assist in the gathering of relevant client information (Whitehead & Crowell, 1991).

Very important to the counselling process when working with this population is the management of fears and misconceptions, and the impartation of education and reassurance. Individuals with IBS often fear that they have cancer or some other life-
threatening condition. The client must understand that although painful and distressing, IBS does not lead to serious disorders, such as cancer or ulcerative colitis, nor does it effect one's life expectancy (Whitehead & Crowell, 1991). Furthermore, there is no lastingly effective cure for this bowel syndrome.

The available drugs, although sometimes helpful\(^\text{10}\), may have undesirable side-effects and are not permanent solutions. Because these drugs do not produce the same results in everyone, the client may want to experiment with the various bulking agents, antispasmodics, and/or antidepressants traditionally used to treat this syndrome. In addition, clients may benefit by investigating their bodies' reactions to different foods and eliminating those that prove problematic. A third strategy would involve exercising regularly to reduce stress.

Also of importance is that the client understands that irritable bowel syndrome is an intestinal motor disorder. It is chronic and recurrent, and is influenced by several factors, including drugs, food, and stress (Whitehead & Crowell, 1991). This information should reassure the client that recurrences are part of this bowel disorder and are not indicative of inappropriate diagnosis or inadequate treatment. As Whitehead & Crowell state: "This will alleviate one of the stresses that every person with IBS undergoes: concern about the significance of persistent, recurrent, or intensified symptoms" (1991, p. 259).

A number of psychological treatments have been demonstrated to be extremely

\(^{10}\)For those that suffer from painless diarrhoea, or from alternating bowel habits accompanied with abdominal pain, Loperamide (Imodium) has shown promising results. This over-the-counter drug has no side effects and no addictive potential (Hovdenak, 1987; Read, 1993). However, for those who suffer from alternating bowel habits with no pain, this drug is generally ineffective, and those who are constipation-predominant generally feel worse on Loperamide.
effective for the alleviation or eradication of IBS. The predominant focus in these approaches is an emphasis on current problems and on developing ways of coping with stressful situations (Whitehead & Crowell, 1991). There are a number of stress management treatment options available, some of which include relaxation training (progressive muscle relaxation, biofeedback and hypnosis), time management, lifestyle changes, and cognitive restructuring. (For an overview of these techniques, please see Appendix D.)

While a variety of these treatment options have produced significant reductions in both psychological and bowel symptomatology, cognitive therapy appears to be the most promising. Cognitive therapy has produced stronger and more consistent results in the treatment of IBS than any other psychological therapy (Blanchard & Malamood, 1996). Up to 80% of IBS patients who receive cognitive therapy experience significant reductions in the areas of diarrhoea, constipation, abdominal pain and tenderness, belching, bloating, flatulence, nausea, and depression and anxiety (Greene & Blanchard, 1994). Even after counselling has ended, patients have been shown to experience further numerical improvements in both psychological and physiological symptom reduction (Payne & Blanchard, 1995).

The following quote highlights the efficacy of cognitive therapy for reducing the symptomatology associated with irritable bowel syndrome:

In the past several decades, cognitive therapy has been successfully used to help patients with depression [italics added], panic disorder, phobias, anxiety, anger, stress-related disorders [italics added], relationship problems, drug and alcohol abuse, eating disorders, and most of the other difficulties that bring people to therapy. (A. T. Beck in Greenberger & Padesky, 1995, p. v)

Finally, it is very important for the counsellor to work in close collaboration with a gastroenterologist, because so many gastrointestinal disorders, including inflammatory
bowel disease (IBD), lactose malabsorption, and intestinal parasites, can mimic irritable bowel syndrome (Blanchard & Malamood, 1996). If the client hasn’t already done so, he or she should be referred to a gastroenterologist for testing before counselling takes place.

Conclusion

According to Blanchard and Malamood (1996), gastroenterologists don’t typically think to refer IBS patients for psychological treatment, despite the recommendation for such referrals by two leading IBS authorities, Drossman and Thompson (1992). If a gastroenterologist is approached, however, he or she is likely to refer the most refractory or problematic IBS patients to the counsellor. Success with a few of these "difficult" patients (where "success" may mean the individual decreases the almost weekly phoning of the doctor) can cement a good working relationship and referral base as well as enable one to help many who suffer from irritable bowel syndrome.
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Appendix A

Identification of Sub-groups of Functional Gastrointestinal Disorders

Irritable Bowel Syndrome


C. Functional Bowel Disorders

The functional bowel disorders are functional gastrointestinal disorders having symptoms attributed to the mid to lower gastrointestinal tract. They include symptoms of abdominal pain, bloating or gaseousness, bowel dysfunction or any combination.

C1. Irritable bowel syndrome (IBS) is defined here by more restrictive criteria than may have been used previously. Terms such as spastic or irritable colon are no longer recommended. At the Rome International Congress in 1988, the irritable bowel syndrome was defined as "a functional gastrointestinal disorder attributed to the intestines and associated with symptoms of: (a) abdominal pain, and/or (b) disturbed defaecation, and/or (c) bloatedness or distention" (Thompson, Dotevall, Drossman, Heaton, & Krulis, 1989, pp. 92-95).

(a) Symptom criteria for irritable bowel -
Continuous or recurrent symptoms for at least three months of:
1. abdominal pain or discomfort, relieved with defecation, or associated with a change in frequency or consistency of stool; and
2. an irregular (varying) pattern of defecation at least 25% of the time (three or more of):
   (i) altered stool frequency;
   (ii) altered stool form (hard or loose/watery stool);
   (iii) altered stool passage (straining or urgency, feeling of incomplete evacuation);
   (iv) passage of mucus;
   (v) bloating or feeling of abdominal distention.

(b) Diagnostic studies - As with all the functional gastrointestinal disorders, care should be taken to avoid unnecessary investigation which may be costly or harmful. Blood may be drawn for a complete blood count and erythrocyte sedimentation rate. Sigmoidoscopy is recommended to exclude inflammation or to diagnose concurrent disorders such as melanosis coli. Further testing depends upon the individual situation and may be

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11 The committee recognizes that some [researchers] may require abdominal pain as an essential criterion, and others may not. The decision to permit either categories 1 or 2 will be left to the [researcher].
influenced by the age of the patient, the nature and duration of symptoms, the region of practice, cost and other factors. Tests may include stool examination for occult blood, leucocytes, ova and parasites, and further colon investigation.

(c) Physiological data (Thompson, 1984; Mitchell & Drossman, 1987) - While baseline motility studies usually show no difference from normal subjects, patients with IBS may differ from normals by having increased motor reactivity in response to various stimuli including meals, cholecystokinin, balloon distention of the rectosigmoid and psychological stress. Other studies report patients to have an enhanced rectal sensitivity to balloon distention, suggesting increased activity of afferent receptors or a reduced rectal compliance. It is presumed that these findings explain the observation the [sic] IBS patients report more frequent or severe bowel symptoms in response to meals or psychological stress, and have relief of pain with defaecation. The mechanisms for increased motor reactivity and/or increased sensitivity to environmental stimuli and symptom generation are not well understood, and current investigative efforts are addressing the possibility of altered smooth muscle myoelectric activity or abnormalities in CNS and enteric neurotransmitters or their receptors.

It is most likely that IBS may be sub-classified (for example) into those having predominant constipation due to motor dysfunction from disturbances in enteric nervous system functioning, predominant diarrhoea with dysfunction relating to incomplete bile salt absorption at the ileum, or predominant bloating due to motility disturbance or impaired absorption of carbohydrates. Sub-groups may also be identified by using provocative physiological stimuli. For example, a sub-group of IBS patients appear to have a hypersensitive rectum characterised by symptoms of rectal urgency, low pain thresholds to rectal distention, higher anxiety scores, and a greater tendency to have diarrhoea (Ritchie, 1973; Whitehead, Engel & Schuster, 1980; Sun & Read, 1988) than do IBS patients without increased rectal sensitivity. The selection of patients for study using physiologically-based symptom criteria would permit more valid and reliable results when pharmacological interventions are directed toward these proposed mechanisms. (Drossman, Talley, Funch-Jensen, Janssens, & Whitehead, 1990, p. 164-165)

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Appendix D

Stress Management


What is Stress?

Stress occurs when you feel that you are not able to deal effectively with the pressures of life. When others make demands, job challenges emerge, or personal relationships change, you may feel overwhelmed and unable to meet these situations. You may feel "stressed," unable to function in a situation to the level required, or be able to perform the tasks but feel miserable while doing so.

We are not talking about people with severe psychological problems like suicidal depression or schizophrenia. Rather, we are talking about ordinary people who are mostly able to function well, but are in a situation where stresses are not being handled as well as they could.

What are the Common Types of Stress?

There are three common ways for stress to manifest:

Anxiety - This is when a person feels constantly worried, mentally going over and over problems, not being able to "let go" of, or deal with, these problems. Worrying does not lead to productive solutions and persistent anxiety may interfere with enjoyment of pleasurable activities. Sometimes people feel agitated and jumpy, overreacting to small events and unable to relax. There may be a sense of fear in particular situations (for example, dreading the beginning of a workday or becoming nervous in a bank line-up).

Discouragement - This refers to the sense that you will not be able to get the work done, or be able to deal with a problem or, at least, not effectively. You may feel overwhelmed, become demoralized, find it hard to motivate yourself and/or find the "energy" to keep on trying. A job may begin to feel frustrating, like wading through a marsh, and the needs of others begin to feel like demands you cannot possibly satisfy.

Physical Symptoms - Psychological stress problems can affect the body, causing physical symptoms to appear, or a worsening of symptoms that were already there. A symptom may include muscle tension, where muscles of the neck and back, for example, are being held tightly for an extended period of time and pain results. It may become difficult to release this tension. Headaches may occur, triggered by excess tension in forehead or neck muscles, or by general over-activation of the body. Insomnia is a frequent complaint at times of worry and anxiety, which makes it even harder to handle stressful situations.

Studies show that stress induced anxiety will worsen the symptoms of gastrointestinal disorders. A person with a disease or disorder of the gastrointestinal system is vulnerable to the effects of anxiety specifically in the area of their existing illness. Anxiety may also increase the experience of pain, aggravate the disease process,
and interfere with healing. We should note that research has not shown whether or not anxiety can cause structural problems in the gastrointestinal system. However, one study has found changes in the bowel mucosa lining in people who had experienced many stressful events in the previous year. While studies have not confirmed that stress can cause gastrointestinal problems, we are certain that stress can make existing conditions worse.

**How Does Stress Trigger Gastrointestinal Problems?**

Our bodies handle sudden emergencies by going into a "red alert" state, called the fight-or-flight response. It is a state of high arousal. In this state we are ready to take action so as to deal with the emergency. Physical changes of this response include increased muscle tension, faster thinking, rapid breathing, and a shift of blood flow away from the digestive system. It is this last change that is important in gastrointestinal problems.

An individual who is not able to handle difficult situations effectively may be remaining in the high arousal state for much of the time. The body is being maintained in an overactivated condition. As one effect of this high arousal state is to "turn-off" the digestive system, it disrupts normal operation.

Many of us have experienced the gut distress that accompanies extreme fear. The continued high arousal of the person with stress problems will interfere with gut function therefore triggering symptoms in those with a gastrointestinal disease of disorder.

**What Treatment is Available for Stress?**

Psychologists have developed a range of methods for helping people to handle stress more effectively. Here are some of the more frequently used treatment methods:

*Relaxation Training* - This involves teaching the stressed person how to relax more effectively, both physically and mentally. Frequent advice given to highly stressed people is to "just relax." This does little to help the patient. The psychologist's role is to instruct and encourage the patient in proven methods of releasing tension and anxiety. There are many types of relaxation training, that include:

- **progressive muscle relaxation training** - learning to use imagery to lower the body's activation level;
- **biofeedback** - using precise measurement of body tension to gain better control;
- **hypnosis** - using suggestion and imagery to foster a relaxed state of being.

The psychologist will use some combination of methods to find a custom approach that works for a specific person.

*Time Management* - The stressed person learns to systematically review specific use of time and energy so as to allocate resources more effectively. There is a focus on establishing priorities, monitoring one's use of time (finding out "where it goes"), goal setting, and efficient planning.

*Lifestyle Changes* - Learning to change lifestyle patterns that contribute to stress can be an important part of treatment. Such lifestyle changes can include reaching an appropriate level of fitness activity, reduction in tension making habits like caffeine use,
increasing social involvements, etc. While people often have a sense of needing to change, psychologists will teach them how to implement change in a way that actually works.

*Cognitive Restructuring* - Stressed individuals learn to identify patterns of thinking which are contributing to stress problems, and to change these "negative cognitions" into more adaptive ones. The cognitive restructuring method is an important part of learning to manage stress more effectively.

There are a wide variety of other methods used by psychologists to combat stress problems - *assertiveness training, systematic desensitization, brief psychotherapy*, etc.

We do not have the space here to describe these approaches, but they are among the resources which psychologists draw upon in finding a treatment approach for dealing with a particular person's problems. Any or all of these methods may prove relevant in helping an individual deal with a stress problem that may be triggering gastrointestinal symptoms.