

EATING DISORDERS IN FEMALE PATIENTS WITH
A DIAGNOSIS OF IRRITABLE BOWEL SYNDROME.
A MULTIMETHOD STUDY.

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This thesis is the sole work of the author. All references and sources of data within the thesis are from original sources.

ABSTRACT

TITLE

Screening for potential eating disorders in female patients with irritable bowel syndrome. A multimethod study.

INTRODUCTION

Irritable bowel syndrome (IBS) is a common functional gastrointestinal (GI) disorder, with an unknown aetiology. A link between IBS and Eating Disorders (EDs) has been suggested (Perkins et al., 2005). EDs can result in significant physical and psychological and social morbidity, of which characteristic signs are: preoccupation with weight and/or appearance, feelings of shame and isolation, regular episodes of self-induced vomiting, use of diuretics or laxatives, strict dieting and/or fasting, or vigorous exercise, need for control, distorted body image, and secretiveness about food among others. It is well recognized that health-related quality of life (HRQoL) can be severely impaired in patients suffering from these conditions. However, studies are not conclusive to date. Although research on both IBS and EDs is vast and growing, little attention has been paid to the patient experience with these conditions and identification of both remains unsatisfactory. This study sought to address the lack of information in this field.

AIMS

To explore the potential presence and the experience of EDs in female IBS patients, and to examine GI nurses' perception and knowledge of each condition.

STUDY DESIGN

A cross-sectional multimethod design integrating two phases was selected. The first and quantitative part of the study encompassed the completion of two EDs screening tools and a battery of questionnaires by one hundred and thirty-four patients, seeking to evaluate participants' symptoms, HRQoL, and general well being. From this population, twenty-five interviews were conducted in order to explore the participants' experiences

and their views on GI symptoms. Transcripts were analysed using thematic content analysis. In addition, ninety-one GI nurses completed a questionnaire on attitudes and perceptions towards IBS and EDs patients.

RESULTS

Screening tools proved helpful in the GI setting to identify potential EDs among female patients with IBS. SCOFF tool highlighted a 24.6 % of the study population as potential cases, appearing as the tool of choice. Quantitative analysis highlighted statistically significant ($p<0.05$) impairment of HRQoL for the study participants, this impact was particularly noted in those individuals identified as potential EDs cases. Emerging themes from the qualitative data underlined the complexity of the individual patient's journey, and the variety of strategies adopted to comprehend and manage their condition. Suffering, social isolation, unmet support needs and lack of control appeared inherent to the condition. Results suggested that diet and modifying eating habits can be used as a management strategy to control IBS symptoms. The need for nurses' further education and training regarding IBS and EDs was highlighted by the study findings.

CONCLUSIONS

This study gives strong support to the suggestion of IBS and EDs comorbidity, though the specific incidence is yet to be determined. The use of EDs screening tools was useful and economical in the outpatient setting. IBS appeared to be intrinsic to patients' lives, and it was surrounded by a great deal of uncertainty and self-isolation. Dietetic habits appeared altered for most patients jointly with deteriorated HRQoL. Before more substantive conclusions can be drawn, a better understanding is required of IBS and EDs as diagnostic categories, and of the patients' experiences. The need for more nurse education and development of specialist qualified nurses in this area was underlined, which may help to provide more effective patient management.

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I declare that this thesis embodies the results of my own research, that I am the full author of this thesis and that it does not include work forming part of a thesis presented by me for another degree in this or another University.

Signature:

Date Feb -'08

María Sandra Tricas-Sauras

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LIST OF ABBREVIATIONS¹

AED: Academy for Eating Disorders

AN: Anorexia Nervosa

APA: American Psychiatric Association

BED: Binge Eating Disorder

BMI: Body Mass Index

BN: Bulimia Nervosa

BSG: British Society of Gastroenterology Guidelines

BSG: British Society Gastroenterological Guidelines

C.I.: Confidence Interval

CAM: Complementary and Alternative Medicine

CBT: Cognitive Behavioural Therapy

CI: Coefficient Interval

CMR: Crude mortality rates

DSM-IV: Diagnosis and Statistical Manual of Mental Disorders

ED: Eating Disorder

EDA: Eating Disorders Association

EDs: Eating Disorders

FGID: Functional Gastrointestinal Disorders

GI: Gastro Intestinal

GP: General Physician

¹ Most commonly used in this study

HRQoL: Health Related Quality of Life
IBD: Inflammatory Bowel Disease
IBS: Irritable Bowel Syndrome
ICD-10: International Classification of Diseases
IP: Interpersonal Psychotherapy
NHS: National Health Service
OCD: Obsessive Compulsive Disorder
Q: Question
QoL: Quality of Life
RCT: Randomised Controlled Trial
RN: Registered Nurse
ROC: Receiver Operating Characteristics (curve)
SD: Standard Deviation
VAS: Visual Analogue Scale
WHO: World Health Organisation

Chapter 1

Introduction

This doctoral thesis began while working as a mental health nurse with patients with eating disorders (EDs) and from the experience whilst working in a gastrointestinal (GI) out-patient clinic. The quality of life (QoL) of patients in both settings seemed to be severely impaired, and many patients reported symptoms that appeared synonymous with both irritable bowel syndrome (IBS) and eating disorders (EDs). A review of the literature revealed numerous similarities between these two groups of patients. This work commenced as an investigation of the potential presence of EDs amongst IBS patients, but the journey incorporated the significant experiences of the patients, as well as the perceptions of the nurses. The question of how well patients were being assessed and managed was the main impetus for the researcher to conduct this study.

This research addresses issues that are pertinent to policy and practice. By underlining some of the difficulties that patients may have in being identified and well managed, it is hoped that the need for newer alternatives may be acknowledged. Although health services seem to be making an effort to raise awareness of IBS and EDs in general, there is still a long journey ahead. Numerous misconceptions and inaccuracies are present in both fields, particularly in relation to aetiology, treatment and outcomes. By contributing to the knowledge in this area, it is hoped progress can be made, and that implications for a better identification of the patient, clarification of the terminology, and enhanced management strategies from more knowledgeable professionals can be considered.

1.1 BACKGROUND TO THE RESEARCH

IBS is a worldwide phenomenon (Thompson et al., 2000); a clinical GI disorder with no definitive biochemical or structural changes, physical findings, or gold standard diagnostic tests to determine its presence (Ringel and Drossman, 2002). The symptoms appear to be due to the dysfunction of the intestine and are said, therefore to be “*functional*” (Heaton and Thompson, 1999). Patients characteristically present unexplained abdominal pain or discomfort associated with defecation or change in bowel habit and disordered defecation (Thompson et al., 1999).

IBS prevalence is elevated (between three and twenty two per cent of individuals in the community), up to seventy five per cent of whom are females (Talley, 1999). Moreover, IBS is believed to account for between eight and ten per cent of consultations in primary care in the UK (Thompson et al., 2000; Jones and Murfin, 1993) and up to fifty per cent of all referrals to outpatient gastroenterology clinics (Smith et al., 2004).

Detection of IBS presence and its impact appear to be underestimated and poorly quantified (Hungin et al., 2005) despite the increasing prevalence figures for this condition (Markowitz et al., 2000).

The second condition this study deals with is EDs. These are characterised by severe disturbances in eating behaviour and a significant cause of physical and psychosocial morbidity (Fairburn and Harrison, 2003; APA, 1994). They are becoming a significant and increasing health problem for Western countries (Kelly et al., 2005). The most commonly known EDs are: anorexia nervosa (AN), bulimia nervosa (BN), and eating disorders not otherwise specified (EDNOS). All of them are disabling conditions with overlapping symptomatology and aetiologies, mainly affecting females (Perkins et al., 2006).

Interest in EDs has mushroomed in the past twenty years (Kalodner, 2000). However, despite the attention they attract, these conditions still seem to be poorly understood. EDs have a secretive nature; and therefore prevalence figures could

underestimate the real numbers. Although a slightly controversial point, obesity is not (currently) considered an ED because it is not associated with consistent behavioural and psychological features, despite presence of marked psychological symptoms such as unhappiness and depression (Birmingham and Beumont, 2004). Agras (2005) argues that overweight and obesity have become international major problems, and obesity in particular has been declared an epidemic (Tricas-Sauras, 2006b). It could be said that the incidence of EDs in general has risen over the past fifty years (van Hoeken et al., 2003). It is hard to be sure of this, however, since diagnosis is complex and often hindered by the secrecy of these disorders which could have an impact on detection.

1.2 THE LINK BETWEEN IBS AND EDS

Although apparently unconnected, several pieces of research have suggested a potential association existing between IBS and EDs; however none of these investigations has incorporated the nursing perspective.

The researcher's clinical experience pointed out numerous cases of IBS patients who frequently reported altered eating patterns, excessive focus on weight, misuse of compensatory measures to control symptoms and/or to lose weight, and high levels of anxiety sometimes accompanied by frustration and low mood. Similarly, during a two year period working with EDs patients, patients often complained about altered bowel habit, pain, and bloatedness. Additionally, a number of those individuals noted suffering from IBS. To a certain degree, this theoretical link was pointed out by practice and by listening to patients, leading the researcher to investigate this aspect further. The next section will focus on the possible association between IBS and EDs as suggested by the literature so far.

Several authors have suggested a potential link between EDs and IBS¹ (Svedberg et al., 2002; Bennett et al., 1998, Porcelli et al., 1998; Tang et al., 1998). However, the

¹ A number of research pieces have also explored the relationship between GI complaints and potential development of EDs (Ogg et al., 1998; Crowell et al., 1994; Walker et al., 1990)

nature of this link remains poorly understood and has been described in terms of “*chicken and egg*” scenario.

Sullivan et al. (1997) explored the link between IBS and EDs in patients with BN using a diagnostic test named Eating Attitudes Test (EAT; Garner and Garfinkel, 1979). A sample of forty eight new patients with a confirmed diagnosis of IBS completed the EAT instrument. The instrument was also completed by thirty two patients attending a specialised ED clinic, thirty one patients attending a GI outpatient clinic with a diagnosis of inflammatory bowel disease (IBD) and twenty eight normal controls. This study revealed no differences between IBD patients and the control group when comparing EAT scores. However, EAT scores for the group with EDs were markedly more elevated than in the other groups. Using analysis of variance, the overall EAT score recorded by the IBS group was greater than the scores of both the IBD patients and the controls. Sullivan et al. (1997) did not support the idea that the difference among the three groups was due to a higher than expected comorbidity between IBS and bulimia as predicted, however, the possibility of a higher than expected comorbidity between IBS and EDs as a whole was not excluded. Findings from this study should be interpreted with caution as there were several study design limitations. IBS differences in relation to symptom severity or IBS type were not assessed in this study, which could have proven valuable to clarify this suggested relationship amongst IBS and EDs. Although sub-grouping of IBS type was briefly addressed in the present study (Chapter 5) no significant assumptions could be made since this aspect was not explored in sufficient depth.

Tang et al. (1998) conducted a similar study, which examined the relationship between certain features of IBS and EDs. With a sample of sixty IBS individuals (forty three females and seventeen males) the Eating Disorder Inventory (EDI, Garner et al., 1983) was completed. Results highlighted the fact that IBS diagnosis was generally unrelated to the subscales of body dissatisfaction, perfectionism and ineffectiveness identified by EDI; however symptom severity correlated with the perfectionism and ineffectiveness subscales. Additionally, Tang et al. (1998) suggested that severe bouts of vomiting were associated with desires for a lower weight and reported bingeing-purging behaviours. These findings highlighted the

need for further examination of the link between IBS and EDs. According to Tang et al (1998) the suggestion of a link between IBS and ED appeared to have valuable connotations both as a framework for prospective research as well as a “*theoretical model for the conceptualization and treatment of both disorders as non-discrete conditions*” (Tang et al., 1998; pp.117).

Krahn et al. (1996) explored dieting severity and GI symptoms in a sample of females attending college in the US. Over three hundred females were interviewed for their study, and findings illustrated that severity of dieting was positively related to frequency of abdominal pain, bloating, diarrhoea and constipation. Additionally, females reporting three or more symptoms would regularly score higher on a scale indicating dieting severity. This study did not specifically explore the relationship between dieting severity and clinical IBS, however the authors suggested that dieting was associated with a very particular group of GI symptoms. Dieting has been addressed in this thesis, although the severity of dieting was not quantified. In retrospect, this may have been a missed opportunity for further clarification. However, in the qualitative part of this study, the findings supported evidence of disrupted dietary regimes which appears relevant.

Anderson et al. (1997) explored the physiological effects that BN had on the GI tract. They noted that the expression of the disease in the GI tract may play a critical role in the diagnosis of BN. Some of those effects included: esophagitis, changes in gastric capacity or gastric emptying, gastric necrosis, and alterations of the intestinal mucosa, as well as dental caries, enamel erosion, enlargement of the parotid gland. In addition, intense abuse of laxatives or diuretics, repeated vomiting episodes, and fasting would have an impact on the GI tract with severe long term consequences.

Perhaps the most comprehensive study to examine the link between IBS and ED was conducted by Porcelli et al. (1998). This research aimed to assess past EDs in patients with functional gastrointestinal disorders (FGID) based on commonly reported functional complaints within ED patients. A total of one hundred and twenty-nine outpatients (mean age of thirty-nine) were assessed, obtaining the following diagnosis: eighty one met the criteria for functional dyspepsia, sixty five

for IBS and twenty two for functional abdominal pain. The control group consisted of one hundred and sixty-three patients with gallstone disease. All patients were assessed for EDs, current distress (anxiety and depression), and GI symptoms. Results highlighted the fact that of the GI subjects, twenty (15.5 per cent) reported a past history of an ED, (reported recovery occurring three to sixteen months before the interview). In the control subjects, five patients (3.1 per cent) reported a lifetime ED. The results showed that a past history of EDs was significantly more frequent in the GI sample than in the control group. The GI subjects also presented more psychological distress than the control group. GI individuals with a past history of an ED tended to be female, younger, more educated, and with more anxiety and depression than GI patients without such a past history. Porcelli et al. (1998) concluded that a previous history of EDs appeared more prevalent for subjects presenting functional GI diagnosis than for the control subjects (15.7 per cent versus 3.1 per cent). Most subjects with EDs developed their GI symptoms during the time of the ED, and those symptoms seemed to continue even after recovery. The study supported the association of GI symptoms and EDs, underlining that those functional GI symptoms may persist after ED potential recovery, particularly for psychologically distressed patients.

Although the suspicion of a link between IBS and EDs has been raised, there is limited evidence to support this link. A more recent study by Perkins and colleagues (2005) further examined this poorly understood relationship. They tried to determine the prevalence of IBS in a sample of individuals presenting with an ED. To do so, two hundred and thirty-four ED participants were examined using an IBS questionnaire created for the investigation in conjunction with the Eating Disorders Examination-Questionnaire (EDE-Q, Fairburn and Beglin, 1994). They reported that sixty four per cent of their sample met the Manning criteria² for IBS (see Chapter 2), and that eighty seven per cent of the participants had developed their ED before IBS symptoms commenced. Perkins et al. (2005) concluded that the presence of an identified EDs may elevate the chances of developing IBS. Perkins's study used

² Manning Criteria is presented in Chapter 2.

Manning criteria for diagnosis as at the time of study design the Rome criteria³ were under review. The choice of classification would appear controversial as Rome II appears to be the most widely used classification amongst IBS researchers. Another limitation of this study relates to the sample size used and the volunteer nature of the sample, which would appear insufficient for any generalisation. Furthermore, completion rates were limited to fifty per cent of the sample which may imply potential misreporting. Although identified as potential IBS and EDs cases, participants had not been professionally diagnosed which could have several implications, especially when relying on individuals' personal accounts. It can thus be seen that although debatable, the indication of a potential link existing between particular GI conditions, especially IBS, and EDs is present within the scientific literature.

The literature review (see Chapter 2 and Chapter 3) highlights the fact that diagnosis of both IBS and EDs may be a lengthy and complex procedure. There is the potential for delay in diagnosis for several reasons, such as: unclear signs, the need to rule out organic disease, and lack of clear markers that determine the conditions. However, the need for early identification, particularly in the case of EDs, has been pointed out since it appears to be related to a better prognosis in patients suffering from EDs (Treasure et al., 2003), conditions that can be fatal. However, the detection of ED cases is challenging due to their presentation and complex nature. A useful option to identify potential cases appears to be the use of screening instruments to assist healthcare professionals in this endeavour. Therefore, the researcher considered the benefit of incorporating screening tools into the present study in order to identify potential cases presenting in the GI field. The selection of screening tools was based on ease of administration and the need to use a friendly format. The basis for this choice is introduced in the next section.

³ Rome Criteria is presented in Chapter 2.

1.3 EARLY IDENTIFICATION OF EDS AND SCREENING TOOLS

The precise diagnosis of EDs has long been problematic and authors have explored new approaches to identifying cases (Callahan et al., 2003). In Chapter 3 of this thesis, the Diagnostic and Statistic Manual of Mental Disorders, IV revision, (DSM-IV, APA, 1994) and the International Classification of Diseases and Related Health Problems, (ICD-10,WHO, 1992) are introduced to provide the diagnostic criteria of EDs. However, these clinical diagnoses are only applicable to a very specific range of disorders. Sub-clinical disorders, although present within the scientific literature, appear more difficult to detect, as no specific tools have been previously available (Callahan et al., 2003).

A range of diagnostic tools have been developed and multiplied during the past two decades (Allison, 1995). Some of those have become established and widely used across the international community, such as: the Bulimic Investigatory Test, Edinburgh (BITE, Henderson and Freeman, 1987), Eating Disorders Examination (EDE, Cooper and Fairburn, 1987), EAT, (Garner and Garfinkel, 1979), among several others (Allison, 1995). However, their use is generally complex and they must nearly always be administered by a trained professional. On the other hand, for individuals to be assessed and subsequently diagnosed, there needs to be a preliminary identifying step.

Recognition and detection of individuals struggling with a potential ED or at risk of developing one are truly daunting. In many cases, individuals do not seek the aid of health professionals for a problem related to an ED, and therefore it would seem logical that good detection instruments appear necessary to help the professional to detect certain difficulties.

A number of instruments or screening tools for detecting potential EDs exist. These do not necessarily need to be administered by mental health professionals, and appear easier to use than their diagnostic tool counterparts. However, to date not many of them have been found to be rigorous enough, with a few exceptions, such as the SCOFF screening tool (Morgan et al., 1999), or the Eating disorder Screen for

Primary care, (ESP; Cotton et al., 2003) which will be described in detail in Chapter 4. These two instruments potentially open a new line of enquiry that if appropriate, could have a key role in the detection of new potential EDs cases.

1.4 IBS, EDS AND QUALITY OF LIFE

The scientific literature suggests that both IBS and EDs have an important impact on Quality of Life (QoL) (El-Serag et al., 2002, Padierna et al., 2000). The clinical experience of the researcher also strongly suggested that the QoL of some patients was fairly poor. Whether this was exclusively related to the condition, or a result of the numerous tests that sometimes had to be conducted, the different therapies used, or its management was not obvious, so a need for further examination was also imperative.

Therefore, this study set out to examine the impact that their situation may have on health related quality of life (HRQoL). The concepts of QoL and HRQoL are briefly defined and examined next, and Appendix 1 will provide a short overview of the measurement of those concepts. Additionally, Chapter 2 and Chapter 3 will specifically review HRQoL and IBS and HRQoL and EDs respectively.

1.4.1 Quality of Life

Quality of life (QoL) is a vague term that remains difficult to define despite its use in common daily language. QoL portrays the essence of attitudes and behaviours in the physical, social and emotional domains of lifestyle. Shin and Johnson (1978) first defined it as *“the possession of the resources necessary to the satisfaction of individual needs, wants and desires, participation in activities enabling personal development and self actualisation and satisfactory comparison between oneself and others”*. Patterson (1975) adopted an alternative approach based upon measurement of general health, performance status, general comfort, emotional status and economic status of the individual. Because of its varied meaning to different people, its convenience as a meaningful descriptor may be seriously compromised. Only a part of QoL is a consequence of physical health status, but ill health has been

suggested to be a significant contributor to QoL and the field of HRQoL has subsequently emerged (Berg, 1975).

QoL was introduced by Medline and the Index Medicus as a heading more than thirty years ago, which led to acknowledgement and acceptance by several scientific bodies. A subsequent explosion of interest in both HRQoL and its measurement took place in the early 1970s (Bech, 1992) and has since spread to nearly all disciplines (De Haes and Kippenberg, 1985). Important advances in medicine had led to prolonged life, but for many patients this may entail surviving at the expense of unpleasant side effects of therapy. Therefore, QoL appears as an equally important issue as survival for the provision of health care (Torrance, 1986).

1.4.2 Health Related Quality of Life

The theoretical framework of HRQoL is mainly based on a multidimensional perspective of health based upon a combination of physical, psychological and social wellbeing. The most comprehensive definition of HRQoL was provided by the World Health Organisation Quality of Life Group (WHOQOL) in 1991, presenting a definition that included individual perceptions and relationships with the environment :*“Quality of life is defined as an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept, affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, and their relationships to salient features of the environment”*. Another version by Schipper and colleagues (1990) shortened the definition of HRQoL to: *“the functional impact of an illness, and its consequent therapy, upon the patient, as perceived by the patient”*. This distinguishes HRQoL from other forms of QoL assessment, such as patient-reported subjective assessments, evaluating sensory function, mobility, activities of daily living, physical, social, emotional and cognitive function. Health and disease related attitudes and satisfaction are also important components of HRQoL.

1.5 PROFESSIONALS' ATTITUDES TOWARDS IBS AND EDS

Nurses are often at the frontline of providing care to patients with chronic illnesses such as IBS and ED, and it would appear that the quality of care they provide may be influenced by the attitudes they may hold in relation to a particular condition.

In this respect, it has been suggested that many nurses hold a negative view of patients with IBS. Most significantly, Letson and Dancey (1996) questioned two hundred and fifty-four qualified nurses about their perceptions of IBS and their attitudes towards people suffering from the condition (see Chapter 2). They reported that the vast majority of nurses found IBS patients to be “*demanding*”, “*unable to cope with life*”, “*lazy*”, “*crave attention*” and “*wasting doctors*” valuable time. It has also been suggested that health professionals in general and nurses in particular may be suspicious, unsupportive and cautious of individuals with EDs (Boule and McSherry, 2002; Bursten et al., 1996; Morgan, 1999; Cahill, 1994). Some professionals may portray ED patients as “*untrustworthy*”, “*obstinate*”, “*demanding*”, “*bothersome*”, or “*manipulative*” amongst many others (Noordenbos, 2003). This may contrast with the idea that trust, confidence, commitment (Morse, 1991), empathy, support, consistency and a non-judgemental attitude (Ramjan, 2004) appears crucial to develop a therapeutic relationship with EDs patients (Ryan et al., 2006; Tricas-Sauras, 2006b; Birmingham and Beumont, 2004). Therefore, the need to explore further the attitudes of those nurses working with IBS patients and who may be occasionally exposed to ED patients was identified in order to see whether any particular pattern was to be seen.

1.6 THE STUDY

The study evolved from personal and professional interest in the way in which patients with EDs are identified, and particularly the challenges that health professionals may encounter to identify patients that are present in a variety of settings (other than the psychiatric services), or with a “*not so clear*”⁴ presentation.

⁴ “Not so clear” by contrast to the stereotypical image of the anorexic patient who may appear more obvious due to a marked low weight.

After a period of time spent in the GI setting, the researcher developed a particular interest in IBS patients. Following up the interest in both conditions together highlighted a dearth of research that incorporated both sides. There was a clear need to develop a study that addressed the impact that IBS may have on patients' daily routines and wellbeing, as well as to explore whether EDs could be somehow present in this area. Additionally, this study aimed to gather patient experiences and to incorporate them into the research, in order to achieve a fuller understanding of the potential link between IBS and EDs.

As a nurse, the researcher had previous experience of the difficulties that health care professionals may have when dealing with both EDs and IBS patients, and the rejection of patients by nurses that these difficulties sometimes lead to. As a consequence, it was decided to further explore the perceptions that nurses may have of both conditions and of those who suffer from them.

1.7 AIMS OF THE STUDY

Considering the information just presented, the study had several aims:

1. To investigate the potential presence of eating disorders in a female IBS sample by using two eating disorders screening tools (ESP and SCOFF).
2. To compare the performances of ESP and SCOFF screening tools.
3. To investigate HRQoL in this sample of patients.
4. To evaluate anxiety and depression in this sample of patients.
5. To use a thematic content analysis technique
 - a) to assess qualitatively the presence of potential eating difficulties in a female GI sample.

- b) to assess the participants' experiences of IBS and/or EDs in a female GI sample.
6. To explore nursing perceptions and attitudes towards IBS and/or ED in a sample of specialist GI nurses.

From these aims, the following research questions were derived:

1. What is the presence of potential EDs in a female IBS sample when using two screening tools (ESP and SCOFF) for the detection of eating disorders?
2. What are the differences between performances of ESP and SCOFF screening tools?
3. What is the HRQoL for this sample of patients?
4. What levels of anxiety and depression are present in this patient group?
5. How do patients live the experience of having IBS and a potential ED?
6. What are the perceptions of a sample of GI nurses of IBS and EDs and those who suffer from them?

1.8 METHODOLOGY

In order to get as rich and full a picture of the research questions as possible, a mixed-method sequential and explanatory design (in accordance with Creswell and Plano-Clark's, 2007 classification) was selected. This combination of quantitative and qualitative approaches in pursuit of a fuller understanding of the clinical-experiential reality of IBS-EDs is an example of methodological triangulation (Smith, 1975, pp.290-291).

Data collection consisted of three strands reflecting the research aims. Briefly, these were:

Strand 1:

1. Two EDs screening tools: ESP and SCOFF.
2. A scale to identify current symptoms.
3. A battery of general and disease-specific HRQoL and wellbeing questionnaires: SF-36, EQ-5D, IBSQoL, and HAD scale.
4. Objective measurements (height and weight) that were used to generate Body Mass Index (BMI)⁵ measurements.

Strand 2:

5. Semistructured interviews with a group of patients identified as potential ED cases to explore their experience of their condition/s.

Strand 3:

6. The adaptation of a questionnaire by Letson and Dancey (1996) to explore the perceptions of a sample of GI nurses of IBS and EDs and those who suffer from them.

1.11 OUTLINE OF THE THESIS

Following this introduction to the study, **Chapter 2** and **Chapter 3** will present a review of the literature. The literature review shows the split in the relevant literature on IBS and EDs and is deliberately separated into two chapters due to the differences

⁵ BMI: Body Mass Index (See Chapter 4 for further details).

between these conditions. It also addresses HRQoL issues for both conditions, the limited literature on patients' experiences and the nurse's position in this process.

Chapter 4 describes the study methodology, and argues for the combination of quantitative and qualitative data in a mixed-method research. Three different strands are identified: quantitative and qualitative data in relation to the patients, and quantitative data in the nurses' study.

The study results are presented separately. **Chapter 5** will examine the quantitative results from the screening tools, questionnaires, and objective measures used in the patients' study, followed by the findings from the nurses' questionnaires.

Chapter 6 will present the qualitative findings from the semistructured interviews conducted and subsequently analysed using thematic content analysis. The different themes emerging from the data will guide the presentation of the chapter.

Chapter 7 will present an in-depth discussion of the most important outcomes of the research conducted.

Chapter 8 will conclude the thesis with an emphasis on the findings and the value of this research. Limitations for the study are described together with recommendations for further research.

Chapter 2

Irritable Bowel Syndrome

2 A NOTE ON THE SEARCH STRATEGY

A systematic and comprehensive review of the literature was included within this work including the terms: irritable bowel syndrome, gut disease, functional bowel disorders, eating disorders, anorexia nervosa, bulimia nervosa, atypical eating disorders, eating disorders not otherwise specified, nurse attitudes, professional attitudes, professional perceptions, nurses perceptions, multimethod studies, mixed-method studies, qualitative studies, quantitative studies.

The searches included materials published from 1990 onwards (however, earlier material has been used when appropriate), and a wide range of keywords and thesaurus were used, that have been summarised in the table below (Table 2.0). Due to the evolution of this study, several comprehensive searches were undertaken by the researcher throughout the research.

Electronic databases searched were: MEDLINE, CINAHL, EMBASE, PSYCHINFO, PUBMED, CUIDEN, Cochrane Central Database of Controlled Trials, and ISI Web of Knowledge. Additionally, internet sites such as Department of Health, Scottish Executive, National Institute for Clinical Excellence (NICE), and the Eating Disorders Association (EDA) websites were regularly checked for information relevant for the study. In addition, hand search was also performed to retrieve particular materials jointly with search of historical journals as a secondary source at certain times. In addition, hand searches of grey literature, special collections and other published documents were accessed.

All types of study designs were included within the search strategy due to the multimethod orientation of this study. Most of the literature used was in English language, although particular documents and articles in Spanish, Italian and French were used.

The materials selected were used to develop the literature review, establish the research aims and questions as well as to establish the study design.

Table 2.1: Keywords Terms

Primary	Secondary
Eating Disorders	Anorexia Nervosa, Bulimia Nervosa, EDNOS, BED
Disordered Eating	Aberrant Eating Distorted Eating Eating Difficulties Atypical Eating Disorder
Research Instruments	Questionnaires, Interviews, Tools, Screening Tools
Multimethod Studies Mixed Method Studies	Descriptive Studies Exploratory Studies Explanatory Studies
Data analysis	Content Analysis Thematic Content Analysis
Patient screening Patient identification	Early identification
Attitudes of Health Professionals	Physician Attitudes Nurses attitudes Nurses perceptions

2.1 INTRODUCTION

Irritable bowel syndrome (IBS) is a complex functional gastrointestinal (GI) disorder which to date remains poorly understood (Camilleri et al., 2002). IBS is the most common non-infectious GI diagnosis and second only to the common cold as cause of work absenteeism (Thompson, 2002).

There is an increasing body of knowledge related to many aspects of IBS. For the purpose of this dissertation it would be unfeasible to include or discuss all aspects of this chronic condition. Therefore this chapter aims to present a synthesis of some of

the most relevant materials to the present study. To do so, the first part of the literature review will present and explore the term IBS, its definition, incidence, classification, diagnosis, and management approaches. Those aspects will be examined along with some implications for the patient’s HRQoL and a review of the nursing role in the management of IBS.

2.1.1 What is Irritable Bowel Syndrome?

IBS accounts for a group of clinically diverse conditions known as GI disorders of function. IBS is “*classically*” described as a chronic condition characterized by a range of physical symptoms including abdominal pain or discomfort, which may be accompanied by altered bowel function (Camilleri et al., 2002). Additionally, IBS may also present with non-intestinal manifestations such as fatigue, back pain, lethargy, poor sleep, and dyspareunia amongst others (Lee et al., 2001). A summary of the most common symptoms associated with IBS is presented in Table 2.1.

Table 2.1: Common Symptoms Associated with IBS

GI clinical common features	Non-GI clinical common features
Recurrent abdominal pain	Lethargy
Disturbed bowel habit	Poor sleep
Disturbed defecation	Fibromyalgia
Cramping pain in the lower abdomen	Backache
Changes in bowel habits	Urinary frequency
Bloating	Dyspareunia
Immediate need for a bowel movement	Pain in the chest, abdomen, back or pelvis
Relief after bowel movement	Fatigue and low energy
Feeling incomplete emptying after bowel movement	Headaches, dizziness
Mucus in the stool	Diminished libido
	Poor concentration
	Others
	Anxiety, Depression, Somatisation

(Adapted from BSG, Jones et al., 2000)

2.1.2 Historical Perspective

Historically, there are many references to gut dysfunction within ancient and early European literature, and bowel problems have been probably treated since the ancient times. Greek historians wrote about the intestines, and Hippocrates put forward the view that young individuals whose intestines were relaxed appeared to get over their illness before than those constipated or older (Talley, 1986). However, the earliest English language descriptions of IBS did not appear until the nineteenth century. Powell (1818) drew attention to the three cardinal symptoms of IBS; abdominal pain, “*derangement of digestion*” and “*flatulence*”. As early as 1849 Cumming stated “*the bowels are at one time constipated and at another lax in the same person...how such a disease can have two such symptoms I do not propose to explain*”. Thompson (1999) stated that one hundred and fifty years later much of the enigma of IBS remains unexplained. Through the nineteenth century many terms have attempted to describe functional disorders of the bowel, these included: “*autointoxication of the colon*”, “*spastic colitis*” and “*hyperacidity*”. It was not until 1962, nearly one hundred and twenty years after Cumming’s initial treatise, that evidence of a systematic attempt to bring some discipline to the condition appeared. Chaudhary and Truelove (1962) presented a retrospective review of patients whom they described with many of the features currently recognised as IBS, and termed this condition ‘irritable colon syndrome’. Their report heralded an era of increased scientific publication on functional bowel disorders.

The first attempt to classify functional gastrointestinal disorders appeared in the text ‘*The Irritable Gut*’ (Thompson, 1979). In recent years, much has been written about the origins of IBS, its characteristic features, diagnoses, epidemiology and treatment. However, it would seem somehow contradictory that after many years of intense research and scientific dedication to the investigation of IBS, quite often it appears that there is a lack of consensus about some of the basic terms regarding IBS.

2.2 DEFINITION

IBS has been defined as a constellation of symptoms that comprise dysfunction of the intestine and are said to be functional (Camilleri et al., 2002).

IBS is defined by Badía et al. (2002, pp.750) as a “*functional gastrointestinal (GI) disorder that is diagnosed on the basis of clinical symptoms and is characterized by recurrent episodes of abdominal pain and/ or discomfort associated with changes in defecation patterns*”.

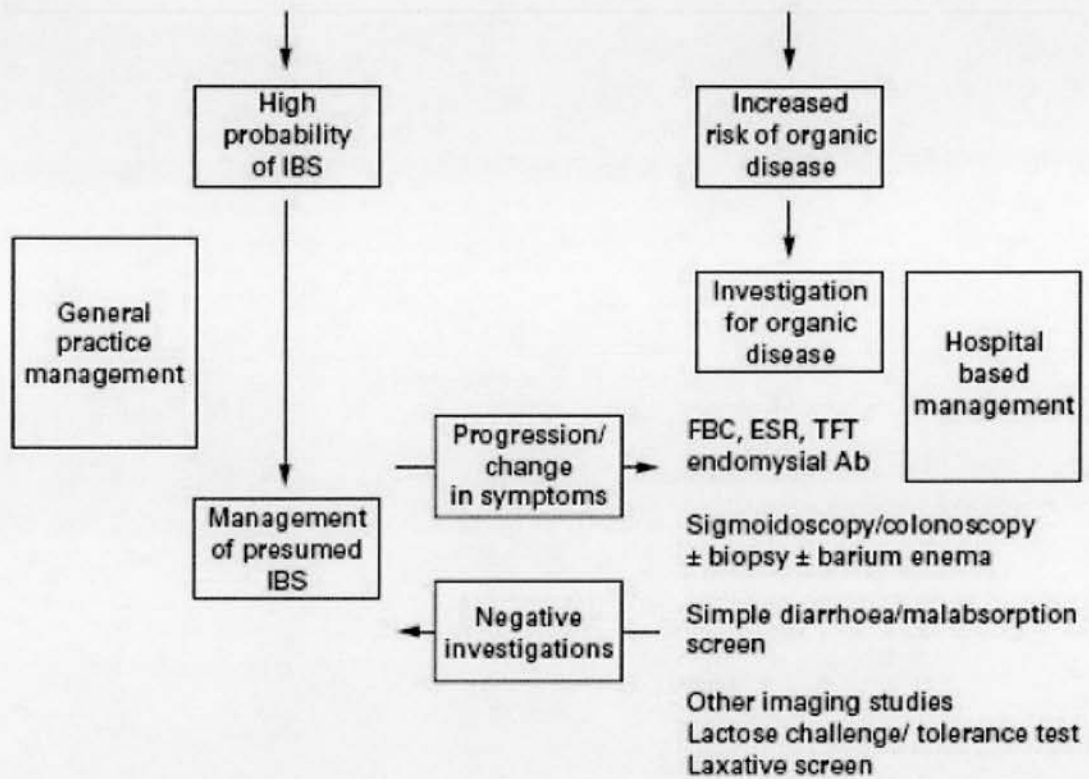
In contrast to organic GI disorders neither structural lesions nor pathophysiological explanation have been found to cause the symptoms (Heaton and Thompson, 1999). The debate of whether IBS embodies a primary psychiatric condition or a distinct bowel disease seems to continue nowadays (Jones et al., 2000). Nevertheless, it appears that IBS most likely represents a group of organic, possibly neurological bowel diseases (Talley in Camilleri and Spiller, 2003). Although there is evidence that the patient gut is malfunctioning, technology so far appears to be insufficient to precise the origin of the same. A diagnosis of IBS is currently made when a health care practitioner recognises a pattern of symptoms as described by the patient.

2.3 IBS CLASSIFICATION AND DIAGNOSIS

Presently diagnosis of IBS is problematic, mainly due to the fact that it cannot be confirmed by any objective diagnostic test or physical finding. Establishment of a diagnosis requires the identification of particular symptoms which are consistent with the condition and additionally, careful exclusion of other conditions with similar presentations. Consequently, the symptom based diagnostic criteria employed emphasise a positive diagnosis instead of using specific test to exclude other possible diseases (Boyer, 2006). Using specific diagnostic criteria should be also supplemented by careful physical examination, clinical history, and also specific tests may be employed when in doubt of comorbid conditions. A sequence of the stages in the evaluation of IBS as suggested by the BSG (2000) management guidelines is provided in Table 2.2 next.

Table 2.2: Stages in the Evaluation of IBS (Adapted from Jones et al, 2000)

< 45 year old pain +/- altered bowel habit	Age	> 45 year old pain +/- altered bowel habit
Longstanding	Onset	Recent onset
Fluctuating	Natural History	Progressive
Not present	Sinister features	Present
Present	Other functional symptoms	Absent



2.3.1 IBS Classification

Several symptomatic criteria such as Manning Criteria (1978), Rome I (Thompson et al., 1989), Rome II (Thompson et al., 1999) and the recent Rome III (Drossman et al., 2006) have been defined and validated in order to identify IBS features for clinical purposes. The Manning criteria was the first one to appear and has been widely used, although currently Rome II criteria appears as the preferred by investigators. For the purpose of this study, Rome II criteria were used, since at the time that this research was designed and conducted Rome III criteria, which will supersede Rome II, had not been fully finalised. Table 2.3 below, presents Manning and Rome II and the recently established Rome III criterion.

Table 2.3: Criteria for IBS Diagnosis

Manning Criteria	Rome II criteria for IBS diagnosis	Rome III criteria for IBS diagnosis
Diagnose IBS if ≥ 3 are present: - Abdominal pain - Relief of pain on defecation - Increased stool frequency with pain - Looser stools with pain - Mucus in stools - Feeling of incomplete evacuation “Red flag” signs Evaluate further if the patient is aged > 50 or has: Weight loss Blood in stools Anaemia Fever	Within the preceding 12 months there should be at least 12 consecutive weeks of abdominal discomfort or pain that has two of the following three features: - Relieved with defecation, and/or - Onset associated with a change in frequency of stool, and/or - Onset associated with a change in form of stool.	At least 3 months, with onset at least 6 months previously of recurrent abdominal pain or discomfort** associated with 2 or more of the following: - Improvement with defecation; and/or - Onset associated with a change in frequency of stool; and/or - Onset associated with a change in form (appearance) of stool ** (Discomfort means an uncomfortable sensation not described as pain)

(Adapted from Thompson et al., 1999 and Drossman et al., 2006)

IBS diagnosis is divided into three main subgroups, depending on the predominant symptomology: IBS-D or diarrhoea predominant, IBS-C or constipation predominant, or IBS-A or alternating which makes reference to those patients experiencing both diarrhoea and constipation. Although numerous studies have been conducted regarding IBS type characterization (Guilera et al., 2005; Tillisch et al., 2005). A systematic review by Guilera and colleagues (2005) compared bowel habit subtypes according to sample origin and diagnostic criteria and addressed IBS temporal patterns from follow-up studies. They noted that IBS subtypes distribution appear to differ depending on the population researched as well as the location and IBS criteria employed to address subtypes. It is generally accepted the each of the three identified IBS subgroups account for one third of the IBS population (Smith et al., 2004).

2.3.2 IBS Diagnosis

Despite accumulating evidence that IBS is still a diagnosis of exclusion, Malagelada’s (2006) suggestion of the importance of making a positive diagnosis in

IBS with constipation (with the aid of algorithm based on identify-probe-eliminate parameters) has opened the debate for further consideration of whether IBS diagnosis should be a positive or rather a negative diagnosis. Jones and Rubin (2006) supported the idea of a positive diagnosis based on its usefulness within the primary care setting, and also on the fact that it would appear less complex than Rome criteria. However, the recent establishment of Rome III criteria suggests that this debate will continue for some time, unless other avenues are proven to reach a consensus which is acceptable to all healthcare professionals. Additionally, Rome criteria, has been criticized for being research based and not patient focused (Saps, 2005), which appears relevant to this study seeking to incorporate patients' perspectives into the whole equation of IBS identification and subsequent management.

Cash and Chey (2004) believed that a confident diagnosis could be established by the identification of typical symptoms, normal physical evaluation and the absence of red flag signs. In this sense, most IBS research complies with the use of either Manning or Rome criterion to establish diagnosis of the condition. Saito et al. (2000) compared Rome and Manning criteria for IBS cases identification. A cross-sectional survey was used for this purpose, and a postal modified version of the Bowel Disease Questionnaire (BDQ) was sent to eight hundred and ninety-two eligible subjects with a final sample of six hundred and forty-three participants. They reported varied prevalence rates according to either Rome or Manning and its definitions. This study was a valid contribution to the existing literature, since hardly any work had been done to compare both criteria. Nevertheless, their study failed to discuss which of the definitions was better, and the need for further research is still required. Taking forward this point, Agréus (2000) criticized the lack of consensus and titled his piece, "*Rome? Manning? Who cares?*" he emphasized the confusion that exists between definitions, and even worse the lack of agreement regarding prevalence depending on the criteria used. To date, the accuracy of both definitions still require further validation. Another problem with Manning or Rome classifications relates to the difficulty that non-specialist clinical practitioners, such as GP's and nurses, may have using it. Such difficulties were also noted by Agréus (2000) and Charapata and Mertz (2006) in relation to IBS disease classification for non GI specialists.

2.4 INCIDENCE AND PREVALENCE

The first population survey of functional gut symptoms found IBS in fourteen per cent of the adult population in England (Thompson, 1986), but it has been estimated, that approximately ten to fifteen per cent of the general population have IBS (Talley, 1999). Prevalence rates of twenty-three per cent have been demonstrated in the Chinese population (Bi-Zhen and Qi-ying, 1988). The prevalence rate of IBS appears to be similar in populations in Asia and parts of Africa when compared to the USA and UK. Within the USA, Hispanics and Blacks have similar prevalence to Caucasians (Zuckerman et al., 1995). The incidence rate of IBS is substantially lower than the prevalence although limited data are available (Thompson, 2002). To date, prevalence rates for IBS in the general population are estimated between ten to twenty per cent although true prevalence may be higher due to many individuals who do not seek healthcare advice (Stones and Price, 2002).

2.5 EPIDEMIOLOGY OF IBS

IBS affects all ages, races and both sexes (Ringel et al., 2001). However, IBS symptoms appear to be twice as common in females as males (Jones et al., 2000), and even higher within the hospital setting where the ratio has been estimated to be three or four to one (Heaton and Thompson, 1999). They also suggested that in English practices, eighty per cent of those consulting about IBS symptoms are females. It has been argued that disparity in the sex ratio may be related to the emphasis given to particular IBS symptoms, or that females are more likely to report their IBS symptoms than males. It would appear therefore, that females are either more prone to suffer from this condition or more likely to seek advice for this condition (Williams et al., 2006).

2.6 AETIOLOGY

Heaton and Thompson (1999) argued that despite evidence of intense research on IBS, present understanding remains rudimentary. They play with the confusion surrounding the term by noting that it would not be inappropriate to name it

“Intestinal Symptoms Cause Unknown”. Certainly, there is no shortage of suggestions as to which is the aetiological cause of IBS, but once more consensus does not exist (Croghan and Heitkemper, 2005). The British Society of Gastroenterology (BSG) Guidelines for the management of the IBS discussed different potential factors that could be related to IBS origin, including: abnormal gut motility, visceral hypersensitivity, post infective bowel dysfunction, psychological morbidity, consulting behaviour, abnormal illness behaviour, role of stress, and diet (see BSG Guidelines, Jones et al., 2000).

2.6.1 Psychological Morbidity

Most IBS patients seen in the primary care setting do not present with major psychological morbidity (Jones et al, 2000). However, it has been reported that the incidence of psychological symptoms and psychiatric disease increases in those patients who progress to the secondary care setting (Lembo et al., 1996). Also IBS patients have shown elevated scores for anxiety, depression, hostile feelings, sleep disturbances and interpersonal sensitivity when compared to healthy populations (Gomborone et al., 1995). Attention has been paid to the potential effect of precedent negative life events in IBS (Jones et al., 2002). Stressful life events appear to have a key role in the onset of functional GI symptoms (Bennet and Kellow, 2002). Higher levels of emotional distress have been reported in patients with both IBS and other functional gastrointestinal disorders (FGID). In addition, a range of other non-intestinal symptoms potentially related to stress appear to be comorbid with IBS such as fatigue, regular headaches, and insomnia. According to Bennet and Kellow, (2002) this has been loosely named *“somatisation”*, which to date remains controversial (Spiegel et al., 2005).

Corney and Stanton (1990) evaluated the physical symptom severity, psychological and social dysfunction in a series of outpatients with IBS. Results highlighted the fact that approximately fifty per cent of those patients would link the onset of their symptoms to a stressful event. Negative life events appear to be common before the first episode of IBS, and remarkably psychiatric illness or negative life event

preceded onset of bowel disorder in a great number of IBS patients (Camilleri and Spiller, 2002; Jones et al., 2002; Heaton and Thompson, 1999).

2.6.2 Abnormal Illness Behaviour

Patients with a confirmed IBS diagnosis are thought to present with elevated number of consultations for somatic complaints and/or minor medical problems (Jones et al., 2000). Heaton et al. (1992) suggested that patients presenting a variety of symptoms, as well as those with more psychological symptoms are more likely to consult the clinician. Smith et al. (1990) suggested that relationship between psychosocial disorders and recurrent outpatient clinics attendance is not exclusive for IBS but common for other chronic conditions. Van der Horst and Van Dulmen (1997) proposed that patients attending outpatient services were more likely to believe that their condition was not related to stress but on the contrary, they feared organic or more serious disease. According to Jones et al. (2000) patients' health complaints could relate to a previous experience of secondary gain as a result of being ill.

2.6.3 Sexual Abuse

Sexual and physical abuse is thought to play a role in the development of IBS (Heaton and Thompson, 1999). Many females IBS patients report a history of abuse (Ross, 2005; Thomson, 2002). Delvaux et al. (1997) noted that abuse was not unusual in IBS patients and quoted figures in region of twenty to thirty per cent. They estimated a higher incidence in IBS patients than within the normal population, where the incidence estimated in less than ten per cent (Delvaux et al., 1997). A recent investigation by Creed et al. (2005) suggested that reported sexual abuse may help predict impaired functioning in IBS patients. Two hundred and fifty seven patients who attended a GI clinic and were questioned and thirty-one (12.1 per cent) reported a history of rape, and twenty-eight (10.9 per cent) individuals noted previous unwanted touching in both groups impaired HRQoL was identified, particularly in relation to pain and physical function.

2.6.4 Food and Diet

IBS patients frequently report that their symptoms are triggered by food and often blame specific food intolerances (up to twenty to sixty-five per cent of IBS patients) for their bowel signs, however food allergy is rarely confirmed (Park and Camilleri, 2006). These beliefs are thought to have either a rational or emotional basis, as food intolerance is very hard to prove objectively (Jones et al., 2000). Patients have been reported to often undergo strict and often illogical or irrational diets in order to exclude food that they may identify as potentially harmful. It is not uncommon for patients to consult a doctor having already made dietary alterations (Jones et al., 2000). The commonest foods that UK patients felt they were intolerant of are wheat, dairy products such as cheese, yoghurt and milk, coffee, potatoes, corn, onions, beef, oats and white wine amongst many others (Nanda et al., 1994). However, foods seen as problematic seem to vary from individual to individual.

Park and Camilleri (2006) reviewed the role of food allergy in IBS, and noted the lack of epidemiological and sound studies addressing this popular topic. Dietary treatment is subsequently common among IBS patients, however evidence based studies are limited (Burden, 2001).

One important point, in relation to this research project, relates to the fact that the act of eating physiologically stimulates the intestine into greater activity. Consequently, eating food could induce bowel symptoms in a non-specific way in predisposed individuals. This may be of particular relevance in eating disorders, or disordered eating behaviour.

Patients' perceptions of the relationship between diet and IBS have received scant attention from researchers. However, a phenomenological study conducted by Jarrett et al. (2001) described the perceptions of thirty five IBS females regarding what they thought was causing their symptoms. Most of them linked food and IBS, and when that happened, diets would be modified in order to manage IBS symptoms. Apart from a fresh insight into the patients' perspective, Jarrett and colleagues (2001) underlined the importance of listening to the individual to realize what they consider as linked to their symptoms; since that would determine the strategies that patients

would follow to manage symptoms. Additionally, the importance that females attached to diet and eating behaviours in managing IBS should be emphasised.

2.7 APPROACHES TO MANAGEMENT

Due to the varied, diverse and unpredictable nature of IBS management can often appear problematic (Smith, 2006b). After a confident diagnosis has been made, and excluded organic disease, a management plan should be established (Jones et al., 2000). Although some researchers give the management leading role in the clinician (Greenberg et al., 2002), it would appear that a multidisciplinary approach is more efficient (Graef, 2003); particularly when considering the “*poorly understood*” nature of IBS (Lewis, 2001). Since no “*gold standard treatment*” for IBS has been identified to date (Smith, 2006), different management approaches coexist. A table summarising the main avenues used for IBS treatment is provided in Table 2.3 and Appendix 2.1 (BSG guidelines, 2000) followed by a brief review.

Table 2.4: Main Management and Treatment of IBS Avenues

Diagnosis and Explanation	Pharmacological treatments	Psychological treatments	Dietary management	Alternative therapies
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Adapted from BSG Guidelines, Jones et al. (2000)

Pharmaceutical, psychological and complementary therapies emerge as the principal management alternatives for IBS. Other method such as self-help also plays an important role (Heitkemper et al., 2004); however treatments are not mutually exclusive. Research has shown the importance of reassessment to maximise the route taken with the patient in order to evaluate treatment adequacy and whether the individual could benefit from alternative or combined approaches (Heaton and Thompson, 1999).

The BSG (2000) guidelines advocated for sensible information and reassurance as an important first step to set the grounds of patient management. Sensible lifestyle modification including dietary advice, drug use, and prevention stressors should be discussed with the new patient. Diagnosis should be carefully explained and special

attention should be also paid to listen to what the patient has to say or enquiry about (Meisler, 2001). It is also argued that particular lifestyle adaptations might prove more effective than medication for IBS management (Heaton and Thompson, 1999). Accurate diet and lifestyle history appear key to understanding individual circumstances and to plan measures that could prove effective for the patient's performance. Food identification, preferences, deficiencies, daily fibre intake, exercise pattern, toilet habit and use of aids to manage her bowel should be recorded. Patient should be encouraged to fill a symptom diary (Jones et al., 2000; Heaton and Thompson, 1999), including relevant information regarding IBS symptoms, stressful events, food intake, and other issues that can assist the identification of damaging factors. The management of IBS is not the main focus of this dissertation; subsequently the following section will provide a brief overview of the most common management approaches.

2.7.1 Pharmacological Management

Despite numerous researches for IBS drug treatment, pharmacological agents have not yet proven to be effective for IBS management. Therefore, to date there is not a single pharmacological agent that can be used for the global IBS management (Camilleri, 2004; Camilleri, 1999). As a result, a range of agents are used in order to manage specific symptoms in order to improve overall wellbeing, after identifying individuals' main complaints. Table 2.5 provides a brief summary of the pharmacological agents most commonly used in IBS management (BSG Guidelines, 2000) to target mainly abdominal pain, diarrhoea and faecal urgency, constipation, and bloating.

Table 2.5: Guideline Summary of the Pharmaceutical Management of IBS

Abdominal pain	<ul style="list-style-type: none">• Antispasmodics: anticholinergic agents (dicyclomine).• Antidepressants: tricyclics (amitriptyline/trimipramine) especially where insomnia prominent may however aggravate constipation.• Selective serotonin reuptake inhibitors still under evaluation
Diarrhoea	<ul style="list-style-type: none">• Loperamide 4–12 mg daily either regularly or prophylactically (e.g. before going out).• Codeine 30–60 mg, 1–3 times daily can be tried but CNS effects often unacceptable.• Cholestyramine may specifically benefit a small number but often less well tolerated than loperamide.
Constipation	<ul style="list-style-type: none">• Increase dietary fibre (bran); if symptoms exacerbated try ispaghula/psyllium.
Bloating	<ul style="list-style-type: none">• Try reducing intake of fibre/lactose/ fructose as relevant.

Adapted from BSG Guidelines, Jones et al. (2000)

2.7.2 Psychological Therapies

A number of psychological interventions have been suggested for the management of IBS patients. This type of intervention focuses in symptoms control and its availability within the UK appears irregular, which has restricted its use to the most difficult patients (Jones et al., 2000). Relaxation therapy, gut-directed hypnotherapy, biofeedback, dynamic psychotherapy, and cognitive behavioural therapy (CBT) are the psychological interventions most commonly employed for IBS management. They are briefly reviewed next.

2.7.2.1 *Relaxation therapy*

This type of therapy has been described as the most commonly used and a fairly simplistic approach to treat stress related IBS (Smith, 2006a). It is founded on the rationale that (when stress has been identified as an aetiological factor of IBS) when diminishing emotional tension by using specific relaxation methods, this would aid to alleviate physical symptoms and to induce a sense of wellbeing in the patient by allowing the individual to feel more in control (Boyce et al., 2000; Jones et al., 2000). Common elements of this type of approach include: sitting or lying in a relaxing position, abdominal breathing, closing the eyes to limit visual stimulation,

relaxation exercises, and using visual images to educe calm circumstances, and meditation amongst others (Keefer and Blanchard, 2001).

2.7.2.2 *Gut-Directed hypnotherapy*

There is compelling evidence that hypnotherapy is an effective treatment strategy for IBS (Gonsalkorale and Whorwell, 2005). Recent research has underlined that gut-directed hypnotherapy benefits seem to be long lasting which means decreased consultation and less medication required (Gonsalkorale et al., 2004; Gonsalkorale et al., 2003; Gonsalkorale et al., 2002). This technique involves the therapist inducing the patient into a trance-like state of deep relaxation by using techniques of imagery, progressive muscular relaxation and a slow repetitive vocal cadence (Smith, 2006a). The establishment of an altered state of consciousness renders the patient susceptible to the therapists' suggestions which use bowel-directed imagery to modify gut function (Smith, 2006a). Despite the fact that hypnotherapy mechanisms are not fully understood, modifications in colonic motility and rectal sensitivity have been proven (Gonsalkorale and Whorwell, 2005). Despite its beneficial outcomes, and positive impact upon HRQoL, gut-directed hypnotherapy is still an expensive and prolonged approach, which limits patients' access. Research has suggested that nurses can incorporate this technique into their clinical practice, and also that nurses could be the ideal health professionals to provide this technique (Chapman, 2004).

2.7.2.3 *Biofeedback*

Biofeedback applied to IBS treatment has been timidly reviewed within the scientific literature. Norton and Chelvanayagam (2001, pp.156) noted that the aim of biofeedback is "*to provide immediate and accurate visual or auditory feedback on bodily functions not normally consciously appreciated or controlled*" with the intention of re-educating or enhancing the performance of those particular functions. Biofeedback is commonly used by doctors (Papachrysostomou and Smith, 1994), and also by some specialist nurses; and it involves the provision of a detailed explanation of normal gut physiology and a re-education in order to achieve the best possible defecatory patterns (Chiotakakou-Faliakou et al., 1998).

2.7.2.4 *Dynamic psychotherapy*

This approach suggests that present problems may have their roots in past experiences, and therefore that current behaviour could be led by feelings derived from past experiences. Therapists usually work with the patients based on the assumption that problems will emerge in the relationship with the therapist as well as in other relationships with peers. Dynamic psychotherapy primarily seeks to alleviate undesirable symptoms by exploring patient's individual conflicts and potential emotional problems. When used for IBS treatment, it is aimed to provide patients with insight into their particular situation and see connection with changes in the individual's life.

Despite promising findings (Guthrie, 2002), still some authors appear sceptic to employ this technique based on the fact that there seems to be not enough evidence to support dynamic psychotherapy (Jones et al., 2000). Other authors, such as Hadley and Gaarder (2005) insisted on the fact that this type of therapies should exclusively considered for motivated patients who have more severe or disabling symptoms.

2.7.2.5 *CBT*

CBT works under the assumption that IBS symptoms would stem from particular responses to certain life events. Considering IBS nature then as behavioural, CBT would work on assisting the patient towards recognition of wrong patterns of thinking and behaviour that would favour symptoms onset (Jones et al., 2000). CBT aids the patient to find a more healthy way of dealing with underlying difficulties, and the CBT professional gives patient control over their symptoms through the implicit assumption that they are related to abnormal cognitions that can be modified without specific consultation to a health professional.

2.7.3 Dietary Management

Research evidence proving the role of dietetic advice in the treatment of IBS is limited (Burden, 2001). However, this does not mean that patient does not need

specific advice and support. Health professionals working in GI settings may be prepared to offer nutritional guidance in collaboration with other specialised services. Due to the nature of this study, particular attention will be paid to dietary management of IBS. The literature review suggested that a significant proportion of IBS patients may feel that some dietary agents (e.g. lactose, gluten), food allergy, food intolerance or similar may be responsible for their symptoms; which may lead to diet manipulation or restrictive diet in an attempt to manage symptomology (Park and Camilleri, 2006). In 2000, the BSG Guidelines for the management of IBS suggested that dietary treatment should start by a detailed diet history, followed by a strict exclusion diet, supported by a food and symptoms diary, and telephone contact with the dietician.

Parker et al. (1995) suggested that patients should omit from their diets foods that the patient believes may be the cause of their symptoms; followed by the reintroduction of foods on a steady manner to produce a diet that avoids those foods they may be intolerant to. Although Jones et al. (2000) suggest that simple dietary advice will benefit IBS patients; it could also be argued that most guidelines are still vague and may have a detrimental impact on the individuals when specific advice is not provided. It looks that currently, advice tends to be too vague for patients who need clear guidance and support. Additionally, hospitals may produce informative sheets for IBS patients that in an attempt to be simple may end up being regrettably vague. As an example, Norfolk and Norwich University Hospital (NHS) produced a two pages document as "*Dietary Management of IBS*", with guidance sentences as the following "*you need to alter your diet according o the symptoms that you suffer*", and very briefly gives some advice to those that may suffer from constipation and diarrhoea mainly, leaving aside those who may alternate both forms. Furthermore, dietary advice for each IBS type is not much more unambiguous, such as the suggestion to "*have white rice and pasta*" for those with IBS-C, or "*try increasing the fibre content of the diet*" for those with IBS-D. Unfortunately, the document gives no information about quantities or how often or for how long patients should follow these diets, again leaving the patient with an open avenue again for dietary manipulation (Boyer, 2006).

Burden (2001) undertook a systematic review addressing interventions regarding diet for IBS management. This review highlighted the inconclusive evidence in this area as well as limited availability of RCTs (mainly concerned with IBS and dietary fibre), despite an apparent abundance of articles regarding IBS and dietary components. Dietary assessment, food intolerance, non-starch polysaccharides role, sorbitol, fructose, lactose, and caffeine were particularly explored by Burden (2001) and a summary of dietary guidelines are provided in Table 2.6.

Table 2.6: Guidelines Summary For The Dietary Treatment of Patients with IBS

Dietary assessment	This is essential for all patients referred with IBS to determine their present dietary intake. A 7-day diet history supported by a food and symptoms diary. Any unusual or abnormal eating practices need to be assessed in relation to the patient's symptoms.
Symptoms	Inquiry with regard to symptoms suffered and the history of their onset is essential. It is important to determine if the onset of symptoms is related to any changes in the individual's eating pattern .
Regular meals	A regular meal pattern should be encouraged with all patients.
Caffeine	The amount of tea and coffee consumed should be assessed . Excessive intakes should be avoided. A lethal dose of caffeine is between 3 and 10 g, and therefore 22 cups of coffee containing 143 mg of caffeine could potentially provide a lethal dose. However, symptoms of IBS may well be exacerbated by much less.
Non-starch polysaccharides	An assessment of the type and quantity of NSPs consumed should be made. The addition of bran should be discouraged along with large proportions of insoluble fibre in the diet unless the individual feels this is of direct benefit in symptom control. More emphasis should be placed on increasing the proportion of foods containing a higher concentration of soluble NSPs.
Fluid	An assessment of the fluid intake of patients is essential and critical if a patient's predominant symptom is constipation. If an increase in soluble NSPs is recommended, this is essential and also important in patients who have a high dietary intake of insoluble NSPs.
Wheat	The form in which wheat is ingested needs to be assessed; a trial of a wheat-free diet may be helpful for some patients to relieve symptoms.
Lactose sensitivity	A trial of a milk-free or lactose-free diet should be tried in those patients in whom dairy products are associated with symptoms. If patients continue on this diet, their calcium intake should be assessed and supplements recommended if necessary.
Sorbitol/Fructose malabsorption	If a dietary assessment reveals patients are taking large quantities of sorbitol in "slimming products" , this should be discouraged, especially if their predominant symptoms are pain or diarrhoea.
Food intolerance	Exclusion diets should only be tried when patients complain of multiple food intolerance and single food avoidance has not helped control symptoms.

(Adapted from Burden, 2001)

2.7.4 Complementary and Alternative Medicine (CAM) Approaches

It has been estimated that up to one third of IBS patients might consider complementary therapies at some point of their treatment period (Heaton and Thompson, 1999). The term CAM is often used to refer to this group of interventions that include Complementary and Alternative Medicine, and that are not considered as part of conventional medicine practice (Hussain and Quigley, 2006). As its name indicates, complementary medicines are used jointly with conventional treatments, and alternative medicines on the other hand are employed in place of conventional management. The number of methods is vast and growing, but Hussain and Quigley (2006) classify them into five main categories that are summarised in Table 2.7 next.

Table 2.7: Summary of IBS Alternative Treatments

Type	Involves	Examples
Manipulative and body-based methods	Mainly based on the application of manipulation, pressure or movement to either one or different parts of the body.	Massage, chiropractic, osteopathic manipulation
Mind-body interventions	Designed to enhance the capacity of the mind to influence or control bodily functions and alleviate symptomology.	Meditation, hypnosis, CBT, patient support groups, prayer.
Biologically based therapies	Products found in nature, or natural products to obtain relief.	Herbal products, dietary constituents, additives.
Energy healing therapies	Intended to affect the energy field surrounding and penetrating the human body. Use of bio-electromagnetic fields.	Qi gong, acupuncture, Reiki and therapeutic touch Pulsed field therapy, magnetic field therapy, direct/alternating current fields.
Alternative medical systems	Involve all encompassing theory and practice of medicine and may include diverse therapeutic methods	Homeopathy, traditional Chinese medicine

(Adapted from Hussain and Quigley, 2006)

To date, the efficacy of all those approaches has not been scientifically proven. Nevertheless, in many cases alternative options might act as placebo which can have a positive effect on patient's acceptance of their condition. Additionally, numerous choices appear available for the IBS patient, whom without the adequate guidance may become overwhelmed by the wide range of products commonly advertised as treatments for IBS. Literature regarding CAM appears vast, but quality seems uneven. Homeopathy, acupuncture, aromatherapy, aloe vera, peppermint oil use

appear as some of the popular routes that patients may take with the hope that may be beneficial for their symptoms. Just recently, the proposed scope for NICE guidelines regarding IBS (in press, expected to be published in 2008) underlined the need to clarify the benefits that those options may have for the patients, since most of them would be offered in the private setting and may end up in a excessive expenditure for the individual and in the end, not provide the expected results. A systematic review conducted by Spanier et al. (2003) alerted about the lack of good quality studies that examined this topic, and suggested guarded optimism regarding CAM efficacy. Commercial preparations such as ginger, aloe vera, and peppermint oil can be easily acquired by the patient since regulation is deficient. Despite investigations, results are varied and evidence remains poorly assessed. Spanier et al. (2003) underlined the need for further serious work that address this vast and ambiguous field, since even when there are alternatives that are likely to be efficacious in IBS treatment, medical evidence remains scarce. Leahy and Epstein (2001) suggested that CAM approaches appeared beneficial for IBS management, but also underlined its potential placebo effect. Vozeh (2003) suggested that CAM appeared as the new placebo intervention. Even when further research is compulsory, a recent systematic review highlighted the fact that not all CAM interventions have the same credibility, and that research so far supports the use of hypnotherapy, certain forms of herbal therapy, and probiotics until more controlled studies are available (Hussain and Quigley, 2006).

2.8 NURSING AND IBS

The role of the nurse in the management of the IBS patient is both diverse and specialized (Boyer, 2006). Nurses are involved throughout all the stages of the journey from the forefront of assessing and managing patients with this condition to the provision of diagnosis, testing period and treatment management (Heitkemper et al., 2002). It would be expected that nurses caring for patients with IBS should not only embrace specific knowledge about the condition but also display some expertise in patient management. According to Boyer (2006) nurses' skills such as assessing, questioning, listening and answering patients' queries as well as providing

appropriate information are of great relevance in IBS. Appropriate skills are very relevant in this area, since very intimate issues can be disclosed, and problems may arise when nurses lack the abilities to assess how patients may feel about a specific condition (Maguire, 1985).

To date, there has been limited nursing research to evaluate this panorama. Dill and Dill (1995) proposed an American Registered Nurses' (RNs) programme to effectively manage IBS within medical setting. They suggested nurses should assume a more comprehensive role due to the complex nature of IBS. Initial assessment suggested patient satisfaction, reduced medical cost to IBS patients, enhanced patient productivity, and better scores for general well being.

Letson and Dancey (1996) explored UK nurses' perceptions of IBS and sufferers of IBS, via a specially designed questionnaire to evaluate those perceptions. The questionnaire used was piloted before and its final version comprised fifty-four items exploring beliefs and attitudes by identifying perceptions of others related by sufferers of IBS as identified by previous work conducted by Dancey and Backhouse (1993). The questionnaire was completed by two hundred and fifty-three qualified nurses (twenty-two men and two hundred and thirty-one women) from a total of eighteen different London hospitals. An opportunity sample was used in an attempt to represent both NHS and private practices. The questionnaires were mainly distributed by senior nursing personnel. Surprisingly, the authors failed to clearly address the analysis technique used in order to evaluate the questionnaire, but merely noted that questionnaire items fell into four broad categories. Those encompassed: attitudes held by nurses towards sufferers of IBS, nurse' beliefs about their IBS knowledge, general awareness of IBS and a fourth one related to the nurses' beliefs about the knowledge and understanding of IBS that other health professionals seemed to display. Letson and Dancey (1996) study highlighted the fact that the majority of nurses examined seemed to hold negative attitudes towards IBS sufferers. However, only half of those nurses stated that they would be able to identify IBS symptoms. Results indicated that neither older nor more experienced nurses, nor even those suffering from IBS themselves would appear as mores sympathetic than younger nurses. Letson and Dancey (1996) suggested that negative perceptions may

potentially have a detrimental effect on IBS patient management. Several implications for nursing were underlined, as the fact that attitudes towards patients and specific conditions may affect the quality of care provided to a patient. The need for further awareness and knowledge about IBS was expressed by the authors of this study, which in their opinion, would lead to more sympathetic, practical and supportive care for IBS patients. More recent work by Nunn (2003) highlighted that negative perceptions towards IBS patient may have changed, as nurses appear to understand the need for support, reassurance and professional and dedicated advice (Smith, 2006b). Furthermore, Smith (2003) implied that an understanding of the nurses' role in the IBS patient evaluation and management, particularly with regards to education, reassurance and psychological well being is recognized. Although results regarding nurses' attitudes appear somehow contradictory, treatment quality and nurse's skills appear to be related. Moss (1988) insisted that the way patients reacted and the judgments that professionals might make on them influences the person's life. Unfortunately, many IBS patients still feel that their symptoms are not taken seriously and that they are occasionally treated as insignificant (Letson and Dancey, 1996).

Chen and McCutcheon (2001) explored Taiwanese nurses' knowledge, perceptions and beliefs about caring for patients with IBS and to determine their specific learning needs for nurses. They explored nurses knowledge gaps using a descriptive research design and via an adapted questionnaire version of Letson and Dancey's (1996) original scale. Although one hundred and fifty nurses were originally approached, an eighty per cent of participation rate was achieved with a total of one hundred and twenty responses. The study had several clear limitations, such as, the use of purposive sampling. Despite these limitations, results highlighted the importance of information provision for nurses caring for IBS patients. This was especially significant due to the fact that participants were developing their practice within IBS settings. Chen and McCutcheon (2001) insisted that greater awareness and information of IBS should be sought by nurses working in clinical practice. They also suggested that some understanding of the effects that living with chronic illness

in general, would guide nurses towards being more sympathetic towards their patients.

Educated and professional nurses with up to date contemporary knowledge of IBS would be in an ultimate position to facilitate enhanced care for IBS patients (Colwell et al., 1998). Dill and Dill (1999) echoed this arguing that nurses with additional training appear in an ideal position to take on an important role involving organized patient education, monitoring, and support. Chen and McCutcheon (2001) noted that the role of the nurse in the management of patients with IBS has become significant within health care provision not only because of the increase in the incidence and prevalence of this condition but also because of the knowledge and skills that nurses bring into practice.

The nurse caring for the IBS patient is a key element of the multidisciplinary team (Smith, 2006a). Colwell et al. (1998) suggested that nurses are in a pivotal position to facilitate improved care for patients with IBS. Enhanced care should be based on evidence and also be rooted in a solid nursing education.

2.9 PATIENTS' EXPERIENCE OF IBS

Despite the presence widespread and extensive research within the IBS field, one of the areas that has received limited attention relates to the patients' experiences of IBS. The limited research pieces that have addressed the patient perceptions regarding IBS, or those that aimed to a better understanding of IBS patients have been mainly conducted by nurses. Corney and Stanton (1990) explored symptom severity and psychosocial dysfunction in a series of IBS outpatients. They reported more than forty per cent of the participants complained about issues such as work, travelling, social life, sexual relationships, leisure activities, and food consumption. However, this study lacked detail in relation to their findings, which limited further interpretation. A more comprehensive study by Dancey and Backhouse (1993) explored symptoms, previous medical tests, feelings regarding their treatment, and the way that IBS affected their lives via questionnaire that was completed by one hundred and forty-eight (out of two hundred) random IBS patients belonging to an

IBS network. Even when the question of the generalisability of the results may be limited by the fact that patients belonged to a particular IBS network, which would exclude input from those not participating in self-help organisations, findings were valuable due to the scarce information in this area. Dancey and Backhouse (1993) questionnaire gathered both quantitative and qualitative information, which was supplemented in many cases by additional letters sent to the investigators to fully explain how IBS was present and affected the patients' lives. This point is relevant, as it would appear that patients often feel that their experience and stories are unheard. Unfortunately, Dancey and Backhouse (1993) failed to address how their questionnaire was analysed or how data presented was interpreted. Important implications for nursing were drawn, regarding patient management and the importance of showing adequate understanding of what the IBS patient may be facing, as well as providing constant reassurance when working with the individual. Despite opening a new line of enquiry into understanding the patient experience of IBS, Dancey and Backhouse's (1993) study did not fully illuminate the patient experience. Also, their approach would also appear limited by the fact that no real interaction existed with the patient, and the fact that patients seemed to suggest that the questionnaire used was not satisfactory to explore certain issues since many individuals sent supplementary information as private letters. Keefer et al. (2005) aimed to gain better understanding of the IBS patient by focusing on measures of anxiety, worry and intolerance of uncertainty that some IBS patients may experience. Forty six IBS (Rome II confirmed) individuals part of a RCT placebo controlled multisite CBT trial for IBS took part in the study and completed a semistructured clinical interview (The Albany IBS History; Blanchard, 2001), and a battery of psychological questionnaires. In addition, patients were asked to monitor their GI symptoms on a daily basis for one month prior to consultation. Despite their positive findings, the researchers failed to address or discuss patients' experiences or to extrapolate deeper understanding from their study (Keefer et al., 2005). One of the few studies that specifically addresses IBS patient experience was a conducted by Meadows et al. (1997). The study used an inductive, exploratory design to interview fourteen patients (ten females and four males), and twelve supportive individuals identified via snowballing technique. Interview material was analysed using constant

comparative method to identify analytical categories and subsequent themes emerging from the dialogues. They provided an interesting compilation of themes that helped to portray the patient's experiences and the journeys followed by them from the onset to the moment they were asked to share their individual accounts. They linked IBS stories to IBS journeys that often seemed to originate after stressful events. Elongated periods of symptoms passed before many patients were diagnosed, that involving numerous tests and treatments that seemed inefficient for most of them. Many patients changed doctors during this period as they felt their medical practitioners were unsympathetic to their situation, or that they simply could not find the reason behind their symptomology due to incompetence. Patients seem to long for understanding and considerate professionals to guide them throughout their often secretive journeys. Furthermore, IBS patients seemed to demand a cure, although patients also seemed to demand further sympathetic approaches as well as satisfactory or more efficient treatments that enable them to lead normalised lives. Meadows et al. (1997) study presented some limitations that cannot be obviated, such as when addressing their methodology and noted that their study was guided by grounded theory and "*other qualitative approaches*" (pp.157) but they failed either to address those or comment further. Sample size could be debatable, although data saturation was somehow implied. However, the way the researchers used patients and relatives data remained unclear. On a more positive point, Meadows et al. (1997) opened a much needed line of enquiry that places the patient in the centre of the study, and by that they are enabled to express their views and experiences with the uniqueness of their accounts.

An important and recurring issue regarding patient experience is stigma. Although this may be concealed by the patient, healthcare professionals or society in general Dancey et al. (2002) pointed out the particular relevance this concept may have for the patient experience. Dancey et al. (2002) explored the concepts of illness intrusiveness¹, perceived stigma and QoL. They used a naturalistic research design to evaluate the former concepts, assessing IBS symptom severity, perceived stigma,

¹ Illness intrusiveness defined as: "*the extent to which one's illness and/or its treatment interfere with continued involvement in valued activities and interests-increases emotional distress and compromises psychological wellbeing in chronic conditions*" (Devins et al., 1993 in Dancey et al. 2002 pp 382).

illness intrusiveness and QoL. To do so, two validated questionnaire were used, the Illness Intrusiveness Ratings Scale (IIRS, Devins et al., 1983) and the IBS-QOL (Hahn et al., 1997). An eleven item questionnaire was designed for the study to evaluate perceived stigma and a similar format was used to assess symptom severity. Postal questionnaires were sent to two hundred and one potential respondents, and a final sample of fifty-four men and sixty-three women was obtained as recruited from two UK national IBS charities. Despite no direct contact with the patients, statistical analysis highlighted relevant issues, such as the fact that patients may feel stigmatized by health problems, but particularly in the case of IBS where embarrassing symptoms are involved. Perceived stigma correlated with impaired HRQoL, and symptom severity. Despite certain sex differences among individuals, results portrayed the important impact that symptoms may have in the patients HRQoL and in the self image that seems to be damaged depending on the IBS presence. Although this study did not use validated questionnaires to assess all the concepts, it introduced a line of enquire that was previously neglected in IBS research such as stigma and illness intrusiveness. Stigma could be particularly detrimental for IBS patients since individuals who feel stigmatised are likely to avoid social interaction. Colleagues may not accept IBS symptoms as valid reasons for absence due to the lack of medical explanation for this condition (Dancey et al., 2002), which can explain negative attitudes towards individuals (Letson and Dancey, 1996). Also, stigma could be related to the perception of the symptomology that would affect self appreciation. Patrick et al. (1998) noted that individuals would use self offensive statements to define themselves, such as feeling unclean or fat due to IBS symptoms. The reality is that attitudes of those surrounding the IBS patient as well as the patients themselves may have an important impact in the individual feeling stigmatised. This has been suggested to have important implications regarding emotional health and HRQoL (Dancey et al., 2002). Next section will explore the concept of HRQoL within the IBS setting.

2.10 HRQoL IN IBS

Despite the fact that IBS is a non threatening condition, it can affect the entire life of the patient, and as such it has numerous implications for daily life (Jones et al., 2000; Heaton and Thompson, 1999). As a result, patients' HRQoL can be greatly impaired (Gralnek et al., 2002; Hahn et al., 1997). Recent research has challenged the idea of IBS not being a serious condition, since the impairment experienced by the individuals could have an important psychosocial impact and lead to more serious issues, such as addressed by Miller et al. (2004) who indicated important rates of suicidal ideation experienced by IBS patients.

HRQoL studies on IBS are numerous, and they usually combine generic and disease specific measures to examine patients' presentation. Generic HRQoL measures are designed to assess aspects that are comparable across diseases, and individuals, which can consequently provide the foundation for comparison with data from the general population (Smith, 2006b; Frank et al., 2002). On the other hand, disease specific measures are particularly employed in clinical trials in order to specifically address IBS symptomology (Longstretch et al., 2005; Wiklund et al., 2003; Groll et al., 2002; Drossman et al., 2000; Hahn et al., 1997).

Numerous investigations have looked at HRQoL within IBS exploring clinical determinants of HRQoL for the IBS patients (Dean et al., 2005; Chang, 2004; Spiegel et al., 2004; El-Serag, et al., 2003; El-Serag, et al., 2002). Smith (2004) noted that most of those studies have been conducted within secondary care settings, which could have implications for the generalizability of the information. As noted in the introductory chapter, several ways of measuring HRQoL exist, and a number of IBS specific questionnaires are available, such as IBSQOL (Hahn et al., 1997), IBS-QOL (Drossman et al., 2000) and GSRS-IBS (Wiklund et al., 2003). Measuring HRQoL provides relevant information in order to understand how the symptoms and management may affect the individual's life. A British study by Akehurst et al. (2002) highlighted the fact that IBS patients presented with lower HRQoL than healthy control group matched for age, sex and social characteristics. Akehurst et al. (2002) noted that perceived physical role, bodily pain and perceived general health

were markedly impaired for the IBS patients. Several authors have suggested the fact that impaired HRQoL figures in IBS, could be related to psychological factors (Locke et al., 2004; Halder et al., 2004).

In an attempt to establish whether similar patterns can be observed across countries, HRQoL measurement has been also compared worldwide. Talley et al. (2000) study evaluated GI symptoms across four different countries and data suggested that symptoms patterns seemed comparable within the Western world. Other authors have suggested that HRQoL impairment could vary depending on the country (Hahn et al., 1999); and other authors have suggested that differences could be related to cultural issues (Heaton and Thompson, 1999), or the patient's sex, since it has been suggested that that females would present with more impaired HRQoL (Faresjö, 2006).

In addition to patients' assessment, several pieces of research have addressed the consequences that IBS may have not only for the patient, but also for the employers, or the healthcare services (Creed et al., 2001). Martin et al. (2001) examined the economic implications of IBS management practices and formulated several recommendations on the basis of their review. Martin et al. (2001) suggested that IBS patients are 1.6 times more likely to present for medical care than patients with similar symptoms, which would consequently have an impact on the raise of health expenditure, and economic burden of society as a whole. This burden is heavy and growing (Fullerton, 1998), so specific guidelines appear indispensable. Martin et al. (2001) suggested the careful revision of the management strategies in an attempt to cut costs at the expense of the patient till effective routes can be addressed. Dean et al. (2001) reviewed the impairment in work productivity and HRQoL in patients with IBS in USA. They aimed to assess the impact that IBS has on the employed population and its economic implications. Dean et al. (2001) two phase survey was completed by a total of one thousand and seventy-six (out of 11,806) employees of a large US bank, which presented with IBS (according to Rome II). Results linked IBS to a twenty-one per cent of activity reduction (equivalent to four to five days work) and a significant reduction of their HRQoL as evaluated by SF-36. Surprisingly, the important impact that impaired HRQoL and reduced work may have for the

employers, was emphasised by Dean et al. (2001) although restricted sympathy was shown for the patient.

A British study by Silk (2001) explored the impact that IBS may have on personal relationships and the workplace. A sixty items questionnaire was sent to over three thousand subscribers of a particular educational publication (IBS Bulletin) which was completed by one thousand and fifty-five of them although analysis was restricted to one thousand and ninety-seven due to inadequate completion. Despite the particular sample approached and potential biases related to the participants that decided to take part on the survey, findings proportionate a good insight into the IBS patients' views. From the sample, patients had suffered IBS for 16.6 years (mean), and eighty per cent of them were under treatment. Nearly a fifth of the respondents noted that their partner experienced difficulties in having an intimate relationship with them, and nearly half of them stated that sexual life was affected by their symptoms. Over thirty-five per cent of the participants reported taking time off work due to IBS, and an important twelve per cent of them stated that they had quit their jobs altogether due to they symptomology. Silk (2001) conclusions supported the suggestion that IBS has a significant impact on personal relationships as well as work environment, however further research appeared necessary to address personal relationship issues or job difficulties related to IBS.

Research regarding non-attendance at work and IBS appears to be popular, and was recently examined by another American study by Zacker et al. (2004), which concluded that in their comparison of six hundred and thirty IBS patients and one thousand and sixty normal controls, IBS related work absences would be increased for up to a sixty-nine per cent in comparison with the control figures, highlighting the pejorative image that some of the IBS patients may have within their workplaces. An element of blame seems to emerge to some of the research pieces evaluating IBS expenditure, as expressed by the authors as if the patient was responsible for not being "*careful enough*", or should even limit the visits that they pay to the specialists, or regulating the days they may miss from their workplaces.

2.11 CONCLUSION

This chapter has provided an overview to IBS. It has introduced the term IBS, its definition, diagnosis, epidemiology, jointly with recommended approaches to management. It has also reviewed the nursing role in IBS and the IBS patient experience. In addition, HRQoL issues in relation to IBS have been presented.

The literature review on IBS presented in this chapter indicated some of the difficulties regarding IBS such as recognition, diagnosis, and the need for optimizing diagnostic testing and management, as well as the patients' experience of suffering from IBS. The impact on HRQoL has been also highlighted as clinically significant in IBS patients.

Having presented a selective review of the literature on IBS from a nursing perspective, the review suggests that despite the vast literature existing on this topic, IBS is still an ambiguous concept, which may difficult IBS identification and patient management. Patients seem to be stigmatized to a certain degree, and health professionals may exhibit some derogatory attitudes towards IBS patients.

The qualitative research literature in this area seems to be limited, and little research has addressed the patient's experience of IBS, which underlines the need for further research in this direction.

The following chapter on EDs will complete the literature review, setting the scene for the subsequent chapters.

Chapter 3

Eating Disorders

3.1 INTRODUCTION

Eating disorders (EDs) are conditions characterised by serious disturbances in eating habits and excessive concern about body weight and body shape. In addition to their effects on psychological well-being, EDs have a potentially devastating effect on health due to the many physiological consequences of altered nutritional status or purging (Becker et al., 1999). Mortality rates associated with EDs are alarming (Fairburn and Harrison, 2003; Lucas et al., 1999).

EDs are common conditions which primarily affect females (Royal College of Psychiatrists, 2000). They affect millions of individuals throughout the world and the incidence appears to be increasing (Treasure et al., 2003). EDs can occur at any age and include anorexia nervosa (AN), bulimia nervosa (BN), and eating disorders not otherwise specified (EDNOS) as well as their variants (Royal College of Psychiatrists, 2000).

The efficacy of available treatment varies (Pratt and Woolfenden, 2002). It has been suggested that individuals with EDs often experience substantial delays between the onset of symptoms and commencement of treatment. It has been suggested that this delay may relate to the secretive nature of EDs, as even within clinical settings up to fifty per cent of cases go undetected (Royal College of Psychiatrists, 2003; Becker et al., 1999).

Approaches to EDs have changed dramatically in the last decade (Birmingham and Beumont, 2004; Garfinkel, 2002). In particular, there have been notable

improvements in the detection and understanding of EDs (Gilbert, 2005). Advances in the reduction of the morbidity and mortality in AN and BN appear to be closely related to a greater understanding of the disease (Garfinkel, 2002).

However, further research is required within many areas, and a number of challenges endure within the EDs field, such as early identification, classification competence, effective treatments, and HRQoL issues.

EDs are associated with an element of stigma and false glamorisation (Tricas-Sauras, 2006a), and despite intense research in this area, understanding of the experience of these conditions still appears to be at an embryonic stage. This chapter will firstly explore the differences between “*eating disorders*” and “*disordered eating*” and then will go on to describe the most common presentations of EDs (AN, BN and EDNOS), clinical diagnosis, epidemiology, risk factors, and management. The nursing role within the EDs field and the literature regarding the ED patient experience along with HRQoL will be also examined in the latter part of this chapter.

3.2 WHAT IS AN EATING DISORDER? EATING DISORDER VS DISORDERED EATING

EDs refer to those cases of disordered eating that are considered as illnesses because they are connected to a regular cluster of behavioural and psychological features, imply a predictable course, and are seen as constituting a clinical problem requiring treatment (Birmingham and Beumont, 2004). As the main characteristics of EDs are behavioural and psychological, they are included among psychiatric disorders¹ (APA, 1994).

Eating is a normal daily routine modulated by a number of factors such as appetite, food availability, family, peer and cultural traditions and attempts at voluntary management motivated a vast number of reasons (National Institute of Mental Health, 2001). On the other hand, dieting in order to manage weight appears a common routine among individuals, and particularly within the female population

¹ The diagnostic criteria according to the American Psychiatric Association (DSM-IV, 1994) will be presented in the next sections.

(Strauss, 1999). Occasionally, dieting may be directed towards achieving a body so lean that an individual may compromise their health and seriously impair their eating habits by subsequently developing an ED. “*Bingeing*” and “*purging*” are commonly used terms related to this kind of behaviour and appear to have become a part of the language of popular culture, in the same way that the term “*anorectic*” has become synonymous with underweight (Fairburn, 1995). Unfortunately, the true meaning of several of the terms used to describe disturbed eating may have become too imprecise. Magazine articles often present and hypothesise about terms such as “*eating problems*” and “*EDs*”, using them interchangeably without regard to the distinction between the two. The fact is that having an eating problem does not equal an ED, any more than anorectic means extremely thin. However, this lack of precise terminology is not confined to magazines. Even in the literature, arrays of terms are used interchangeably, in most case with no attempt at clarification. Some of the commonly used terms related to eating disorders include: “*eating problems*”, “*disordered eating*”, “*weight problems*”, “*troubled eating*”, “*dieting Disorders*”, “*aberrant eating behaviour*”, “*major eating disorders*” and “*minor eating disorders*” (Birmingham and Beumont, 2004; Treasure et al., 2003; Kuba and Harris, 2001). Fairburn (1995) investigated the terms “*eating problem*” and “*EDs*”, and tried to establish when an eating problem became an ED. Birmingham and Beumont (2004) favoured the expression “*dieting disorders*” over “*EDs*”, based on the fact that restricted eating, with or without reactive overeating, appears to be involved in most cases.

Fairburn (1995) noted that most people who binge have neither an eating problem nor an ED. Their bingeing is often more sporadic than recurrent, does not involve gigantic amounts of food and does not have an effect on their HRQoL. However, considerable numbers of individuals who binge eat disrupt their overall QoL, and their binges may be common, regular and distressing. These individuals would be classified as having an eating problem.

However, other researchers associated the term “*eating problem*” with the difficulties that certain patients may have in relation to the process of eating. Perry and McLaren (2004) and Larsson et al. (2002) addressed eating problems and eating difficulties in

post-stroke and neck cancer patients. There are numerous examples of other diseases or conditions which may be related to eating difficulties (Buchholz, 1998; McHorney and Rosenbek, 1998). Kuba and Harris (2001) outlined the lack of consistency regarding terminology associated with EDs. They highlighted the fact that some of the terms associated with EDs are used interchangeably which can present difficulties for the reader who wishes to differentiate between individuals who have been diagnosed, those who present particular behaviours that may resemble a potential ED, or those who appear as confounding cases. Kuba and Harris (2001) explored contextual factors in the development of disordered eating in Mexican American women. They used terms such as “*eating disturbances*”, “*eating disorders*”, “*classic eating disorders*”, “*disordered eating*”, “*eating disorder symptoms*” and “*eating disordered patient*” interchangeably. Additionally, many binge eating problems would also fit the criteria for a number of EDs, bringing even more confusion into the debate.

Certain authors have suggested that theoretically, only AN can be unmistakably identified since “*other problems have not been defined well enough to be characterized clearly*” (Fairburn, 1995, p.68). This would suggest a clear diagnostic path to recognizing AN, and to some extent would imply that the most recent that the most recent diagnostic classifications (DSM-IV² and ICD-10) fail to address the features of those illnesses grouped under the heading “*Eating Disorders Classification*” in sufficient detail. The former affirmation presents some challenges, since one of the characteristics of AN (as with the rest of EDs) is secrecy, and identification can be daunting despite its extensive description, as the first of the EDs to be studied. Additionally, and regarding the failure of the international diagnostic manuals to address the features of all EDs, not only AN, appears not completely erroneous. Both DSM-IV and ICD-10 have been described as man-made lists of signs or symptoms (Newell and Gournay, 2000), artificially constructed by academics, and that may fail to address other aspects which are not included in the lists. It would appear that such a wide array of names generates confusion among

² The Diagnosis and Statistical Manual or DSM-IV (American Psychiatric Association, 1994) and its counterpart the International Classification of Diseases, or ICD-10 (World Health Organisation, 1992).

both health professionals and lay individuals, and still fails to address the true nature of these disorders. It would seem that the term EDs appears quite limited in the sense that it only refers to the eating component, whereas in fact a number of psychological, mental, attitudinal and behavioural correlates surround those conditions but are somehow not reflected in the terminology.

It should be noted that although eating patterns are altered, these are accompanied by a variety of behaviours such as overexercising, laxative misuse, self-induced vomiting, self-evaluation influenced by body shape and weight and depressive mode amongst others, which despite not directly addressing the “*eating*” part of the ED, can be equally damaging for the patient. Therefore, and despite attempts at categorisation and classification of the EDs terminology, many aspects still need be taken into account such as categories refinement and patient identification, as well as clarification of disturbed eating patterns and the behaviours that accompany them in order to improve its value.

For the purposes of this thesis, the term “*potential ED patients*” will be used to identify individuals who may be at risk of developing an ED, or have never been diagnosed but present an indication that such problems may be present.

3.3 EATING DISORDERS DIAGNOSIS

Diagnosing an ED appears problematic as previously suggested, and the misleading terminology surrounding EDs is not the only factor that makes diagnosis difficult. A further difficulty is actually reaching a diagnosis, since individuals may struggle in silence for a long time before a clinical judgement can be made, and many ED cases may go unidentified for long periods of time. In order to comprehend some of the problems that the identification of EDs entails, the current diagnostic criterion for EDs and some of the challenges relating to it is presented next.

Diagnosis of an ED is an extremely complex task, modulated somewhat by the secretive nature of these conditions as well as by the empirical classifications used to offer a clinical diagnosis. Despite the fact that ED nosology has become more

sophisticated over time, several challenges still exist, such as greater differentiation among EDs per se, and subsequent assessment and management (Sloan et al., 2005).

In 1994 (pp. 349), Beumont and colleagues noted: “*with the best will in the world, it is difficult not to become disillusioned with the diagnostic system for eating disorders*”. Unfortunately, little seems to have changed since then, despite the introduction of diagnosis criteria for the varied presentations of EDs. Although this fact appears to have been a major achievement towards helping to guide professionals through the process of identification, the establishment of the diagnosis itself and subsequent management strategies have not been exempt from controversy (Birmingham and Beumont, 2004). To date, diagnosis is made according to the two main diagnostic manuals existing within the mental health care setting: The Diagnosis and Statistical Manual or DSM-IV (APA, 1994) and its counterpart the International Classification of Diseases, or ICD-10 (WHO, 1992). The latest version of the DSM classification appeared in 2000 as a revision of the fourth edition of the manual published by the APA, under the name DSM-IV-TR, although EDs diagnoses were not affected by the latest version. DSM-IV is commonly used in research, and most reference papers use DSM standards. Early interest in diagnosis of EDs was guided by the Diagnostic and Statistical Manual III (DSM-III) of the APA in 1980. When EDs were first introduced into the manual, clinical diagnosis was made simply by differentiating them from the diagnosis of obesity (Stunkard, 1997). However, obesity was eventually reclassified as a somatic disorder, reducing psychiatric diagnoses to those related to behavioural disorders (Agras, 2005; Stunkard, 1997). The DSM-IV (APA, 1994) diagnostic criteria³ for AN, BN and EDNOS can be found in Tables 3.1, 3.2, and 3.3 within this section.

3.3.1 Anorexia Nervosa Diagnosis

The word anorexia derives from the Greek, meaning a lack of appetite or avoidance of food (Blinder and Chao, 1994). AN was first described by Morton in 1689 (Morton, 1720) and was named by Gull (Gull, 1874) in 1868. It usually begins in

³ This study will present the current diagnostic criteria for EDs as described by the DSM-IV (APA, 1994)

adolescence or early adulthood, but it can start at any point between six and seventy two years (Freeman, 2002), and age range figures appears to be widening. In 1980, two different expert of teams reported similar findings (Casper et al., 1980 and Garfinkle et al., 1980) in what seemed to be the division of AN into two subgroups: one characterised by severe restriction of food intake and the other by binge eating followed by vomiting. Seemingly, the two subgroups offered different psychopathological features with the bulimic patients recording greater scores in anxiety, depression and guilt.

To date, four main criteria are applied in the diagnosis of AN according to DSM-IV (APA, 1994): dramatic loss of body weight; intense fear of gaining weight or becoming fat; disturbance in the way body weight or shape is experienced and amenorrhea. Additionally, for children under fourteen years, presenting features should include weight loss, food restriction, fear of fatness, preoccupation with weight and calories, excessive exercise, and self-induced vomiting (Society of Adolescent Medicine, 2003; Lask and Byant-Waugh, 1992). For AN patients, weight loss is self-inflicted and no organic origin exists. Weight loss and failure to recover weight are achieved generally by dramatic dieting, fasting and overexercising. Additionally, pathologic fear of being fat could be described as the essential psychopathologic feature of AN and BN, being the morbid fear which drives semistarvation and subsequently weight loss. Individuals with AN present with a distorted perspective of their body size estimation and a seriously disturbed affective quality of body image (Cash and Deagle, 1997). Another common feature is the amenorrhea present in most AN patients, and related to starvation which leads the body to stop menses as a result of the lack of body fat stores necessary to continue them.

According to DSM-IV, AN diagnosis has two subtypes: the restricting subtype characterised by intake restriction and the binge-eating/purging subtype characterised by episodes of bingeing and purging (also called bulimic-anorexic type). Significant differences have been identified between the AN restricting type and the bulimic-anorexic type, such as premorbid weight and family history of obesity. Impulsivity rates are also higher for the bulimic type than for the restricting type, which is

characterised by a higher obsessive level and social isolation (Walsh and Garner, 1997).

Table 3.1: Diagnostic Criteria for Anorexia Nervosa: 307.1 (DSM-IV, 1994)

-
- A. Refusal to maintain body weight at or above a minimally normal weight for age and height (e.g. weight loss leading to maintenance of body weight less than 85% of that expected, or failure to make expected weight gain during period of growth, leading to body weight less than 85% of that expected).
 - B. Intense fear of gaining weight or becoming fat, even though underweight.
 - C. Disturbance in the way in which one's body weight or shape is experienced, undue influence of body weight or shape on self-evaluation, or denial of the seriousness of the current low body weight.
 - D. In postmenarcheal females, amenorrhea (i.e., the absence of at least three consecutive menstrual cycles).
-

3.3.2 Bulimia Nervosa Diagnosis

Bulimia Nervosa (BN) has been presented as a potentially more dangerous ED since it is not that easily recognised (Gilbert, 2000). The first paper which recognised BN as a distinct medical entity was presented by Russell in 1979 and entitled: "*Bulimia Nervosa: An Ominous Variant of Anorexia Nervosa*". Despite initial consideration of BN as a version of the most recognisable AN, the essence of Russell's paper presented the combination of AN with bulimia or binge eating as well as vomiting and subsequently, named the condition BN. Despite Russell's initial reluctance to recognise this disorder as a syndrome, due to premature findings, BN was soon incorporated into the DSM-III (APA, 1980).

BN diagnosis is based on three main criteria: recurrent episodes of binge eating and subsequent compensatory behaviours, jointly with morbid fear of fatness. The bingeing component entails two different sides, related to the amount of food eaten, and the second component relates to the loss of control. Binges are characterised by the fact that food is usually consumed in a very short period, and the amount of food consumed is dramatic. As can be seen in the table regarding BN diagnostic criteria,

the DSM-IV defines the binges as a food quantity that most individuals would consider excessive under similar circumstances. This definition is quite unclear, since what an individual may consider as a normal amount could be considered excessive by other collectives. The intake in a single binge session has been estimated to entail up to 15,000 calories (Cooper, 1993), and it should be considered that in certain cases, binges can take place more than several times per day. Loss of control, where the individual feels unable to stop eating once the binge has begun, is closely linked to BN diagnosis. Very often, individuals use compensatory strategies to balance the effects of the binges by using laxatives, diuretics, enemas or vomiting, as well as other routes to control weight increase. It has been also described that certain diabetic patients would manipulate or avoid insulin dosages to control the binges (Nash and Skinner, 2005).

In accordance with AN patients, the body appearance and weight of BN patients are very relevant, and can become an overvalued notion for the patient. Despite the fact that BN patients are not diagnosed based on weight loss, many of them manage to reduce their initial weights dramatically (Treasure et al., 2003; Cooper, 1993), although one of the difficulties with diagnosis is the fact that most BN patients generally maintain their weights within normal body mass index (BMI)⁴ ranges.

⁴ Body Mass Index is a measure of weight for height that will be further explored in Chapter 4.

Table 3.2: Diagnostic Criteria for Bulimia Nervosa: 307.51 (DSM-IV, 1994)

-
- a. Recurrent Episodes of binge eating. An episode of binge eating is characterised by both of the following:
 - b. Eating, in a discrete period of time (e.g., within any 2-hour period), an amount of food that is definitely larger than most people would eat during a similar period of time and under similar circumstances

A sense of lack of control over eating during the episode (e.g., a feeling that one cannot stop eating or control what or how much one is eating).

Recurrent inappropriate compensatory behavior in order to prevent weight gain, such as self-induced vomiting, misuses of laxatives, diuretics, enemas, or other medications; fasting; or excessive exercise.

The binge eating and inappropriate compensatory behaviors both occur on average at least twice a week for 3 months.

Self-evaluation is unduly influenced by body shape and weight.

The disturbance does not occur exclusively during episodes of Anorexia Nervosa.

TYPES

Purging Type: during the current episode of BN, the person has regularly engaged in self-induced vomiting or the misuse of laxatives, diuretics, or enemas.

Nonpurging Type: during the current episode of BN, the person has used other inappropriate compensatory behaviors, such as fasting or excessive exercise, but has not regularly engaged in self-induced vomiting or the misuse of laxative, diuretics, or enemas.

3.3.3 Eating Disorders Not Otherwise Specified (EDNOS) Diagnosis

The current DSM-IV classification (APA, 1994) favours the term “*eating disorder not otherwise specified*” often abbreviated to EDNOS to describe atypical eating disorders. This category seems to cover any ED of clinical severity and symptomatology which does not meet the criteria for any of the other EDs presented earlier. Actual EDNOS diagnosis reveals very little information about the clinical presentation of ED symptoms despite the significant proportion of individuals who are assigned this diagnosis. (Norrington and Palmer, 2005). A weakness of the EDNOS category resides in the limitations of its criteria which are somewhat vague (Nielsen and Palmer, 2003). Consequently, EDNOS diagnosis seems significantly complex due to the fact that it is considered a residual category (Birmingham and Beumont, 2004). The EDNOS category has only one positive criterion, which is that individuals should be deemed to have an ED of clinical severity, and one negative criterion, which is that the ED should not be compliant with either AN or BN

(Nielsen and Palmer, 2003). Despite the fact that EDNOS has been estimated as the most prevalent of the EDs diagnoses, a lack of clarity in this diagnosis is evident. One of the disadvantages of this category is based on the limitations of its dual criteria, and to date DSM-IV has not appropriately specified how diagnostic judgement should be made.

The DSM-IV EDNOS (APA, 1994) criteria can be found in Table 3.3. Although imperfect, it is the current status of the most prevalent ED categories. As noted by Palmer (2003), when diagnosis is made from a quantitative point of view, there is a high chance that many patients will not comply with the strict AN or BN criterion, and subsequently, many patients will be considered part of this diagnostic criterion.

The diagnostic criteria for AN, BN and EDNOS have been presented jointly with their characteristic features. It has been seen that the existing criteria are unsatisfactory and need constant revision in order to offer the most appropriate and comprehensive routes to identify ED patients. Generally, ED diagnosis is made by a specialist, although most individuals can be identified in other settings, such as GP clinics, dentist's surgeries, or schools. Professionals in these settings can point out that a potential problem exists, and should refer individuals to a specialist or encourage them to seek the help that many of them would deny needing.

Therefore, appropriate diagnosis appears necessary to establish the adequate management strategies that would be relevant for each individual. Nevertheless, before diagnosis can take place, identification of potential cases appears compulsory. As noted earlier in this chapter, patient recognition may be hindered by several facts. However, the need for early identification in order to avoid the severe complications that these chronic conditions may have has been noted (NICE, 2004).

Table 3.3: Diagnostic Criteria for EDNOS: 370.50 (DSM-IV, 1994)

-
- A. For females all of the criteria for AN are met except that the individual has regular menses.
- B. All of the criteria for AN are met except that, despite significant weight loss, the individual's weight is in the normal range.
- C. All of the criteria for BN are met except that the binge eating and inappropriate compensatory mechanisms occur at a frequency of less than twice a week or for a duration of less than 3 months.
- D. The regular use of an inappropriate compensatory behavior by an individual of normal body weight after eating small amounts of food.
- E. Repeatedly chewing and spitting out, but not swallowing large amounts of food.
- F. BED: recurrent episodes of binge eating in the absence of the regular use of and inappropriate compensatory behaviours characteristic of BN.
-

3.3.4 Binge Eating Disorder

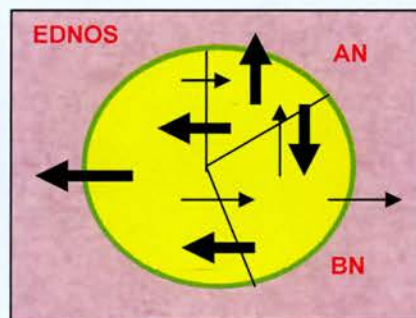
The essential feature of this disorder is bingeing, as in the case of BN, but in contrast BED patients do not present the compensatory behaviours described within BN classification. BED was first described in 1992 by Spitzer and it appears to be more prevalent in obese individuals. To date, and until the next compilation of diagnostic criteria appears, it is considered a provisional diagnosis by the DSM-IV and included in the EDNOS criteria. However, BED appears to be a diagnosis in its own right and many authors have referred to it as such (Munsch and Beglinger, 2005). The amount of ongoing research regarding BED is vastly increasing.

This section has presented DSM-IV's most common diagnosis for EDs. However, it should be remembered that both DSM-IV and ICD-10 are the products of committees informed by tradition, or man-made classifications. These should provide stability to the concepts but must be open to criticism and improvement that specialists and researchers may endorse (Nielsen and Palmer, 2003). Man-made compilations, even when rigorous, need to revise and incorporate relevant new issues. Therefore, several inconveniences currently exist. One of those regards the

fact that DSM-IV does not clearly differentiate between EDs, and symptoms appear to overlap, since they are not specific to a particular condition (Thaw et al., 2001). Additionally, the distinction between patients who comply with the full diagnostic criteria and those who do not is limited, and therefore the EDNOS category is increasingly applied, currently used to categorise almost one third of all ED patients (Sloan et al., 2005). Another problem is the fact that the EDNOS category seems to comprise a number of diverse ED syndromes as well as subthreshold AN and BN cases, and the particular case of BED (Delfin et al., 2003). Moreover, and despite the usefulness of the empirical classification, the fact that some ED patients may move between categories has opened the debate as to whether diagnosis would be better represented by a continuum approach (Perosa and Perosa, 2004; Beumont et al., 1994). The figure below illustrates the idea that EDs may temporarily move between diagnostic categories, as suggested by Fairburn and Harrison (2003; pp. 409).

Figure 3.1: Schematic Representation of Temporal Movement Between EDs*

(*Arrow size indicates the likelihood of movement in direction shown. Arrows pointing out outside the figure suggest recovery)



* Adapted from Fairburn and Harrison (2003)

Transdiagnostic approaches to identify and understand EDs have been proposed (Wade, et al., 2006). To date, it seems that despite support for the current taxonomic approach within EDs, several issues need to be refined, and the continuum versus categorical debate continues.

3.4 EARLY IDENTIFICATION OF POTENTIAL EATING DISORDERS AND DISORDERED EATING

It has been suggested that early diagnosis may be related to better outcomes for ED patients (Treasure et al., 2003). Some authors have highlighted the importance of this fact since the current preventive strategies have not shown efficacy (Levine and Smolak, 2001). Pratt and Woolfenden (2002) reviewed the interventions for preventing EDs in children and adolescents. Based on the data examined (one thousand and sixteen titles), they concluded that no evidence could be found that ED preventive programmes were harmful for individuals, but nor could any conclusive findings be made regarding a positive impact. Therefore, the full value of such approaches is still open to debate. Additionally, attempts been made to explore those areas of the population thought to be more susceptible to developing EDs. Mickley (2000) noted that EDs may be overlooked by many practitioners during normal assessment. In 2003, the Royal College of Psychiatrists emitted a press release noting that over half of EDs go undiagnosed. Carter and Millar (2004) insisted on the need to assess the ED situation within Scotland, and similar suggestions have been made not only across Europe (Tölgyes and Nemessury, 2004; Hugo et al., 2000), but also worldwide (D'Souza et al., 2005; American Academy of Pediatrics, 2003; Le Grange et al., 1998). EDs numbers appear to be elevated, but if suspicions are correct, many other patients may be going undetected.

This poor detection rate of EDs may lead researchers to consider the appropriateness of existing facilities for identifying and caring for this considerable group of individuals. The reality is that although the panorama is improving, resources are still limited (Lemouchoux et al., 2003) and healthcare professionals outside psychiatric services may not be skilled enough to recognise or identify patients. Within the UK, several specialised private ED centres exist, but not every patient will be able to afford the substantial bills that private care generates (Richards, 2003). On the other hand, although the NHS provides support for patients with an ED in the UK, its resources are limited, with extremely long waiting lists in some cases (Duffy, 2005).

Mickley (2000) argued that primary care clinicians are often in a privileged position to identify and subsequently help manage EDs. Nurses have also been seen as essential professionals within this process, an idea which will be further examined later in this chapter (Root and Tilsley, 2003; Szweda and Thorne, 2002; Irwin, 1993). Other groups who may play a role in this area include dentists, other health professionals, teachers, and families (Noordenbos, 2003). Noordenbos (2003) discussed some of the problems that may influence early identification of EDs patients, such as patient delay on presenting with the eating problem, communication difficulties, attitudinal biases, gender differences between GPs and eating disordered patients, delay in the diagnosis at an early stage for fear of “*alarming*”, and subsequent inadequate interventions by failing to refer patients for further assessment.

Some identified cases may refute further intervention or even treatment, and that should be acknowledged by health professionals. However, a lack of specific interventions to detect those individuals at risk appears noticeable. This was revisited by the Scottish NHS’ new recommendations for management and treatment of EDs (available from November 2006) which again emphasised the need for “*opportunistic intervention*” in order to support early identification of ED cases.

3.5 EPIDEMIOLOGY OF EATING DISORDERS

The particular nature of EDs suggests that most cases avoid professional help (Hsu, 1996) and therefore many of them go unreported as repeatedly noted throughout the literature (NICE, 2004; Yager et al., 2005). This may have an impact on the accuracy not only of global figures but also of risk factors and the efficacy of subsequent interventions planned using the available data.

According to Birmingham and Beumont (2004), EDs can be considered as either high-prevalence conditions of a moderate severity, or as low-prevalence conditions of major severity. This is determined by how strictly a diagnostic criterion is applied, which again underlines the issue of diagnostic tools and diagnostic criteria not always being equally applied universally. Epidemiology of EDs has been reviewed

by Hoek et al. (1998, 1995, 1993), Hsu (1996) and van Hoeken et al. (1998) among other authors, however most of the studies did not provide data specifically addressing EDNOS. Due to the separate classifications of EDs, epidemiological data are briefly individually presented for AN, BN and EDNOS.

3.5.1 Epidemiology of Anorexia Nervosa

Lifetime prevalence of AN among women in the US has been estimated at 0.5% (Klein and Walsh, 2003), and figures for Europe have been estimated at 0.3% (van Hoeken et al., 2003). Although a number of individuals portray partial forms of the syndrome, they do not meet the full diagnostic criteria for AN and are not estimated as AN cases (Birmingham and Beumont, 2004; Treasure et al., 2003).

AN is overrepresented in females at a ratio ranging from 10 to 20:1 (Birmingham and Beumont, 2004; Klein and Walsh, 2003). Additionally, mortality rates for AN are alarming. Sullivan (1995) meta-analysis reported crude mortality rates of 5.9% or 5.6 % per year. The most common causes of death were complications due to the ED itself (54%) and suicide (27%). Recent data provided by Nielsen (2001) estimated that patients with AN have an almost four-fold risk of dying compared to a healthy population of the same characteristics.

3.5.2 Epidemiology of Bulimia Nervosa

BN presents higher prevalence rates than for AN, ranging between 1.1% and 4.2% of the population (Birmingham and Beumont, 2004). Again, BN seems to be more present among females but it is not as marked as in the case of AN. The female: male ratio has been estimated to be 1:10 approximately (Klein and Walsh, 2003).

Research so far has indicated that adolescent girls and young females seem to be more vulnerable to BN, but recent studies have shown that older females and males appear to be affected too (Klein and Walsh, 2003).

It would appear that incidence rates have risen sharply over the past twenty five years (Currin et al., 2005). However, Treasure et al. (2003) argued that despite

already appalling figures, the real incidence cannot be estimated due to the existing taboo regarding BN and also to the fact that BN is not as easily discernible as AN.

3.5.3 Epidemiology of EDNOS

The difficulty of accurately describing EDNOS and the ongoing debates on its categorisation, classification and accuracy of the diagnostic criteria (Fairburn and Bohn, 2005) appear to have led to epidemiological ambiguity in an under-researched area (Birmingham and Beumont, 2004). The prevalence of EDNOS has been estimated at between two and five per cent in young women (Hay, 1998), but researchers in this field seem to agree on the fact that the real prevalence of subclinical EDs would be substantially higher than any other ED.

3.6 AETIOLOGY OF EATING DISORDERS

The aetiology of EDs has been widely examined by researchers (Schmidt, 2003; Dingemans et al., 2002; Gowers and Shore, 2001) but to date; there is no consensus (Schmidt, 2003). Studies have explored diverse avenues and numerous classifications of potential aetiological factors have been suggested. Gilbert (2005) divided potential aetiological factors into eight categories; these categories are used to explore EDs aetiology in this section. This is merely one of the many existing classifications, but it simplifies some of the most commonly discussed potential aetiological factors.

3.6.1 Psychosomatic Theories

Psychosomatic theories share the idea that overeating is a response to emotional distress, and particularly related to anxiety and depression. However, those ideas have been challenged by experimental research (Gilbert, 2005). On the other hand, the idea that some people tend to eat more than others when experiencing psychological stress appears particularly popular with specialists. Greeno and Wing (1994) reviewed the issue of stress-induced eating; however due to length restrictions this thesis will not explore this aspect further.

“*Comfort eating*” is a term widely used by the lay public, and it is also the focus of attention of psychosomatic theorists. They suggest that people who overeat do so as a means of achieving comfort and well-being from food, or as a way of avoiding feelings of emptiness (Gilbert, 2005). This theory has been sustained by many pieces of research (Parker et al., 2006; Townsley and Robinson, 1997) which makes it difficult to summarise the ideas at its core. The power of comfort eating has been also described as a compulsion, or addiction to eat, and this has been frequently related to certain foods in particular, such as carbohydrates, or sugary foods (Aikmana et al., 2006). Interestingly, research has suggested that carbohydrate consumption may result in a temporary decrease of negative mood states for individuals experiencing varied types of emotional and physical disorder (Treasure et al., 2003; Christensen and Pettijohn, 2001).

3.6.2 Eating Disorders Related to Other Psychiatric Conditions

It has been hypothesised that EDs could be a manifestation of an affective disorder, implying predisposition to general neurotic morbidity of a genetic nature (Gilbert, 2005). High comorbid prevalence of affective disorders was suggested by Halmi (1991). Based on the idea that EDs could have an underlying affective disorder origin, antidepressant therapy has been used to treat these conditions (as examined further in Section 3.7).

The role of obsessive compulsive disorder (OCD) has also been linked to high lifetime prevalence for people with EDs (Gilbert, 2005). In BN patients, this link manifests itself in the ways bulimic patients use to “*undo*” their binges to compensate for the effects of overeating (Treasure et al., 2003).

3.6.3 Sexual Abuse and Eating Disorders

Studies investigating a potential association between sexual abuse and EDs have reported a great variability of results that suggests a lack of agreement (Smolak and Murnen, 2002; Connors and Morse, 1993). Certain aspects such as methodologies employed, assessment techniques and populations surveyed, amongst others, could

be blamed for part of the data discrepancy. However, Connors and Morse's (1993) thorough review of childhood sexual abuse suggested that on the whole, figures for ED patients sexually abused in childhood account for up to a third of the total, that figure being comparable with rates normally found in standard populations. Their review proposed that sexual trauma and disturbed eating could be linked for a number of patients, but data appeared inconclusive and therefore it is perhaps better to consider sexual abuse as a risk factor rather than an explanatory fact. Other authors have proposed the idea that figures of abuse appear to be higher amongst patients suffering an ED, although figures seem to vary depending on the nature of the ED (Smolak and Murnen, 2002). Wonderlich et al.'s (1997) review supported the idea that childhood sexual abuse appears to be a non-specific risk factor for BN, especially if psychiatric comorbidity exists. Nagata et al. (2001) suggested that similar physical punishment histories existed amongst Japanese and American patients, and suggested that physical abuse could be related to whether patients presented restrictive or bulimic signs, rather than posing as a risk factor for developing an ED in general. Still, the inconclusive findings highlight the need for further research in this area. Abused patients' stories have been examined in order to explore whether abuse may contribute to aggravate ED symptoms, and with them the overall prognosis (Molinari et al., 2003). In this sense, Luadzers (1998) evaluated a sample of eighty-two female ED inpatients to explore treatment outcome, categorising it as "good", "intermediate" or "poor" at follow-up, which suggested that sexual abuse may have a role not only in ED onset but also on recovery rates.

3.6.4 Role of the Family in the Development of an Eating Disorder

For many years, family dynamics have been blamed for being a strong component in the onset of EDs (Kugu et al., 2006). However, these ideas have since been strongly challenged. Similarly, psychological traits across families were once suggested as a way of explaining EDs (Treasure et al., 2003). Disturbed relationships between parents or between parents and sufferers have also been an object of study. Overprotective traits, lack of conflict resolution, rigidity and lack of privacy environment have also been implicated (Serpell and Troop, 2003). The role of the

family in EDs and their resolution appears to vary from patient to patient, and research exploring some of these aspects has found conflicting outcomes (Orbanic, 2001; Blouin et al., 1994).

An interesting hypothesis is the notion based on the emotions expressed by/in a family and how this would affect the offspring's behaviour, for example by expressing negative or positive emotion towards the children during mealtimes (Kessler et al., 2006; Rodriguez-Santos and Vaz-Leal, 2005; Uehara et al., 2001). Therefore, it looks as if erroneous beliefs about food and eating and subsequent maladaptive uses of eating behaviour itself could be fostered at a very early stage (Gilbert, 2005).

3.6.5 Eating Disorders as Sociocultural Conditions

A popular aetiological explanation relates to the idea that EDs are diseases which are a consequence of a modern society that has idealised thinness and healthy looks and criticises fatness. An unconventional study by Garner and colleagues (1980) studied the pictures in Playboy magazine and of the winners of Miss America competitions over a period of years. Garner et al. suggested that body mass index (BMI) appeared to reduce over the years, with thinner females appearing each year. Additionally, an increased proportion of material on dieting and healthy behaviour appears to be common in publications aimed at both females and males and even at teenagers (Polivy and Herman, 2002; Reaves, 2001). The role of the media in the genesis of a variety of disorders has been widely discussed within the scientific literature (Vasterman et al., 2005; Zahl and Hawton, 2004; Harrison, 2000) Equally, the role of the media in EDs has been carefully discussed both for females and males, with special attention paid to its role as an aetiological trigger (Hofschire and Greenberg, 2002; Harrison, 2000).

The role of the media in promoting EDs recently received a great deal of attention in Spain, and was severely criticised by both health professionals and laypeople. As a result, since 2000, fashion magazines, advertising and fashion shows have been regulated to some extent by the Spanish Parliament. Also, in an attempt to offer

healthier female role models, the most important Spanish fashion event, Pasarela Cibeles, took a radical measure in September 2006 by banning models that did not portray a healthy look and/or had a body mass index (BMI) under eighteen. According to the event organisers⁵, this measure was taken with the aim of preventing EDs by showing role models with a healthy body size, and it seems that this measure will be continued in the future (El País, 2007⁶). A spokesman for Milan Fashion Week (December 2006) noted that their next event would also take measures to contribute to promoting healthier feminine figures (Smith-Spark, 2006). In January 2007, the Academy for Eating Disorders (AED) published the Guidelines for the Fashion Industry, with the intention of providing guidance in this area. Although naïve, this attitude reflects the extended idea that EDs may have a sociocultural and particularly media-related origin. Although the role of the media cannot be dismissed, no concluding remarks exist for this suggestion.

The culture of dieting has also been studied by researchers (Gowers and Shore, 2001; National Task Force on the Prevention and Treatment of Obesity, 2000; Brink and Ferguson, 1998) who noted the high numbers of individuals who acknowledge either having dieted or currently being on a diet. Figures of people who commonly diet are high (the regular dieters) and its higher prevalence over certain periods along the year (eg. summer vacation, post Christmas period) may equally reflect a general attitude towards diet and body shape. Gilbert (2005) went further and suggested that in many cases, thin seems to equal health and fat is commonly associated with bad health. Prejudices against fat are not uncommon in our society. In this sense, Klesges et al. (1990) suggested that overweight people are less likely to be offered high-powered jobs, and also that being perceived as fat may have a powerful influence on the attitude to her health and capacity to do the job of a prospective employer. Oberrieder (1995) also suggested that trained dieticians have been found to have negative attitudes towards obese people.

⁵ This event is significantly subsidised by the Spanish Government.

⁶http://www.elpais.com/articulo/sociedad/Pasarela/Cibeles/2007/volvera/aplicar/medidas/anorexia/elpepusoc/20070114elpepusoc_2/Tes

Several research pieces have looked at the prevalence of EDs in males (Aruguete et al., 2005; Kaminski et al., 2005) and homosexual samples (Moore and Keel, 2003; Russell and Keel, 2002) finding that figures reveal higher prevalence rates for male homosexual populations. Moore and Keel (2003) noted that sexual orientation may be related to particular EDs in women. However, to date, homosexual and heterosexual females display more significant similarities than differences (Gilbert, 2000).

The question that remains unsolved is how far EDs are triggered by the stress of dieting alone, and how far it arises as a result of a combination of factors. Although there seems to be consensus amongst researchers that dieting may be a clear risk factor for the development of an ED, this is not the sole prerequisite.

3.6.6 Eating Disorders and Learned Behaviour

It has been suggested that certain individuals imitate dieting habits as a way of achieving attention and a sense of achievement (Birmingham and Beumont, 2004; Treasure et al., 2003). Some of these cases may have been triggered by an earlier criticism of body size or sporadic remarks that for some reason have impacted on the individual who then feels committed to learn from and imitate other role models, such as friends or relatives. It is argued that when dieting provides results, and the individual is then complimented, this creates a sense of success that encourages the person to continue with that behaviour. Therefore, fear of weight gain or bingeing episodes may be also perceived as a sense of failure with dangerous consequences when present, since this may lead the individual to enter a vicious circle from which it is very difficult to exit (Gilbert, 2005).

3.6.7 Eating Disorders as a Corollary to Dieting and Food Deprivation

Some authors have hypothesised that dieting may render certain individuals more prone to developing bingeing episodes (Huon, 1994). A classic study by Keys and colleagues in 1950 studied the effects of starvation as a means of understanding the experiences of individuals during wartime. Seventy four individuals were put on a

diet for a three month period. Participants lost around twenty five per cent of their weight, and according to Keys et al. (1950), individuals displayed symptoms similar to AN. The second part of the study involved subsequent refeeding to recover the individual's original weight. This revealed that certain individuals refused refeeding, and began to display dieting and bingeing episodes that alternated in a frantic fashion. A further suggestion in relation to this section is the idea as suggested by investigators that dieting may also encompass harmful physiological consequences, which seem to be linked to the suggestion that dieting may reduce metabolic rates which would make achieving target weight difficult for those individuals dieting cyclically.

3.6.8 The Restrain Hypothesis

Issues of control, such as the simple thought of having to be in charge of the eating process, could act as important stressors related to the subsequent appearance of EDs (Gilbert, 2005). Restrained eaters appear to be continuously on a diet and their worries about food and weight appear to be endless. An example of this is the case of diabetic patients who have been found to present with a higher prevalence of comorbid EDs (Rodin, 1996). Polivy and Herman (1999) suggested that the disinhibition of eating may have a psychological function for individual dieters.

To sum up, it should be noted that although much research has been conducted regarding the aetiology of EDs, no conclusive data exist as yet. A recent review by Schmidt (2003) with the promising title "*Aetiology of EDs in the 21st century: new answers to old questions*" aimed to rediscuss some of the topics just presented, and suggested that biotechnological theories had opened the debate again on the biological and genetic contribution towards the development of EDs. However, despite intense research in this area, there seems to be a lack of consensus on what is the cause of EDs. It could be said that multi-causality would be accepted by most researchers.

3.7 RISK FACTORS

A wide variety of potential risk factors have been associated with the development of EDs (Stice, 2002). However, there is a lack of strong evidence to support the links. A short summary of several risk factors associated with the development of EDs is provided below.

The literature in this area is broad and continuously growing, but some of the most commonly cited risk factors appear to be: female gender; family history of eating disorder; family dieting and adverse comments from family members about eating appearance or weight. Further risk factors include childhood obesity, parental obesity, early menarche, and exposure to presentation of affective disorder, substance abuse or obsessive-compulsive disorder (Birmingham and Beumont, 2004; Treasure et al., 2003). A number of researchers have highlighted the fact that there seems to be a strong familial association with these conditions (Wade et al., 2006; Strober, 1991), and argue that there may be a contributing genetic element for the development of an ED.

Treasure et al. (2003) categorised risk factors into two main categories: context of the individual and individual characteristics. The context of the individual includes classical suggestions as social class, level of industrialisation, level of urbanisation, and occupation. Traditionally, it was thought that, defying the existing tendency of most psychiatric disorders to be related to lower socio-economic classes, EDs showed higher incidence rates in individuals from higher economic classes (Margo, 1985; Fairburn and Cooper, 1984). However authors like Gard and Freeman (1996) and Rogers et al. (1997) criticised this idea by noting that in many cases those statements had been made on the basis of biased and methodological research problems, and reducing economic class to a myth. However, in 2001 McClelland and Crisp, yet again challenged Gard and Freeman's (1996) conclusions and reopened the debate. They examined the social class status of female patients with AN over a thirty three year period, using a retrospective survey of patients who had attended a specialist centre for the assessment and treatment of AN to assess differences in clinical features between social classes. McClelland and Crisp (2001) suggested that

social class reflects a sociocultural influence, and that this could be a product of the disorder significantly often arising as an avoidant response to the conflict between family values or attitudes related to social class, as well as adolescent turbulence within those families. It could however also be argued that their findings were related to the fact that patients coming from higher class families potentially would have had more opportunities to seek help. Gard and Freeman (1996) concluded that in the case of BN, figures reflected the common psychiatric tendency to predominate (as noted before) among lower socio-economic groups.

Other examples of potential risk factors identified and linked to EDs include eating alone, parents' marital status, use of radio and girls' magazines (Martínez-González et al., 2003), media exposure (Stice, et al., 1994), television advertising (Myers and Biocca, 1992), mood and televised images of attractiveness (Cattarin et al., 2000). To date there is limited evidence to support the link between these factors and EDs.

3.8 APPROACHES TO THE TREATMENT OF EATING DISORDERS

Pratt and Woolfenden (2002, p.1) noted that EDs are “*extremely difficult, time consuming and costly conditions to treat*”, and it has been suggested that EDs are rarely fully “*cured*”, mainly due to their chronic nature (Birmingham and Beumont (2004, p.115).

In order to review UK national provision for the treatment of EDs, a number of surveys have been conducted (Royal College of Psychiatrists, 1992, 2000, 2004) by health authorities and boards, examining NHS and private services providing specialist treatment for patients with EDs. The executive summary of year 2000 noted that services for the assessment and treatment of EDs remained inadequate in large parts of the UK, and the Royal College of Psychiatrists (2000) subsequently presented an extended document where several strategies were proposed in order to tackle deficient provision, management and professional training. Access to treatment is still problematic as highlighted in November 2006, by The Scotsman newspaper, which noted: “*more money is needed if guidelines to improve the care of*

patients with EDs in Scotland are to have any effect.” This is despite recent recommendations published by the NHS Quality Improvement Scotland (2006) that called for adequate resources to treat these conditions and appears particularly relevant since about 80,000 individuals, in Scotland alone, are thought to suffer from an ED and adequate resources do not appear to be in place.

Treatment of EDs needs a holistic and multi-professional approach in order to manage the multiple aspects involved in the journey (NICE, 2004⁷). Despite growing numbers of publications regarding ED treatment, evidence-based materials seem limited (NICE, 2004). There have been few randomised controlled trials (RCTs) regarding treatment of AN and EDNOS, or atypical EDs, which means that to date treatment recommendations have to be tentative (Fairburn and Harrison, 2003). BN appears to be the exception, and it looks as if the extensive attention that BN treatment has received over the last twenty five years has finally translated into evidence-based management.

Based on the numerous reviews, articles, official documents and guidelines identified by the review of the literature, the following sections will summarise ED management based on each ED diagnosis. Additionally, a summary of the current NICE Guidelines (2004) for the management of EDs is presented in Appendix 3.1.

3.8.1 AN Management

Research on AN treatment appears insufficient and inappropriate to date. According to Fairburn and Harrison (2003), four main aspects to management seem to emerge: helping the patient to see the need for assistance and motivation throughout the journey; weight restoration; addressing individuals’ overconcern with shape and weight, eating behaviour and psychosocial functioning, and finally the use of enforced treatment for particularly severe cases.

⁷ British NICE Guidelines were commissioned by the National Institute for Health and Clinical Excellence (NICE) and developed by the National Collaborating Centre for Mental Health on care of people with eating disorders. The document was published in January 2004 and covers core interventions applying to adults, adolescents and children from the age of eight. Recommendations are made regarding identification, treatment and management of AN, BN, and EDNOS.

Pharmacological treatment is still ambiguous, and no drug has proven effective for the general management of AN. Although Fluoxetine appeared to show promising results regarding relapse reduction in individuals presenting restored weight (Kaye et al., 2001), further research appears necessary. A recent systematic review of the use of antidepressants for AN conducted by Claudino et al. (2006) concluded that no evidence could be found of the efficacy of antidepressant use in AN (especially for acute phases).

On the other hand, psychological treatment appears beneficial for the AN patient (Herzog and Hartmann, 1997). The psychological treatment of EDs was recently reviewed by Wilson and Shafran (2005) who also highlighted the relative absence of AN treatment research. According to NICE (2004), psychological treatment of AN is a key element of both inpatient and outpatient management strategies, however there is a lack of evidence as to which particular approach may be best (Meads et al., 2001). Nevertheless, and according to NICE (2004), psychological treatment should provide a focus on both eating behaviour and attitudes to weight and shape, as well as psychosocial issues. Treasure and Schmidt (2005) concluded that there is no strong research evidence that supports the idea that any specific treatment works for AN. Accumulation of evidence however suggests that early intervention is effective and that working with the family may have a strong effect in stopping illness development.

3.8.2 BN Management

BN seems to benefit from a particular status among EDs research. Review of the literature identified over fifty RCTs evaluating BN treatment options, which mostly offered consistent findings (Nakash-Eisikovits et al., 2002; Hay and Bacaltchuk, 2002; Wilson and Fairburn, 2002). Despite the fact that nearly all the pieces of research appeared to focus on efficacy rather than effectiveness, findings appeared relevant for management within most psychiatric settings (Fairburn and Harrison, 2003). Traditional reviews (Wilson and Fairburn, 2002) and the results of meta-

analyses (Whittal et al., 1999) support the idea that CBT⁸ has the most empirical support as the treatment of choice for BN. NICE's (2004) rigorous assessment also supported CBT leadership regarding BN treatment and was based on a thorough revision of the RCTs conducted on the efficacy of CBT for BN. NICE's (2004) findings imply a mandate for clinicians in the UK to practise evidence-based treatment, and therefore to provide CBT for BN patients as the first choice.

Three main lines of sound findings can be identified within BN research, although the most successful treatment identified to date is CBT. Secondly, research has suggested that antidepressants showed antibulimic results, resulting in a prompt reduction of binge frequency, purging, and mood improvement. However, results are not as positive as those obtained by CBT and further research appears necessary. Finally, no consistent predictors of outcome have been identified (Fairburn and Harrison, 2003). To date, CBT appears to be the treatment choice for BN. Whilst it is not without shortcomings, it appears beneficial for a wide range of patients, however restricted use of this approach has been criticised (Mussell, et al., 2000).

Other forms of psychotherapy have also been portrayed as beneficial for BN treatment, such as Interpersonal Psychotherapy⁹ (IP) (Kalodner, 2005) and self-help interventions (e.g. Cooper, 2001; Gomez, 1999; Cooper, 1993). The latter were also recommended by the NICE (2004) guidelines as potential initial steps, particularly when patients may not have direct access to CBT treatment (Perkins, et al., 2006).

Perkins et al. (2006) reviewed the existing evidence from RCTs and controlled clinical trials for the efficacy of self-help interventions and guided self-help strategies¹⁰. This thorough review examined and rated studies in the field and concluded that both individual and guided self-help strategies¹¹ may be beneficial for

⁸ CBT: focuses on the modification of particular behaviours and disruptive patterns of thought that patients may hold and which may contribute to the maintenance of the ED (Gilbert, 2005)

⁹ Interpersonal psychotherapy focuses on helping clients understand their relationships with people (Kalodner, 2005).

¹⁰ Self-help encompasses using books, tapes, CD-ROMs, the World Wide Web (www), or other sources of information to manage and gain control over the ED (Bará-Carril et al, 2004).

¹¹ Two main types of self-help interventions were identified: pure self-help (individual working with materials) and guided self-help (therapist guiding the journey of the individual working with the materials).

the individual as an initial step in treatment. However, the efficacy of other interventions such as family therapy for BN has yet to be determined (Le Grange et al., 2003).

Extensive reviews have been also conducted evaluating pharmacological management of BN. One of the most recent ones by Bacaltchuk and Hay (2006) assessed the use of antidepressant agents and placebos in the treatment of BN. The authors concluded that single antidepressant use appeared clinically effective when compared with placebo administration. Despite greater remission numbers existing for antidepressants, a higher rate of dropouts existed. No significant discrepancies regarding the efficacy or tolerability among the different agents reviewed could be identified. Similarly, NICE (2004) suggested antidepressants trials as an alternative or additional first-step to using CBT in BN patients. Selective serotonin reuptake inhibitors (SSRIs) in general, and specifically Fluoxetine, appear to be the medications of choice for BN treatment. Valuable effects are fast and likely to decrease binge eating frequency and purging (NICE, 2004).

3.8.3 EDNOS Management

EDNOS treatment is rarely mentioned in published reports addressing EDs management, and it is challenging to find serious or methodologically appropriate researches that explore this umbrella term. Curiously, the NICE guidelines (2004) along with other relevant authors (e.g. Fairburn and Harrison, 2003) stated that based on the absence of evidence to direct the management of EDNOS, treatment guidance should follow the ED diagnosis that most closely resembles the individual patient's symptoms. This summarises the frustratingly wide range of options that EDNOS patients face when finally identified. Even though this category of EDs appears to be the most prevalent one, management strategies lack clarity and evidence based guidance.

This chapter has made particular reference to the NICE guidelines, since this is a UK study, but practice guidelines have been developed across countries with varying emphases that may highlight particular issues for different countries. As an example,

intense emphasis on outpatient management exists in the USA, which could be due to pressure exerted by insurance companies on that country's health system in order to reduce expenses (Kalodner, 2005).

In summary, a variety of mainly psychological and pharmacological treatment strategies are available for EDs. Although presented separately in this work, this does not imply that treatments are mutually exclusive. On the contrary, in many cases, a combination of approaches has been suggested as a promising strategy (NICE, 2004). Identifying effective treatments, along with early identification of the individual, seem necessary for achieving the best outcomes that may otherwise course with chronicity and severe morbidity for the patient.

Next section will examine the role of the nurse in the EDs field, and the relevance of her work in this area.

3.9 NURSING AND EATING DISORDERS

Birmingham and Beumont (2004) described caring for patients with an ED as both extremely rewarding but also enormously challenging. Nurses can be involved in all phases of care for the ED patient. From early identification, to diagnostic stages, and especially as treatment provider, the nurse works closely with the ED patient (Clarke and Paine, 1997).

There are a wide variety of nursing roles within the management of the ED patient (Kong, 2005). It has been noted that the nurse should be competent to work within a framework of excellence, and also expert in both identifying and interpreting the variety of signs, symptoms and potential complications that EDs entail (Birmingham and Beumont, 2004). Additionally, the nurse should take particular care to preserve clear professional boundaries when working with the client, while showing a sympathetic, empathic and non-judgemental approach in order to maximise her work and subsequent patient benefit (Birmingham and Beumont, 2004). Being able to combine being flexible but strong when necessary, appears essential to assist the patient along the road of recovery from an ED.

Nurses' education has been suggested as key in order to enhance skills and experience (King and Turner, 2000; Lowther, 2005). Close collaboration with other professionals may also help the nurse to incorporate theory into practice, as well as to enhance a multi-disciplinary approach from which everyone can benefit. Frequent clinical supervision and debriefing sessions also appear vital to achieve excellent levels of nursing within the ED field (George, 1997).

There are a variety of roles for nurses working on EDs (Newell, 2004), and some of these are briefly reviewed in the next section.

Identification of the patient with an ED

Nurses are involved in the detection of patients with EDs (Maradiegue et al., 1996; Mickley, 2000; Szweda and Thorne, 2002) as well as patients with disordered eating behaviour (Al-Subaie, 2000; Waldrop, 2005). Research suggests that many patients go unidentified despite the fact that customary screening could possibly identify individuals struggling with particular issues regarding EDs. The need for new strategies to identify those patients appears evident. This is particularly relevant since early identification of potential EDs has been suggested as crucial, given that interventions at early stages are related to a better prognosis (Treasure et al., 2003). However, most of the nursing literature on EDs relates to specialist nurses, which suggests that although general nurses may also frequently encounter individuals with an ED, or disturbed eating patterns, a limited emphasis has been placed on supplying those professionals with adequate information regarding the identification of EDs.

Diagnosis of EDs

Nurses may also be directly involved during the process of diagnosing ED patients. This can be as part of the team working towards a specific diagnosis, helping within research (Szweda and Thorne, 2002), or being responsible for specific parts of the patient's assessment (Root and Tilsley, 2003).

Development of rapport between the patient and the treatment team

The nurse often acts as a mediator between patient and team, especially during the first stages of the treatment (Irwin, 1993). To do so, it has been suggested that the nurse herself should build up trust with the patient, becoming familiar with the individual's circumstances while displaying an empathic and non-judgemental style (Birmingham and Beumont, 2004).

Monitoring the patient's physical and mental state

As highlighted in this chapter, EDs affects all aspects of an individual's life, therefore frequent assessment of both physical and psychological states is required (Wolfe and Gimby, 2003). Specific routines should be in place to guarantee the adequate supervision of the patient. Those will aid the nurse to plan initial interventions when required (Irwin, 1993).

Establishing a therapeutic milieu with the patient

A healthy therapeutic relationship with the ED patient should be pursued in order to maximise treatment and the patient's benefit from it. George (1997) noted that empathy, positive outlook, acceptance, a non-judgemental attitude, trust, guaranteeing confidentiality, responsiveness, coherence, transparency and consistency were key characteristics for achieving a therapeutic and healthy milieu with the patient. Irwin (1993) suggested that nurses should be committed to a professional relationship with the patients they care for, trust being a key element of this aspect.

The nurse as educator, role model and group facilitator

King and Turner (2000) noted a lack of education programmes to support nurses caring for young people with EDs. They recommended that nurses should be more proactive and contribute to assessing and restructuring specific care protocols. Although this appears to be a common need throughout nursing in general, specialist nurses who commonly work with ED patients should recognise the need to establish better programmes that may improve the quality of their care (Lowther, 2005).

Clinical supervision among nurses

Regular supervision sessions appear valuable and necessary for nurses working within the EDs field, as described by Macmillan (1997) in the development of a specialist nursing-led eating disorders unit. Supervision can provide support and reassurance, and nurses themselves can coordinate this type of colleague supervision.

Research

White (2000) methodically reviewed and criticised some of the controversial findings that specialised research has yielded. Strategies for prevention of EDs were presented by White (2000) with a specific emphasis on the role that advance practice nurses may have in developing, collaborating and managing those strategies. In addition the need for further research by nurses in this area was also emphasised. Nurses may be involved in the regular evaluation of their own care programmes as well as programmes with a wider spectrum. Kong (2005) evaluated the effects of day treatment programmes for patients with EDs compared to those in the traditional outpatient setting in South Korea and found that day programmes seemed more effective in modifying certain eating behaviours, weight and certain psychological symptoms, having a more positive impact on the patients' self-esteem than the traditional outpatient treatment. The study also highlighted the fact that creative modification of programmes should be encouraged, taking into account the characteristics of the specifically targeted group.

In summary, the role of the nurse working within the ED field is varied and complex and nurses are an essential member of the team working with the ED patient. Nurses are skilled and deal holistically with the aspects of EDs, both in primary and hospital settings. In addition, they actively participate in research to improve the quality of patient management, and patients can benefit from the experience and attitude of the nurse throughout the recovery process. Nursing brings a unique blend of understanding to the treatment of the individual with an ED. Due to the unique position of nurses within the multidisciplinary team; they are able to contribute in varied ways to enhance adequate patient management (Irwing, 1993).

3.10 PATIENT EXPERIENCE OF EATING DISORDERS

Despite numerous pieces of research regarding EDs, a very relevant aspect again seems to be left aside by researchers: the patient experience of these conditions.

Hepworth (1994) noted that EDs have traditionally had a positivistic emphasis, since the first investigations presented by Lasegue (1873) and Gull (1874). Surprisingly, very little research focuses on the individual's understanding or meaning given to the ED per se, and it could be said that qualitative enquiry in relation to EDs is minimal. Most researchers use interviews as part of structured enquiry, to detect or evaluate progression of the ED (Keel et al., 2005), but very few pieces attempt to delve deeper into this area. The absence of qualitative work in EDs research could be related to weak developing theory and important implications for clinical practice (Hepworth, 1994). Using discourse analysis, Hepworth (1994) analysed interviews with UK health professionals caring for AN patients in an attempt to look at prevalence, maintenance and care, as well as the limited efficacy of AN treatments. Despite Hepworth's (1994) interesting approach, he did not incorporate any patients into his research, which once again underlines the unheard descriptions of patients. Other studies have tried to investigate the impact that an ED may have on family life. Hillege et al. (2006) aimed to understand patients' experiences in order to maximise appropriate clinical decision-making. This Australian study interviewed nineteen mothers and three fathers recruited via advertisement placed in a parent support organisation newsletter and using a snowballing technique. Qualitative analysis of the semistructured interviews identified themes through in-depth analysis, which highlighted social isolation, financial impact, inability to cope, stigma, and family disintegration. EDs may have a severe impact on the family, due to their particular nature and evolution and the constant struggle to deal with them. Hillege et al. (2006) concluded that increased involvement and integration into the treatment sequence would benefit families, if they were considered an important resource. However, this point appears debatable if families are not considered and seen as a whole and separated from the ED patient.

Haworth-Hoppner (2000) examined the influence of culture and family in the aetiology of EDs using a qualitative approach. The author explored how particular families may mediate cultural ideas about thinness and how those may affect the individual family members. To do so, thirty two middle class females with and without an ED diagnosis were interviewed and asked to discuss body image and eating problems. Qualitative comparative analysis was used to categorise family characteristics and combinations that could be related to the existence of an ED. Haworth-Hoppner (2000) noted that critical family atmosphere, coercive parental control, and discourses dominated by weight and appearance in the family unit seemed very relevant to the manifestation of an ED.

An interesting exploratory study by Nevonen and Broberg (2000) stimulated by grounded theory explored the emergence of EDs in a sample of one hundred and twenty-five Swedish patients with ages ranging from eighteen to twenty four years. Of those, twenty two had AN, sixty five had BN and thirty eight an EDNOS diagnosis. Patients' responses were analysed in relation to age of onset, why the ED had begun, and what the sequence was at the time. A mixture of interpersonal, as well as weight related problems, dieting, and other circumstances was identified by the patients as the main risk factors for the emergence of the ED. In this sample, mean onset age was sixteen which underline the long-term implications when it is considered that for many of those individuals the ED would have a chronic nature. Nevonen and Broberg (2000) used a semistructured clinical interview to obtain a systematic evaluation of a comprehensive clinical assessment that patients were attending for a semistructured clinical interview (The Rating of Anorexia and Bulimia Interview, Clinton and Norring, 1999). They combined this with a subsequent open interview to address the points raised in the first interview, which was then analysed using the constant comparison method and content analyses. The relevance of Nevonen and Broberg's (2000) study rests on the fact that particular attention was given to the facts that patients highlighted as important or relevant, and which many other pieces of research put aside as if the use of more sophisticated measures could provide just as accurate a picture of the patient experience, without actually having to gather personal accounts from the patients themselves. Their aim was to recognise the

interaction between factors that could be related to the onset of an ED and provided a stepping stone into the insufficiently understood patient insight. Nevenon and Broberg (2000) found that even when patients presented with very different EDs, their narratives were more parallel than expected, particularly concerning the beginning of the disorder. Additionally, by giving the patient the chance to speak freely, the patients' own understandings and representations of their EDs was presented, which empowers the individual and may picture a different and contrasting picture to the more traditional medical model.

Similarly, a recent study by Weaver et al. (2005) emphasised once again the fact that relevant qualitative literature in ED is scant. Their study addressed the limited understanding that specialists have regarding recovery from an ED, in relation to the patient's family, community or the wider society. Weaver et al. (2005) used a feminist grounded theory approach, and they explored the perceptions of twelve women recovering from AN. This study generated a substantive theory, providing a self-development model for recovery from the ED itself, and moving from perilous self-soothing (with behaviours such as bingeing, smoking, suicidal behaviour) to informed self-care. According to Weaver et al. (2005), their findings provide a much needed explanatory framework to inform women, clinicians and health policy makers to assist them in prevention and treatment programmes. Despite a reduced sample and the fact that this study only addressed AN patients, the results appear to make a significant contribution to this field, and reminds the reader that listening to the voices and accounts of the patients is imperative. By planning interventions that are based on the patients' accounts, the research bridges individual and research in an attempt to offer a comprehensive route for more effective management of EDs. Weaver et al.'s (2005) findings underlined the fact that the ED journey is a lonely one, and that recovery is impaired when there is a lack of social or therapeutic support. The authors insisted that more research is necessary to explore individuals' perceptions of treatment strategies so further statements can be made.

Although minimal, qualitative research in EDs appears to be present nowadays, and is making a more obvious contribution to the scientific literature. However, many more advances still need to be made and fresh research that incorporates qualitative

research into the field may be of significant benefit for the understanding and improvement of the complex subject of EDs.

3.11 HEALTH RELATED QUALITY OF LIFE AND EATING DISORDERS

It has been highlighted that psychiatric disorders are associated with impaired HRQoL, and this is the case for EDs (Al-Windi, 2005; Padierna et al., 2000; Jacobson et al., 1997). Few studies have evaluated HRQoL of individuals with EDs, and most of those used generic measures of health status (Nielsen and Bará-Carril, 2003). Most of them addressed AN and BN individuals and no studies were identified that specifically explored HRQoL for this extensive group of patients.

A recent review by Hay and Mond (2005) highlighted the fact that only fifteen papers could be identified after reviewing the MEDLINE database and *Quality of Life Research Journal* papers exploring HRQoL and diagnostic symptoms. A number of articles explored HRQoL and EDs in relation to other conditions, such as angina, transplant candidates (Keilen et al., 1994), diabetes (Grylli et al., 2005), mental disorders (Spitzer et al., 1995) and morbid obesity (de Zwaan et al., 2002) amongst others. Other pieces of research explored HRQoL only as part of a general assessment, or when evaluating a particular treatment (Silveira et al., 2005). But in general, studies that specifically address QoL or HRQoL in relation to EDs in general or a particular ED still only account for a small and very recent percentage (Las Hayas et al., 2006; Engel et al., 2006; Doll et al., 2005; Padierna et al., 2002; Padierna et al., 2000).

Padierna et al. (2000) investigated ED patients' perceptions of HRQoL in an ambulatory sample of Spanish individuals in relation to severity of eating symptomatology and psychological comorbidity. One hundred and ninety-seven consecutive patients were recruited from an outpatient EDs clinic. A combination of instruments were used to assess HRQoL in this sample: a generic HRQoL tool, SF-36, a psychological wellbeing instrument, HAD scale, and finally the EAT-40 test, an ED diagnostic test which was used in their study to evaluate the most frequent

symptoms in patients with EDs. Despite its generic nature, SF-36 appeared useful for measuring health deterioration in ED patients, and appeared to discriminate among various grades of severity of ED as supported by EAT-40 results. Several limitations to this study have been noted. The first one relates to the fact that the sample used in this study was part of a clinical sample of treated patients, which may relate to more severe symptoms and/or greater awareness of their condition. Repeated presence of psychological morbidity in the sample appeared to have an impact on the HRQoL results. Denial is a common feature in EDs, and Padierna et al. (2000) suggested that denial may have contributed negatively to the portrayal of the impact of their disease in this study, since results showed a dramatic impact on the HRQoL in patients with a significant association between severity as measured by EAT-40 and SF-36. No significant differences were found for the varied diagnostic groups. In summary, and despite limitations, Padierna et al.'s (2000) study corroborated the suggestion that subjects with EDs present global deterioration in their perception of their HRQoL (Keilen et al., 1994). In this case, this was especially manifest for the SF-36 areas dealing with vitality, emotional role, social functioning and mental health. The HAD and EAT-40 results were associated with a perception of greater impairment on all SF-36 subscales.

Another study by Padierna et al. (2002) explored the changes in HRQoL among patients treated for EDs. To do so a prospective design study was employed. A total of one hundred and thirty one ED diagnosed¹² Spanish patients with an age range from fourteen to sixty five constituted the study sample. Again, SF-36, HAD and EAT-40 questionnaires (Spanish versions) were used in this research as well as sociodemographic and clinical data. Each individual completed them on two dates (beginning and at twenty four months follow up). Study participants received psychopharmacologic and psychotherapeutic treatment over a period of two years¹³. It was found that of the 131 patients, thirty three per cent were restrictive anorectic, thirty six per cent were purgative anorectics, and thirty one per cent were bulimic patients, in a mostly female (98.5%) sample with an estimate ED mean duration of

¹² Based on DSM-IV (APA, 1994) criteria.

¹³ Treatment included: CBT, nutritional orientation, counselling, psychoeducation, motivational therapy, social skills training, therapy to modify distorted perception of body image tailored to each patient's needs and provided by a multidisciplinary team.

5.3 years. Padierna et al. (2002) did not differentiate between bulimic diagnosis or EDNOS. This study (Padierna et al., 2002) showed that despite certain improvements regarding HRQoL patients, perceptions, ED patients appeared more dysfunctional as pictured in the SF-36 analysis. Additionally, the severity of EDs symptoms was correlated with the degree of dysfunction experienced by the patient. This highlights both the chronicity and morbidity of ED symptoms and its impact on individuals, who see how HRQoL may be severely impaired by the ED. Despite breaking new grounds for assessing changes in the perception of HRQoL among patients with EDs over two years of treatment and subsequent follow-up, several limitations to the study were identified, which mostly related to specific questioning in some of the SF-36 instrument subscales. This opens the debate of whether generic instruments such as SF-36 specifically address information related to certain domains (e.g. hyperactivity, present in many EDs, is more likely to be considered healthy behaviour by SF-36). Padierna et al. (2002) argued that despite certain constraints, the use of generic tools in EDs assessment appears both justifiable and sound since it enables comparison and evaluation of the impact on psychiatric as well as non-psychiatric pathologies, and in the case of SF-36 is a *“simple, fast and effective instrument for the assessment of patients with EDs”* (Padierna et al., 2002; pp.551). However, the authors underlined the need for developing specific HRQoL measures that would specifically address relevant domains for EDs.

Mond et al. (2005) examined QoL among subgroups of ED patients by using two self-reported measurements (Medical Outcomes Study 12-Item Short Form Mental Component Summary Scale and the World Health Organisation Brief Quality of Life Assessment Scale, WHOQOL-BREF) on an eighty seven patient Australian sample referred for day programme treatment. A control group of four hundred and ninety-five young adult females was employed. AN purging type patients (n=15), AN restricting subtype (n=19), BN (n=40) and BED (n=10) patients made up the final sample. Mond et al. (2005) concluded that assessing QoL in ED patients with one single tool is likely to yield misleading results, and encouraged the use of multidimensional approaches when assessing ED patients. The authors emphasised the challenges that assessment of restricting AN patients may entail. Some issues

require special attention in this study. Patient numbers were limited, particularly for the AN and BED subgroups. Despite interesting findings, generalisability is compromised by sample size. Nevertheless, the findings seem to be consistent with Padierna et al.'s (2000) study, where significant differences emerged for both QoL measurements. Secondly, purging behaviour was used to classify AN cases, based on self-report measurements which is controversial as suggested by other authors (Carter et al., 2001). Thirdly, Mond et al. (2005) would have benefited from completion of data regarding sensitivity of a number of measures to treatment change as highlighted by Padierna et al.'s (2002) follow up study.

Authors have also tried to explore HRQoL on a more general basis. An example of this was an ambitious recent British postal survey of students' health conducted by Doll et al. (2005). The aim of this survey was to evaluate HRQoL on individuals with an ED; assessing ED type, longstanding illness, depression, and self-harming behaviours. The study was part of a larger UK survey gathering information on the health and lifestyle of approximately 1,500 students. A questionnaire booklet was produced to gather information on the student's physical and emotional wellbeing, attitudes and beliefs to health and prevalence of risk factors for future ill health as presented by Stewart-Brown et al. (2000). Doll (2005) and colleagues' main aim was to describe perceived HRQoL and other health issues in students with a history of ED of clinical severity. A secondary aim was to assess whether the SF-36 generic tool provided a valid assessment of HRQoL in subjects with EDs. The SF-36 scores of students with a history of ED were compared to those with no history of EDs and the relation between ED subtypes was examined. A response rate of forty two per cent was obtained for this study (1,439 of 3,750 students) which could have been influenced by the forty minutes needed by the student to complete the posted booklet (despite incentives ranging from a gift of £100 to £250). Curiously, Doll et al. (2005) noted that demographic information, BMI data, and SF-36 questionnaires were included along with questions taken from well-validated questionnaires used in national or regional surveys, but failed to address all those tools, which somewhat lessens the study's credibility. Another problem with Doll et al.'s (2005) study related to the ED diagnosis. According to the authors, questions on ED were

designed in consultation with appropriate professionals to diagnose a history of ED but again failed to include them in their research piece. Nevertheless, Doll et al. (2005) provided some of the questions included in the booklet. Although final conclusions highlighted the fact that the results obtained seemed consistent with the literature so far, generalisation of the results appears questionable especially regarding ED diagnosis. Doll et al. (2005) found $n=83$ ED patients out of 1,439 respondents and qualified this finding as “*large*”, therefore accounting for up to six per cent (95%) of the students (who would be considered as having an ED history). Doll et al. (2005) stated that this prevalence appeared somewhat elevated although consistent with other studies such as the one conducted by Gotestam and Agras (1995) which reported an ED prevalence rate of 8.7%. Doll et al.’s (2005) paper also highlighted emotional and psychological problems as being more prevalent in the individuals with a history of EDs; the high prevalence of suicidal ideation among this group, which corroborates previous studies reporting elevated suicidal ideation, seems particularly distressful (Johnson et al., 2001; Carpenter et al., 2000). Doll and colleagues (2005) found that regarding emotional and physical wellbeing, EDs were more strongly related to the emotional than to the physical dimensions of the SF-36 scores, as similarly reported in another study by Padierna et al. (2001). A particular finding by Doll et al. (2005) and also substantiated by Padierna et al.’s (2001) study revealed that the poorest SF-36 scorings were for binge eating patients, in contrast with the highest scores obtained by anorectic individuals. A potential explanation for this result may be the under-reporting of the AN subjects, as suggested by Doll et al. (2005) that could have led to misleading findings. SF-36 may not address specific emotional or even physical domains as specific psychiatric instruments (Bullinger, 1997) but it appears very useful for more generic purposes and group comparison. When using certain instruments for the assessment of the ED patient, it appears that personal interviewing could help the professional to elucidate certain aspects that may remain unclear if only one point of view is used.

The importance of specific HRQoL instruments was highlighted earlier, but it was not until 2006 that Engel et al. (2006) appropriately presented the EDQOL instrument that specifically addresses QoL for eating-disordered patients. Five

hundred and thirty eight female participants participated in Engel et al.'s (2006) study which aimed to demonstrate EDQOL's properties within ED patients. EDQOL is a well regarded tool that combines a shortened version of the original Structured Clinical Interview for DSM-IV Axis I Disorders (SCID) by First et al. (1995), certain probes from the EDE (Carter et al., 2001) and EAT-26 (Garner et al., 1982). Question generation for EDQOL was conducted by a panel of six experts in ED and HRQoL research in three steps: domain generation, content generation, and item generation. Therefore, EDQOL was presented as a twenty-five item scale with four subscales (psychological, physical-cognitive, work-school, and financial) plus a total meaningful score. According to its authors, EDQOL psychometrics appeared to be quite good, showing internally consistent subscales that showed good test-retest reliability. EDQOL appeared to be sensitive to group differences between disordered eating and non disordered eating groups, differentiated groups based on symptom severity, explained more symptom severity and group related variance than generic HRQOL instruments and demonstrated adequate convergent and discriminant validity (Engel et al., 2006). Although very promising, EDQOL presents certain limitations that should be addressed. First of all, because it has only very recently been developed, further testing is needed to verify its appropriateness for subsequent samples. The sample used to test it was not racially diverse (95% White, 2% Afro-American, 1% Native American), no men were included in the testing process, and all the data collected in the development of the tool were obtained from self-report instruments and no interviews or observations were taken into account. Lastly, existing data did not offer adequate sample size of each diagnostic group sufficient to make comparisons across groups. Despite these objections, EDQOL opens a new line of investigation that may be very useful for the research of HRQoL in the EDs area together with the similarly brand new HeRQoLED¹⁴ questionnaire presented by Las Hayas et al. in 2006. In a similar fashion to EDQOL, Spanish investigators proposed a self-report instrument of fifty questions that measures eight health-related domains, including symptom index. The team behind HeRQoLED's development included four specialised Spanish psychiatrists, epidemiologists, psychologists, patients, family members, and a multidisciplinary group of experts. Las Hayas et al. (2006)

¹⁴ HRQOL instrument for EDs.

proposed a new tool to measure HRQoL in the ED patient group, which presents good psychometric properties except in one original domain (binge eating) that was eliminated from the original version. Limitations also exist for this new tool, which requires further attention to certain domains (e.g. “*symptoms domain*” despite showing acceptable psychometric qualities), length of the questionnaire, and validity and reliability of the diagnoses of the psychiatrist used for inclusion of the study participants. Additionally, the application of HeRQoLED in further settings would provide further information on psychometric and sensitivity characteristics of this tool. Finally, and despite good prospects, HeRQoLED’s original format is in the Spanish language, which may hinder its incorporation into the research community until it has been translated.

A review of the literature suggests that there has been a recent improvement in the number and quality of studies that address HRQOL in people with EDs (Hay and Mond, 2005). To date, most of those studies use generic measures, SF-36 being a popular tool amongst them, and specific HRQOL measurements for patients with EDs appear necessary. Recent tools appeared in 2006 (e.g. HeRQoLED and EDQOL) which seem promising although further revising appears required due to their novelty. The design of instruments that specifically address each ED appears necessary, although numerous challenges connected to the nature of EDs surround this venture.

The importance of measuring and developing new avenues of research addressing HRQoL for EDs appears to be widely accepted among the scientific community. However, this is still under development. Adair et al. (2006) suggested that new ways should be opened to enhance research in this area and proposed the Internet as a source of data that could increase research within this field. Web research and its implication for nursing research in particular was discussed by Cotton (2003) who noted the wealth of opportunities offered by the World Wide Web (www) for conducting online health research. Although a potentially fascinating area, a series of ontological, epistemological, methodological, ethical, legal and professional issues and concerns regarding cyberspace research should be taken into account before

embarking on serious research concerning the *www* and HRQoL in EDs and research particularly.

Moving from broad spectrum research to more focused studies, it appears that research on HRQoL has neglected the patient as a source of information. Despite the relevance of individuals' views regarding their own QoL or HRQoL, very little consideration has been paid to this topic within the ED literature. A recent article by de la Rie et al. (2007) explored personal views of ED patients on their QoL. De la Rie and colleagues used a self-report questionnaire to address the most relevant aspects of the patients' lives and how they related to those identified aspects. Patients were recruited via magazine advertisement, the internet, leaflets, and via specialised centres. Despite this infrastructure, a modest sample of one hundred and forty-six former and current patients agreed to participate. Lifetime self-reported diagnosis for a DSM-IV ED (APA, 1994) was required from the patients based on EDE-Q (Fairburn and Wilson, 1993), and BMI and menstrual status were included in the final study. In order to assess patients' views on QoL, de la Rie et al. (2007) used a procedure based on the Schedule for the Evaluation of Individual Quality of Life (SEIQOL) (Joyce et al., 2003; Hickey et al., 2001) which is a semistructured interview that evaluates a person's QoL on a three step basis (de la Rie et al. (2007) used a written version). The five most important areas in their lives were identified by the patients and subsequently rated according to the level of functioning. Additionally, QoL was rated on a VAS15 scale from zero to ten for the five aspects previously selected, and finally quantification of the relative importance of each domain to the perception of the overall QoL was assessed, which enabled calculation of the "SEIQOL Index *Score*". This last step was simplified by de la Rie et al. (2007), although reasons for this were provided. Qualitative analysis examined aspects mentioned by the participants and were subsequently coded by using the KWALITAN (Peters, 2000) software programme to enable clustering of items and categories. Quantitative analysis examined differences between current and former ED patients and diagnostic subgroups by using a χ^2 test, and t-tests were employed to investigate differences between the use of purging and non purging ED patients

¹⁵ VAS: Visual Analogue Scale

without addressing diagnostic subgroups due to low frequency among domains. Results highlighted a “*sense of belonging*” as the domain most commonly noted by the participants (ninety three per cent for both current and former patients). Domains referred to as contributing to QoL encompassed health, wellbeing, work, education, disease specific psychopathology, sense of self, life skills and a sense of purpose or meaning. Interestingly, current ED patients reported poorer QoL in most domains (higher for self-image and wellbeing) than former patients, although these scores appeared just above average. Also, purging ED patients reported poorer QoL on disease specific psychopathology than non purging ED patients. Although promising, de la Rie et al.’s (2007) work presented several limitations that should be addressed. Limited participation and the peculiar recruitment strategy could imply a particular bias determined by individuals willing to participate in such a study. Additionally, the self-report measurement of QoL and the overall presentation of the questionnaire appeared limited and a more qualitative emphasis may have opened further avenues. No control group was present, which may reduce the validity of the conclusions. However, de la Rie et al. (2007) opened an important path into QoL assessment in EDs by taking into account patients’ views. This could be advantageous to further studies assessing individuals’ HRQoL views.

To sum up, it seems that HRQoL work within the EDs field is growing but uneven, and specific areas need further exploration, particularly those regarding patients’ views.

3.12 SUMMARY

EDs comprise a range of syndromes encompassing physical, psychological and social features. EDs are characterised by a morbid preoccupation with weight, shape and food that manifest as chaotic or distorted eating behaviour.

As identified in this chapter, the most common EDs are classified into three main diagnostic categories: AN, BN and EDNOS. These conditions are extremely disabling and present overlapping symptoms and similar aetiological factors. Raised mortality and high levels of physical and psychological comorbidity appear to be

present. Additionally, serious implications for the sufferer's HRQoL, work and social functioning have been highlighted by the literature.

To date, treatment efficacy is still limited and most of the investigations have focused on AN and BN conditions, which highlights the need for further research on EDNOS treatment strategies. This may be hindered by the lack of clarity that surrounds this most prevalent subtype of the EDs compound.

The growing numbers of EDs have been pointed out in this chapter, both for younger and older patients, however a significant proportion of cases still seem to be going undetected. This point seems crucial for obtaining a more accurate picture of ED patients, which would then help to identify patients and their needs to subsequently develop enhanced management and treatment strategies. The need for early detection of EDs has been identified.

Chapter 4 will introduce the methodology used in this study, along with the tools employed in the different phases of this investigation.

Chapter 4

Methods

4.1 INTRODUCTION

This chapter describes the process of the research project development. The aims for the study and the research questions are set out below. The rationale for the choice of methods is also discussed and the use of a mixed method approach to data collection is justified. The conducts of both the quantitative and qualitative parts of the study are described and finally, ethical issues and the analysis of data and are considered.

4.2 RESEARCH AIMS AND RESEARCH QUESTIONS

The overall aim of this mixed method study was to further explore and understand the suggested link between IBS and EDs (Boyd et al., 2005; Porcelli et al., 1998; Tang et al., 1998; Sullivan et al., 1997). This study evolved directly from the researcher's clinical nursing experience in both the mental health and general setting and from a thorough review of the scientific literature.

1. To investigate the potential presence of eating disorders in a female IBS sample by using two eating disorders screening tools (ESP and SCOFF)
2. To compare ESP and SCOFF screening tools' performances.
3. To investigate HRQoL in this sample of patients.
4. To evaluate anxiety and depression in this sample of patients.
5. Using a thematic content analysis technique:

- a) to qualitatively assess the presence of potential eating difficulties in a GI female sample.
- b) to assess the participants' experience of IBS and/or EDs in a GI female sample.

To explore nursing perceptions and attitudes towards IBS and/or ED in a sample of GI specialist nurses who were members of a national GI Society.

To explore the experience of individuals with IBS and potential EDs and in order to meet the proposed aims of the study, the researcher elected to investigate the following research questions:

- What is the presence of potential EDs in a female IBS sample when using two screening tools (ESP and SCOFF) for the detection of eating disorders?
- What are the differences between ESP and SCOFF screening tools' performances?
- What is the HRQoL for this sample of patients?
- What levels of anxiety and depression are present in this patients' group?
- How do patients live the experience of having IBS and a potential ED?
- What are the perceptions of a sample of GI nurses of IBS and EDs and their sufferers?

In order to answer the research questions previously addressed, three strands of data collection were conducted. Briefly, these were:

Strand 1: The administration of a battery of questionnaires to the participants in the study who had been previously selected with a confirmed Rome II criteria diagnosis of IBS and according to inclusion-exclusion criteria as detailed further in this chapter. Those questionnaires included the following instruments (Appendix 4):

Current Symptoms Scale, ESP, SCOFF, SF-36 (Ware et al., 1993), EQ-5D (Euroqol Group, 1990), IBSQoL (Hahn et al., 1997) and HADS¹ (Zigmond and Snaith, 1983). Additionally, weight and height measurement were taken, and BMI measures were then produced.

Strand 2: Semi-structured interviews conducted on a subsequent sample of participants who had been identified as “*potential cases*” according to the screening tools (SCOFF and ESP) used to identify potential EDs.

Strand 3: The evaluation of nurses’ perceptions and attitudes towards patients with IBS and EDs using an adapted version of a questionnaire by Letson and Dancey (1996) on a sample of GI nurses.

As outlined in Chapter 1, few studies have focused on exploring the patient’s experience of IBS and EDs. To the researcher’s knowledge, no studies have examined the incidence of potential eating disordered behaviour in patients with an IBS diagnosis and the impact of this upon the patient.

This study, focused uniquely on female patients, and was conducted in an out-patient department of a general hospital.

4.3 RESEARCH DESIGN

In order to explore and answer the proposed research questions of the study, an appropriate research design had to be selected. The study aimed to examine the link between IBS and EDs and to explore, the experience of suffering from these conditions.

After much consideration of alternatives and due to ethical considerations, resources, financial constraints and time limitations the researcher decided to employ a mixed methods sequential explanatory design (Plano-Clark, 2007; Creswell, 2003). This type of design consists of two different stages, a first quantitative part and a second

¹ Also known as HAD Scale.

qualitative part. The quantitative data are collected first followed by the qualitative data that help to explain and elaborate on the data obtained in the first strand of the study. The rationale for choosing this approach is that the quantitative data and subsequent analysis provide a general understanding of the research problem. Qualitative data and its analysis refine and help to explain the statistical inferences by exploring the participants' views in more depth (Creswell and Plano-Clark, 2007; Creswell, 2003). Additionally, methodological triangulation was used according to Smith (1975, pp.290-291).

This combined approach was chosen in order to apply the most appropriate method for each research question. Multimethod research is usually used when multiple approaches are employed to address a particular research problem, and generally characterizes research pieces where both quantitative and qualitative data are retrieved and further analyzed (Polit and Beck, 2004, p.724).

To date no other studies have used mixed methods to examine the impact and experience of these conditions, this study was explorative. The lack of studies that have been undertaken in this area and the outcome of other studies suggest that no single data collection tool could produce valid and reliable results for this study. To enhance the reliability and validity of the findings the researcher combined a number of data collection tools to address specific research questions. Quantitative data collection methods could have been used to study many of the variables within each research question. However, the researcher's experience and knowledge of the issues under investigation indicated that sole use of quantitative tools to investigate some of the sensitive and experiential issues would be inappropriate for this study. To gain insight into the patients' experiences of having a potential ED associated with IBS and to explore issues regarding this subject, it was felt that methods of a qualitative nature had to be employed.

According to the literature, the ways of combining qualitative and quantitative data into particular research are endless, and is determined mainly by the creativity of the researcher and also the feasibility and adequacy of the project. In the case of this study it was thought that different stages of data collection would be beneficial for

the study's development. Using this approach meant that the researcher could analyze the quantitative data, and use it to guide the qualitative contribution from the patients' interviews. In addition, it was thought that information from the first quantitative part of the study would be useful to select the sample of patients who would then participate in Strand 3 of this research.

4.3.1 Multimethod Design

Historically, nursing research has been led by quantitative studies (Johnstone, 2004; Polit and Beck, 2004). Qualitative studies found their place and acceptance within the nursing literature at a slower pace (Flick, 2002) and it was not until the 1980s that methodological pluralism seemed to emerge (Creswell et al., 2004). Nowadays a growing number of researchers are presenting the case for integrating qualitative and quantitative research methods (Plano-Clark, 2007; Burns and Grove, 2003). By integrating different data collection methods within a single study the weaknesses of either quantitative or qualitative data methods on their own can be overcome (Sells et al., 1995).

The quantitative versus qualitative debate has been present within the nursing literature for many years reaching relatively intense levels over time (Polit and Beck., 2004). Quantitative approaches employ numeric data to examine the phenomenon in question under controlled conditions (Polit and Hungler, 1997), whereas qualitative methods use a narrative description to explain the phenomenon according to the researcher's interpretation (Burns and Grove, 2001). However, several authors have emphasized the potential benefits of combining both approaches in order to supplement and strengthen the quality of the obtained data. The methodological dispute appears to have finally waned and nowadays there seems to be a general recognition that each approach provides a valuable contribution to nursing research (Parahoo, 1997). Indeed, at the present time, and given the complexity of many of the phenomena of interest to nurses, a combination of approaches appears to be the natural choice for numerous researchers (Tolson, 1999). This strategy is known as multimethod or mixed-method research.

Multimethod research can contribute towards research in general, and nursing research in particular, in different ways. Hypothesis generation, explanation and validation of constructs, instrument development, understanding relationships and causal processes, as well as illustration or clarification of data are some of the applications of merging research methods (Polit and Beck, 2004). It is this last aspect of clarification, which is especially relevant for the purpose of the study, where multimethod research is hoped to aid the researcher into finding patient's personal contributions towards a further understanding of the quantitative data collected. In addition, complementarity, enhancement of theoretical insights, incrementality and enhancement of validity are some of the positive aspects that Polit and Beck (2004) discussed as constructive sides of multimethod research. Data can be supplemented by using this type of approach, using the idea that potential weaknesses of a single approach, such as failing to capture particular nuances of a specific study, could be reduced by relying on multiple ones. Unquestionably, particular attention should be paid to control limitations inherent to both approaches. As noted by Polit and Beck (2004, pp.274), a combination of methods can "*supply each other's lack*". Secondly, quantitative and qualitative research might respond to different ways of perceiving the outside world and subsequently interpreting it according to an alternative basis. Combining data can guide the researcher towards an integrative insight of the phenomena studied². Research designs combining different methodologies are not unproblematic since, these methods belong to traditionally diverse paradigms with fundamentally different epistemological frameworks (Foss and Ellefsen, 2002). Several authors (Barbour 1999a; Polit and Beck, 2004) have suggested that multimethod research is unlikely to put equal emphasis on qualitative and quantitative methods, but this does not necessarily imply breaking with basic paradigmatic assumptions. Despite its detractors, multimethod research or mixed-method research³ has been presented by other authors as entailing many advantages over a single methodological approach (Green and Caracelli, 1997). However,

² For this purpose, triangulation emerges as a way of working towards converging on the same truth. Several authors have pointed out the benefits of triangulating quantitative and qualitative methodologies in health research. However, this can also prove problematic. Triangulation derives from navigation, where different bearings give the current position of an object (Silverman, 1993). However, triangulation is not always compulsory and it will depend on the nature of the study whether this technique is applied.

integration of methods is not free of controversy and can be problematic at times (Foster, 1997). Taking into account that combining methodologies can represent a great challenge and that in many cases difficulties from both approaches might be added, whilst the researcher recognizes that some positive aspects of integrating designs also exist and will be presented here.

A further problematic aspect is that, the development of a particular problem or research project is rarely unidirectional, needing from explorations and reflection that require constant evaluation. Atkinson (1995) and Frei (2005) suggest that research questions frequently emerge once the particular research gets underway. This may have a direct impact on the subsequent development of the study or indeed cause the development of the research to take an unforeseen course. According to Polit and Beck (2004), developing a body of evidence for nursing practice is usually incremental, relying on various feedback circles. Finally, using mixed-method approaches might enhance the validity of new discoveries. As noted in the literature review, no perfect method exists, and therefore even the most refined projects can benefit from the corroboration provided by other methods (Patton, 2002; Morse, 1991).

4.3.1.1 Types of multimethod design

Sandelowski (2000) and Green and Caracelli (1997) provided two different ways of categorising research designs when using a mixed-method approach. The former provided a particular typology of multimethod design which concentrates on the primacy of the approach selected as leading. Sandelowski developed a matrix with diverse templates where qualitative and quantitative data would be then used to supplement designs in a varied way. Green and Caracelli (1997) identified two broad categories: multimethod integrated designs and multimethod component designs.

Multimethod integrated designs are defined as the merging of data in ways that amalgamate the elements from the paradigms, providing the possibility of generating more insightful understanding of phenomena. This particular type presents higher

³ The author will use both terms interchangeably.

integration of the different methods at all times of the project, from the beginning to the end.

Multimethod component designs are characterized by the fact that qualitative and quantitative components are implemented as discrete components of the overall inquiry and remain somehow separated during the processes of data collection and data analysis. The combination of the components usually takes place during the interpretation and reporting of the data. This was described by Miller and Crabtree (1994) as concurrent design.

Three subtypes of component designs were described by Green and Caracelli (1997): triangulated design, complementarity design and expansion design. The first type refers to those designs where both quantitative and qualitative approaches are directed towards grasping the same aspect of research, and further validating it by triangulation. The second type refers to designs when one type of method is enhanced or clarified by results from the other type, as is the case in this particular study, where final qualitative interviews were used to supplement quantitative data with the unique contribution of the participants' interviews. The final kind refers to designs where varied methods are used for different examination components. When using this particular approach, results are usually presented separately, instead of merging them into a single account (Green and Caracelli, 1997). The project presented here is driven by an a priori theoretical framework, and quantitative methods take precedence but are complemented by qualitative methods.

4.3.2 Setting

The study took place in a GI outpatients' clinic of the hospital selected. This particular location was chosen due to the fact that it is one of the main university teaching hospitals in the region and also because the GI services in this site receive most of the referrals of patients with functional GI problems in the area. Patients are commonly referred to the specialized services from a broad range of health services. The university teaching hospital is located in Edinburgh, Scotland and is part of the Scottish NHS Services.

4.3.3 Subjects and Sample Selection

Subjects in this study were female IBS patients attending a motility clinic of a Scottish hospital. They were selected on the basis of the inclusion/exclusion criteria presented below.

To estimate the sample size needed, statistician advice was sought in order to ensure that adequate numbers were obtained for the quantitative sample. On this basis, a total of one hundred and thirty-four females were included in the final sample, after exclusion of those participants who had not completed the total of the questionnaires provided.

4.3.4 Inclusion Criteria

For the purpose of this study the following inclusion criteria were chosen:

1. Female patients with a diagnosis of IBS based on Rome II criteria
2. Age range: eighteen to sixty years old
3. Able to read and write in English
4. No concomitant major disease

For the purpose of this study, the researcher examined the impact of IBS and EDs on female patients. As addressed in Chapter 2 and Chapter 3, both these conditions are significantly more prevalent in females than males (Treasure et al., 2003; Camilleri et al., 2002). The researcher chose to examine these conditions in women up to the age of sixty with the rationale that most of the studies exploring potential EDs are conducted on adolescents or young females. If EDs appear to have chronic development and to be of a secretive nature it would be possible that such cases pass undetected. In the light of Mangweth's (2005) findings, which suggested that EDs can be found in older women, it was decided to conduct this study on a female population with a wider age range.

4.3.5 Sampling

The target population for this study was patients with IBS attending a motility GI outpatient clinic. A non probability purposive convenience sample form of sampling was used for the initial quantitative stage of the study. Purposive sampling is defined by Polit and Beck (2004, p.729) as a non probability sampling method where the researcher selects potential participants based on personal judgment about which ones will be most representative or informative for the study.

Over a six month period all IBS patients with an established Rome II criteria diagnosis were recruited by the researcher. This may lead to some limitations as convenience sampling has been criticized as a potentially poor way of selecting patients for a study due to its inability to control bias (Cormack, 1991). However, the aim, disease process and ethical considerations of the study dictated that a convenience form of sampling was the most appropriate for this study.

A consecutive sample of patients who presented as “*potential ED case*” was later used for the qualitative part of the study. It was acknowledged by the researcher that this form of sampling would not allow the collation of generalisable data. However, as this was not the purpose of this part of the study, this type of sampling appeared appropriate (Burns and Grove 2003). The reason for incorporating semi-structured interviews was to add depth and meaning to the initial study data, and by selecting patients appropriately, the researcher aimed to generate data that would reveal the patient’s experience of living with IBS and potentially an ED. Twenty five patients with positive SCOFF2 scores (or potential cases) were selected for subsequent interviewing.

4.3.6 Informed Consent

As participation within this study required the patient to participate in activities that would not normally be deemed necessary, informed consent was required.

Potential patients were approached by the researcher who explained the study to them. Additionally, potential participants received the Patient Information Sheet (see

Appendix 8) which provided additional information about the study. Patients were given the time until their next visit to the clinic to consider whether they wished to be part of the study. If patients agreed to be part of the study they completed a standard written consent form before the interview took place. It clearly stated that participation for this part of the study was voluntary and that participants were free to withdraw their consent at any time without any prejudice to them.

4.3.7 Ethical Approval

Ethical approval for this study was sought and fully gained from Lothian Regional Ethics Committee. Application REC reference number (06/S1102/6) was granted and approved prior to commencement of the data collection period (see Appendix 3).

4.3.8 Ethical Considerations

A multimethod study of IBS and potential EDs had several ethical implications. In the first instance, these related to confidentiality and anonymity. Informed consent ensured that patients were fully informed of their right to withdraw from the study and made fully aware that withdrawal would not disadvantage them in any way.

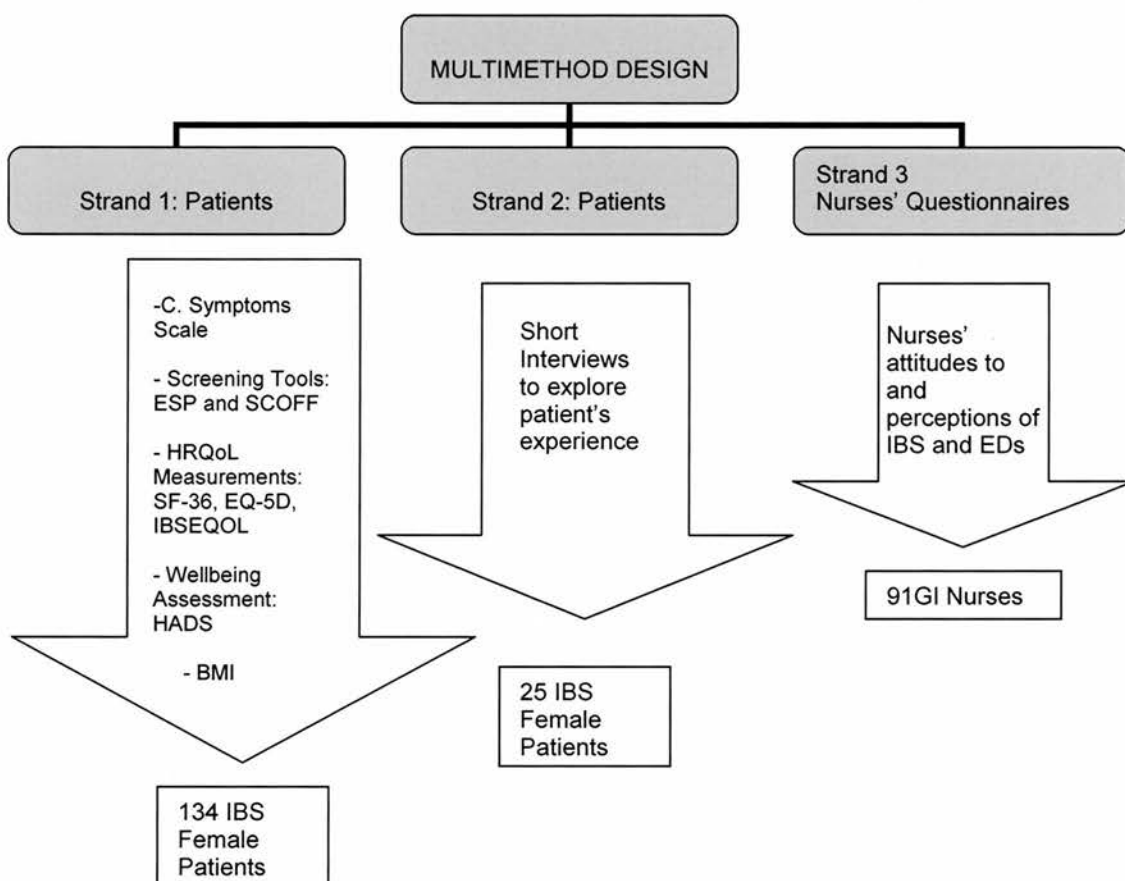
Patients were assigned a unique study number at the onset of the study to protect their identity. All data was safely and securely stored until study completion. Data Protection Act regulations were followed throughout the research process.

The nurse researcher was aware of professional accountability and took all the precautions not to induce harm and prevent the patient from coming to harm (NMC, Code of Professional Conduct, 2004). The dual role of nurse and researcher was difficult to manage at times. The research nurse had experience in the field of management of EDs and is a member of the EDA, therefore was aware that the dependent relationship which may develop between researcher and patient may have some influence on the study. An example of this would be if a patient presented with an ED that required urgent clinical management. In such situations, the researcher would inform clinical staff to ensure that the patient was appropriately managed. To minimize the impact that this had upon the study findings, the researcher documented

each time a situation like this arose in an attempt to control the impact the intervention may have on the study results.

4.4 DATA COLLECTION PROTOCOL

This section is divided into two main parts: quantitative data collection and qualitative data collection. Each part will provide an account of how data was collected and the rationale behind the choices made.



4.5 STRAND 1: QUANTITATIVE DATA

The section will introduce the part of the study that used a quantitative approach to assess patients. Subsequently, it will explore the use of questionnaires and screening tools, and each of them will be addressed individually. In this study, the combination of both validated questionnaires and established clinical screening tools was used to

strengthen the design chosen. In addition, the use of two screening instruments was used to explore the potential use of such screening tools in the GI outpatients' setting.

During a period of six months all female patients within the inclusion criteria who attended the outpatient clinic were approached by the investigator. The outline of the study was explained to the patient and an information sheet (see Appendix 8) was provided. The researcher encouraged potential participants to discuss any doubts or concerns that they might have. Patients were given one week to consider their participation and the next time they attended the clinic they were again approached by the nurse investigator when they freely decided whether to take part in the research or not. If patients agreed to participate they were asked to complete a consent form and the first stage of the data collection process commenced. The number of potential participants approached and compliance are shown in the table below.

Table 4. 1: Patient Numbers

Patients approached for Strand 1 (Questionnaires)	Patients agreeing to take part in the study	Patient completing all data questionnaires	Patients approached for Strand 2 (Interviews)	Patients interviewed
172	163	134	27	25

A total of one hundred and seventy-two patients were approached, and a further one hundred and sixty-three participants agreed to take part in Strand 1 of this study. However, when the data was checked, it emerged that certain individuals had failed to complete the full package of questionnaires. Several hypotheses could explain this. One is the fact that the layout of the questionnaire was not appropriate. Both sides of the paper were used in order to reduce paper waste and as a result, some patients failed to realize that they had not completed the whole task. On the basis of initial poor completion rate, the questionnaire was slightly modified and as a result, data completion improved in the following weeks. Reasons for non-completion of questionnaires included: length of the full package noted by four patients, and two

individuals who failed to complete questionnaires due to indisposition while at the clinic. Finally, one patient refused to complete the questionnaires because she did not agree with the questions asked by the HRQoL instruments. She made suggestions throughout the entire document but refused to answer it.

4.5.1 Study Variables

The variables measured in this study were determined on the basis of the literature review and the researcher's own experience of dealing with this patient group. An outline of them can be seen in the following table. A rationale for its selection is provided below. A combination of data collection methods was used within this study to explore each variable. These are summarised in Table 4.2.

Table 4.2: Outline of the Data Collection Methods Employed in this Study

Variable	Data Collection Method	Data Collection Tool
Symptoms	Quantitative and Qualitative	Current symptoms Scale and Interview
Presence of Eating Disorders	Quantitative and Qualitative	Screening Tools: ESP and SCOFF and Interviews.
Anxiety and Depression	Quantitative and Qualitative	HADS and Interview
Health Related Quality of Life	Quantitative and Qualitative	SF-36, EQ-5D, IBSQoL
BMI	Quantitative	Weight and height measurement
Nursing Attitudes and Perceptions of IBS and EDs	Quantitative	Adaptation of Letson and Dancey (1996) questionnaire
Patient experience	Qualitative	Semi-structured Interviews

A combination of data collection methods was used within this study to explore the selected variables.

a. Current Symptoms: IBS patients present with a wide variety of symptoms, therefore it was the intention of this study to describe the most common symptoms for this particular sample.

b. Presence of Eating Disorders: The link between IBS and EDs is still unclear. By using two recent screening tools, this study aimed to provide further information in this particular field. It was not the intention of this study to diagnose EDs, but to identify patients with potential problems. A further aim of introducing ESP and SCOFF in the GI setting (which to the author's knowledge had never been undertaken previously) was to further knowledge regarding the performance of both tools

c. Anxiety and Depression: Both are common amongst IBS (Gonsalkorale and Whorwell, 2005) and ED (Treasure et al., 2003) patients. This research wanted to attain further understanding of the psychological wellbeing of the selected sample, and the particular traits that individuals could exhibit.

d. Health Related Quality of Life: IBS and EDs appear to have a significant impact upon the individual HRQoL (Porcelli et al., 1998). Therefore, several HRQoL measurement tools were used in order to explore this concept within the study sample. Additionally, interviews were conducted to explore this same area to provide another perspective and in depth data.

e. BMI: This represents one of the most commonly used methods of weight categorization (DHHS, 1988) and has previously been shown to be related to problem eating and body dissatisfaction (Sanchez-Villegas et al., 2001). It is easy to generate and it was thought useful in enabling this research to paint an accurate picture of the study participants.

g. Patient experience: Most of the studies regarding EDs and IBS are quantitatively oriented. To the author's knowledge, no study had explored the IBS patient with a potential ED experience from a qualitative point of view.

f. Nurses' Perceptions of IBS and EDs: It has been suggested that nurses' attitudes and beliefs towards a particular condition influence the quality of treatment they provide. By evaluating nurses' attitudes and knowledge of IBS and EDs, this study

aimed to gain further information regarding knowledge gaps, or particular stereotypical ideas that nurses may hold regarding any of those conditions.

The following sections will present the instruments used to investigate the research questions and the study variables.

4.5.2 IBS Classification Checklist: Current Symptoms Scale

Assessment of physical symptoms was undertaken with the use of a specifically designed symptom checklist sheet. This confirmed the presence of IBS in line with Rome II criteria (see Appendix 5), although diagnosis was confirmed by medical practitioner or the clinical nurse specialist at the clinic.

4.5.3 Eating Disorders Screening Tools: SCOFF and ESP

Participants in this study completed both the SCOFF (Morgan et al., 1999) and ESP (Cotton et al., 2003) screening tools. Several authors have emphasized the importance of the early identification of potential EDs (Birmingham and Beumont, 2004). Early diagnosis favours recovery in EDs (Pritts and Susman, 2003), which is particularly important when it is considered that in many cases these conditions may become chronic (Treasure et al., 2003).

The assessment of potential EDs has been traditionally done by the use of complex and lengthy questionnaires, such as BITE (Henderson and Freeman 1987), EDE (Fairburn and Cooper, 1993), SCID (Spitzer et al., 1987), BULIT-R (Thelen et al., 1991), QWEO-R (Spitzer, Yanovski and Marcus, 1993), ESI (Whitaker et al., 1989), BES (Gormally et al., 1982), EDI-2 (Garner, 1991), EAT (Garner and Garfinkel, 1979) and EDI (Garner et al., 1983) (amongst many others) that might require professionally trained interpretation (See Chapter 2). Although, in most cases, extended questionnaires appear reliable, the literature review identified the need for shorter tools that might be of use when exploring wider populations, or when settings simply do not favour the use of lengthy instruments. A number of shorter tools aimed at identifying potential subjects that might be at risk of developing an ED in the clinical setting have emerged in recent years, including ESP and SCOFF.

Screening tools or screening instruments are defined as the instruments used “to determine whether potential subjects for a study meet eligibility criteria or also whether a person has a specified condition” (Polit and Beck, 2004; p.731). They appear useful for population-based interventions and can be helpful in the identification of a population in need (Jacobi et al., 2004). When accurate, they might also play a major role in the efficient use of resources.

Both screening tools are presented and briefly examined below.

4.5.3.1 *SCOFF (Morgan, Reid and Lacey, 1999)*

SCOFF is a screening tool designed to “raise suspicion of an eating disorder” (Morgan et al. 1999, p.1467). Potential cases should then undergo a clinical evaluation with referral and treatment as required.

The analysis set the threshold for SCOFF at two or more abnormal⁴ responses as indicative of potential ED, obtaining, according to the authors, a sensitivity of 100% for both AN and BN. Morgan and colleagues (1999, p.1468) described their tool as “highly effective as a screening instrument for ED” and also “memorable” due to its easy-to-use approach. It should be acknowledged the fact that SCOFF’s purpose is to raise suspicion and not to make diagnosis.

The written version of SCOFF was re-examined for reliability by Perry, Morgan, Reid et al (2002) in order to compare verbal and written responses. Their study showed good replicability of the written version of SCOFF, and the authors supported the use of written SCOFF as a valid and reliable screening tool for EDs. SCOFF’s performance in primary care was examined by Luck et al. (2002) and based on its “excellent validity in clinical population and reliability in the student population” the authors recommended its use for adult women in primary care and promoted work to assess validity in other populations (Luck et al., 2002). SCOFF has aroused particular interest in Spanish speaking countries. Ayerbe-García et al. (2003) discussed the benefits of SCOFF and promoted further validation of it in the Spanish

setting. Rodríguez-Martín et al. (2004) described SCOFF as highly effective for detection of ED, very sensitive and easy to apply, and Rueda-Jaimes, et al. (2005) recently validated SCOFF for use on school adolescents in a Colombian sample.

Raising awareness of potential ED is one of the positive aspects of SCOFF. Even in the cases where false positives are obtained, it would be necessary to discuss the results with participants to find out more about participants' situations and to investigate why those scores were reached.

Table 4.3: SCOFF Questionnaire

SCOFF Questions
<ul style="list-style-type: none">• Do you make yourself sick because you feel uncomfortably full?• Do you worry that you have lost control over how much you eat?• Have you recently lost more than one stone in a three-month period?• Do you think you are too fat, even though others say you are too thin?• Would you say that food dominates your life?

According to the authors, in order to analyze SCOFF, one point is given for every “yes” answer. Therefore, a score of two or more would indicate a likely case of ED. In Morgan et al. (1999) study, the sensitivity was estimated to be 100% and the specificity 87.5 %.

4.5.3.2 *Eating Disorders Screen for Primary Care (ESP)* (Cotton, Ball, and Robinson, 2003)

Cotton et al (2003) developed a set of questions named ESP (Eating Disorders Screen for Primary Care) that aimed to highlight potential ED in primary care. Cotton et al validated SCOFF in primary care patients and a high-risk population (university students), assessed the ESP tool which had its origin in other studies (Anstine and Grinnenko, 2000; Freund et al., 1993; McNulty, 1997) and compared the performances of the two tools. Cotton et al's (2003) results suggested that SCOFF was less helpful than previously reported. ESP results maximized sensitivity at 100% when the cut-off point was set at two or more abnormal responses. Higher

⁴ Abnormal as defined by the Morgan et al. (1999).

sensitivity was achieved by ESP (100%) than by SCOFF (78%) but SCOFF's performance in specificity (88%) was better than that of ESP (71%). Cotton et al (2003) advocated the use of ESP and SCOFF in populations with a lower presence of ED, something that would enhance their screening power. The researcher is of the opinion that the joint use of ESP and SCOFF could be valuable in the GI setting due to their short presentation and suggested effectiveness.

SCOFF and ESP screening tools were completed by all patients in the study. The sensitivity and specificity of SCOFF and ESP as screening tools was examined using ROC curves, which are introduced later and further discussed in Chapter 7.

Table 4.4: ESP Questionnaire

ESP Screening Tool (Cotton, Ball and Robinson, 2003)
<ul style="list-style-type: none"> • Are you satisfied with your eating patterns? • Do you ever eat in secret? • Does your weight affect the way you feel about yourself? • Have any members of your family suffered with an eating disorder? • Do you currently suffer with or have you ever suffered in the past with an eating disorder?

According to Cotton, Ball and Robinson (2003), in order to analyze ESP, again one point is given for every “*abnormal*” answer. Therefore, a score of two or more would suggest a likely case of ED.

4.5.4 Health Related Quality of Life Assessment

There are a variety of instruments which aim to measure HRQoL, ranging from single questions to scales and more elaborate specific tools. The two types of tools most commonly used to measure HRQoL are generic and disease-specific instruments. The researcher decided to combine generic and disease-specific HRQoL measures in this study to avoid missing unexpected outcomes and ensuring recognition of all clinically important information (Irvine, 2004).

Additionally, because measurements were exclusively taken at one point in time due to the characteristics of the sample, normative values from those HRQoL instruments

were used to compare the study sample values, and therefore to examine the impact of IBS/ED upon HRQoL in order to obtain a fuller picture of the participants.

Table 4.5: HRQoL Assessment tools completed by patients.

Measurement	Type
SF-36 (Ware et al., 1993)	Generic
EQ-5D (The EuroQoL Group, 1990)	Generic
IBSQoL (Hahn et al., 1997)	Disease-specific

The HRQoL assessment tools selected for this study are briefly presented next.

4.5.4.1 *SF-36 (Ware et al., 1993)*

The Short Form-36 Health Survey of the Medical Outcomes Study questionnaire (SF-36, Ware et al., 1993; see Appendix 4) was originally intended as a generic indicator of health status for use in population surveys and evaluative studies of health policy (McDowell and Newell, 1996). SF-36 is a generic, multipurpose, comprehensive tool created to be employed in all social and demographic groups regardless of age, disease or treatment group (Corcoran and Durham, 2000). SF-36 is a short form scoring system with 36 items, (self-administered questionnaire) that was constructed to bridge the gap between lengthy surveys and comparatively coarse single item measures of HRQoL (DeOreo, 2001; Kalantar-Zadeh et al., 2001). As its name indicates, it consists of thirty-six questions, thirty-five of which are grouped into eight multi item scales: physical function (ten items), social functioning (two items), mental health (five items), role limitation due to physical problems (four items), energy/vitality (four items), role limitation due to emotional problems (three items), pain (two items), and general health perception (five items).

SF-36 quantitative scoring system independently addresses each scale. A final score between zero and one hundred is calculated on the basis of well-defined guidelines with a higher score total suggesting a better state of health. The standard version of SF-36 (Ware et al., 1993) denotes changes in health status in the past four weeks. Two main dimensions or components summarize SF-36 scales, being the first four

domains relevant for the “*physical health*” one and the rest would account for the “*mental health*” component. Nevertheless, vitality and general health are considered as part of both dimensions. Additionally, SF-36 incorporates a self-evaluation question concerning change in health during the past year, which accounts for the total dimension of the SF-36 score.

According to McDowell and Newell (1996), all SF-36 scales appeared sufficiently reliable for comparing groups and the physical functioning scale appeared reliable enough for comparing individuals. The SF-36 manual gives criterion validity information on the scales, comparing scales scores to ability to work, symptoms, use of care, and to a range of criteria for the mental health scale. Each comparison suggested significant and consistent association with the validation criteria (McDowell and Newell, 1996). Validity and interpretation of the SF-36 scores are well documented within the scientific literature, and in general the scale has performed well in most tests published to date (Ware, 2000). Ware and Gandek (1998) presented an excellent overview of the development and psychometric evaluation of the reliability and validity of SF-36. The authors insisted that a major objective in creating this tool was achievement of high psychometric standards (Ware, 2000), and although high standards were used in its development, there are still areas to be improved. However, SF-36 is continuously reassessed in order to improve its applicability. SF-36 is thorough and has a well documented scoring system which has been widely used and validated as a HRQoL assessment tool for both the general population as well as numerous conditions (Kalantar-Zadeh and Unruh, 2005; Brazier et al., 2004; Wilson et al., 2004; Corcoran and Durham, 2000). SF-36 has been comprehensively researched as a generic HRQoL measure in surveys of general populations, clinical trials and clinical practice and also in a variety of settings. Many studies use SF-36 as their principal health outcome measurement tool, and also a great number supplement SF-36 with other questionnaires in order to use the former as a generic nucleus. This helps the researcher compare results across different research pieces and groups studied; contributing to the body of knowledge pertaining to SF-36. It can also be used jointly with disease-specific measures as an outcome measure in clinical practice and research. It is a short, generic measure of subjective

health status, which is psychometrically sound and applicable to a variety of health care settings.

Furthermore, SF-36 has been widely used in IBS and ED research projects (Doll et al., 2005; Padierna et al., 2002; Padierna et al., 2000), SF-36 seems to be a useful tool for discriminating among different levels of severity of EDs and other psychological comorbidities of these patients (Padierna et al., 2000). On this basis, SF-36 (Ware et al., 1993) appeared an appropriate instrument for this project.

The mean SF-36 (Ware et al., 1993) scores in this study were compared to established normative population values and analyzed using descriptive statistics and one sample t-test.

4.5.4.2 *The EuroQoL Quality of Life Scale*

(EuroQoL: EQ-5D, Euroqol Group, 1990)

The European Quality of Life measure expresses health status in a single index score. It was mainly intended for use in evaluative studies and policy research (Brazier et al., 1993) although its use has increased throughout the years, and across disciplines. It is a generic scale intended to form one component of a measurement battery supplemented for example by disease specific questions, and it was originally developed for use in Europe (Bowling, 1997a).

EQ-5D covers five dimensions of health: mobility, self-care, role activity, family and leisure activities, pain, and mood where the respondent is asked to choose from one of the three items that appears to best describe him. It includes a visual analogue scale (VAS) where the respondent rates her “*own health today*” with values from 0 (worst imaginable health state) to 100 (best imaginable health state). EQ-5D defines a total of two hundred and forty-three health states that can be determined in a number of ways (Sapin et al., 2004). This measure is easy to fill in, can be completed quickly (McDowell and Newell, 1996) and has been translated into numerous European languages.

Although literature on psychometric properties appears limited (Rapley, 2003), the test-retest reliability for the EQ-5D has been reported as 0.86 for group level coefficients calculated for each state and averaged over health states and 0.90 for a coefficient derived from individual correlations considering all health states simultaneously (van Agt et al., 1994). Evidence for construct validity of the first version has been drawn from the pattern of responses across age, gender, and socioeconomic groups and between those who had recently used health care services and those who had not. The instrument identified significant contrast in the anticipated direction for most of these comparisons across most of the dimensions.

A concern with EQ-5D is the “*coarseness of its categories*” (McDowell and Newell, 1996; pp. 483). It appears insensitive to variations in well-being at the upper ends of the health continuum. However, EQ-5D appears suitable for measuring health in populations with major morbidity, and research on the newer versions suggested an improvement in its applicability in general population studies (Anderson et al., 1993).

The literature search supported the idea that EQ-5D appears as a popular measure for HRQoL assessment, despite unfortunate combinations. Konig et al. (2005) describe it as a simple health state classification system to detect changes in the health status of a specific group of people. The EQ-5D tool has been used to assess IBS quality of life aspects as in Akehurst et al.’s (2002) study, where HRQoL and cost impact of IBS were explored in a UK primary setting. To date, and after the literature review, no research has been used EQ-5D (Euroqol Group, 1990) as an evaluative tool to investigate HRQoL in patients with potential EDs in the way this study proposes.

It would appear that SF-36 and EQ-5D have very similar domains, however the relationship between responses has not been well defined (Dorman et al., 1999) and it was therefore deemed appropriate to incorporate both instruments to investigate this relationship further.

The mean EQ-5D (EuroQol Group, 1990) scores in this study were compared to established normative population values and analyzed using one sample t-test, which is further explored in Section 4.5.7 and Chapter 7.

4.5.4.3 IBSQoL (Hahn, Kirchdoerfer, Fullerton and Mayer, 1997)

Despite growing attention to the assessment of IBS upon HRQoL, there seems to be a lack of consensus about which measurement tool is to be the preferred outcome (Bijkerk et al., 2003), and some of those instruments include: IBS-QOL (Patrick et al., 1997), IBSQOL (Hahn et al., 1997); FDDQOL (Chassany et al., 1999), IBS-HRQOL (Wong et al., 1998), and DHSI (Shaw et al., 1998). A recent review by Bijkerk et al. (2003) noted that a number of instruments appeared of choice, but that those would be determined by the type of research purpose.

The IBSQOL was developed to assess the impact of IBS on HRQoL (Hahn et al., 1997). IBSQOL has thirty items measuring nine dimensions of health: emotional functioning; mental health; sleep behaviours; energy; physical functioning; diet; social role; role physical functioning and sexual relations, scored using a five to six point Likert scale. Each item asks respondents to indicate the extent to which their IBS has interfered with their health during the previous four weeks. IBSQOL questions are asked in the context of the previous month, to allow patients to average their experience over that period of time (Hahn, et al., 1999). According to its authors, IBSQOL appeared easy to complete and did not take too long to fill out (Hahn et al., 1997).

IBSQOL construct validity was examined by administering it to two hundred and eighty IBS patients who belonged to a particular American support group. IBSQOL was also evaluated using group technique where statistical analysis performance demonstrated adequate validity (Hahn et al., 1997).

Statistical analysis to test IBSQOL validity and reliability was performed using Cronbach's alpha coefficient. Test-retest techniques were not used to assess IBSQOL reliability due to the fact that potential problems might arise when using this

approach to evaluate HRQoL measures. The authors noted that IBSQOL demonstrated satisfactory validity and reliability. Polit & Beck (2004, pp.730) described reliability as the degree of consistency or dependability with which an instrument measures the attribute it is designed to measure. According to Hahn et al. (1997), IBSQOL also measured the theoretical constructs it was intended for. Finally, they established that IBSQOL appeared sufficiently disease-specific and a well constructed instrument (Hahn et al., 1997).

The researcher incorporated IBSQOL into this study in order to gain further understanding of the patients' experience of IBS from a quantitative point of view, since it was a disease-specific measure, and the sample population presented with IBS. Mean IBSQOL scores in this study were compared to established normative population values and analyzed using one sample t-test, which is further discussed in Section 4.5.7 and Chapter 7.

4.5.5 Psychological Wellbeing: HAD Scale (Zigmond and Snaith, 1983)

The scientific literature has underlined the fact that both anxiety and depression are widely present among IBS (Ringel and Drossman, 2002; Dancey and Backhouse, 1993; Badía et al., 2002) and ED patients (Birmingham and Beumont, 2004; Corcos et al., 2000; Padierna et al., 2000). In this study the researcher wished to investigate whether anxiety and depression were prevalent in the study group. Several popular measures of mood, distress, anxiety and depression exist, such as the Profile of Mood States (POMS, McNair et al., 1971), the State-Trait Anxiety Inventory (STAI, Spielberger et al., 1983), the Symptoms Distress Scale (SADS, Endicott and Spitzer, 1978) and many others. Amongst all of them, the Hospital Anxiety and Depression, or HADS (Zigmond and Snaith, 1983) assesses both anxiety and depression, as suggested by its name.

The HAD scale is a reliable self-assessment tool that can be utilised outwith and within the hospital setting. It has been recommended as a sound tool because it is concise, does not contain any somatic items, and it appears well accepted amongst

patients (Bowling, 2001). HAD scale has its roots in clinical experience and not in factor analysis, and it is a brief assessment of anxiety and depression, consisting of fourteen items that are separated into two subscales assessing the emotional state over the past week. The patient rates each item on a four point Likert scale where individual items are scored from 0 to 3 and 3 to 0 depending on the direction of the item wording (none=zero, a little=one, a lot=two, unbearably=three) (Bjelland, et al., 2002). Items are subsequently added up and the higher scores indicate the presence of problems. As an example, and when using psychiatric diagnoses as a gold standard, HAD scale depression scores of seven or less would not be considered as cases, but scores of eight to ten would be “*doubtful cases*” and scores over eleven would suggest a certain case (Bowling, 1997a).

According to Bowling (1997a), the authors of HAD created it with two aims, firstly to detect mood disorder and secondly to develop a system whose scoring was not affected by physical illness. In comparison to other tools utilized to screen psychological disorders e.g. General Health Questionnaire (Goldberg, 1972), HADS separates the concepts of anxiety and depression, assesses the degree of change and is claimed to be user-friendly for both the researcher and the participant. Although originally intended for use with hospital patients, it has been used extensively in primary care (Wilkinson and Barczak, 1988). A recent review by Bjelland et al (2002) confirmed promising consistency and validity remarks, as previously suggested by Snaith and Taylor (1985). Since its creation, HAD scale has been translated into numerous languages and is quite commonly used in investigations of a diverse nature.

The HAD scale is a test of psychological wellbeing which has been commonly used in research on IBS (Longstreth et al., 2005; Gonsalkorale et al., 2004; Longstreth et al., 2001) to evaluate patient wellbeing and treatment efficacy. Several authors have also used HAD in order to evaluate anxiety and/or depression in patients with EDs (Lane, 2003, Padierna et al, 2002; Guilbaud et al. 2000), but HAD scale is also widely used amongst many other conditions (Pallant and Bailey, 2005). After careful consideration the researcher decided to use HAD scale to determine the potential presence of anxiety and depression in the study population. Within this

study, the HAD score was collected at one point in time. The mean HAD scores were compared to established normative population values using descriptive one sample t-test techniques.

4.5.6 Objective Measurements: Body Mass Index

The tool most widely used for assessing weight for height is the body mass index (BMI) and it has been recommended for research from childhood through to adulthood (Cole, 1991). According to Birmingham and Beaumont (2004), this is the most appropriate technique to measure the degree to which a patient is under or over their appropriate weight, as was the purpose of this study.

BMI is a measure of weight for height. It represents one of the most commonly used methods of weight categorization (DHHS, 1988) and has previously has been shown to be related to problem eating and body dissatisfaction (Sanchez-Villegas et al., 2001; Thomas et al., 2000). It expresses the relationship between height and weight at any given age for males and females, and is also known as Quetelet⁵ Index. BMI is determined by dividing the patient's weight in kilograms by the square of their height in metres as seen in the following figure:

Fig 4.1: BMI Formula

$$\text{BMI} = \text{Weight} / (\text{Height})^2$$

BMI's formula result is a figure which normally ranges from 20 to 25. According to Gilbert (2000), BMI figures of 26 and above show increasing degrees of overweight; whereas individuals presenting BMIs of 19 or below could be said to be increasingly underweight. The defined normal BMI ranges from 18.5 to 24.9 (WHO, 1995). However, it appears that this does not correlate to the lay female perception of normal weight (Kjaerbye-Thygesen et al., 2004).

⁵ Owns its name to its creator: Lambert Adolphe Jacques Quételet (1796-1874) Belgian astronomer, mathematician, statistician and sociologist.

Hammer et al. (1991) published standardized percentile curves of BMI for white children and adolescents using data from the First National Health and Nutrition Examination Study in the US from 1971 to 1974. Standards were developed and published for males and females from the ages of ten to twenty-two by the American Medical Association. More recently BMI-for-age charts have become available from the National Centre for Health Statistics from the Centres for Disease Control (CDC) in the US (Birmingham and Beaumont (2004). Generally, BMI percentiles are used to define whether undernutrition is present or if overweight exists. Particularly in the case of children, younger adolescents and shorter people, BMI percentiles can prove a more accurate indicator of undernutrition than BMI figures alone. The WHO (1998a) defined four levels of overweight: “*pre-obese*” starts at a BMI of 25.0; Level I starts at BMIs over 30.0; Level II refers to BMIs over 35.0 and the highest level of overweight is Level III, with BMIs greater than 40.0. Associated health risks are thought to increase at higher obesity levels (van Hoeken et al., 2003). BMI is commonly used when assessing obesity because it is correlated with body fat percentage and is unrelated to stature.

BMI is commonly used in research assessing IBS (Boreham et al., 2005; Bundy et al., 2004; Burr et al., 2000; Peñas-Lledó and Waller, 2001) or EDs (Colton et al., 2004; Edman and Yates, 2004; Striegel-Moore et al., 2004), making BMI a popular measure when measuring height and weight and possible changes over time. BMI is also frequently used on a varied basis in research exploring ED, and quite often BMI is used as an established objective outcome measure (Pratt and Woolfenden, 2002). One of the deficiencies of BMI is that this measure does not address body composition, which in certain cases might be necessary to clarify whether even if an individual is within a normal BMI range (in terms of healthy) they lack body fat, or have an excess. It is worth noting that this case could be quite common in standard populations, however, it was not the intention of this study to deepen into this particular issue but to use BMI as a quick indicator of whether patients’ BMI presented any potential variation according to BMI percentiles classification.

BMI should be used as a first indicator which can aid the professional to determine whether the patient presents any weight alteration. BMI can be supplemented in

several forms as it is anthropometry (Birmingham and Beaumont, 2004), which would estimate total body fat. Anthropometry appears as a precise and economical way of measuring body fat, but special training is required. For the purpose of this study, BMI was chosen as a primary measure that as addressed before would help the researcher to identify patients who might need further assessment. In this study the purpose of using BMI objective measurement was to explore the characteristics of the sample in terms of an adequate weight for height, and whether these differed from normative values.

All patients had height and weight recorded at clinical visit to make BMI calculation possible. Body weight and height were used in combination as simple and reliable measurements for evaluating nutritional and overall health status and screening for over and /or underweight (Kuczmarski and Flegal, 2000).

4.5.7 Statistical Analysis

Quantitative data was analyzed using techniques suitable to the type and quantity of data generated. The analysis of questionnaires was carried out using the Statistical Package for Social Science (SPSS v.13) software. Several steps were taken to control the quality of data entry and coding. Field definitions were put in the SPSS database to limit errors in data entry, since a great number of variables were included due to the use of several questionnaires. Additionally, each variable was examined individually for the presence of outliers by the main researcher and the statistician.

The statistical and qualitative tests of analysis the researcher applied to each of the data sets were determined by the study design and the analysis technique for each data collection tool is listed next in Table 4.6.

Table 4.6: Data Collection Tools and Method of Analysis

Data collection tool	Type of data	Method of analysis
Current symptoms	Statistical	Descriptive statistics, Normative value comparison, Bivariate correlation.
Screening Tools: ESP and SCOFF	Statistical	Descriptive statistics, ROC curves
SF-36 (Ware et al., 1993)	Statistical	Descriptive statistics, Normative value comparison, Bivariate correlation.
EQ-5D (EuroQol Group, 1990)	Statistical	Descriptive statistics, Normative value comparison, Bivariate correlation.
IBSQoL (Hahn, Yan and Strassels, 1997)	Statistical	Descriptive statistics, Normative value comparison, Bivariate correlation.
HADS (Zigmond and Snaith, 1983)	Statistical	Descriptive statistics, Normative value comparison, Bivariate correlation.
BMI	Statistical	Descriptive statistics, Bivariate correlation.
Semi-structured interviews	Qualitative Analysis	Thematic Content Analysis

To analyze the data generated, the researcher employed: descriptive statistics, one sample t-test, correlation, bivariate correlations, ROC curve and factor analysis.

Summary statistics were used to describe the obtained data. Summary statistics consisted of measures of central tendency as the mean, median and mode and sample distribution using the standard deviation. In addition to measures of central tendency, some measures of the spread of deviation were considered adequate to describe the distribution. Standard deviation was used for this purpose assuming the “*normality*” (Gauss curve) of the sample taken. This was useful for the subsequent interpretation of the data when statistical inference was used. Therefore, parametric testing was employed under the assumption of normally distributed data-taking as suggested by Rowntree (2004). T-test measurements were employed to test the differences between the means of two or more dependent variables, considered at the same time respectively. Finally, some correlation coefficients were produced when associations between particular variables were explored. For this purpose, Pearson’s Product Moment Correlation Coefficient, or Pearson’s r , was employed. All these statistical

estimations and inferences will be explored in more depth in Chapter 5 where analysis and results are presented.

4.5.7.1 *ROC curves*

The Receiver Operating Characteristics (ROC) curve is a graphical display of the false-positive rate and the true-positive rate from multiple classification rules (Baker, 2003, p.511). The true-positive rate is commonly represented on the vertical axis whereas the false-positive rate is on the horizontal axis. Conventional ROC curves are created by calculating a continuous value for each individual. The classification is positive if the value is above a certain threshold (Baker, 2003). ROC graphs usually display a cloud of false-positive and true-positive rate points, and according to Baker (2003), the optimal ROC curve is the line connecting the points highest and furthest to the left.

ROC curves appear popular (Rueda-Jaimes et al., 2005; Obuchowski et al., 2004; Deeks, 2001) and they are widely used for describing and comparing the accuracy of medical diagnostic tests (Rueda-Jaimes et al., 2005; Beglin and Fairburn, 1992), clinical chemistry (Obuchowski et al., 2004) and an array of other disciplines (Deeks, 2001). ROC curves are frequently used in studies of diagnostic accuracy to illustrate the pattern of sensitivities and specificities observed when the performance of the test is evaluated at several different diagnostic thresholds. In general the diagnostic performance of a particular test can be evaluated by the position of the receiver operating characteristic line. This would mean that poorer tests would have lines close to the rising diagonal, whereas the lines for perfect tests would rise steeply and pass close to the top left hand corner, where both the sensitivity and specificity are 1 (Deeks, 2001 pp.158).

Kappa coefficient value was calculated as part of the assessment of the two screening tools. A Kappa value of 0 indicates that the association is random and a value of 1 indicates that is complete determined; values between 0.40 and 0.60 are supposed to indicate a moderately determined process (Hemminki and Granström, 2002).

In this study, ROC curves were produced in order to depict both ESP and SCOFF performances. As noted earlier, ESP and SCOFF variables were recoded after analysis and two new variables were created: ESP2 and SCOFF2 (corresponding to those individuals identified as potential cases). For the purposes of this study and based on the literature review, SCOFF (as SCOFF2, see Chapter 5) was selected as the gold standard measurement. ROC curves were therefore produced which highlighted the relationship among the two screening tools with the aid of SPSS v.13 and STATA v.8.2 statistical packages.

4.5.7.2 *Incomplete data*

By using a high number of data collection tools the researcher endeavoured to gain as much information as possible about the subject group. However when using multiple measurement instruments, incomplete data is often a concern. In quantitative research, missing data may be the result of ‘unit non response’, meaning an entire assessment is missing, or of ‘item non response’, meaning that an assessment has only been partially completed. Methods have been proposed for the imputation of missing data when using quantitative analysis. Mean imputation refers to the substitution of the mean score from the observed patient to the patients who are unobserved; this method can be enhanced by calculating the mean for the group of patients with similar characteristics (Wood, 2003). For the purpose of this study it was decided that only complete data sets would be analyzed and reasons for incomplete sets were recorded and assessed. In the quantitative part of this study, a number of patients failed to complete the whole battery of questionnaires. After careful consideration and despite reduction in the final number of participants included for data analysis, it was decided to exclude those cases from the study.

4.6 STRAND 2: QUALITATIVE DATA

As indicated below in this chapter, the second stage (Strand 2) of this study incorporated qualitative information that was generated by the conversations with participants who were considered “*potential cases*” according to the screening tools used to detect potential EDs. A purposive (Coyne, 1997) consecutive sample of

twenty five female patients took part in Strand 2 of the study. The purpose of the semi-structured interviews was to gain further knowledge of the individuals' experiences regarding IBS, symptoms, potential EDs, and HRQoL amongst other topics, portraying the patients' actual experience in ways that the quantitative instruments cannot do (Stange and Gotler, 2006).

4.6.1 Semi-structured Interviews

Semi-structured interviews were chosen as the preferred qualitative method to gather data in this multimethod research. Semi-structured interviews are defined by Polit and Beck (2004) as those in which researchers have listed topics to cover rather than specific questions to ask. The interview schedules were prepared in advance with a topic guide that would lead the meeting (See Appendix 7). Before the interview took place, the purpose of the research was again explained to participants. Verbal and signed consent was required before the interview could take place, and it was clearly noted that participation for this part of the study was again voluntary and that participants were free to withdraw their consent at any time during the conversation.

The researcher encouraged the participants to talk freely about the topics being presented. According to Parahoo (1997), this technique ensures that researchers obtain the information required by giving the respondents the freedom to respond in their own words, provide as much detail as they wish and offer illustrations and explanations if desired. A copy of the interview guide used in this research can be found in the Appendix Section, although the researcher was able to introduce certain variations depending on the situation, and always conforming to qualitative research procedures. Additionally, participants were encouraged to raise their own issues or worries. Interviews were recorded and notes were taken during the meeting to facilitate subsequent data analysis. After each meeting, the researcher read the interview notes and supplementary notes were made if necessary to clarify particular points which had emerged during the meeting.

Every interview was transcribed personally by the researcher and transferred into the qualitative data management package chosen for the analysis of the participants'

material. Transcriptions took place on the same day as the interview to maximize the quality of the information, with the exception of two participants who rescheduled their interviews due to personal circumstances.

Interviews were undertaken on a subsample of the overall study group to provide illustrative examples and quotations that illuminated the findings generated within the quantitative part of the study, and to ensure that invalid conclusions would not be drawn from the researcher's assumptions and interpretation of the quantitative data generated (Silverman, 2004).

4.6.1.1 Reliability and validity of the semi-structured interviews

Qualitative data gathering and subsequent analysis entailed particular issues regarding reliability and validity. Again, reliability makes reference to the replicability of the instruments, responses or analysis that a particular research has employed (Parahoo, 1997). Validity refers to whether those instruments and/or analysis record and describe data adequately (Parahoo, 1997). Several authors advocate different ways of addressing those issues, in order to ensure adequate reliability and validity, such as Quinn Patton (1990) and Lomborg and Kirkevold (2003). Although data generalizability is not the main objective within qualitative research, adequately addressing reliability and validity would generate results which could be extrapolated to wider audiences. In order to maximize reliability and validity within this study, Guba and Lincoln's (1988) model was followed. Guba and Lincoln (1988) proposed a model comparing reliability and validity in qualitative research with the well known quantitative model. A summary table can be seen below and the four qualitative areas are discussed to explain how they were established for this study.

Table 4.7: Measures for Reliability and Validity in Quantitative and Qualitative Research

Factors	Quantitative Research	Qualitative Research
Truth Value	Internal Validity	Credibility
Applicability	External Validity	Fittingness
Consistency	Reliability	Auditability
Neutrality	Objectivity	Confirmability

* (Adapted from Guba and Lincoln, 1988)

To illustrate the preceding table, the terms regarding qualitative measures will be briefly defined next.

Credibility: This term refers to the truth value of a study. A qualitative study is credible when the descriptions or interpretations of a human experience are immediately recognizable, by those having that experience, as being similar to their own.

Fittingness: Applicability or transferability of a qualitative study is referred to as fittingness. A qualitative study meets this criterion when its findings fit into context outside the study situation and when its audience views the findings as meaningful and applicable in terms of its own experience.

Auditability: This term is used in qualitative research as an equivalent of the quantitative reliability term, referring to the consistency of a study (Guba and Lincoln, 1988). A study is auditable when another researcher can clearly follow the study all the way through and its logic appears understandable. For the purpose of this study, the researcher kept all documentation safely, and a reflective journal was kept throughout the process. The researchers' supervisors also had full access to the data and it was discussed and cross-checked regularly.

Confirmability: This last aspect can only be achieved in qualitative processes when auditability, truth-value and applicability have been previously established. The commonest road to ascertain confirmability is to enquire whether the study could be replicated (Miles and Hubberman, 1994).

In order to be rigorous, the researcher was faithful to the sequence just presented, trying to be as meticulous as possible during the process in order to maximise the research outcome.

4.6.2 Pilot Interviews

Four pilot interviews were carried out with two fellow researchers and two patients, in order to train the researcher in the use of this format in order to maximize data gathering and the process itself. Several issues were raised after those meetings which were very valuable and led the researcher to restructure the order of the questions posed to the participants in the final study. Practical issues such as use of the recorder, optimal distance of the microphone to the speaker, and pace of the interview also emerged during this process.

4.6.3 Computer Software for Qualitative Data Management and Analysis

A varied range of software packages exists to aid the researcher both manage and analyze qualitative data. Some examples are: Ethnograph, ATLAS.ti, NUDIST and QSR Nvivo . The process of managing, coding the existing material, which can be vast, and finally analyzing it can be facilitated by a number of programmes. Additionally, they may be particularly useful when intricate inferences are to be made (Farley and McLafferty, 2003). On the other hand, using computerized databases also has disadvantages, in terms of the time required to learn how to utilize and maximize them and in many cases also price. In this particular case, data management was initially conducted using the QSR Nvivo package. This specific package was chosen due to its capacity to deal with large volumes of data and also because of its recognized flexibility to use the coding and recoding. QSR Nvivo data search and data coding tools appeared especially useful for the purpose of this study

as the investigator was not an expert in the management of qualitative information. Despite the fact that quite some time had to be invested in learning how to work with the package, QSR Nvivo proved useful for a part of the analysis although later stages of the analysis and subsequent data interpretation mainly relied on manual analysis as guided by the author who had expertise in the area, and who had become very familiar with the qualitative material after several months immersed in it.

4.6.4 Thematic Content Analysis

After an extensive literature review was conducted it was decided that Thematic Content Analysis would be used to examine data obtained from the semi-structured interviews to investigate themes and patterns emerging from the qualitative data. This was intended to provide a descriptive account that would complement findings emerging from the previously obtained quantitative data.

Data was analyzed using Burnard's (1991) stage by stage method which was adapted from Glaser and Strauss' (1967) grounded theory approach, which aimed to produce a detailed and systematic recording of themes and issues addressed in the semi-structured interviews as suggested by Breeze and Repper (1998). This particular method assumes semi-structured and open ended interviews to categorize and codify the transcripts through a series of stages that are incorporated in Table 4.8 below. This particular method of analysis attempts to produce a detailed and systematic recording of the themes and issues addressed by the participants and to connect those themes under a logical category system (Burnard, 1991).

Table: 4.8: Stages of Analysis According to Burnard (1991)

Stages of the Analysis: Burnard, 1991	
Stage 1	Notes made after each interview.
Stage 2	Transcripts read through and notes made. Immersion in the data.
Stage 3	Rereading of the transcripts. Heading generation. Open Coding.
Stage 4	Grouping of the list of the categories.
Stage 5	Working out of the new categories list.
Stage 6	Request to colleagues to generate categories. Adjustments made.
Stage 7	Transcripts reread along refined categories.
Stage 8	Each transcript worked out through categories as by Stage 7.
Stage 9	Each coded section cut out of the transcripts and collated together.
Stage 10	Cut sections are collated again under appropriate headings/ subheadings.
Stage 11	Selected respondents asked to check appropriateness of findings.
Stage 12	Sections filed together for writing up the findings.
Stage 13	Writing up process begins.
Stage 14	Researcher decides to link/not link findings to the literature.

4.6.4.1 *Validity when using Burnard's model(1991)*

The issue of validity was addressed earlier, but validity of the data when using this particular approach should be also addressed. Two particular ways of checking for validity were suggested by Burnard (1991): “*colleague checking*” of the category generation process and returning the processed material to the interviewees, in both cases to make potential adjustments to the researcher’s categorization system. In this particular study both options were employed. In the first instance, data was discussed with one of the participants who had agreed to do so after initial analysis. Additionally, categories and themes were discussed with two researchers with expertise in the process of category generation. Both comments from the patient and the two colleagues helped to redefine some of the emergent categories and to reorganize data on the particular route that will be presented in Chapter 6.

4.6.5 Presenting Qualitative Data

Stage fourteen of the analysis according to Burnard’s (1991) model specifically addresses the writing up phase where the researcher is confronted with the way of presenting the data. Two options exist. The first one would be to use verbatim

examples of the data to exemplify the sections presented and the second to present findings alongside references to the literature, in which case the findings become both presentation of the findings and comparison of those findings with the existing work. In this case, the first option was chosen due to the multifaceted design of this piece of research. Nevertheless, it was decided that interpretation of the qualitative data would be incorporated into the quantitative data in an attempt to present and discuss findings in a simultaneous manner, since results had been presented independently as can be seen in Chapter 5, Chapter 6 and Chapter 7.

4.7 STRAND 3: NURSES' PERCEPTIONS OF IBS AND EDs AND THEIR SUFFERERS.

A twenty-eight item questionnaire was developed by the researcher to measure attitudes and knowledge of nurses towards IBS and EDs. This questionnaire was based on items identified by Letson and Dancey's (1996) study and used with the agreement of these authors. The scale was initially developed for IBS and subsequently adapted by the research for use in EDs. Nurses rated statements relating to IBS and ED on a Likert scale from disagree (one) to agree (five). Data from the variables of the nursing perceptions towards GI conditions questionnaire was split into dichotomous variables. Positive agreed related to "agreed" and "strongly agreed" responses and "not sure", "disagreed" and "strongly disagreed" were viewed as negative variables".

Table 4.9: Nurses Participants

Nurses approached for the study	Nurses completing questionnaires	Final number of nurses' questionnaires valid
160	102	91

4.7.1 Factor Analysis

Factor analysis is a statistical technique intended to reveal whether the pattern of responses on a number of items can be explained by a smaller number of underlying

factors (de Vet et al., 2005; Streiner, 1994). The aim of using this technique could be simply data reduction, assessment of the factor structure (dimensions) being measured by the instrument, or investigating if the questionnaire shows the same dimensions across different groups (structural reliability) (de Vet et al., 2005).

Factor analysis is a complex, but flexible analytical procedure (de Vet et al., 2005) that was used in this questionnaire as explained below. According to de Vet et al. (2005), if no precise ideas about the factor structure (number of dimensions and associations) exist, the factor structure of an instrument can be best investigated by means of exploratory factor analysis. When prior hypotheses exist, based on theory or previous analyses, confirmatory factor analysis appears more adequate: it can be used to assess if data would fit a premeditated factor structure (Floyd and Widaman, 1995). Exploratory factor analysis was applied to the data from the questionnaires to examine the relationship between attitudes and knowledge. Statistical analyses similar to those described in the development of a scale to measure HRQoL in patients with inflammatory bowel disease were employed (Smith et al., 2002).

Exploratory factor analysis, involving principal components analysis followed by oblique rotation, was performed using SPSS version 13.0. This statistical package was also used to determine the internal reliability of the items used in the construction of the IBS/ED attitudes and knowledge base questionnaire. In principal components analysis there are initially as many factors as there are variables, in this instance, twenty eight. The criterion of the Eigen values greater than one was used to determine the number of putative factors.

4.8 SUMMARY

A combination of quantitative and qualitative methods was deemed appropriate to design a mixed methods study to explore the potential presence of IBS and potential EDs in the GI setting. To do so, two ED screening tools were employed (ESP and SCOFF), jointly with several HRQoL instruments (SF-36, EQ-5D and IBSQoL), a psychological wellbeing tool (HAD scale), and objective measurements (weight and

height). Secondly, semi-structured interviews were used to explore the patients' experiences regarding their condition.

Additionally, an adapted questionnaire (Letson and Dancey, 1996) was employed to evaluate nurses' attitudes and perceptions towards IBS and EDs in a sample of ninety one GI nurses.

Chapter 5

Quantitative Analysis

5.1 INTRODUCTION

This chapter will present the quantitative data obtained in this study. The chapters is divided in two main sections that will introduce the data gathered after assessing patients who took part in Strand 1 of the study, followed by the findings of the questionnaire used to evaluate nurses' perceptions of IBS and EDs.

Strand 1 tools included: Current Symptoms checklist, ESP, SCOFF, SF-36, EQ-5D, HAD scale, and IBSQoL. Descriptive data, comparison with normative values and a number of correlations are presented.

Finally, a questionnaire to measure attitudes and knowledge of nurses towards IBS was adapted and applied to a group of GI nurses to examine their views on both IBS and EDs. Descriptive statistics and factor analysis were performed.

5.2 STRAND 1: PATIENTS QUANTITATIVE RESULTS

5.2.1 Study Population

A total of one hundred and thirty-four patients were finally included in Strand 1 of the study, who completed the instruments previously addressed.

A database was created (SPSS v.13.0) containing the entire data. The information gathered was explored and "*cleaned*" in order to detect missing cases and potential mistakes related to data management or entry several times throughout the study.

Missing values were identified and it was decided that they would be left for the purpose of the analysis, since SPSS program could recognise “*system-missing values*” and provide valuable information after data treatment. No data transformation procedures were used in this study.

5.2.2 Demographic Data

The following demographic data was gathered from the study population.

Age was recoded into four different age ranges in order to facilitate analysis and comparison across groups. The youngest participant in the study was twenty years old and the oldest fifty-nine. Mean age was 39.93 years (10.94 SD) and Median age was 41.50 years. Age groups were grouped in order to explore the potential influence of age in this study.

Table 5.1: Age Groups

n=91	
Participants Age	Frequency (%)
20-29	64 (47.8)
30-39	19 (14.2)
40-49	31 (23.1)
50-59	20 (14.9)
Total	134 (100)

5.2.3 Education and Employment

Participants were asked whether their education had continued after the minimum school leaving age in Scotland. Nearly, 60% had continued their education, and nearly half of the sample held a degree or equivalent professional qualification.

Nearly half of the patients (48.9%) were employed at the moment of the interview. A quarter (14.8%) of the participants noted doing Housework, a 9.1% were retired, a 3.4% of the sample were students.

5.2.4 Smoking

A 21.6% of the patients were current smokers, followed by a 29.6% of the sample that confirmed being ex-smokers and a larger 48.9% of participants who had never smoked.

5.3 SYMPTOM CHECKLIST

All the study participants completed a specifically design symptom checklist that was used to establish IBS diagnosis according to Rome II criteria (as described in Chapter 2). Respondents are in the position to confirm the presence of several symptoms at any given point. These findings are summarised in Table 5.2.

Table 5.2: Current Symptoms Summary

Symptoms	n=134	Presence	Frequency (%)
Abdominal Pain/ Discomfort		NO	33 (24.6)
		YES	100 (74.6)
Abnormally infrequent motions		NO	68 (50.7)
		YES	65 (48.5)
Abnormally hard stools		NO	107 (79.9)
		YES	26 (19.4)
Abdominal fullness, bloating or swelling		NO	45 (33.6)
		YES	88 (65.7)
Urgency		NO	59 (44.0)
		YES	74 (55.2)
Straining during a bowel movement		NO	76 (56.7)
		YES	57 (42.5)
Passing mucus during a bowel movement		NO	91 (67.9)
		YES	42 (31.3)
Other		NO	1 (0.7)
		YES	121 (90.3)

As seen in the table above, over three quarters of the participants noted experiencing pain or discomfort on a regular basis. In addition, nearly half the participants expressed suffering due to abnormally infrequent motions and altered bowel functioning. Participants who reported regularly suffering from abnormally hard

stools accounted for a 19.5% of the total sample. Also, two thirds of the participants reported experiencing abdominal fullness, bloating or swelling regularly. Figures for “urgency” appeared quite similar. Nearly half of the participants (42.9%) noted experiencing straining during bowel movements regularly.

Additionally, participants were asked to describe whether they regularly experienced other symptoms that were not identified by the questionnaire to evaluate current symptomology, however very few participants completed this section.

Data regarding pain highlighted the fact over two thirds of the participants did not experience relief, which would suggest constant discomfort. A table is provided below (5.3).

Table 5.3: Current Symptoms 2

Symptom	n=134	Response	Frequency (%)
Pain is relieved when I pass a motion		NO	88 (66.2)
Pain comes on when I have a bowel problem		NO	79 (59.4)

Questions regarding both sections enable the professional to assess part of the Rome II criteria. In this case, all study recruits demonstrated a confirmed IBS diagnosis on the basis of this classification, and would therefore be considered as an IBS case.

Constipation was reported by nearly a third (28.6%) of the participants, with similar numbers reporting diarrhoea. A third of the participants noted having to cope with both diarrhoea and constipation (described as IBS-A, or alternators). Additionally, over half (57.6%) of the participants reported their IBS symptoms to be erratic and unpredictable (see Table: 5.4).

Table 5.4: IBS Frequency and Pattern of Symptoms

Bowel disturbances	Frequency (%)	Pattern of IBS Symptoms	Frequency (%)
None	10 (7.5)	Fairly regular	47 (35.6)
Constipation	38 (28.6)	Erratic and unpredictable	76 (57.6)
Diarrhoea	38 (28.6)	Predictable	9 (6.8)
Both	43 (32.3)		
Neither	4 (3.0)		n=134

In relation to frequency of IBS symptoms (Table 5.5), two thirds of the patients reported suffering from IBS symptoms on a daily basis. Duration of symptoms produced a variety of results. Half of the participants expressed having to cope with their IBS symptoms for more than 14 days once they appeared. The most common duration of IBS symptoms in the study population was 1-2 days (18.2%).

Table 5.5: Frequency and Length of Symptoms

Frequency of IBS symptoms?	Frequency (%)	Length of symptoms	Frequency (%)
Daily	87 (65.9)	Less than a day	18 (13.6)
Weekly	31 (23.5)	1 to 2 days	24 (18.2)
Monthly	10 (7.6)	3 to 4 days	19 (14.4)
Less Frequently	4 (3.0)	5 to 7days	4 (3.0)
		8 to 14 days	1 (0.8)
n=134		More than 14 days	66 (50.0)

Results for the Current Symptoms scale highlighted that IBS symptoms were erratic and unpredictable. Most common bowel disturbances were diarrhoea and constipation, although nearly a third of the patients experienced both of them regularly. Pain, fullness, bloatedness, urgency, infrequent motions, hard stools, and urgency were present on a varied fashion among patients. Therefore data underlined a puzzle of symptoms variation, duration and intensity that may had an important impact in patients' lives. This will be explored in later in this chapter when presenting HRQoL and wellbeing measures.

5.4 SCREENING FOR EATING DISORDERS

This section will introduce data on the screening tools selected to determine the potential existence of EDs within the study sample.

5.4.1 ESP Screening Tool

ESP screening tool comprises five questions. As identified in Chapter 4, two or more abnormal responses would indicate a potential case¹. Subsequently, a new variable was created to select those participants identified as potential cases, ESP2, which would represent those individuals scoring more two or more abnormal responses and that would identify a potential ED case. According to ESP criteria, a 59% of the individuals would be susceptible to further evaluation (ESP2=59%), since they were identified as potential cases.

Table 5.6: ESP2 Frequencies

ESP2	Frequency (%)
0-1	55 (41)
>= 2	79 (59)

Table 5.7: ESP Responses in Study Population (n=134)

ESP ABNORMAL RESPONSES	Frequency (%)
Not Satisfied with Eating Patterns	48 (35.8)
Eating in secret	24 (17.9)
Weight affect the way you feel about yourself	91 (67.9)
Members of the family suffer from ED	12 (9.0)
Ever suffered from an ED	25 (18.7)

The most common abnormal responses for ESP related to weight affecting how individuals felt about themselves in 91 patients (67.9 %) and 48 individuals (35.8%) expressed not being satisfied with their eating habits, and 24 patients (17.9%) noted eating in secret.

¹ As suggested by Cotton et al. (2003).

5.4.2 SCOFF Screening Tool

SCOFF screening tool also encompasses five questions. Again, the criteria used to detect potential cases related to individuals scoring two or more abnormal responses², and for the purposes of the analysis a new variable named SCOFF2 identified those subjects who scored two or more abnormal responses and were therefore considered as potential cases. Nearly a fourth of the cases (24.6%) were considered as potential cases, by SCOFF compared to a 41% of the cases as identified previously by ESP screening tool.

Table 5.8: SCOFF2 Frequencies (n=134)

SCOFF2	Frequency (%)
0-1	101 (75.4)
>= 2	33 (24.6)

In this study data showed a lower number of potential problems when using SCOFF as opposed to ESP. The abnormal responses for SCOFF are presented in Table 5.9. The most common abnormal response related to individuals who thought they were fat despite others seeing them as thin for a third of the study group (37.3%). Also, one fifth of the patients noted constantly worrying about how much they ate and approximately one sixth of the patients expressed that food dominated their lives.

Table 5.9: SCOFF Responses in Study Population (n=134)

SCOFF ABNORMAL RESPONSES	Frequency (%)
Ever make yourself sick if uncomfortably full	18 (13.4)
Worried about how much you eat	26 (19.4)
Lost recently more than one stone in 3 months	12 (9.0)
Believe to be fat when others say you are thin	50 (37.3)
Food dominates your life	20 (14.9)

5.5 ESP AND SCOFF ABNORMAL RESPONSES

The analysis of both screening tools highlighted differences amongst them, since ESP appeared less specific suggesting that up to a 59% of the sample would be a

² As suggested by Cotton et al. (2003).

potential ED case, as opposed to SCOFF analysis that suggested that a 24.6% of the sample would be categorized as potential cases. The frequencies and percentages of individuals in relation to the abnormal responses obtained are presented below for each instrument.

Table 5.10: Screening Tools and Abnormal Responses (n=134)

Screening Tool	Abnormal Responses	Frequency (%)
SCOFF2	0-1	101 (75.4)
	>= 2	33 (24.6)
ESP2	0-1	55 (41.0)
	>= 2	79 (59.0)

Table 5.11: Abnormal Responses by Tool (n=134)

Abnormal responses	Frequency ESP (%)	Frequency SCOFF(%)
0	7 (5.2)	61 (45.5)
1	48 (35.8)	40 (29.9)
2	56 (41.8)	19 (14.2)
3	14 (10.4)	9 (6.7)
4	8 (6.0)	4 (3.0)
5	1 (0.7)	1 (0.7)
Total	134(100.0)	134 (100.0)

As indicated in the table above, 24.6% of the study participants would have scored two or more abnormal responses for the SCOFF tool; patients which would need further assessment. This contrast which a 59% of individuals who would be seen as presenting a potential ED according to ESP. This highlights a relevant difference between instruments regarding patient identification, with nearly double the detection rate with ESP.

5.6 ESP AND SCOFF ROC CURVES ANALYSIS

In order to further explore the screening tools performance, ROC curves were produced. For the purposes of this study and based on the literature review, SCOFF was selected as the gold standard measurement. ROC curves were produced as

shown below, which highlighted the relationship among the two screening tools. Crosstabulation tables for the two instruments are presented next (Table 5.12).

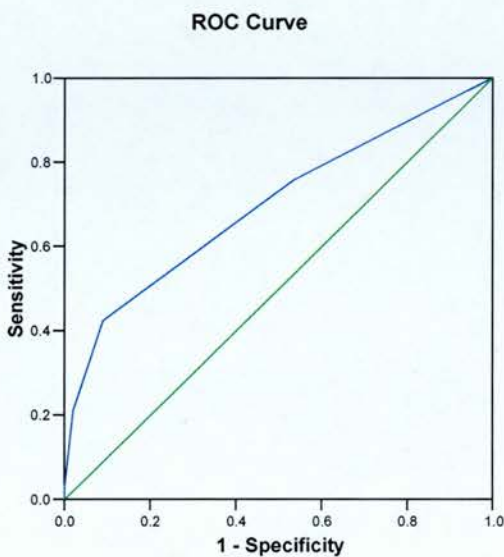
Table 5.12: Crosstabulation ESP2 * SCOFF2

		scoff2		Total
		0-1	>= 2	
esp2	0-1	47	8	55
	>= 2	54	25	79
Total	n=	101	33	134

Kappa test was used to measure the agreement between variables, obtaining a value of 0.152 and SE (0.064). As suggested by Hemminki and Granström (2002) this value would indicate a low association between the two screening tools.

Case processing indicated that according to the new SCOFF2 variable, the number of patients identified as potential cases was 33. The obtained ROC curve can be seen below.

Table 5.13: ROC Curve for ESP and SCOFF



The diagram obtained indicated that although an area of 0.687 (C.I. 95%) was generated; the concordance among the two screening tools was not excellent. ESP

screening tool did not obtained a perfect match which underlined the differences existing between the tools.

5.7 ASSESSMENT OF HRQOL

The following section will present a comparison of the obtained values in this study in line with the normative values existing for the selected questionnaires. Results for specific dimensions are addressed individually.

5.7.1 SF-36 Analysis

Results for SF-36, highlighted significant differences between the study participants and normative general population data generated by Jenkinson et al. (1999) for similar sex and age distribution. Those differences were particularly marked in certain areas as presented in this section.

Table 5.14: Mean (SD) Scores for the Eight Dimensions of the SF-36

p ≤ 0.05	Normative Values (%)	Study Participants (%)	CI 95%
n=	8889	134	
Physical function	87.99(19.65)	71.90 (29.38)	(-21,77 to -10,40) (t=-5,61; p<0,001)
Social functioning	82.77(23.24)	46.81 (14.02)	(-38,65 to -33,25) (t=-26,4; p<0,001)
Role function physical	87.17(22.01)	50.23 (44.11)	(-45,43 to -28,44) (t=-8,62; p<0,001)
Role mental	85.75(21.18)	54.40 (43.96)	(-39,81 to -22,88) (t=-7,34 ; p<0,001)
Mental health	71.92(18.15)	56.26 (20.83)	(-19,67 to -11,64) (t=-7,73 ; p<0,001)
Energy/vitality	58.04(19.60)	39.01 (21.84)	(-23,23 to -14,82) (t=-8,97 ; p<0,001)
Pain	78.80(23.01)	47.54 (25.51)	(-36,17 to -26,34) (t=-12,61; p<0,001)
General health	71.06(20.43)	42.27 (14.43)	(-31,56 to -26,00) (t=-20,53; p<0,001)

*One sample t-test used as statistical test.

As can be seen in the table above, SF-36 results in this sample suggested a very impaired HRQoL results in the study participants. Particularly relevant appeared the Social Functioning dimension (mean 46.81 compared to a mean 82.77 for normative population), Role Physical and Role Mental dimensions were markedly impaired too

in the patients' sample. In general, SF-36 HRQoL scores portrayed an obvious negative impact on the patients' sample.

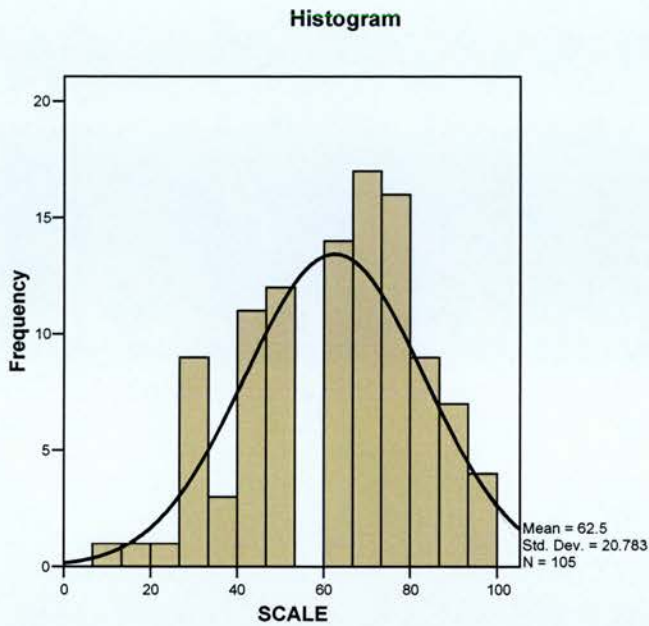
5.7.2 EQ-5D Analysis

The EQ-5D scale analysis was undertaken and the mean values generated. The main analysis conducted with this utility tool was to compare EQ-5D VAS scale with normative values as suggested by Kind et al. (1998).

Descriptive values highlighted that nearly two fifths of the participants expressed having problems performing usual activities. Also, pain was uniquely not experienced by one fifth of the participants, whereas two thirds of the sample noted experiencing moderate and constant pain. EQ-5D also estimates anxiety and depression, as does HAD Scale. Results highlighted the fact that half of the patients noted being moderately anxious or depressed.

As mentioned earlier, VAS scores were compared to normative values in order to further explore data. The picture below provides a general overview of the VAS scores distribution.

Table 5.15: VAS Scores for the Study Group.



*Frequency of individuals' scores and actual scoring in the VAS scale.

Participants were asked to select a number from zero to 100 represented by a thermometer and suggesting the participant to rate “*your own health state today*” to describe how they were feeling at that time. Figures ranged from “*worst imaginable health status*” (0) and “*best imaginable health status*” (100) as indicated by the visual analogue scale (VAS) of the EQ-5D. VAS scores means comparisons are shown in the figure below.

Table 5.16: EQ-5D Means Comparison

p ≤ 0.05	Number of patients	Mean(SD)
Normative values	3395	82.5 (17)
VAS Scores patients sample	134	62.50 (20.73)
ESP2	79	62.73 (20.93)
SCOFF2	33	65.14 (21.40)

Results highlighted a significant difference of nearly twenty points for the selected sample. This again, translates into a deprived perception of the general health as experienced by the patients approached in this study. The higher the score in the VAS the better, which underlined the lower scores obtained in this study. A mean difference of 20.00 (C.I. 95%) was obtained when compared with normative values.

5.7.3 IBSQoL Analysis

Analysis of the IBSQoL questionnaire focused mainly on two dimensions: IBSQoL Emotional and IBSQoL Mental Health. Values were compared with normative values presented by Han et al., (1999). The obtained means and comparison with normative values are presented below.

Table 5.17: IBSQoL Means Comparisons

$p \leq 0.05$	Normative Values (SD)	Study Participants	CI 95%
IBSQOL emotional	42 (22 SD)	42.86 (26.30)	(-4,23 to 5,95) (t=0.34; p=0,73)
IBSQOL mental health	64 (21 SD)	65.62 (27.96)	(-3,79 to 7,03) (t=0.59; p=0,55)

*One sample t-test used as statistical test.

Surprisingly, the two dimensions particularly explored with IBSQoL questionnaire suggested very similar figures for normative and patients' values, suggesting quite parallel findings to the normative values by Hahn et al. (1997). As just mentioned, results for the emotional dimension were 42.86 (26.30 SD) as opposed to mean value 42 (22 SD); whereas mental health dimension values for the study group were 65.62 (27.96) opposed to mean values of 64 (21 SD).

Descriptive information though underlined the fact that nearly and 80% of the patients noted feeling “*not as happy as usual*” due to symptoms and nearly 75% of them noted being “*less satisfied with life*” as related to their condition. Nearly 90% of the individuals expressed feeling fed up or frustrated.

On the other hand, and according to IBSQoL descriptive information, nearly 60% of the patients seemed “*more nervous than usual*” due to symptoms. Most importantly, an 80% of those individuals noted that their situation made them felt downhearted and blue. Sleep also seemed to be compromised for up to a 60% of patients who noted that symptoms had prevented them from falling asleep with a varied emphasis (every night, 5% ; most nights, 12%; and some nights, 40%). Additionally, nearly 90% of the patients stated that IBS made them feel emotionally worn out and tired.

Diet appeared to be equally compromised for the participants, and over half of the individuals reported that during the past month symptoms would have caused them not eating meals, and up to an 85% of the individuals noted having avoided certain foods found unappealing at some point for nearly three quarters of the participants. On top of compromising participants’ diets, 75% of the participants noted that symptoms made them feel socially uncomfortable, and up to 60% of the individuals had to avoid certain social activities due to stomach symptoms. Understandably, over three quarters of the assessed patients, noted feeling socially embarrassed about themselves due to their condition.

The findings just presented can be found in the following table.

Table 5.18: IBSQoL Symptoms

N=134 Question Item	Frequency Response	(%)
How often in the past month did you not feel as happy as usual?	Always	17.1
	Often	41.0
	Sometimes	81.0
How often in the past month did you feel less satisfied with life?	Always	15.2
	Often	38.1
	Sometimes	72.4
How often in the past month fed up or frustrated?	Always	22.9
	Often	52.4
	Sometimes	89.5
How often during the past month your stomach make you feel More nervous than usual?	A little of the time	19.0
	Some of the time	21.9
	A good bit of the time	7.6
	Most of the time	5.7
	All of the time	8.6

N=134		Frequency Response	(%)
Question Item			
How often during the past month your stomach make you feel Downhearted and blue?	A little of the time		28.6
	Some of the time		24.8
	A good bit of the time		9.5
	Most of the time		8.6
	All of the time		8.6
During past month, did you experience trouble falling sleep due to stomach symptoms?	Every night		4.8
	Most nights		7.6
	Some nights		26.7
	A few nights		21.9
How often past 4 weeks symptoms caused not to eat at meals time?	A little of the time		21.9
	Some of the time		22.9
	A good bit of the time		15.2
	Most of the time		3.8
	All of the time		4.8
How often in the past 4 weeks symptoms made you avoid certain foods/drinks?	A little of the time		17.3
	Some of the time		25.0
	A good bit of the time		19.2
	Most of the time		13.5
	All of the time		11.5
How often past 4 weeks symptoms made you find foods unappealing	A little of the time		22.9
	Some of the time		22.9
	A good bit of the time		20.0
	Most of the time		7.6
	All of the time		2.9
How often in the past 4weeks did your stomach make you feel socially uncomfortable?	A little of the time		17.3
	Some of the time		25.0
	A good bit of the time		12.5
	Most of the time		11.5
	All of the time		9.6
How often in the past 4 weeks did your stomach make you avoid certain social activities?	A little of the time		10.5
	Some of the time		19.0
	A good bit of the time		13.3
	Most of the time		9.5
	All of the time		6.7
How often in the past 4weeks did your stomach make you feel socially embarrassed about yourself?	A little of the time		22.9
	Some of the time		14.3
	A good bit of the time		15.2
	Most of the time		10.5
	All of the time		13.3

5.8 HAD SCALE

As presented earlier (see Chapter 4) HAD scale entails two sections that independently evaluate anxiety and depression. Descriptive values are presented first, followed by comparison with normative data.

5.8.1 HAD Anxiety

Data for HAD anxiety underlined elevated levels of anxiety for the study participants, also supported by subsequent mean comparison with normative values for this measurement tool. Over 94% of the participants felt tense or wound up ranging from time to time to most of the time. Only a 12% of the patients noted that they could and feel relaxed; underlining the uneasiness of the participants in the study, in relation to their symptoms. Additionally, over three quarters of the participants expressed getting a *“frightened feeling, as butterflies in the stomach”*, (occasionally to very often). Finally, a quarter of the participants experienced *“sudden feelings of panic”* on a frequent basis and a 13% of them noted experiencing those on a *“very often basis”*. Symptoms seemed to suggest quite a disabling panorama for the patient.

5.8.2 HAD Depression

Interesting results were also obtained in relation to this dimension exploring depressive symptoms within the sample. Approximately, an 80% of the sample seemed to have changed the *“way the enjoyed things they used things”* in relation to their circumstances. Also, nearly half of the individuals stated that they could not *“see and laugh at the funny side of things”* anymore, and nearly half of the participants felt “sometimes” slowed down. Participants were enquired whether they felt they had lost interest in their appearance. Nearly 45% of the participants stated that they did not take as much care as usual. Additionally, 60% of the participants stated looking to things with less enjoyment than they used to. Entertainment, was also compromised for the study participants, especially for nearly a 40% of them who noted not *“being able to enjoy a good book, radio or TV program”* due to their situation.

HAD scores were calculated and subsequently compared to normative values (Spinoven et al., 1997). The table below shows one sample t-test values for HAD scores.

Table 5.19: HAD Scale: Anxiety and Depression Comparisons

$p \leq 0.05$	Study Subjects(SD)	Normative Values(SD)	CI 95%
	n=134	n=199	
Total anxiety	9.26(4.35)	5.1(3.6)	(3,41 to 4,90) (t=11,03; p<0,001)
Total depression	7.05(4.08)	3.4(3.3)	(2,95 to 4,35) (t=10,31; p<0,001)

*One sample t-test used as statistical test.

Mean differences indicated statistically significant differences for both anxiety and depression total scores. For the case of anxiety, slightly elevated values were obtained than for the depression scores. Mean scores for anxiety in the normal population were of 5.1(SD 3.6) opposed to the obtained in the study which were of 9.26 (SD 4.35). Mean scores for depression, had a 3.65 mean difference (95% CI) and whereas normative data for this group was of 3.4 (SD 3.3) the obtained results in the study were of 7.05 (SD 4.08). This suggested that both anxiety and depression dimensions appeared impaired in selected sample.

5.9 BODY MASS INDEX

BMI figures were explored and classified into different BMI categories as by WHO (1998) classification (see Chapter 3). BMI's for the study population are summarised in Table 5.20.

Table 5.20: BMI Groups

BMI study group	n=134	Frequency (%)
Underweight if BMI <18.5	3	(2.2)
Normal if BMI 18.5 to 24.9	58	(43.3)
Overweight if BMI 25.0 to 29.9	24	(17.9)
Obese I if BMI 30 to 34.9	10	(7.5)
Obese II if BMI 34.9 to 39.9	3	(2.2)
Obese III if BMI over 40	2	(1.5)

Table 5.21: BMI Groups for ESP2 and SCOFF2

BMI Groups for ESP2 n=74	Frequency (%)	BMI Groups for SCOFF2 n=33	Frequency (%)
Underweight if BMI <18.5	2 (3.4)	Underweight if BMI <18.5	1 (4.2)
Normal if BMI 18.5 to 24.9	32(55.2)	Normal if BMI 18.5 to 24.9	14 (58.3)
Overweight if BMI 25.0 to 29.9	13(22.4)	Overweight if BMI 25.0 to 29.9	4 (16.7)
Obese I to Obese III (BMI 30 to 40)	11(19.0)	Obese I to Obese III (BMI 30 to 40)	5 (20.8)

Overall, over half of the individuals (56.7%) presented weight outside the normal BMI ranges. BMI calculations categorisations were compared for the two different screening tools used, to see if any differences were identified. Although results were quite analogous, a larger proportion of individuals seemed to present with normal BMI ranges for SCOFF2, whereas a slightly higher percentage of obese individuals (I to III) was present according to the same tool.

5.10 INTERRELATIONSHIP OF VARIABLES

This study managed a wide range of variables that provided valuable information. The relationships between the scales employed in this study were initially studied using a correlation matrix. A correlation is a single number that describes the degree of relationship between two variables, and it is one of the most common and most useful statistics. The correlation matrix is the representation of the correlation coefficients of the columns of a matrix. The following section would present some

of the most relevant correlations as found by combining variables retrieved from the data set. Table 5.22 illustrates some of those interrelationships.

5.10.1 Current Symptoms

Although bivariate correlation did not underline very strong relationship amongst variables, interesting trends can be highlighted. Moderate correlation relationships were found between individuals presenting abnormally hard stools and pain and discomfort (0.546**). And a strong correlation (0.631**)³ was found between those patients suffering abnormally infrequent motions and abnormally hard stools.

5.10.2 ESP2, SCOFF2 and HAD Scale

Correlation techniques, highlighted moderate correlation values for total values of anxiety and depression in the HAD Scale. This would suggest that individuals presenting higher values of anxiety would appear more prone to similarly present higher values of depression (0.583**).

5.10.3 ESP2, SCOFF2, EQ-5D and SF-36

Rol-Emotional scores and Mental values from SF-36 scale showed elevated values (0.480**) indicating moderate relationship among variables. This would suggest that higher values in the Rol-Emotional area that indicates worst emotional state would be related to a more impaired mental score in SF-36 values. Both estimates would suggest that higher values indicating morbidity for anxiety and/or depression for EQ-5D would be related to higher morbidity values for the Rol-Emotional component of SF-36. Equally, the anxiety/depression subscale from EQ-5D showed moderate relationship with the Mental subscale from SF-36. This would indicate that according to EQ-5D, the more anxious or depressed the patient, the worst mental health values would present according to SF-36. In addition, moderate correlation values were found for the EQ-5D VAS scale and Usual Activities subscale from EQ-5D. This

³ Correlation values are significant at the 0.01 level (2-tailed) and indicated as “***”.

would mean that the better the individuals were able to perform their usual activities, the higher that they would estimate their health according to VAS.

5.10.4 Diet, ESP2 and SCOFF2

Interesting correlations were found for those individuals considered as potential cases by ESP and SCOFF and the questions regarding diet habits by IBSQoL.

Strong relationship was found among those individuals whom were not able to eat their meals at time due to their symptoms and those who noted symptoms would make them find their food unappealing (0.750**). Additionally, moderate relationships were found for individuals who noted avoiding social activities (0.502**) and those whose symptoms made them not eating at meal times. A strong relationship (0.595**) was found for those individuals complaining that symptoms would hinder the ability to succeed and those that felt socially uncomfortable. And even clearer appeared the case that the more socially uncomfortable patients felt due to their symptoms, the more they would avoid certain social activities, which correlation estimate was of 0.753**.

Stronger correlations were identified for those individuals who noted symptoms would make them avoid certain social activities and those who noted they would feel socially uncomfortable due to their symptoms (0.753**), and would also feel that their ability to succeed was equally compromised (0.595**).

5.10.5 ESP2, SCOFF2, Depression and Anxiety.

Curiously, ESP2 and SCOFF2 did not show significant correlations with anxiety or depression totals as evaluated by HAD Scale. Patients who noted having lost interest in their appearance, strongly correlated (0.613**) with higher depression totals as evaluated by HAD Scale. In this sample, the more anxious the patients were, the higher it seemed they would score in the depression scale for HADS (0.583**).

5.10.6 Other Findings

Numerous explorations were run in order to search for relevant correlations that helped to understand this particular sample. This section will highlight a number of findings.

Strong correlations were found for those individuals who noted feeling downhearted and blue due to their symptoms and those who noted feeling more nervous than usual due to their symptoms (0.712**). Higher scores for the body pain aspect as evaluated by SF-36 moderately correlated to higher values for pain discomfort for EQ-5D (0.572**). Regarding usual activities of the participants, those would negatively correlate with body pain and vitality, which would translate into the less usual activities accomplished, the more body pain experienced (-0.459**) and the less vitality showed by the individuals (-0.425**). Finally, some moderate correlations were found for those individuals noting that symptoms would made them wake up at night and those experiencing body pain (0.452**), and equally those individuals would note that they would not feel as happy as usual (0.438**).

Table 5.22 Correlation Matrix of Selected Variables

	Total									
	Anxiety	Depression	Symptoms caused not to eat at meal times	Symptoms made avoid foods	Symptoms made finding foods unappealing	ESP2	SCOFF2	SF-36 MENTAL	SF-36 ROL EMOT	VAS
Total Anxiety	1.0									
Total Depression	0.583	1.0								
Symptoms caused not to eat at meal times	0.185	0.373	1.0							
Symptoms made avoid foods	0.060	0.127	0.480	1.0						
Symptoms made finding foods unappealing	0.214	0.353	0.750	0.548	1.0					
ESP2	0.067	-0.049	-0.078	0.107	-0.035	1.0				
SCOFF2	0.251	0.096	0.109	0.028	0.154	0.195	1.0			
SF-36 MENTAL	-0.539	-0.551	-0.428	-0.259	-0.359	-0.103	-0.291	1.0		
SF-36 ROL EMOT	-0.403	-0.446	-0.356	-0.365	-0.096	-0.199	-0.223	0.480	1.0	
VAS	-0.032	-0.352	-0.396	-0.330	-0.384	0.015	0.079	0.323	0.342	1.0

5.11 STRAND 3: ATTITUDES AND KNOWLEDGE OF EATING DISORDERS IN IRRITABLE BOWEL SYNDROME.

Exploratory factor analysis was applied to the data obtained from the questionnaires that nurses had completed on knowledge and attitudes towards IBS and EDs patients. The principles of which are described in Chapter 4. Statistical analysis similar to those described by Smith et al. (2002) in the development of a scale to measure health related quality of life in patients with inflammatory bowel disease were employed. As outlined in Chapter 4, the exploratory factor analysis technique is used to investigate the underlying structure of a compilation of observed variables, when there are no a priori hypotheses about the factor structure (Fabrigar et al., 1999). Exploratory factor analysis, involving principal components analysis followed by oblique rotation was performed. SPSS statistical package was also used to determine the internal reliability of the items used in the construction of the IBS/ED attitudes and knowledge base questionnaire.

5.11.1 Demographic Information

Firstly, some demographic information regarding the nurses' sample is provided. A total of 91 nurses completed the questionnaire (See Appendix section). Mean age of the participants was 42 years (8.12 SD), and they had been working in their current post a mean of 7.98 years (5.61SD). A 97.8% of the respondents were females and only 2.2% of them were male. Job description of the participant nurses is presented below.

Table 5.23: Demographic Information for Participating Nurses.

	n=91	Mean (SD)
Age		42.04 (8.12)
Time working in current post (years).		7.98 (5.61)

Table 5.24: Job Description for Participating Nurses.

JOB DESCRIPTION	Frequency	%
Nurse Practitioner	27	29.7
Staff Nurse	20	22.0
Stoma Nurse	33	36.3
Lecturer	2	2.2
Other	9	9.9
(n=91)	91	100.0

Participating nurses were also enquired regarding whether they had suffered from IBS and/or EDs at some point in their lives. Results are presented in the table below. When questioned about a personal history of IBS (42.9%) of nurse reported a history of IBS, and six nurses had suffered from an ED.

Table 5.25: IBS and/or EDs Sufferers for Participating Nurses

n=91	Frequency
Suffered IBS (yes)	39 (42.9%)
Suffered ED (yes)	6 (6.6%)

A 42.9% of the nurses noted suffering IBS at some point, whereas a 6.6% of the nurses themselves noted having suffered from an EDs.

5.12 EXPLORATORY FACTOR ANALYSIS

In principal components analysis there are initially as many factors as there are variables, in this instance, twenty-eight variables existed. The criterion of the Eigen values greater than one was used to determine the number of putative factors.

5.12.1 Nurses' Perceptions of IBS and Sufferers of IBS

In this study principal components analysis followed by oblique rotation revealed that a simple structure was not achieved with the set of variables. The loadings on Question 1 (Q⁴1) and Q18 suggested a better solution could be derived by omitting these variables from the analysis:

⁴ The symbol Q will be used to refer to question numbers.

Q1 *“Patients who suffer form IBS are difficult”*

Q18 *“IBS is linked to having abdominal surgery”*

Issues related to Q1 and Q18 suggested that these items were treated as outliers.

Issues associated with nursing attitudes are addressed in Q2, Q3, Q4, Q5, Q6, Q7, Q8, and Q24. In this part of the study the rotation which yielded the highest loadings on the relevant factors and the lowest loading on the other three is presented in Table 5.26.

The derived solution obtained by oblique rotation suggests that Q2, Q3, Q4, Q5, Q6, Q7, Q8 and Q24 load on Factor 1 (nursing attitudes). Q9, Q10, Q11, Q17, Q19 and Q25 load on Factor 2 (knowledge related to clinical practice), Q13, Q14, Q 15, Q16, Q20, Q21 and Q22 load on Factor 3 (textbook knowledge) and Questions 23, Q26, Q27 and Q28 load on Factor 4 (nursing perceptions).

On the basis of the literature review suggested names for the four factors are:

- | | |
|----------|--|
| Factor 1 | Nursing attitudes |
| Factor 2 | Knowledge related to clinical practice |
| Factor 3 | Textbook knowledge |
| Factor 4 | Nursing perceptions |

Table 5.26: Factors Identified and Cronbach's Alpha

Cronbach's alpha of identified factors		Cronbach's alpha
Factor 1	Nursing attitudes	0.801
Factor 2	Knowledge related to clinical practice	0.760
Factor 3	Textbook knowledge	0.681
Factor 4	Nursing perceptions	0.534

5.12.1.1 Results

Principal component analysis followed by oblique rotation of the data obtained from the questionnaire as can be seen in the following table.

Table 5.27: Questions and Factors Identified

Question	Factor 1	Factor 2	Factor 3	Factor 4
Q5	.779	-.189	-8.286E-02	-.112
Q4	.709	-5.263E-03	-.173	.167
Q2	.691	-.175	-4.910E-02	-.148
Q7	.683	-6.163E-02	.116	.192
Q3	.620	.369	1.645E-02	8.002E-02
Q8	.543	.213	7.521E-02	-.141
Q6	.537	-.240	-7.220E-02	-.188
Q24	.419	-.257	-7.750E-02	-.257
Q9	.197	-.845	-4.019E-02	-5.515E-02
Q10	-.100	.832	7.333E-02	-.122
Q11	-3.433E-02	.730	.408	-.281
Q17	-.149	.547	-6.759E-02	.111
Q19	.105	.327	7.368E-02	.136
Q25	.292	.319	-4.652E-02	1.694E-02
Q15	-8.998E-02	5.737E-02	.735	-.110
Q14	-.184	3.237E-02	.664	-.190
Q22	.179	6.094E-02	.638	-3.371E-03
Q12	-9.040E-02	.524	.584	-.140
Q16	.237	-.133	.521	.330
Q13	.160	.390	.497	.330
Q20	.169	2.760E-02	-.455	-3.637E-02
Q21	-7.391E-02	.131	.294	-1.341E-02
Q26	-.149	-6.549E-02	-3.243E-02	.795
Q27	2.992E-02	1.256E-02	-9.427E-02	.745
Q28	1.263E-02	1.737E-02	-.140	.680
Q23	-.247	.274	.179	.396

The loadings on variables on each of the factors which are greater than 0.3 are shown in bold. The derived solution was obtained by oblique procedure using SPSS (V13.0).

Baseline assessment of the IBS/ED attitude/knowledge base questionnaire resulted in the identification of nursing attitudes, knowledge related to clinical practice, textbook knowledge and nursing perceptions factors.

5.12.1.2 Descriptive of individual variables

In the next section, descriptive statistics are presented on the items for the four identified factors.

5.12.1.3 Factor 1

The selected variables from this factor were Q2, Q3, Q4, Q5, Q6, Q7, Q8 and Q24. They are summarized and presented in Table 5.28.

It would appear from the data that 91 nurses completed this question “*people who have IBS have it all in the mind*” that only 5.5 % (n= 5) believed this to be the case. Interestingly, over a 40% of the nurses described IBS individuals as demanding, and even when those were GI nurses, a 13.2% of the nurses noted not being really interested in IBS per se (see Table 5.28).

Table 5.28: Nurse Responses in Factor 1 (Nursing attitudes)

		Positive Agreed %	Agreed Disagreed %
Q5	People with IBS are lazy and crave attention	10 (11)	76 (83.5)
Q4	People with IBS are unable to cope with life	16 (17.6)	72 (79.1)
Q2	People who have IBS have it all in the mind	5 (5.5)	83 (91.2)
Q7	People with IBS are neurotic	12 (13.2)	76 (83.5)
Q3	People with IBS are demanding	37 (40.7)	51 (56.1)
Q8	People with IBS have low pain threshold	22 (24.2)	68 (72.5)
Q6	Individuals with IBS waste doctor’s time	5 (5.5)	83 (91.2)
Q24	I am not really interested in IBS	12 (13.2)	79 (86.8)

5.12.1.4 Factor 2

The selected variables for this factor were Q9, Q10, Q11, Q17, Q19 and Q25. Those are summarized with a table below in this section.

It would appear from the data that of the 91 nurses who completed this questionnaire, nearly half of the sample believed that their knowledge of IBS was limited, and a 42.9% of the sample was not confident either with their understanding of IBS or with the idea of explaining the syndrome to a patient, which appeared to be the case for a 45.1% of this group of GI nurses (see Table 5.29).

Table 5.29: Nurse Responses in Factor 2 (Nursing knowledge related to clinical practice)

		Positive Agreed %	Negative Disagreed %
Q9	My knowledge of IBS is limited	44 (48.4)	42 (46.2)
Q10	I have a good understanding of IBS	39 (42.9)	49 (53.9)
Q11	I could confidently explain IBS to a patient	41 (45.1)	48 (52.8)
Q17	IBS causes the muscle of the gut to react	57 (62.6)	32 (35.2)
Q19	There is a self-help group for IBS	74 (81.3)	14 (16.5)
Q25	IBS is not a serious illness	25 (27.5)	66 (72.5)

5.12.1.5 Factor 3

The selected variables for this factor were Q13, Q14, Q15, Q16, Q20, Q21 and Q22. Those are summarized with a table below in this section (see table 5.30).

Results suggested that of the ninety-one nurses who completed this questionnaire, nearly a 75% of them believed that IBS could have multi-causal origin. Nearly half of the sample suggested that doctors could only speculate about IBS causes and nearly 70% of the nurses noted that there was no cure for IBS.

Table 5.30: Nurse Responses in Factor 3 (Nursing knowledge related to textbook)

		Positive Agreed %	Negative Disagreed %
Q13	Psychotherapy has been successful in the short term in alleviating the symptoms of IBS	28(30.8)	61(65.9)
Q14	IBS results from a variety of causes	68(74.7)	21(23.1)
Q15	Some of the symptoms are abdominal, pain, flatulence and diarrhoea	86(92.5)	3 (3.3)
Q16	Doctors can only speculate about the causes of IBS	43(47.3)	46(50.6)
Q20	There is a cure for IBS	26(28.6)	63(69.2)
Q21	IBS is a digestive disorder characterized by unexplained abdominal pain	52(57.1)	39(42.9)
Q22	There is no universal agreement about the causes of IBS	67(73.6)	24(26.4)
Q24	I am not really interested in IBS	5 (5.5)	86(94.5)

5.12.1.6 Factor 4

Finally, some of the selected variables for Factor 4 were Q23, Q26, Q27 and Q28. Those questions are summarized with Table 5.31, below in this section.

It would appear that in general, nurses agreed that IBS is a common disorder, which was supported by a 94.5% (n=86). Interestingly, a 65.9% of the nurses thought that doctors had poor knowledge of the syndrome and the same percentage suggested that IBS was not taken seriously by the health care professionals.

Table 5.31: Nurse Responses in Factor 4 (Nursing perceptions)

		Positive Agreed %	Negative Disagreed %
Q23	IBS is a common disorder	86 (94.5)	5 (5.5)
Q26	Health prof. have a poor understanding of IBS	82 (90.1)	9 (9.9)
Q27	Doctors have poor knowledge of IBS	60 (65.9)	31 (34.1)
Q28	IBS is not taken seriously by health professionals	60 (65.9)	31 (34.1)

5.12.2 Nurses' Perceptions of Eating Disorders and Sufferers of Eating Disorders

The original IBS questionnaire was adapted for application in relation to EDs. enquiry, with no success. However, factor analysis for 1, 2, 3, and 4 dimensions were attempted and did not demonstrate any structure. Therefore the adapted IBS questionnaire for this study would appear to have limited application in Eating Disorders.

Nevertheless, descriptive analysis of the questionnaire suggested that GI nurses appeared to demonstrate a limited understanding towards ED, as highlighted by some of the answers given by them and that are presented below (see Table 5.32).

Table 5.32: Nurse Responses in Relation to EDs

		Positive Agreed %	Negative Disagreed %
Q 9	My knowledge of ED is limited	72(79.1)	16(17.6)
Q 12	I would recognize EDs without too much difficulty	16(17.8)	72(79.1)
Q 11	I could confidently explain what it means to have an ED to a patient	4 (7.7)	82(79.2)
Q 23	EDs are common in our society	55(60.4)	11(12.1)

From results it seems that despite the fact that over 60% of the nurses acknowledged that EDs were prevalent in today's society; nurses' knowledge was severely limited, and that they would not be able to provide patients with information in the case that was required. This is particularly relevant for this study due to the close relationship that seems to exist between GI conditions (IBS in particular) and EDs. This fact underlines the relevance of adequate educational programmes that discuss EDs in depth, and that provide GI nurses with a good overview and foundation on this group of disorders.

5.13 CONCLUSIONS

This chapter has presented the quantitative analysis of the data gathered in this study both for the patients and the nurses' study.

Quantitative techniques applied to the data obtained in the main study suggested important differences between the selected screening tools. This highlighted an apparent superiority of the SCOFF screening instrument that was also supported by ROC curve analysis.

On the other hand, HRQoL was assessed in patients by using SF-36, EQ-5D and IBSQoL which suggested impaired HRQoL for the study patients and that was particularly notable when compared to normative values. This was particularly relevant for the social, mental health, and vitality dimensions in those individuals identified as potential cases.

HAD scale also suggested elevated values for both anxiety and depression scores, although results seemed to be more markedly so for the anxiety dimension. Comparison to normative values also highlighted this finding.

The second part of this chapter analysed data regarding the adapted questionnaire intended to assess nurses' perceptions of IBS and EDs and sufferers of IBS and EDs. By using exploratory factor analysis four factors could be identified for the part of the questionnaire regarding to IBS, however results regarding the EDs section of the questionnaire showed limited value for the EDs field.

Next chapter will introduce the analysis of the qualitative data obtained in Strand 2 of this study using thematic content analysis.

Chapter 6

Qualitative Findings

As described in Chapter 4 an inductive and exploratory approach was taken in Strand 2 of the study.

The rationale for undertaking this Strand 2 of the study was based on three main points:

- First, the author's suspicion that despite the value of ESP and SCOFF tools (employed in Strand 1 of the study) additional information was required to clarify certain aspects (e.g. altered eating pattern, gastrointestinal symptoms, food restriction) regarding the potential eating problem.
- Second, to follow up the suggestion that the biomedical model which still structures most treatment regimes in this field may fail to address certain key areas such as the patient's personal accounts of their experience of illness (Brown and Williams, 1995).
- Finally, and from a nursing perspective the acknowledgment and value of personal experiences as a fundamental part of the evidence base for good practice (Polit and Beck, 2004).

Semi-structured interviews were conducted on a consecutive sample of twenty-five female IBS patients considered as "*needing further exploration*"¹, as identified by

¹ Patients were considered as "*needing further exploration*" when as described in Chapter 4 and Chapter 5 they had scored over +2 for any of the ESP or SCOFF screening tools. Cut off points were used as suggested by Morgan et al. (1999) and Cotton et al. (2003).

either ESP or SCOFF screening tools previously presented. The underlying principle for selection was the potential for a fuller understanding of the experience of living with IBS. This required the selection of information-rich cases, that is, cases that are selected for presenting particular characteristics that would provide elements of information which are thought to be fundamental for the research (Coyne, 1997).

The interview schedule used was informed by issues raised in the literature review, and therefore questions focused on aspects regarding IBS origin, the route to diagnosis, quality of life, anxiety and stress, perceptions of foods, potential presence of EDs, dieting, exercise routines and, finally, expectations. The original guiding questions evolved² throughout the twenty-five interviews, faithful to the qualitative nature of this Strand 2 of the study, so that the areas just addressed were explored during the meetings with the participants.

Data were analysed using Burnard's (1991) stage-by-stage method (see Chapter 4), adapted from the Glaser and Strauss' (1967) Grounded Theory approach. The analysis aimed at producing a detailed and systematic presentation of themes and issues addressed in the semi-structured interviews as suggested by Breeze and Repper (1998). To facilitate the qualitative management and analysis, a computer software package, QRS NVivo[©] version 2 (Richards et al., 2002), was employed in combination with manual coding and handling as presented in Chapter 4.

6.1 INTRODUCTION

Interviews were conducted on a sample of twenty-five female IBS patients attending an outpatient GI clinic of a Scottish hospital. Participants had been previously approached by the nurse researcher and the study scheme had been explained to each individual. Informed written consent had been obtained before scheduling the interview date. All interviews took place in the clinical setting. This appeared to be preferred by the patients since meetings were scheduled on the same day that

² Although a substantive interview guideline was created, the researcher understood that using the selected approach gave greater flexibility in restructuring, adding or deleting questions as interviews progressed.

participants saw their doctor. Interviews were conducted in a private office at the clinic where the researcher was based for the duration of this study. Length of interview was at the discretion of the patients and conversations lasted from 20 to 60 minutes. A summary table with some of the participant characteristics is provided below (Table 6.1). For the purpose of this study, patients' names have been omitted and therefore, numbers will be used to refer to participants in order to preserve their anonymity.

Table 6.1: Background Details of Patients Interviewed

Pt #	PATIENT DETAILS
1	43 years old. IBS diagnosed by a specialist. IBS associated with a very stressful environment. Concerned about body weight and sad about appearance. Feels she needs guidance and advice.
2	37 years old. IBS began six years ago, when she moved to London to work. Diagnosed by a specialist. Notes she “wants to be fit”. Regarding IBS, expresses that she has learnt to cope with it.
3	35 years old. IBS present for over five years. Focused on food and looking for alternative “healthier lifestyles”. Feels the pressure to find an alternative to her situation. Very unhappy about her weight.
4	52 years old. IBS diagnosed six years ago. She feels no difference over time, but feels “fed up” with the situation and requires guidance. History of EDNOS.
5	55 years old. IBS originated while on holiday and after infection. Several admissions to hospital. Very negative towards the future. Hinted that she distrusts health professionals, so she looked for “the herbal solution”. Does not rely on medical treatment. Very anxious.
6	24 years old. She notes that symptoms could have begun three years ago. Just recently diagnosed. Drugs not working for her. Met dietician to find an adequate and “healthy” diet, but she says she is unable to follow dietician’s advice. Her mother suggested that IBS was related to her “erratic dieting behaviour”, but patient laughs about it. Has tried to cut out certain foods, but it is not working.
7	47 years old. Symptoms began 5 years ago, and she initially thought it was due to muscular pain. At time of the onset, she was under a lot of pressure at her current job. History of AN. Still very careful and concerned with what she eats and exercise is part of her routine. She notes “being in control now”. Much emphasis on healthy eating.
8	21 years old. IBS diagnosed by her GP, two years after moving to Scotland. Very stressed about this situation. Big impact on her routines. Stressed and sad about her situation. She says she simply wants to “get rid of it”. Lacks support.
9	27 years old. IBS first manifested after appendicectomy, but it has, or symptoms have become gradually worse. Presents with clear bulimic symptoms, which seem to be aggravated by her IBS according to her. Unable to go on “a proper diet”. Very anxious about this current situation.
10	35 years old. IBS appeared after hysterectomy. She notes symptoms have worsened over the last year. Morbid obesity and “trying to lose weight”. She feels treatment is helping her but on a very slow basis.
11	43 years old. Patient notes “many years of having trouble with her bowel”, which began while on holiday abroad. Patient refers to IBS as not having a proper diagnosis. “I’ve had loads of checks but they never find anything!”. She notes being on a diet due to having put on weight. Anxiety makes her overeat: “I don’t feel confident in case I have an accident, and so I’m very nervous all the time. It gets me down”.

PATIENT DETAILS

Pt #

- 12 26 years old. IBS symptoms emerged during last year of university. Notes that she suffered from BN from 13-17 years old. Overweight and concerned regarding her appearance. Attending a slimming club, but notes "always being on a diet". Emphasises needing support for this and more time for her at the clinic.
- 13 41 years old. IBS appeared over ten years ago and diagnosed by a specialist. Symptoms have worsened over the last 3 years. Overweight, notes that often "eats in secret". Concerned about healthy eating, and potential risks of IBS. She is concerned IBS could turn into cancer.
- 14 39 years old. Symptoms began after giving birth. Specialist diagnosed IBS and since then (12 years ago) she has been in treatment. Treatment not working for her, but appears optimistic.
- 15 18 years old. Patient notes always struggling with IBS. She expresses that she has always been a "bad eater". Evidently underweight. "I control my food due to IBS", exercises intensively over the week.
- 16 34 years old. Not able to recall when IBS first appeared. Overweight and very concerned about pain related to IBS. She says this affects her, and last time she went out she panicked due to symptoms. Medication is not helping her.
- 17 32 years old. A painful initial episode took her to hospital several years ago. IBS symptoms improved with her pregnancy, but have got worse since then. She underwent numerous tests and diagnostic procedures. Impaired self-image. Despite being underweight, notes "feeling big", and she adds "I know I've got a problem". Constant remarks about her appearance. Sad about not being able to control this situation. Numerous dieting attempts.
- 18 43 years old. IBS began four years ago. Numerous IBS "accidents" over the past months. She feels very depressed due to this situation. Suggest potential past EDNOS (anorectic type). Since then, erratic eating pattern.
- 19 45 years old. IBS present for over thirty years; but only diagnosed with IBS at twenty nine years old by the specialist after many visits paid to doctors. Several painful episodes lately. Concerned about potential malignant processes. "Not able to identify damaging foods". She notes "I'm tired about this and cannot be bothered. I'm simply fed up!".
- 20 31 years old. She notes being an "IBS patient" for over eleven years now. Tired of the condition and sometimes feels that "cannot be bothered". Does not consider herself anxious but uses intensive and regular exercise to cope with her situation. Feels misunderstood by both family and friends so avoids sharing her situation with others.
- 21 46 years old. IBS present for over twenty years. She notes one of the worst things about her condition is uncertainty. She believes symptoms could be related to food, so she has modified her diet drastically. Frustrated due to the difficulties she has in "leading a normal life".

PATIENT DETAILS

Pt

- 22 42 years old. Patient notes suffering from IBS over many years, however symptoms have worsened over the past six years. Pain is a problem at the moment. She takes "*herbal*" supplements recommended by fellow colleagues since drugs she was taking did not have the expected effect. Exercises three times a week "*to help keep sane*". Anxious about her situation, several complaints regarding low HRQoL.
- 23 33 years old. IBS present for a long time, however symptoms worsened four years ago. After this, she notes being really stressed, and on two occasions she notes having a nervous breakdown, due to a combination of personal events. Overweight, but eating pattern as related by the patient seems inappropriate.
- 24 26 years old. She was diagnosed with IBS over two years ago. However, she looked for advice outside the NHS network. Evaluating her diet habits, she decided to exclude some of them, and since then she feels much better. Notes "*being always on a diet*", and reducing her weight steadily.
- 25 25 years old. She notes IBS was always there, but worsened over the past five years. Co-morbid asthma currently in remission. She notes that because of IBS she tried to modify her diet and tried several "*exclusion diets*". The patient notes that then she realised that "*foods don't do good to me*". She decided to become a vegetarian and she is very pleased because she has dropped a lot of weight and feels "*rewarded*". IBS symptoms however appeared to have flared up.

The qualitative findings will be presented in the following sections, where the five main themes that emerged from the data are presented with their sub-themes:

- **IBS origin and routes to diagnosis**

- IBS diagnosed by the GP
- IBS diagnosed by a specialist
- IBS identified by others
- IBS origin and stress
- IBS origin related to surgical procedures
- IBS related to an infective process
- IBS related to an initial painful episode
- IBS origin as idiopathic

- **Anxiety and Stress**

- **Potential Eating Disorders**

- Altered eating patterns
- Body Image
- Self-esteem
- Use of compensatory mechanisms
- Use of laxatives
- IBS blamed for altered eating patterns

- **Quality of Life**

- Quality of life, family and intimate life
- Quality of life, social life and friends
- Quality of life and working time

- **Self-management**

- Uncertainty
- Keeping the secret
- Exercise and weight control
- “*Good*” and “*bad*” foods

The identified emerging themes will be used to guide the presentation of the qualitative results. Quotations from the participants have been incorporated in order to highlight the findings. However, due to word limit restrictions it was impossible for the author to include them all. Results will be subsequently discussed in Chapter 7 combined with the quantitative findings from Chapter 5.

6.2 IBS ORIGIN AND ROUTES TO DIAGNOSIS

The following section will present qualitative data regarding individuals' routes to IBS diagnosis as well as their perceptions regarding IBS origin. This particular order has been chosen since it emerged from the data that although all of them had received an IBS diagnosis and therefore a unique and personal route existed, not all of them accepted IBS as "*their real problem*". Therefore, how symptoms were initially identified and by whom will be presented first, followed by the way patients tried to find meaning in the origin of IBS for them.

Participants identified the person or persons who had first suggested IBS diagnosis. Three main paths emerged: IBS diagnosed by the GP; IBS diagnosed by a hospital specialist; and the most frequently occurring one, where IBS diagnosis followed suspicion by the patient herself, by relatives or by work colleagues. Curiously, two thirds of the interviewees had been diagnosed by a health professional (half by the specialist, and the other half by their GPs). For the rest of the participants, IBS had been identified by themselves or by someone from their immediate circle, leading to subsequent professional confirmation.

6.2.1 IBS Diagnosed by the GP

Qualitative analysis revealed that for a third of the interviewed participants it was their GP who first identified and diagnosed IBS. Most of these patients reported having struggled with a variety of symptoms for a significant period of time prior to diagnosis.

"...I would not know...long time ago...I think it was like ... 5 years ago, 5 or 6 years ago in September. I'd worked for a restaurant in the summer in Edinburgh and I didn't eat properly and then in September I went back to teaching and suddenly I started to have terrible pain in my tummy and the back and it was like agony. (...) I, I was teaching and suddenly all pain. I felt like somebody was piercing in my tummy and the pain was terrible. So one day I went to see my doctor and em, (...) that's when she, she said I had strong constipation, something like that. So she gave me like stuff to, to take and, to put up with, suppositories and stuff like that. And then I went away..., and then I was fine for a while and then I started to go out with Michael and changed my diet and then suddenly it started to bother me again. In the meantime I was having problems

going to the toilet as I would normally go. And then it started to get worse. My diet changed completely and em, but it wasn't drastic so I didn't think anything of it...I went to my GP again, and again...and finally, she said it was IBS (...)" (Pt 17)

"Oh dear...It's been many years of having trouble with my bowels...I don't know...maybe eleven years or so (...) but I must say, it's been worse after I went travelling...the past two years have been difficult" (Pt11)³

One overseas patient noted how she had struggled with a variety of IBS symptoms for a while, but it was only when she had moved to Scotland that symptoms became more apparent. She had visited her GP on several occasions and that was how she was initially diagnosed with IBS. The patient was subsequently referred to the GI outpatients' clinic due to the exacerbation of her symptoms. Additionally, patients also noted having been referred to other health professionals, as well as prescribed drugs that in most of the cases proved unsuccessful.

"My GP diagnosed IBS (...) he also referred me to the dietician, who tried to engage me in a healthy diet, so I could cope with IBS. However I knew I would not cope with her regime (...)." (Pt 6)

"I was diagnosed by the GP (...) he then referred me to this clinic (...)." (Pt 10)

It seemed as if GPs appeared as the entry point of diagnosis and treatment for many patients; however not all of them were able or skilled enough in recognising the condition which individuals presented with. Once diagnosed, participants had been subsequently referred to a specialist since symptoms were not being satisfactorily managed in primary care.

6.2.2 IBS Diagnosed by a Specialist

As noted earlier, some patients were diagnosed by a specialist. In most of the cases, patients had struggled for a lengthy period of time (years in most of the cases) before a formal diagnosis was established. Three patients insisted that they had *"to pay many visits to a variety of doctors till IBS was identified,"* (Pt 20). In general, patients who had been diagnosed by a specialist noted that a variety of tests had been

³ The symbol Pt will be used to refer to the numbers that patients were allocated in order to preserve their anonymity.

conducted and it was only after several consultations that IBS diagnosis was finally established. A relevant and frequent comment by several patients was that they felt that despite numerous checks, “*nothing was found*” (Pt 11).

For some of these patients, IBS diagnosis was considered a “*minor*” diagnosis as if it was not consistent with the symptoms experienced by them, or as if they were expecting a more sinister diagnosis, that would agree with their symptoms.

“It was the specialist at this clinic who diagnosed IBS. But I’ve had loads of checks throughout the years, and they never find anything, which is frustrating. It is only IBS!” (Pt 11)

6.2.3 IBS Identified by Others

Other participants reported that initial suspicion or “*potential diagnosis*” had originated in scenarios other than at the GP or a specialist clinic. One patient commented that after struggling for long periods with abnormal bowel function she had consulted a “*health shop*” (Pt 24), and another interviewee noted that it was not till she had discussed her problems with someone at work that she realised that “*something was wrong*” (Pt 2). Curiously, it was this patient who noted that she “*never thought that this (IBS) could be something obscure or serious*” (Pt 2). There is a striking dichotomy in participants’ perceptions of IBS: for one group of patients, IBS was described as obscure and somehow sinister and on the other hand, for a significant proportion it seemed as if IBS was a second class disease, which was not perceived as “*important enough*”.

“After two years with erratic symptoms (...) of course I knew something was wrong, but I never thought this could be something that obscure, that serious...” (Pt 3)

“Well, you see...I want to get sorted...doctors never find anything, so that really gets me down” (Pt 11)

Patients expressed many frustrations they had encountered along the “*road to diagnosis*” (Pt 22). For most cases, this period was lengthy and required numerous investigations prior to final IBS diagnosis. In some cases, before and after the diagnosis, drugs had been prescribed without the desired effect, which patients said contributed to the anxiety and frustration levels presented by the participants.

Patients also implied that similar frustrations would follow after IBS diagnosis was given to them, since having a diagnosis did not guarantee knowing what they would have to face, or the symptoms they would encounter from that moment onwards. Drugs and certain management strategies would often work inconsistently, which again would have a significant impact on the patient.

6.3 PERCEPTIONS OF IBS ORIGIN.

For the majority of patients, the origin of IBS was generally seen with a mixture of uncertainty and disbelief. Also, in most patients noted “*many years of having trouble with her bowel*” (Pt 11).

“I don’t know...I suppose it has always been there, but when I came to Scotland things started to be difficult. Last two years have been really hard (...) (Pt 8).

Or as Pt (8) noted, IBS had been present over time and manifested more markedly at one point.

Five emerging categories were identified within this context which will be commented on in this section. Participants noted that origin of IBS symptoms was associated with:

- A particularly stressful period in life
- Undergoing surgical procedures
- An infective process
- Related to a painful episode
- No particular origin

These categories will be examined in more detail next.

6.3.1 IBS Origin and Stress

Patients described the first manifestation of their IBS symptoms as being related to undergoing particularly stressful periods. One of the participants noted that IBS symptoms seemed to be associated with undergoing a “*very stressful period at work*”

(Pt 7). This woman noted working in a stressful environment where pressure was on the employees “*to perform at a high level*” (Pt 7). Another patient noted that symptoms had flared up when she had moved to London six years ago. This was a stressful period for the participant, as described by her, due to “*numerous adjustments necessary at that time*” which involved “*both professional and personal life choices*” (Pt 2). Again, work related stress was presented by another participant as the most significant circumstance going on at the time IBS first manifested (Pt 1). Finally, one of the participants’ accounts is presented to highlight her description of that period.

“I remember it was a very busy time at the office (...) we had a very important event and numerous projects. But it started as pain in the side, so I thought I had over exercised (...) it was nearly four years of symptoms without being sure of what was the diagnosis...” (Pt 7)

“I think it began about six years ago. I finished University and moved to London with my boyfriend. Job hunting was difficult, the city, my family was far away...I felt I could not cope. I was really stressed then (...)” (Pt 2)

“It was a really stressful time, I had given birth and my spouse was made redundant at work. I felt I could not cope; it was really tough (...) a painful episode took me to hospital and that is when they told me what was going on. Symptoms have worsened since then (...)” (Pt 23)

6.3.2 IBS Origin Related to Surgical Procedures

For a few of the interviewees, the onset of IBS symptoms was preceded by a surgical procedure. Two patients who had undergone hysterectomy developed symptoms shortly after their operation, and symptoms had been present since then.

“In my case, I believe this began after the hysterectomy (...) soon after that, the diarrhoea and the constipation cycle started and that was very very bad, (...) also, I was fainting a lot.” (Pt 10)

Another patient noted that following an uneventful appendicectomy, IBS symptoms had first manifested during the postoperative period. Only one of the patients who noted experiencing IBS symptoms after undergoing surgery specifically commented that the procedure had an impact on the normal functioning of their bowels. This was caused by partial section of the bowel related to caesarean section.

“After my resection, bowels were not functioning normally, and since then the symptoms have been gradually much worse.” (Pt 9)

6.3.3 IBS Origin Related to an Infective Process

Other participants noted that IBS symptoms seemed to have flared up following a pathogen illness. One patient noted that her bowel function had been problematic for several years; however it was only after travelling abroad to Chile that she suffered a gastric infection, and IBS was subsequently diagnosed (Pt 11). A similar pattern was described by another participant. This female had been similarly infected when on holiday and received antibiotic treatment that had not been successful (Pt 4). IBS symptoms manifested soon after this episode, and this particular patient had to be admitted to hospital on several occasions due to intense episodes of recurrent abdominal pain.

6.3.4 IBS Origin Related to an Initial Painful Episode

Several of the interviewed participants believed that their IBS symptoms had first manifested or they felt that they were related to an initial extremely painful episode described by them as *“never experienced before”* (Pt 16), and that in all instances hospitalisation was needed. As an example, Pt 7 clearly described this experience as particularly stressful.

“I have always had an erratic IBS pattern (...) originally it started as an intense pain on the left side of my tummy in 2001, I thought I had “pulled a muscle”, since the pain was so intense (...) it was difficult to cope with it, so I ended up in emergency (...)”(Pt 7)

Symptoms were controlled at that time, but IBS had been present over a few years, as in most of the interviewed patients.

6.3.5 IBS Origin as Idiopathic

The majority of the interviewed participants noted that they could not identify a specific period when IBS symptoms had first manifested. Most of them reported previous abnormal bowel function for many years, and IBS symptoms seemed to have appeared progressively. Several patients noted that they were not aware of these symptoms until they were highlighted by relatives or friends, as they had assumed them to be part of their normal routines. In addition, most of the patients did not see IBS symptoms as connected with a specific episode but as a continuum of bowel problems that seemed to be present on a relatively sustained basis.

“I have had difficulties in moving my bowels and feeling constipated since I was fifteen years old, and it was not until I was twenty-nine that I was diagnosed with IBS.” (Pt 20)

“I cannot think of a specific time that I can associate with its origin, I have had it for a long time,(...) but it’s only over the six past years that symptoms have worsened.” (Pt 22)

“I think IBS was always there, but symptoms have been surely worse for the past five or ten years.” (Pt 25)

“(…) to be honest, I really don’t know but I think I have struggled for over twenty years with it now (...) but at least, I now recognise that there is a problem.” (Pt 21)

As presented in this section, participants identified a variety of situations and circumstances where symptoms emerged and were identified. This appears to be appropriate to what is known about IBS presentation, which may seem conflicting in many cases and could well generate uncertainty in the patient. This may as well be present in the professionals that would be sceptical about patients’ symptoms if they fail to identify IBS.

6.4 ANXIETY, STRESS AND DEPRESSIVE EPISODES

Anxiety, stress and depressive issues are quite common for most patients with IBS diagnosis as well as for eating disordered patients. Those symptoms were obvious during the interviews, and they can also be found throughout this section, where anxiety and low mood appear to be entwined within the participants’ accounts.

Patients frequently noted being stressed, or under pressure due to varied reasons. Low mood or particular depressive episodes were pointed out by the individuals who often noted feeling low, miserable and/or desperate due to their circumstances. Most of the participants interviewed described themselves as being either chronically anxious and/or stressed. Over three quarters of them described themselves as “*very anxious*” and/or “*stressed*” and only one participant described herself as “*not anxious*” and another one emphasised that although she could see that her life was stressful, when compared to other colleagues working with her, she did not feel she was “*more anxious than people at her job*” (Pt 22). This highlights what seems to be particular tolerance of a certain level of accepted anxiety for a particular environment.

In general, participants described themselves as an “*anxious person*”. For this sample, anxiety seemed to have two different origins: environmental and IBS related, as a perpetuating factor.

Some patients disclosed previous life events that may have contributed to their pessimistic view of their condition, but on a general level it seemed that “*anxiety*” was present in their basal state, or at least an important element of every day reality.

“I know anxiety and stress is a major factor in my evolution, but I don’t seem to be able to control it, (...) I guess it increases with time.” (Pt 5)

“I simply feel so low, I’m uncomfortable in my body, with my weight. I’m sad, sick and tired. Of course I am concerned about my weight, (...)I’m ashamed, ...such a mess. Then it’s the job, which is really nerve-racking. My husband is really worried,...well, I suppose I’m very concerned too...” (Pt 1)

Other patients were concerned regarding the role that “*anxiety*” may have played in the evolution of their condition as well as in anxious or depressive episodes that would be related to IBS symptoms evolution, maintenance, or lack of control. For them, life-anxiety and IBS-related anxiety were mutually aggravating.

“Yes, I am a very anxious person. I am aware that symptoms do not benefit from it.” (Pt 8)

“I know that my condition worsens when I’m excited or nervous, but it is difficult to control (...) I regularly use yoga, relaxation tapes, and some drugs to help, but it does not always work.” (Pt 25)

“I am very anxious about my symptoms and the situation that I am in at the moment (...) I wonder if there is something else, something obscure that has not been diagnosed.” (Pt 2)

The extracts above portray patients who have to cope often with intense levels of anxiety. Additionally, it seems that anxiety affects the patient’s whole universe and all their activities are somehow coloured by it.

Some patients tried to deal naturally with stress and others used yoga, or relaxation sessions to cope or keep stress levels within manageable limits. In extreme cases, patients required medication to maintain anxiety and depressive states within safe limits. This was not always possible and individuals noted experiencing feelings of *“losing control”* which may have resulted in added stress to their circumstances.

“I feel I cannot cope with this any more. I had a nervous breakdown some time ago, and I know it was the combination of many events at that time, but still I feel I cannot take it anymore (...) I do take medication for this, but I do not feel it is working.” (Pt 4)

“I know in my case it is a sum of facts, I have had a difficult life and I am still struggling (...) I am so tired of this, it is very stressful.” (Pt 3)

Patients described different strategies to cope with anxiety but some felt that there was nothing they could do to alleviate this situation. Two participants noted that they would cope with anxiety by limiting or overindulging in food. Subsequently, this would bring a *“guilty feeling”* that would raise anxiety, despair, and sadness levels after each of those episodes.

“I cannot help it. The IBS situation gets me depressed, I binge because I feel bad, and I feel bad because I binge (...) so I have to take laxatives because I eat so much, even when I know this is really bad for my IBS. I am really stressed about this situation (...) all the time.” (Pt 9)

In this case, it was clear to the researcher that the patient underlined the difficulty she had to control IBS, and the binges due to bulimic episodes. Anxiety and low mood were also present, which adds to the difficulties that patients may have coping with the sources of added stress or concern (as it is the case of BN and IBS as a vicious

circle). Ultimately, this may contribute to significant levels of anxiety, or exacerbate individuals' low mood.

I have a stressful job, and I know that does not help (...). I have put on a lot of weight and of course I am really concerned about my body weight... it makes me feel uncomfortable and insecure (...)" (Pt 1)

6.5 POTENTIAL EATING DISORDERS

Eating difficulties, eating problems and ultimately potential EDs were explored via screening tools (see Chapter 4 and Chapter 5) and also through subsequent interviews. ESP and SCOFF screening tools had previously made the patients consider certain issues regarding EDs or habits that could be related to disturbed eating patterns. In the interviews, participants were asked whether they felt they had ever experienced any eating difficulties or EDs which they would like to discuss. Responses were varied and despite prior concerns regarding the sensitivity of this topic, none of the patients refused to discuss this issue with the nurse researcher. In fact, patients appeared open to discussing this particular subject.

"I was never formally diagnosed because I was so afraid to go to the psychiatrist (...) at that time there was no information and I did not have the money for that either. (...) I went to see a counsellor though, since my weight was very low and my eating was irregular. I was feeling very down..." (Pt 4)

However, other patients really felt the need to discuss some of the topics, and even when they had tried before; it seemed that their suggestions had been dismissed as noted by (Pt 9).

"There was actually one time...hum... there was a questionnaire thing in a woman's magazine about an eating disorder, and you filled in this questionnaire and it told you if you were fine or anorexic whatever... and I'd filled it in and it had come up with em, some sort of eating disorder. And I'd shown it to my mum and dad, I was only about 18 or something at the time. I'd showed it to my mum and dad and they agreed with the answers that I'd given. So my dad had come with me to see the doctor and she told me it was a lot of nonsense and, yeah...she told me it was a lot of nonsense and it was just one of these silly, magazines articles. I mean it was in a woman's magazine and she was possibly right but it didn't sort of help me. She said she could refer me to the diet, to the practice nurse and I went to see the practice nurse and she gave me a

diet for the Weetabix diet, which was basically just healthy eating. I thought I know what I'm supposed to be eating. I've been going to slimming clubs long enough. I know what I'm supposed to eat and what I'm not supposed to eat. That's not the help that I'm looking for. And I decided after that there was no point in speaking to anybody else about eating" (Pt 9)

This authoritative quotation highlights several important points addressed in this research: the hidden nature of EDs, the patient's request for help, and the failure to recognise and manage symptoms, and the frustration experienced by the patient after her suggestion is dismissed.

Interestingly, more than a third of the participants disclosed having had some form of eating difficulty in the past. A number of patients had suffered from AN previously (which at the moment of the interview was controlled), two participants disclosed clear bulimic symptomatology, and several others openly discussed their "*problems with food*" they had experienced since they were children. Individuals discussed food habits, self image, dieting, use of laxatives and compensatory mechanisms commonly associated with EDs. Issues raised during these discussions included fear of gaining weight, self-esteem, unhappiness about body size and general appearance, comfort eating and unhealthy dieting.

Regarding EDs, topics mainly addressed were: altered eating patterns, use of laxatives, body image, self-esteem, IBS blamed for distorted eating patterns, and professional help regarding potential EDs. Results will be presented below according to emergent categories within this topic in order to facilitate reading.

6.5.1 Altered Eating Patterns

Most patients reported erratic diet patterns which in some cases would enable them to control their weight as illustrated by the following extracts:

"I have tried every single diet to lose weight, so I mixed them up sometimes to achieve results (...), I am concerned about foods and how they affect my symptoms now, so I also try to cut on certain foods as a type of specific dieting." (Pt 6)

Patients were aware of the altered pattern in their eating but felt that was part of their routines now.

"(...) I suppose it is somehow erratic dieting..., but I started eating this way long time ago (...) sometimes I'd have breakfast and sometimes tea and lunch" (Pt 4)

"I used to eat and smoke randomly, that would help me to be lighter but now I'm sad about my weight" (Pt 1)

When discussing diet, many of the participants attributed changes in their normal routines to their IBS. However, patients acknowledged the fact that their diets may not have been healthy enough, as there seemed to be an imbalance between what they considered the "healthy" option and their actual choices. Dieting of one form or another seemed to be a major concern within this particular group, although nearly half of the patients interviewed presented as overweight, or elevated values (on the basis of BMI guidelines).

6.5.2 Body Image

Body image emerged from the conversations with the participants with a varied emphasis. In general individuals were very aware of their body size, and body image was a source of anxiety for many of the participants.

"I went to see a counsellor because I was so focused on my size that I stopped eating. I was happy about my body then (...) but I used to weigh six stones at that time. My body has changed now, but I am still aware of it." (Pt 18)

"I still feel big, (...) and I'm very aware of my weight and size (164 cm, 53kg)." (Pt 17)

These two quotations highlight body concerns that some participants expressed and the importance they placed on this aspect. Body size perception was not always accurate and concern was expressed repeatedly throughout the meetings. In some cases, this would lead to negative feelings of the patient towards herself and they admitted to "feeling low" about this.

"I am worried about my appearance, about my weight, hum... but I do not exercise, I do not have the motivation to be on a diet, (...) but looking at my body makes me feel sad" (Pt 11)

“Of course I’m very concerned about my size, about my weight...I feel enormous and I’m very ashamed and sad about it” (Pt 1)

Again, Pt 1 noted feeling depressed about her body and weight; that had an impact on her mood, which could have had an impact on her self-esteem as was the case for several other participants. This seems to underline a kind of vicious circle that encompasses weight, mood and self-esteem as intimately related to each other.

6.6 SELF-ESTEEM

Self-esteem references were spontaneous and widely addressed by the participants as shown by Pt 8:

“I mean it does affect me with my weight if I’m feeling bloated,...I have always felt fat, at school, at home with my sisters (...) I’m feeling fat and then I tend to sort of get stressed and then I’ll eat more you know,... because I start to comfort eat” (Pt 8)

Another example is the account of Pt 17:

“I have never been diagnosed as having anorexia, but I am consciously always restricting my intake (...) I was an obese child and that stays with you, you know? (...) I know I have a self-image problem, but even my partner notes that I’m the biggest girl he’s ever been with (...) that makes me feel so low” (Pt 17)

This patient presented a BMI of 18.5 which is on the limit between “underweight/normal” weight for height; illustrating some of the factors that may facilitate the perpetuation of wrong ideas these patients may already have. In this particular case, her partner seemed to have a damaging effect for the patient, since those wrong concepts seemed to be also sustained by this person.

6.7 USE OF COMPENSATORY MECHANISMS

When questioned on the existence of potential EDs, no particular queries were raised with regard to other weight compensatory mechanisms. Exercise and intake restriction were fully explored and are discussed in the following section. However some patients recognised occasionally “*being sick*” or “*fasting*” to compensate for

overeating. Intentional “vomiting” was explored within the quantitative analysis, where specific questions were directed to evaluate whether that behaviour was present in the participant’s routines.

“Well when I used to work, when I was working in my old practice em, then one time I remember it was Easter and I’d gone and bought Easter eggs for my cousins at lunchtime and I’d gone back and eaten my sausage roll and my crisps whatever, and then I remembered these Easter eggs were in the locker room. So I took them into the toilet and locked myself in the toilet and ate 4 Easter eggs one after the other, just because I felt stressed or whatever you know... (...) I felt sick, not as if I was going to vomit because I’d eaten so many chocolate. I just felt sick for myself because I’d done that and I felt guilty...but then, I started crying, I felt disgusted and I put my fingers... and vomited. Since then, sometimes...I can’t help it” (Pt 9)

However, other patients that had struggled with EDs in the past noted the importance of keeping those at a minimum, as Pt 7 highlights:

“I had anorexia when I was younger, but it’s over now (...) I am very careful with what I eat, I like to eat healthy, and I’m very careful with my exercise” (Pt 7)

6.7.1 Use of Laxatives

Conversations highlighted the issue of laxative misuse. IBS patients are commonly prescribed laxatives to help their bowel movements. However, laxative misuse may have potential effects on their physical wellbeing, and patients with EDs commonly abuse them. Abusing laxatives may entail detrimental effects and have a subsequent impact on IBS.

“(...) IBS gets me depressed, then I binge because I feel bad, I feel bad because I binge, then I need to take laxatives, or vomit (...) which makes things worse. I know it” (Pt 9)

6.7.2 IBS Blamed for Altered Eating Patterns

Over half of the participants believed that IBS symptoms were the reason why their eating habits had been modified to an extent. Some participants blamed IBS for their “diet experimentation” and “focus on food”, and would routinely test how different foods influenced their IBS symptoms.

"I feel my diet is chaotic because of IBS, I change what I eat so I can cope better with it, but this does not always work" (Pt 11)

"Well, I supposed one thing leads to another...IBS was there, and I started experimenting with food (...) I know I've always had a particular relationship with food, but then...em, I became a vegetarian, I dropped a lot of weight, and that's when I could not stop...I didn't want to stop"

(Pt 22)

However, data did not always corroborate this suggestion since altered eating routines could have been present for a long time before IBS was identified.

"I had always trouble with food. Then, I was diagnosed with IBS and because of that I have tried to modify my diet in so many occasions (...) I'm sure however, that my condition is related to food intolerance or allergy." (Pt 25)

Several patients talked about feeling "greedy" as defined by not being able to control their intakes. One of them stated:

"I'm simply greedy... and I know I have an addictive nature. I have tried loads of diets, but ... (sighs) I just cannot control myself." (Pt 9)

As we will see in greater detail in section 6.9.4 individuals reported consciously avoiding certain foods in order to manage their symptoms. However, despite using specific strategies few were effective. Some participants requested clear guidelines which would allow them to make appropriate choices for food selection and hoped that eating would not be such a major focus in their lives.

To sum up, when participants were asked about potential EDs, eating difficulties or disturbed eating patterns they seemed to be open to discussing this particular topic. A number of them acknowledged having problems with their diet, and a section of them blamed that on IBS. Other participants denied having EDs, or "serious problems", however they would comment on a significant number of "unhealthy" eating habits and weight control strategies as "related to IBS"

. Finally, even when no irregular eating patterns were discussed or noted by the interviewees, it emerged that most of the participants seemed to believe that diet would have an impact on their IBS symptoms. Eating habits would be unavoidably

affected by the dietary strategies or routines adopted by the patient. Additionally, patients would try to find meaning or to understand the way IBS and EDs were related to each other. The following quotation illustrates how a patient explains her understanding of how in her case, IBS and BN seemed to be associated.

“I have often wondered whether there is a connection between my developing IBS (diagnosed at age 20) and a period when I suffered from bulimia (age 13-17, approximately). Considering the harm that I inflicted on my body, it does not surprise me that my digestive system then became highly sensitive to the food I eat and to my temperament. For me, IBS is the physical manifestation of psychological stress and worry. So too is bulimia. However, IBS provokes useful warning signs that my stress levels are too high, often before I am consciously aware of it (...) whilst bulimia was self-inflicted as a result of emotional stress, IBS is a nature’s way of telling me to relax” (Pt 12)

Qualitative analysis in this section of the study does not imply that participants had a full eating disorder. However some of the participants could be located as compliant with EDNOS category, as examined in Chapter 3. By identifying those individuals who may have a potential EDNOS diagnosis, the health professional may be in the position of preventing further deterioration in those individuals, simply by pointing out adequate strategies or referring the individual to the appropriate specialist. Early identification appears to be particularly relevant in EDs. However there seems to be a lack of agreement between the disciplines as to which are the best strategies for achieving maximum success in recognising individuals at risk.

6.8 QUALITY OF LIFE

As seen previously, QoL and HRQoL are complex notions that were defined and examined in Chapters 1, 2 and 3. The quantitative element of this study addressed HRQoL via validated questionnaires which explored the different dimensions comprised by this term. Despite its complex nature, the term “*quality of life*” is frequently used in everyday language by laypeople. The semi-structured interview in this study incorporated a general question regarding quality of life, as interpreted by the patients; therefore the term “*quality of life*” will be used in this section to differentiate from the HRQoL analysis as addressed in Chapter 5. In their replies, participants were asked to comment on their quality of life in order to explore their

individual thoughts concerning this particular term. Participants commented on how they perceived their quality of life, and whether they had the impression that it was somehow influenced by IBS symptoms.

In general, participants' answers highlighted high levels of uncertainty and frustration that consequently may affect their whole life. Even when IBS symptoms appeared to be controlled, patients were aware of small changes and how they may influence normal routines. Disgust, sadness, and embarrassment among others are terms frequently used by the patients regarding themselves and the limitations IBS may encompass.

"It definitely has an impact on my life, I am thinking about it all the time." (Patients 7, 8, 15 and 21)

"I am so focused on my symptoms (...) that I cannot lead a normal life." (Pt 25)

Generally patients saw their quality of life as disturbed by their IBS symptoms. They felt IBS was constantly present in daily activities and that it did have an impact on how they managed their routines. Participants noted IBS *"as a source of uncertainty that compromises normal routines"* (Patients 7, 11, 22 and 25), as *"not being able to enjoy a normal life"* (Patients 25 and 8), as *"affecting their daily routines"* (Pt 17), and a shared feeling of *"not wanting to share with others their difficulties due to the fact that others may feel sorry for the individual, or simply not understand the situation"* (Patients 8 and 11).

This section has been divided into three main subsections that point out themed aspects of the individuals' quality of life as emerging from the data: family and intimate life, social life, and working life.

6.8.1 Quality of Life, Family and Intimate Life

Participants openly discussed their concerns regarding their quality of life. IBS affected them physically, psychologically and socially. One of the main spheres that was identified as altered was family and intimate life, since patients had to balance their symptoms and sharing that with their closer ones. This was not always

achieved, since most patients would try to hide symptoms in an attempt to not share their difficulties either to protect others from worrying or since patients felt it was too difficult for them to explain what was happening to them. A certain level of secrecy and self imposed distance was implied from the conversations, which underlined certain IBS-related problems in the normal family dynamics and intimate lives.

“The reality is that I’m not able to enjoy a normal life. This situation affects me, my husband and my children...and although I’m quite positive and I’m working towards “recovery” ...I feel different than the others. This is present every day, and it’s extremely frustrating, what kind of life do you think I have?” (Pt 25)

The intensity of their symptoms and the evolution of the condition varied over time, as did their coping strategies. Not all of them noted having support from family or friends, and that was seen as a difficulty by the participants; although often it was the patient herself who did not want to share her situation with her partner due to a variety of reasons. Pt17 expressed her not wanting to share her feelings with her husband due to her own husband’s family dynamics, that put an extra pressure on the patient.

“(...) well, you know...my good friends know about it. They know how much it is making me feel bad and really, really (sighs...) I think the one person that I would say that’s got the most problem dealing with this is my partner (...) I think he’s very squeamish when it comes to all medical things and he’s got a problem about it. His mother is constantly ill and stuff and each time she calls it’s like... “I’m not well”. So..., she’s a lovely woman but he gets really irate about it and he can’t be bothered. And I think, having a girlfriend now who’s always ill...I feel really bad. You know... cause he made a comment once, he said... you’re turning into my mother (...) And I said that is disgusting to say that. I said I hope you get something like that and then you can ... but now...I just try to hide it as much as I can...but imagine, our whole life is affected by this, our relationship...you know...” (Pt 17)

This patient also addressed the impact of taking medicines that may not work in her life with her partner.

“(...) I have to say, I’ve been taking that stuff (a specific medication for IBS) for 2 years now and I’m getting tired. I’m really getting tired of it. And I feel, I feel somehow a bit diminished as well for my partner because I’ve got to take that every day and at night and stuff like that

and. I can see it on his face. As soon as I take my sachet. Go like that to open it, it comes out. "Ah it's medication time". Medication. It's ...aggh!. So I have to say that I wish there was something that I could take that was just a quick tablet to take and forget about that! Yeah because it's just me as well. I mean I think it's a big psychological thing as well, having to take that every day ah, when you've been taking that for 2 years. When it's a tablet it's not a problem. I take vitamins and supplements... I take that every morning you know. So, if it was a tablet I would just think oh that's a supplement and that's it, nobody has to see it!" (Pt 17)

Another patient also noted trying to keep things for herself instead of sharing it, since it made her feel uneasy about it with her partner.

"I keep it to myself until it gets to the stage that I can't keep it in any longer and then I blow my top. I tend to keep it to myself...I guess, I don't want him to know, it's too embarrassing even when it's painful... There's been nights it was agony. I get cramps... a lot on the top of my feet, especially, usually the left side that gets the, for some reason. I don't know why. So I lie there, quietly, but don't say anything..." (Pt 9)

The above quotation shows the difficulty some patients may have in sharing their experiences, and the secrecy they may have to impose upon themselves at times, and how draining this could be for the individual.

Another patient notes the fact that IBS and some of its symptoms (e.g. bloating) makes her feel unattractive, and that this may have an impact on her relationship, but she jokes about it by saying:

"My husband is aware of it, but he wouldn't dare tell me though. He'd get a slap" (Pt 24)

Sadly, this quote highlights the fact that IBS can put a strain on intimate relationships, and that not all patients are able to share their feelings and symptoms with their partners. At times, communication seems to be replaced by a shallow discussion or comment on the patients' symptoms but it was clear to the researcher that it seemed difficult for patients to openly acknowledge their feelings in relation to IBS. Whether this was conditioned by the nature of the symptoms or the relationships themselves cannot be established, but daily family life was to some

extent jeopardized by IBS. Uncertainty, fear and insecurity appeared to be intrinsic to the patients' accounts.

6.8.2 Quality of Life, Social Life and Friends

Participants expressed frustration regarding the impact that IBS had on their normal daily routines, and particularly how this affected their social life. IBS appeared as a constant source of insecurity that limited patients' choices when planning activities, holidays, or even their journeys to work. Participants described their struggle planning a holiday, or a day or a simple night out.

"... I feel terrible; it really spoils my social life. It's very frustrating...honestly; it seems that it always starts at the beginning of every evening, you know, whenever I've got plans" (Pt 2)

A common belief was *"I am not able to have a normal life"* (Pt 23). Outings, meals and travels appeared to be dependent on IBS evolution which led the participant to believe that they had a *"limited freedom"*.

"Stress makes it more difficult. I want to be able to control it (IBS), so I can be normal. I want to be able to socialise with ease and not worry about feeling anxious about dinner parties (...)" (Pt 21)

Some individuals complained that IBS was a source of uncertainty and fear so patients themselves imposed certain limitations. IBS's impact on social life was therefore evident, not only for the patient, but also for their friends, relatives, or partners who needed to be equally aware of the individual's situation. As noted before, in some cases, participants admitted not telling their closer ones about their *"real situation"* in order to protect them or simply because they felt misunderstood, different, and like a burden. Additionally, patients noted that a clear element of social stigma existed regarding bowel symptoms.

"I'm fed up, people would ask me whether I'm pregnant...I'm so bloated, and then there is the bad breath, the weight...so I simply avoid going out." (Pt 3)

This added to the burden of this chronic condition, which in some cases would lead the patient hiding their IBS from people and even from their closest ones, as was highly evident throughout the patients' accounts.

6.8.3 Quality of Life and Working Life

Not only social outings appeared to be compromised for the participants. Most of them noted that their concentration levels at work were jeopardised by IBS, and that often they would need to take time off work to stay home due to inability to work or study. It was common for patients to ask for time off work or study leave; in fact over two thirds of them noted that this was common, with the subsequent fear of losing their jobs, or being considered as “*not good enough*”. As Pt 8 noted, she had to take one year off college due to her situation at the time and Pt 2 commented that on several occasions she had been on “*sick leave*” which according to her did not benefit her promotion expectations.

“(...) when I was at Uni I had to concentrate a lot, I was really good, (...)I would say it was the best time ...and then now ... to work for AB and that's just went down hill because being a foreigner I feel I had to produce more ahm. I can speak the language no problem, but sometimes you know, with IBS I'm a bit slower, so I had to work different and more time to be able to be at the same level. Cause obviously I didn't want to be fired or anything. And ah, because it was new as well and it was a lot of responsibility and stuff, I had to concentrate a lot and I was knackered, absolutely knackered (...)” (Pt 8)

Patients also noted the difficulty of having to explain things at work, since they did not feel supported, as Pt 25 explained.

“You, know...it's really difficult to explain things at work. I can talk with my family, but not at work...they're not really my friends. I sit around a lot of healthy people at work...so they make me feel guilty if I don't. I really do not want to take time off, but sometimes is just impossible not to” (Pt 25)

As presented, data highlighted several aspects that patients felt were having an impact in their own quality of life, which at times was severely affected. The next section will introduce how patients tried to manage particular situations they were in,

which also highlighted other problems regarding uncertainty and their reticence to share their situation with others. Those will be further explored next.

6.9 SELF MANAGEMENT

In order to manage their situation, participants followed different routes, especially those individuals who had suffered IBS for longer periods, since most of them had tried several avenues in order to cope with their condition/s and achieve some sense of control into their condition and their life as related to IBS evolution. Four main themes were identified regarding self-management from the interviews with patients: uncertainty, keeping the secret, exercise and weight control and good and bad foods.

6.9.1 Uncertainty Related to IBS Symptoms

Participants' interviews provided a collection of views that portrayed the reality of patients with an IBS diagnosis. A great number of patients hoped that symptoms would be eradicated rather than controlled. Participants openly noted that IBS was a constant source of uncertainty that affected daily life, encompassing work, personal life, and future plans amongst many other aspects. Some individuals commented on ways of coping with their symptoms or associated signs that affected daily life, but the feeling of "*never knowing when*" an IBS episode could occur was seen as both distressing and stressful. In other cases, coping mechanisms did not appear to have developed, or the patient simply felt unable to cope. Low mood was openly present in many of the participants, and some noted that uncertainty made them feel "*sad and miserable*" (Patients 6, 9, and 10).

"Of course, bowels are a source of uncertainty for me (...) I cannot plan anything, outings, dinner parties... it has an effect on everything" (Pt 11)

"I feel I have suffered a lot for this problem and I also sense that there is no answer that may help me." (Pt 4)

The interviews seem to suggest that patients' uncertainty put an extra weight into the patient, who may feel unsure about their diagnosis, or its management. Additionally, patients felt that no adequate answers and/or management strategies existed for their

problems, and some thought that inappropriate symptom management could lead to exacerbation.

“My symptoms have worsened since the first episode, and I believe there is no cure for me.” (Pt 5)

Additionally, when the patient did not feel “*listened to*”, or had the impression that consultations were simply routines, their experience was frustrating.

“I feel frustrated because I have all these questions (...) then I come to see my doctor and there is no time to explain all that worries me, so I’m left with all these questions, and I’m not sure if this is normal, if I’m doing OK (...)” (Pt 6)

Uncertainty was closely linked to patients’ trying to hide their situation, since many of them expressed feeling embarrassed, uncomfortable and self-conscious about their situation, as can be seen below.

6.9.2 Keeping the Secret: Feeling Embarrassed and Self-conscious due to IBS

An element of embarrassment and attempts to hide symptoms was also identified by the participants. Physical manifestations of IBS such as gas, diarrhoea and wind made public appearances stressful.

“I am very concerned about my IBS, especially about the incontinence episodes; I found the whole experience very embarrassing” (Pt 13)

In some cases, people would avoid contact as much as possible, whereas others would try to hide symptoms even from their closest ones, under the impression that they would be unable to understand their condition.

“I’ve learnt to live with pain and avoid taking meds for this...occasionally I would take stronger stuff (...). I don’t give into pain, but sometimes it is excruciating (...) People don’t understand so I avoid discussing this with friends or family” (Pt 20)

“My partner would never understand this (...) I don’t think he’d cope with me complaining about this; so I simply avoid telling him about it, you know...” (Pt 17)

“I feel I cannot tell my boyfriend, I mean, I tried before...talking about the pain, about my bowels... he simply does not understand (...) so I do avoid talking about it.” (Pt 8)

Psychosocial manifestations and the feeling of being a burden were harder to evaluate, even by the patients themselves. Some patients reported guilt associated with their condition as they were aware that *“having a normal routine is difficult”*, which jeopardised regular, and unplanned meetings with friends or partners. In some cases participants expressed feeling like a *“burden”* that their peers or relatives should not have to cope with.

“Oh God. Everyone’s just treating me like some terrible whingeing nutter when you think that’s really unfair and it’s not a fair position to be put in because I think I genuinely have a very bad experience. I’ve been treated very badly but you know, this shouldn’t have happened to me and people should listen to what I’m saying so that they can sort it out so that it doesn’t happen to other people. but I just don’t feel there’s been that, that that willingness to listen to what I’ve said or to try to improve things, in a way it’s sad, but it’s better to keep it to yourself, to be quiet about it!” (Pt 5)

6.9.3 Dieting and Exercise

Patients used different strategies to cope with their individual situation. Two common strategies were dieting and exercise, since food was commonly associated with symptoms and its evolution.

6.9.3.1 Dieting to lose weight

For many of the interviewees, IBS symptoms were related to *“food intolerances”* or *“food allergies”* (in their opinion). Therefore, identification of these foods was seen as important in order to alleviate or improve symptoms. Participants were asked if they used any specific diet and if that was the case, to indicate its purpose. Additionally, they were encouraged to describe special regimes that had been employed to control their IBS symptoms. Two main categories seemed to emerge within this area: dieting to control IBS symptoms and dieting to lose weight.

Over half of the interviewees recognised being on a diet to lose weight at the time of the interview, and noted that they had commonly used dieting techniques in the past in order to manage their weight. Most of these referred to having embarked on “numerous” diet types in the past but that results had not been as positive as expected. A fifth of the interviewees reported “*always being on a diet*”, and several of them reported being very aware of their body size and “*knowing*” that they needed to lose weight. Patients had used several avenues for losing weight including slimming clubs (which seemed very popular among the sample) with a variety of outcomes. However, it was felt that dieting to lose weight *per se* was seen as “normal” or as “*part of normal life*” (Pt 9) by most of the participants. Nevertheless, satisfactory strategies were not always identified since clear weight loss results had not been achieved in the majority of the cases. Most of the interviewees noted that losing weight was seen as a “*reward*” and most also noted that their “*self esteem*” would improve if their target were achieved.

Many patients reported taking “*supplements*” to induce weight loss, but they referred to these as “*herbal*” solutions. In most cases, supplements had been recommended by family or peers. Nevertheless, even when using those resources, patients often experienced an initial weight loss, but with subsequent weight gain during the following weeks. Of those who mentioned trying to lose weight, just one patient stated that she was happy with her current weight. This patient had taken on a very strict regime of dieting and exercise a few months ago, and emphasised the fact that she had lost enough weight to reduce her normal size by three sizes.

“I know I have dropped a lot of weight, but I eat healthy now and I’m happy about this (smiles). I used to be overweight (sight) and I’m happy being lower. I think... I feel happier.” (Pt 25)

Particularly relevant is the way Pt 25 emphasises the fact that she is extremely happy as having managed to reduce her weight. She noted how by severely controlling her diet, she had managed some sort of control in her condition and also in her appearance, which was very important for her. Weight loss was generally experienced as a positive side effect of having to control diet due to IBS symptoms.

Interestingly, another patient noted: “*I’ve tried every single diet to lose weight (...) my mum says that IBS problems are connected with my erratic dieting behaviour*” (Pt 6). This appears relevant since it highlights the patient’s suspicion that erratic eating patterns (as present in eating disorders) could have an impact on the gut symptoms related to IBS. Similarly, another patient relates her problems with IBS and weight fluctuation. This patient describes the weight changes from her childhood, but hardly comments on her IBS as relevant to dieting.

“ Apparently, I was born really small. I was really long, but really small. I looked like a one month old baby, but I was very skinny and I was like that until I was 9. Then when I was 9 I got and after that I just went whooooh. I ballooned and put a lot of weight on and ah, was called many names and stuff like that, as the kids do. And then I started slimming again. So my mum, when I was about 15 years old, I had an aching in my arm, and she put me on a diet. In the hospital as well. I spent a month in the hospital and they put me on a diet as well. I, pfff...dreadful (...) (...) And then when I was 16 years old I just started to lose it and that’s when I became a vegetarian and ah, I stopped eating meat completely and ah, and then I slimmed, slimmed slimmed and, until I was about 9 and a half stone, which is about 55 kilos” (Pt 4)

From the interviewed patients, only two of them reported not being on a diet. One of those insisted on the fact that she was simply not a good eater: “*I just pick at some food but never sit down to eat*” (Pt 18), as implying that hers was a natural way of keep fit.

6.9.3.2 *Exercise*

Patients also were encouraged to comment on their routine level of usual exercise and the importance given to their routines when those were present. Three different stances emerged from the data: individuals who rarely exercised mainly due to motivation; the ones who did not exercise because they were afraid of having an IBS “*accident*” while exercising (in public) and the individuals who felt exercise was mandatory and tried to exercise both intensively and regularly throughout their week.

6.9.3.2.1 Exercise limited to a minimum

Some patients noted the fact that they rejected exercising due to body image concerns. Some of them noted feeling ashamed of showing their body in public. This was also related to self-esteem issues.

*“...I exercise very little now; I don't want to show my body in public (...)
I used to go to the gym, but you see all those girls...hum... and I felt so
fat. I thought they were always looking at me.” (Pt 1)*

6.9.3.2.2 Exercise limited by IBS

A great proportion of the patients commented that they had experienced difficulties related to their IBS symptoms, and that despite having the desire to exercise; a variety of reasons prevented them from working out. Two of these patients expressed that when possible, they would exercise at home, where a “*safer and more comfortable environment*” (Pt 8) existed.

*“...of course I would like to, IBS usually interferes with my routine. I've
given up...well, I don't go to the gym, but I've tried at home in front of
the TV, although it doesn't always work. I also tried yoga, but I didn't
find it useful.” (Pt 8)*

6.9.3.2.3 Exercise “is a must”

A third of the participants however commented that they did exercise, and in some cases this was potentially excessive. Those individuals who exercised regularly noted the fact that exercise was part of a routine which was an aid both for weight control as well as for emotional wellbeing or as noted by Pt 22 “*it helps to keep me sane*”. Exercise was used as a coping mechanism for some patients, who in many cases experienced high levels of stress. Exercise routines used by the participants included controlled exercises at home, long walks, playing basketball, gym classes, and high intensity exercising at the gym.

The importance of exercising was noted by many study participants, although not all of them were able to comply with their ideal routines for various reasons as noted earlier. Participants who avoided exercising in public due to the belief that IBS

would interfere with their routine noted trying other types of exercising such as yoga, or exercising at home, although even then achievement appeared poor. Other participants would simply note that despite the importance they placed on exercising, they “*will always find any excuse to avoid it*” (Pt 9). The rest of the individuals who reported taking exercise regularly seemed to see it as a “*habit and part of their routines*” (Pt 15) and in most cases would try to exercise intensively when possible.

6.9.3.3 *Dieting to control IBS*

Qualitative analysis showed a variety of strategies employed by the patients to manage IBS symptoms through diet. However, patients noted having difficulties with finding appropriate personal diet regimes. Identification of foods that had potentially an “*effect*” on the gut either in a “*positive or negative*” way was mainly described as “*frustrating*”. Interviewees devoted significant time and energy to identifying “*good or bad*” foods, but in many cases the process was very lengthy which resulted in exasperation for most of the individuals. In addition, surveying the foods that were supposed to have a detrimental effect on their symptoms was not a guarantee of finding a reliable pattern to guide patients so they could automatically prevent symptoms exacerbation.

Some patients emphasised concepts such as “*healthy eating*” and “*healthy choices*”. Two participants remarked that since they had to modify their dietetic habits, they were determined to introduce “*healthier diets*” to their families so they “*...could lose weight and... (laughs) potentially feel the benefits of a healthier lifestyle*” (Pt 13). Some concepts as “*superfoods*”, “*detox diets*”, “*elimination diets*” and “*exclusion diets*” were identified and discussed by a number of participants, but confusion seemed to exist regarding the best ways to use those approaches in order to achieve encouraging results. As an example, one patient noted that she had been on many diets before, but at the time of the interview she was on an “*exclusion diet*”⁴ and trying to reintroduce certain foods over a period of time. She added, “*I would like to*

⁴ Exclusion diet: a diet that initially excludes a number of foods that have been found to provoke symptoms in the majority of individuals with food sensitivities. The excluded foods are then reintroduced one by one and if symptoms re-occur that food is excluded for a longer period (usually one year)

be lighter, I know I need to lose some weight, but I lack the motivation of being on a serious diet; (...) let's see what happens with IBS" (Pt 11). Introducing changes takes time and a certain level of research, as Pt 3 noted:

"I've been on a detoxing diet for over two weeks now...but I'm finding it very hard! I am also studying and reading a lot; really... I want to change my diet (...)" (Pt 3)

Curiously, two patients commented that because of IBS they had to modify their habits and they felt now "*obliged*" to have a healthy diet. On the other hand, one patient noted having an "*erratic*" diet only due to financial issues, although at the time of the interview she was trying to eat "*greens*".

As part of the strategies used by the patients to manage IBS, foods were carefully studied and somehow classified. The following section will present some of those approaches and the patients' views on foods in relation to IBS.

6.9.4 "Good" and "Bad" Foods

As previously seen, participants discussed their perceptions of food in general, diet, and particular issues regarding IBS and food consumption. Often, IBS patients try to control their symptoms by controlling their diet and limiting particular foods that may be seen as "*damaging*". The interviewees described those foods they perceived as damaging or related to the exacerbation of IBS symptoms. The particular way that most participants referred to foods deserves a special mention. Individuals tended to classify them as "*good*" or "*bad*" foods. In most cases, the interviewees openly discussed "*good foods*" and "*bad foods*" in relation to the effects that these had on their symptoms. However, analysis highlighted a tendency to extrapolate the same terminology and refer to particular ingredients as again "*good foods*" or "*bad foods*" depending on its caloric value and whether they were perceived as "*healthy options*" or not. Participants were asked to name those foods that seemed to have a detrimental effect upon them, and foods which they tolerated well. Some of the identified nutrients were seen as "*innocent*" by certain individuals whereas in other cases, the same food would have a "*bad*" effect and precipitate IBS symptoms. Additionally, the terms previously noted were not only used to determine the degree

of pain or discomfort that consuming those foods brought, but in many cases, patients clearly used the terms “*being good*” and “*being bad*” with regards to a controlled or “*healthy diet*” contrasted to overeating, and also to foods with a high caloric count versus low calorie products, and the estimated effect on the patient’s figure.

According to the scientific literature (see Chapter 2), a variety of foods can be considered as “*irritating*” regarding IBS (e.g. nuts, spicy foods) and patients were sometimes encouraged to avoid such foods as noted during the interviews. However, the lack of clear and universal guidelines often created confusion among patients, especially when foods that they identified as detrimental were presented as inoffensive or innocent to them. Again, this created a feeling of “*uncertainty*” and “*frustration*” in many of the patients, who dedicated long periods of time to working out which of those foods were detrimental for them.

“The whole process is such a nightmare, I was told to go on it (exclusion diet) for 4 weeks to see if it was a proper intolerance or if it was just something that I maybe had too much of and I had to get it out of my system. That didn’t work so I did it for 6 months and after 6 months I came off it and I started going back to the way it was, so I think that it’s a, a permanent intolerance I have to em, dairy aspartame isn’t so bad... but still, after so long, I’m not sure what is good and what is bad, what is for real, and what is just by chance...(…) and then is like... It’s more difficult eating out. Eating in the house is not a problem because I can pick and choose, but when I go out to restaurants, I don’t know what’s in the food and it’s usually just steaks or burgers that I consider...I guess, the whole process is just frustrating. You can never be sure that you’ll find what’s going on” (Pt 3)

“I tried to isolate the foods that I have become intolerant to, so I could stop the bloating and wind... I was hoping this would work...” (Pt 21)

“I do try to control all the facts that may be related to the symptoms, for instance diet ... I am so concerned about what I eat, and how this affects me; of course, I tried to cut out certain foods, but I cannot do it for long periods.” (Pt 6)

“Someone suggested trying to keep a food diary to study foods and the symptoms...but that was a complete mess; totally unsuccessful.” (Pt 24)

In search of more detailed evidence, patients were asked to identify certain foods that they avoided if they thought they may be linked to their symptoms. A number of

patients identified “hot or spicy” foods, curry, alcohol, fibre and pasta as negative for their symptoms accompanied by dairy products and sugar. Examples of the extensive list of foods identified as detrimental to their symptoms can be seen in Table 6.5, “*Good and Bad Foods*”, below. However no common trend could be identified among the patients’ choices; some of the “*good foods*” identified by certain patients would be in the “*bad foods*” lists of other participants. As an example, Pt 4 presented as “*good foods*” the following: Yako, acidophilus, fruit, soya milk and wheat. This patient noted that when consumed alone, there was no problem, but that she would never have them mixed together. On the other hand, Pt 6 and Pt 16 identified fruits as their “*bad*” choices, and patients 1, 3, 8, 10, 12 and 24 highlighted wheat as one of the foods that would be perceived as more negative regarding IBS symptoms.

Table 6.7: “Good and Bad Foods”

Pt #	ROUTE	“GOOD FOODS”	“BAD FOODS”
1	Patient tries to identify the foods that “benefit” or have a “detrimental” effect on its IBS.	None identified as having a clear positive effect.	Several foods named by the patient as “damaging”; wheat, alcohol, chocolate, spicy foods.
2	Despite trying to identify foods that may be related to IBS symptoms, patient is unable to identify any.	Tries to have a healthy diet in order to minimise IBS symptoms, since no food can be identified as beneficial.	Not able to identify specific food that is related to symptoms onset/ exacerbation.
3	Patient engaged in <i>detoxing diet</i> to evaluate the impact IBS symptoms.	Has not identified “ <i>staple food</i> ”.	After completion of “ <i>detoxing diet</i> ” and subsequent “ <i>elimination diet</i> ” consciously avoids wheat and dairy products that she associates with symptoms onset.
4	Patient has not managed to identify any particular food that is related to IBS symptoms.	None identified yet	None identified yet
5	After diagnosis the patient explored food intolerance and identified certain foods as can be seen within next columns.	Yako drink, Acidofilus seem to alleviate her condition. Fruit, soya milk, wheat are fine but they should never be mixed together. White bread	Normal milk, and spicy food as related to symptom exacerbation.
6	Patient very concerned about food and how it can affect her symptoms. Tried to cut on certain foods as specific dieting identifying certain foods.	Dairy, milk, wheat	Fresh fruits
7	The patient notes that she eats a bit of everything. “ <i>I try to keep a healthy diet.</i> ”	None yet	Has not identified any food in particular, which is seen as frustrating by the patient. Avoids sugars as much as possible.
8	Patient has studied symptoms and relation to food, however she has not identified food that alleviates symptoms.		Trying to cut out pizza, pasta, wheat and yoghurt. “ <i>They might set off my symptoms</i> ”.

Pt #	ROUTE	“GOOD FOODS”	“BAD FOODS”
9	The patient identified several foods that had different outcomes.	Pasta made of wheat Milk	Fibre, vegetables, pasta, French bread
10	This patient noted that she had identified several foods that seemed to have (+) and (-) effect on her symptoms. She also noted that she had to modify the way she ate by using a “not fries-style anymore”.	Muesli, vegetables, milk	Weetabix, corn flakes, porridge
11	This patient had identified two foods that had a (-) impact on her symptoms, but she had not been able to identify any others. Diet was modified and noted that she was conscious of her food choices.	None yet	Gluten, bread
12	Patient has identified certain foods that appear to worsen IBS symptoms.	None yet	Spicy food, alcohol, fibre
13	The patient had tried to identify foods with (+) and (-) effect on her symptoms. So far, results were limited.	“Rabbit food”	Pulses
14	Never attempted “ <i>food examination</i> ”.	Simply tries to eat healthily	N/A
15	The patient noted avoiding foods that might set off her symptoms, which she had identified after scrupulous evaluation of food/presence of symptoms. However, patient highlights frustration due to the time invested in this process with limited results.	UHT milk helps to improve symptoms	Spicy foods, dairy foods
16	This patient had managed to identify several foods considered as (-) by her, however no (+) foods had been recognised.	N/A	Chicken, beef, peanuts, coconut, bread, apples, eggs

Pt # **ROUTE** **“GOOD FOODS”** **“BAD FOODS”**

17	Patient 17 had managed to identify two foods considered as (+) by her, however no (-) foods had been recognised yet, which was seen as frustrating by the individual.	Cheese, bread	None yet
18	The patient describes herself simply as a “ <i>not good eater</i> ”, so she has not attempted food identification, but her intake is markedly limited.	N/A	N/A
19	The patient managed to identify two big groups of foods considered as (+) for her symptoms. However no (-) foods had been identified yet.	Fruit and vegetables	None yet
20	Although this patient tried to explore foods and symptoms, she had not been successful in this venture.	None yet	None yet
21	The patient identified several foods that seemed to have a “ <i>protective</i> ” effect against IBS symptoms, or that at least would not be related to symptoms exacerbation.	Pasta, coffee, white bread, full fat milk, cream, potatoes, chicken (she notes “ <i>unsure about this!</i> ”)	None yet
22	This participant explored how IBS symptoms responded to a variety of foods. Certain foods were identified as “ <i>negative for IBS</i> ”.	None identified	Milk, beans, pulses, fruit
23	Never attempted food exclusion. “Too much work”.	N/A	N/A
24	Tried to keep a food diary to study foods r/c symptoms but unsuccessful, although “ <i>I’m always on a diet</i> ”.	None	Sweetener, fizzy drinks

Pt #	ROUTE	“GOOD FOODS”	“BAD FOODS”
25	<p>This patient devoted a long time to explore the relation between different foods and IBS exacerbation. That led her to modify her diet drastically by becoming a vegetarian (15 years ago). This had proven somehow beneficial for her symptomology, but she noted dramatic weight loss which she was very pleaser about.</p>	N/A	<p>Noted that since her diet was notably modified by the fact that she gave up a bigger group of nutrients. Therefore she was not able to elucidate how many of those would have an impact on her IBS symptoms.</p>

The possibility of crossed comparisons and surprising disagreement about “good/bad” foods highlights the difficulty that patients have in finding foods that should be avoided, limited or eradicated from their diets. Patients complained about lack of professional guidance regarding this point, and most of them noted feeling left alone with their particular “*food experiments*” (Pt 3). Although many patients embarked on a scrutiny of their diets searching for a protective effect on their symptoms, motivation and patience were required from the patient, who in many cases expressed frustration at the lack of results. Most of the interviewed patients had tried “*exclusion diets*” by not including certain nutrients and with the purpose of identifying the foods that potentially exacerbate their IBS symptoms. This emphasised a focus on food that together with the difficulties of having a restrained diet was perceived by the individual as stressful.

“When I was diagnosed, I tried to change, to examine my foods...I don’t know...modifying my diet. I did try “exclusion diets”, to realise the foods don’t do good to me, but still I’m not sure...and I’ve been like this for over seven years now.” (Pt 25)

Some patients referred to being “*so tired*” of trying to identify “*bad foods*” that they had decided to eat a regular diet with no exclusions and cope with their symptoms when they manifested, rather than being obsessively conscious of certain foods that may or may not had an impact on their normal gut function.

6.10 CONCLUSION

The qualitative analysis of the patients’ interviews highlighted several issues regarding the individuals’ experience of the IBS condition and the existence of potential EDs. All participants expressed specific concerns or behaviours that could be somehow related to a disordered eating as emphasised by the screening tools used in this study. Therefore, further exploration of issues raised by the screening tools was seen as positive and in doing this, several issues were highlighted from a qualitative perspective.

Patients described a long and winding road to IBS diagnosis, which in many cases was then viewed with scepticism as if there was “*something else*” to add to the diagnosis. The route to IBS diagnosis seemed to be diverse and disorientating for the individual. Patients seemed to struggle with symptoms for a long period before seeking professional help. Additionally, an unbalance seemed to exist regarding diagnosis acceptance. Some patients argued that doctors had not found “*anything*” referring to IBS and others noted that they would have never expected having something so “*sinister*”. Both uncertainty and lack of control over the situation seemed evident along this route. Similarly, the origin of IBS symptoms appeared to be related to a variety of situations. Stress and food allergies seemed to be the most commonly noted among patients. IBS symptoms origin seemed to be blurred with other situations individuals were experiencing at the time of onset. Most importantly, anxiety, stress and depressive periods frequently coloured participants’ accounts. Intimately related to the latter, “*lack of control*” seemed to be intrinsically present in the patients’ discourses which reverberated in most of the accounts.

The theme of quality of life was significantly emphasised throughout the participants’ accounts. It seemed to be impaired by both IBS and the eating habits exhibited by the individuals. The social element of quality of life appeared to be significantly disrupted for most of the patients. Additionally, it appeared to be modulated by the patients’ conditions and this would seem to have then had a circular effect on the participants’ perception of their situation.

Social interaction difficulties, secrecy and stigma were also noted by the participants. They seemed to be particularly passionate about food and food combinations and how these would affect their IBS symptoms as well as their figure. Most of the interviewed females were on a diet and using a variety of strategies to control their weight, which appeared unsuccessful in most cases. Regarding potential EDs, interviews highlighted a significant number of issues that could be related to disordered eating patterns. In this sample, the “*peculiar*” perceptions of food that patients portrayed were particularly evident. A particular emphasis on the way individuals talked about and considered foods were apparent. The perceptions that individuals exhibited seemed to be closely related to diet and exercise amongst other

actions. Body image also emerged recurrently, highlighting unhappiness related to the individuals' appearance amongst other issues. Patients' accounts of foods that were considered as beneficial or detrimental for their symptoms highlighted a lack of common patterns in our sample. Dieting was indeed present in this sample, with a double edge: those dieting to lose weight and those dieting to control symptoms.

Exercise was part of some participants' routines, although IBS seemed to limit some individuals' pursuit of it. This would be related to lack of confidence in exercising outside safe limits in case they suffered an IBS accident.

Finally, patients' expectations seemed to be modulated by the individuals' contemporary situations. Principally, patients hoped to find strategies that helped them to "*control*" their symptoms and facilitated them "*cop*ing" with the numerous symptoms that either IBS or IBS and a potential ED may manifest with. Some of the participants explained various strategies and routines that helped them to manage their daily life, but patients' expectations concerned also healthcare professionals, hoping they could suggest new strategies that prove somehow more effective. Most of these patients would actively seek advice to enhance current knowledge with other new routes.

Whether "*getting rid of IBS*" or "*finding the way to stop it*" is a realistic thought for an IBS patient is not the subject of debate here. However, nearly a fourth of the participants insisted on the fact that they "*would do anything*" to be "*sorted out*". The concept of getting rid of IBS highlighted issues of acceptance of the syndrome as well as the wide array of symptoms that can accompany it, which in many cases evolved over time.

Despite explicit hope regarding IBS condition improvement; many of the participants would equally express feelings of uncertainty regarding the hope that things could turn better. Some patients noted that since IBS affected life, relationships, and their quality of life in general, a certain feeling of ambiguity for the future was present. Equally, some of them expressed despair, since for most cases participants had dealt

with IBS for many years and seemed to have lost faith in treatments or professional advice:

“I cannot be bothered anymore; it’s been over eleven years with this. Do you really think there’s anything they will tell me that would help? I really don’t know (...).” (Pt 20)

Many participants seemed uncertain regarding their conditions. Also, patients noted needing to gain control to cope with their situation. Whether expectations were realistic or not is debatable, but they seemed to be somehow modulated by whether patients presented a positive, negative or uncertain panorama that would modulate their requests regarding their condition.

To conclude, it could be said that qualitative data confirmed some of the clinical findings from Strand 1 of this study, that it also revealed some serious and perhaps under-reported difficulties patients experienced in living with their conditions.

Next chapter will present a discussion of this study that will address its design, methods and both quantitative and qualitative data.

Chapter 7

Discussion

The aims of this study were to examine the existence of potential EDs in a sample of IBS female patients and to explore the patients' experience of IBS and a potential ED. Additionally, this study sought to assess the perceptions of a sample of GI nurses of IBS and EDs.

This chapter will discuss the work presented so far, by addressing the study, methods, tools and findings.

7.1 THE STUDY

This study employed a mixed method approach with three different Strands in order to answer the research aims.

The presence of potential ED patterns among one hundred and thirty-four GI female patients with a diagnosis of IBS was assessed by using two recent EDs screening tools (ESP and SCOFF). One of them, SCOFF, appeared more reliable than the other screening tool employed in this study (ESP), a fact that appears to concur with the latest investigations within this field (NHS, 2006). Secondly, HRQoL and well-being differences were recognised among patients identified as potential ED¹ cases and subject to further investigation.

¹ According to the screening tools used employed in this study.

During Strand 2 of the study, twenty five semi-structured interviews were conducted on a sample of patients who had been identified as potential ED cases in order to explore patients' experience regarding IBS and the potential presence of an ED.

Strand 3 of the study incorporated a questionnaire that explored nurses' perceptions of IBS and EDs and sufferers of IBS and/or EDs, in a sample of ninety one GI nurses, which highlighted relevant issues regarding attitudes, knowledge and nurses' needs.

By considering these elements in relation to each other, this study aims to offer an integrated view of IBS and EDs in order to gain further understanding of the total impact on the lives of females who may present with both IBS and a potential ED. . The main findings of the empirical research are as follows:

According to the screening tools used in this study (ESP and SCOFF), a significant number of the study patients appeared to be potential ED cases (ESP: 59 %; SCOFF: 24.6 %). Using ED screening tools in the GI setting appears a simple but valuable way to address potential EDs.

HRQoL assessment showed elevated scores for the selected study group when compared to UK normative values. The patients' study group appeared to be more anxious, more depressed and present lower HRQoL scores than normative values.

The levels of anxiety and depression revealed by the HAD scale assessment highlighted that patients presenting with IBS and examined for a potential ED showed statistically significant scores in these domains.

BMI measurement underlined the fact that only 43.3% of the study group individuals presented values that were considered to be in the 'normal range' according to BMI guidelines. Interestingly, potential ED cases according to the ESP screening tool suggested that 55.2% of the patients' weights presented values in the 'normal range'. 58.3% of the potential cases identified by the SCOFF screening tool presented normal BMI values.

The qualitative assessment of the patients' experiences highlighted a number of important issues that could have not been identified exclusively by the quantitative assessment. Additionally, patients openly discussed the existence of potential EDs, and indicated the impact this may have had on their perceived quality of life. Patients' conversations highlighted intense emotional suffering, uncertainty, isolation, frustration, limited support, and continuous attempts to gain control of their situation.

The care given by the health care provider and the quality of its management may be determined by the attitudes of the professional towards particular conditions. The analysis of the questionnaire employed to assess nurses' perceptions suggested that most nurses agreed that they had limited knowledge and a limited understanding of IBS and EDs in general. Additionally, nurses described patients with IBS and/or EDs as "*difficult*", "*unable to cope with life*", and as "*wasting the doctor's time*".

These conclusions are based upon the results of the study already presented. The following sections will examine the findings along with some of the methodological aspects of the study.

7.2 DISCUSSION OF METHODS

This study employed a mixed method design in order to pursue the research aims and questions presented in Chapter 4.

As noted by Creswell (2003), combined methodologies can be used to investigate phenomena where it is necessary to understand and explore the situation in depth as well as to understand the relationship between variables in that situation. This influenced the researcher's choice of a multimethod methodology, which consists of combining different methodologies to study a particular problem. After considering the setting, resources, time and financial constraints, and the review of the literature, it was thought that by incorporating two different strands in the main study, the first focusing on the patients, with a second parallel study on GI nurses; a sufficiently detailed picture would be obtained while using an innovative design.

Using a multimethod approach proved beneficial for the study, as both quantitative and qualitative data highlighted interesting results regarding IBS female patients and HRQoL issues. To the researcher's knowledge, the screening tools used in this study (ESP and SCOFF) had not been previously used in the GI setting, and seemed to work efficiently in the chosen setting. Additionally, semi-structured interviews provided invaluable information regarding the experience of this particular patient group.

The study also found benefits of using self-completion questionnaires in the out-patient setting. There was a high completion rate, although missing values were present. Cases in which a significant amount of data was missing had to be excluded from the analysis, and as a result, data may have been lost. The use of such an extended battery of questionnaires could be the reason for the missing values.

One particular problem that did arise related to patients providing additional comments on the questionnaires used, creating a qualitative dimension to this quantitative research. A number of notes were supplied by the participants that gave additional information regarding some of the questions addressed by the questionnaires. Those comments were mainly related to clarification of terms or gradation of their particular symptoms or situation. The researcher found these comments both relevant and interesting, and although not all of them could be addressed in this study, all the comments have been recorded and it is hoped they can be used and further explored by the author in subsequent investigations. This issue highlighted the fact that despite using sound questionnaires widely used in research, there must inevitably be certain information that is not supplied, or that is not analysed.

This seems to confirm the wisdom of adding the second Strand (2) of the study. We saw in Chapter 6 that this was useful in order to incorporate patients' thoughts and suggestions and it there is a strong possibility that patients in general may have to further explain their symptoms or perceptions when the option that best describes their situation does not appear on a particular questionnaire or screening tool. As noted earlier, the researcher found patients' comments relevant and they, in

conjunction with the literature review, influenced themes explored in the semi-structured qualitative strand of the study allowing participants to raise any comments or suggestions they may have had. The mixed method approach chosen proved valuable for this study as the content of the semi-structured qualitative interviews generated both some refinement and some contradiction of the findings of the quantitative data and allowed the researcher to add depth to the study findings; providing information with regards to the patient experience of living with IBS and a potential ED. This allowed the author to pursue some theoretical underpinnings for the research findings.

7.3 DISCUSSION OF THE ASSESSMENT TOOLS USED IN THIS STUDY

This section will briefly discuss the tools chosen for the development of this study. The questionnaires used in this study had been validated and reliability had been previously established by numerous pieces of research.

7.3.1 Discussion of Screening Tools

As the name indicates, both SCOFF and ESP are screening tools, and consequently they do not seek to establish a diagnosis but raise suspicion of the existence of potential EDs. Although ambitious, this can be a first step towards the identification of those individuals who may be struggling with or be at risk of developing more problematic behaviours and attending a specialist clinic or a setting where individuals at risk may be present. Although professionals do not need to be trained to use SCOFF or ESP, the researcher felt that a certain understanding or sensitivity towards EDs was required or would be beneficial, since particular signs or observations may be useful in order to interpret an individual's situation. It is now the impression of the researcher that familiarity with EDs per se benefited both quantitative and qualitative data interpretation.

7.3.1.1 ESP Screening Tool

This tool was originally presented by Cotton et al. (2003) as an alternative to SCOFF. According to ESP creators, this tool appeared very similar to SCOFF in identifying potential EDs. Cotton et al. (2003) went further and suggested that ESP would be better at ruling out ED diagnoses when compared to SCOFF. However, in this research, ESP did not seem to perform as well as its designers had envisaged. Kagan and Melrose (2003) highlighted that despite SCOFF being less sensitive at detecting EDs, it was more specific than ESP. One of the positive aspects about ESP highlighted by Kagan and Melrose was that its questions appeared more delicate than some of the so-called “*invasive questions*” included in the SCOFF questionnaire, which certain individuals may find difficult. However, the SCOFF tool has performed positively and very similarly in several studies (Rueda-Jaimes et al., 2005; Parker et al., 2005; Cotton et al., 2003; Luck et al., 2002; Perry et al., 2002) whereas ESP properties to date have not yet been tested in other settings, or cultures, which limits the discussion as to which screening tool is more useful. By incorporating both tools in this study, the researcher hoped to contribute further to the current debate. ESP appeared equally easy to use and participants accepted its use well.

EDs are a sensitive area, but this should not mean that certain questions seen as “*invasive*” should sometimes not be asked as suggested by Kagan and Melrose (2003). In this sense, and in the case of patients with a severe EDs that are at risk of committing suicide due to their despair, should questions regarding suicidal thinking or deliberate self-harm be excluded due to obvious invasiveness? Although careful and appropriate wording are paradigms of professionalism, certain questions should always be expected. Maybe it is because of the lack of clarity, or excessive “*delicateness*” that ESP suggested that up to a forty-one per cent of the study participants could classify as potential EDs cases. In the case of ESP, only two questions openly discuss the existence of an ED either for the individual, or within the family context. However, the rest of the enquiry relates to satisfaction regarding eating patterns, eating in secret, and weight affecting the way the individual feels about herself. It could be argued otherwise, but the latter could seem too unspecific for the purpose of ESP.

7.3.1.2 *SCOFF Screening Tool*

This tool has been described as memorable, and as a significant improvement for the detection of EDs (Newton, 1999). But there are some objections to it that must also be discussed. Over-identification of potential individuals in non-clinical samples has been suggested, based on the idea that EDs have low prevalence (Newton, 1999). This last sentence is highly debatable, since EDs appear to be reaching epidemic proportions according to other authors (Gorrell, 2001). The possibility of over-identification in this particular study was balanced by the use of the semi-structured interviews in order to clarify potential cases, as well as obtaining further information. The Positive Predictive Value (PPV)² of SCOFF has also been highlighted as problematic and was discussed in depth by Morgan et al. (1999). However, PPV would be more problematic in the case of diagnostic tools that precipitate referral for treatment. Strictly speaking this is not the case with SCOFF, whose main purpose is to raise suspicion and stimulate specific enquiries that clarify the individual's situation. SCOFF appears to have the potential to raise suspicion of EDs, which is an important step towards early identification of people with an ED. Although the researcher agrees that this is a challenging task, (by using only five questions), this could help many subjects who may be likely to develop more potentially dangerous problems. Another important point that should not be forgotten is that due to the void existing between the classification and taxonomy of EDs, many EDNOS cases may be lost in the process, as also suggested by Milos et al. (2005). Many of the SCOFF false positive cases could possibly be related to those EDNOS individuals. In the researcher's opinion, data analysis corroborated this situation. While quantitative analysis highlighted a significant number of individuals who scored high according to SCOFF, and were therefore considered as potential cases, subsequent qualitative examination highlighted many individuals who would be perfectly compliant with the EDNOS category. King (1999) argued that SCOFF should not be employed until the PPV issue was resolved. However, his suggestion would be more justifiable if high numbers of false negatives had been detected. In the researcher's opinion, it

² PPV: Defined as the probability that a screened positive is actually a genuine case. PPV is strongly related to the prevalence of a problem in the population, and it appears to fall notably when prevalence is below 20%, which appears to be the case of EDs in general.

would be better to continue screening for positive cases rather than missing out a high proportion of cases altogether. There is a risk of obviating EDNOS cases when strict categorisation or assessment of cases exists. A balance between overly alarmed and overly cautious examination of individuals should be aimed at by professionals, since it would seem that many EDNOS cases could be lost if not properly addressed. Further studies should be conducted to refine SCOFF and its expediency since the population in which Morgan et al. (1999) first studied SCOFF raised some debate and acrimony among certain authors (King, 1999). To date, several studies have employed SCOFF and results appear equally promising despite having been used in very different settings (Rueda-Jaimes et al., 2005; Parker et al., 2005; Cotton et al., 2003; Luck et al., 2002; Perry et al., 2002).

Finally, regarding SCOFF's acronym, several authors criticised Morgan et al.'s original (1999) choice (Bunce, 1999; Carvel, 1999), accusing them of being frivolous and going too far with such a name. Despite the authors' openness to suggestions, much of this controversy seemed slightly self-indulgent and irresponsible, bearing in mind that the questions and the reasoning behind SCOFF are far more important than the syntax chosen. Supporting wider use of SCOFF, the Scottish National Management and Treatment Guidelines (2006) have recently proposed its use; in view of the role this screening tool may have in settings others than specialist ones. Leaving aside candid discussions regarding SCOFF, this screening tool proved easy to use and no participants complained of its use or appropriateness. Furthermore, its use engaged discussion regarding EDs and disturbed or aberrant behaviours in several cases. If by including five selected questions and adequately using the information obtained by them, individuals are to benefit, it would appear irresponsible not to employ SCOFF in scenarios that may feature individuals at risk of presenting an ED at some point.

According to SCOFF, 24.6% of the participants in this study were considered as potential cases. This figure would appear worrying if all those individuals were to be firm ED cases, particularly when incidence figures have been estimated to range between 8.1 per 100,000 (for AN) and 11.4 per 100,000 (for BN) of population (van Hoeken et al., 2003). However, the potential link between EDs and IBS could

explain some of those potential cases, as well as the lack of incidence figures for EDNOS or atypical eating disorders that could be responsible for a proportion of those identified as potential cases. In the researcher's opinion, the reason for this figure is not that 24.6% of the participants were clinically ED cases but that many of them presented with altered eating patterns, anxiety, depressive symptoms, and food fascination amongst other aspects that were identified openly by them or with help of the semi-structured interviews. Obviously this does not qualify for a DSM-IV diagnosis, but highlights the need for further assessment. Again, the elevated figures for SCOFF support the need for further research into the EDNOS subcategory that can help to clarify the real presence of individuals that belong to that diagnostic criteria and that have to date been insufficiently identified.

7.3.2 Discussion of HRQoL Instruments

7.3.2.1 *Short Form 36 (SF-36)*

As seen in the literature review, many authors have advocated the use of SF-36 when assessing EDs (Doll et al., 2005; Padierna et al., 2002, Padierna et al., 2000) or IBS (Faresjö et al., 2006; Akehurst et al., 2002). In this study, SF-36 was well accepted by the participants and seemed appropriate and valuable for this research.

Analysis of SF-36 was accomplished by comparison with normative data generated from the general population. This was particularly relevant for this study, since no control group was used.

SF-36 has been reported to have high levels of reliability, validity and responsiveness. Brazier et al. (1992) suggested that SF-36 scores in groups of patients with physical illness should be consistently lower than in normative data provided for the general population and this was indeed found to be the case in this study, both for patients with IBS and also for those scoring as potential ED cases. Although this tool was completed by the study participants, its validity for this specific group of patients remains debatable. The potential difficulties with “*off the shelf*” health indices were emphasised by Jenkinson (1993), and therefore, further

studies are required to define the applicability of SF-36 when assessing both IBS and potential EDs. Although SF-36 is a widely used assessment tool in research worldwide, its generic nature may hinder additional findings due to the unique dimensions that it comprises. Despite its general usefulness, particular aspects regarding mental health and diet alteration appeared of limited value in this study, since the depth of the findings was judged to be restricted. This is one of the reasons that other questionnaires were also employed, which supplemented and addressed specific areas in this study.

7.3.2.2 *The EuroQoL Quality of Life Scale (EQ-5D, EuroQoL)*

The EQ-5D is an example of a popular measure amongst investigators due to its descriptive system based on health state estimations (Johnson and Pickard, 2000), which appeared beneficial for the purposes of this research. The VAS scale was especially useful for assessing participants, providing a very clear indicator of their perceptions. Statistically significant differences were found between the selected sample and normative values, which translated into a self-perceived level of general health as low. This seemed to be in agreement with findings so far that have used EQ-5D as the assessment tool (van de Willige et al., 2005; Akehurst et al., 2002).

7.3.2.3 *Irritable Bowel Syndrome Quality of Life Scale (IBSQoL)*

The IBSQoL questionnaire was selected as the disease-specific instrument to evaluate HRQoL in this study, amongst other instruments with a similar purpose. IBSQoL has been shown to measure the theoretical constructs it was intended to, and has demonstrated adequate validity and reliability (Lea and Whorwell, 2001). In this study, IBSQoL analysis focused particularly on the emotional and mental health dimensions. Results concurred with the rest of the tools employed in the study. However, the strength of including this tool in the present research was the diet dimension specifically addressed by IBSQoL. By taking this aspect into consideration, relevant areas could also be highlighted. For instance, IBSQoL analysis highlighted that diet appeared to be compromised by the symptoms experienced by the patients, and that symptoms caused patients to avoid food, as

stated by nearly ninety per cent of the individuals. IBS symptoms not only compromised an individual's diet but also had a social component, where participants noted feeling uncomfortable when interacting socially which in turn led to nearly three quarters of them avoiding certain activities due to their symptoms exacerbation. These findings are in agreement with Tang et al. (1998), and equally supported by the qualitative findings of the research, which suggested symptoms, diet and social isolation to be intimately related.

7.3.3 Discussion of Wellbeing Assessment: Hospital Anxiety and Depression Scale

HAD scale is a self-assessment tool widely used outwith and within the hospital setting (Snaith, 2003; Mykletun et al., 2001) that appeared as a reliable, valid and useful instrument for this study. The HAD scale has proven to be very robust across studies and is composed of two distinct but correlated factors: anxiety and depression. However, to the author's knowledge, no studies exploring the potential relation between IBS and EDs had employed this tool before, so it was unclear how the scale would perform in such a particular milieu. Nevertheless, its user-friendly format, soundness and straightforward analysis proved useful for this research and the results highlighted important aspects that allowed further assessment.

The prevalence of anxiety and depression in patients with IBS and EDs (particularly for AN and BN) has been explored previously (van Kerkhoven et al., 2005; Simrén et al., 2002; Corcos et al., 2000). Patients accepted this instrument well since it was shorter and probably clearer to understand than other scales they were asked to complete. According to HAD scale, patients in this study presented relative elevated scores for both anxiety and depression. Mean scores suggested statistically significant differences for anxiety and depression total results. This was particularly obvious for the patients identified as potential cases by the SCOFF screening tool where results showed a difference of six points for the anxiety totals and of over five points for the depression totals (see section 5.8.2). The HAD scale also suggested that whilst both components seemed clearly impaired, anxiety scores were very slightly higher than those for depression. HAD scale results for this study appear

consistent with the results of Porcelli et al. (1998) cross-sectional study that showed higher levels of distress measured by HAD scale in individuals with functional GI disorders with a past ED.

7.3.4 Discussion of the Objective Measurement: BMI

BMI is a simple method used to express the relationship between height and weight at any given age, for all genders. Although no strict BMI figures were calculated (since patients were weighed with clothes on although encouraged to go on the scales with as little clothing as was appropriate), this indicator appeared a good measurement for the purposes of the study. A basic weak point of this method is that it does not differentiate between mass and lean mass. This can be clarified by using impedance³ measurements (when not assessing ED patients). However, this study did not incorporate this dimension since BMI was solely intended as a complementary measure to help categorise patients. Nevertheless, further studies that incorporate impedance measurements would be much more definite regarding body fat percentages when this is required by the study. A number of authors (Cook et al., 2003; Galanos et al., 1994; Lehmann et al., 1991) have suggested that BMI measurements may not be reliable for patients of certain ages, especially over 60 years old. This was not a problem in this study, since no patients over that age were included in the sample.

BMI indexes were very useful to classify participants throughout BMI categories which easily identified those patients who were non-compliant with normal standards. An interesting finding was that nearly sixty per cent of the participants in this study presented BMI indexes outwith normal ranges, most of them being overweight and just a small proportion (2.2 %) underweight. These findings appeared compliant with recent reports (WHO, 2005) warning about the epidemic proportions of overweight-obesity figures worldwide. It is far beyond the scope of this study to address the potential health implications that overweight and obesity may have in the

³ Impedance measurement: Generally achieved by using a commercial device that estimates body fat by means of passing an electrical current between two specified points on the body surface. However, this method appears unreliable in patients with disturbed hydration as is common in ED individuals (Birmingham and Beumont, 2004).

future; however this underlines the difficulty of identifying potential EDs based only on the individual's weight and height. Nevertheless, if considering that EDNOS or BN are more prevalent than AN, elevated BMIs could be an indicator of particular problems such as BED, or non-purgative BN, contrasting with lay opinions that may associate EDs with extremely underweight bodies. Although quite analogous, BMI results for individuals identified as potential ED cases varied within screening tools. According to ESP2, 22.4% of individuals were overweight (BMI 25 to 29.9) and 19% of those identified as potential cases by this tool were obese (BMI 30-40), and potential cases with normal BMI accounted for up to 55.2% of the females. According to SCOFF2, more females presented a normal BMI (58.3%), but heavier individuals were differently distributed, since 16.7% were overweight and 20.8% of them were obese, according to the same BMI parameters. This highlights slight differences between screening tools regarding BMI categorisation as suggested by Chi square analysis of both tools, with values of $\chi^2=5,11$; $p=0,024$; $df=1$.

Interviews with the patients highlighted the fact that despite limiting their diets, more individuals were struggling with overeating or bulimic-like symptoms than those disguising the anorectic type, which would support the BMI findings. Although further research would be necessary to clarify BMI distributions, this study highlights the benefits of using BMI as a simple formula by which relevant information can be obtained. This, together with other relevant data, may contribute towards a clarification of the existence of potential EDs problems. Recently, the Scottish NHS in its Recommendations for Management and Treatment guidelines (NHS, 2006) proposed BMI use as part of risk assessment when evaluating potential EDs, which again underlines the appropriateness for this study.

7.3.5 Discussion of Qualitative Assessment: Semi-Structured Interviews

The type of interviewing selected for the second Strand of this study is widely used across research. Its use involved covering a set of preselected topics, without constraining the participants' answers. Although unstructured interviews or additional questionnaires could also have been employed to explore individuals'

experiences, it was felt by the researcher that an adequate topic guide would lead to equally valuable material when semi-structured interviews were employed. Semi-structured interviews required thorough preparation, pre-testing and revision, but finally proved helpful and efficient due to time constraints. In this sense, it was the intention of the investigator to make the most of participants' dedication since they were devoting their valuable time to this research.

Participants appeared to completely engage during the process. Semi-structured interviews were guided, although the researcher worked towards not leading the individual into any particular direction. In this study, interviews were a rich source of information. Illustrative examples of the patients' accounts, and reflections, proved invaluable for the study, and emphasised certain areas that were useful to guide the discussion of the findings.

From both a methodological and clinical perspective, challenges still exist to increasing the understanding of IBS and a potential ED. It was felt that individuals may have been willing to share their understanding, yet were constrained by acute episodes or the fear that symptoms may be brought on or exacerbated by the interview process, or even by the nature of both IBS and EDs. Interviews highlighted a number of facts, beginning at the onset of the patients' symptoms and the route followed towards diagnosis up to the time of interview. Most valuably, interviews helped to reveal intense suffering from patients who in most cases saw themselves as "*not listened to*" by both professionals and society in general. IBS and EDs appeared as socially isolating conditions and individuals found it difficult to share certain signs or symptoms of either, especially if they felt judged or blamed for their situation. Interviews emphasised how individuals tended to hide not only symptoms but their feelings from even their closest ones, as consistently brought out in the qualitative analysis. As suggested by Meadows et al. (1997), patients seemed to share a guilty secret that was even more marked for those who clearly struggled with the eating component.

By using semi-structured interviews, the researcher engaged with the patients in the hope of gaining further understanding of the experience of the participants. It could

be argued that this particular sample had a very specific profile and therefore, sociocultural, ethnic, and age variations could be expected in a sample representative of the UK population, for example. However, by interviewing twenty five participants, it is felt that a first step in this area has been taken, since very limited patient experience information has hitherto existed. Despite the qualitative nature of this Strand, the numbers underlined many similarities within patients' conversations as seen in Chapter 6, which set the scene and opened avenues for further research in this particular subject.

7.4 DISCUSSION OF THE STUDY FINDINGS

The study findings have illustrated that the physical, psychological and social elements of each patient's experience are unique, but there are also many commonalities among individuals.

Data interpretation, especially when incorporating quantitative and qualitative data, has an element of subjectivity that cannot be ignored, as special emphasis may be placed on particular aspects. The main findings according to the researcher are examined below.

7.4.1 Presence of Potential EDs in IBS patients

The potential presence of EDs in this study was explored by using quantitative and qualitative approaches. A clear elevated proportion of the IBS study participants emerged as potential cases from the screening tools used. In the case of ESP, seventy-nine patients (59%) of the sample participants were considered as potential cases, whereas the SCOFF tool identified thirty-three patients (24.6%) of the study participants when using cut-off points as suggested by previous studies (Cotton et al. 2003; Morgan et al. 1999). Despite the differences between the tools (which have been addressed above), the number of potential cases still appeared substantial, particularly when compared to lifetime risk estimations for females of 0.2% to 0.5% for AN and 1.1% to 4.2% for BN (Birmingham and Beumont, 2004). This highlights

the potential implications this may have for female IBS patients in particular and within the GI setting in general.

Additionally, the potential presence of EDs in IBS females was explored in the qualitative part of the study which corroborated the findings of the screening tools but additionally gave the opportunity to discuss some of them in more depth with the patients. Qualitative findings suggested marked altered eating patterns, food fascination, diet manipulation, frequent use of laxatives and self-image issues amongst others. Patients also emphasised the need to be in control of their circumstances, and their emotional suffering. The responses obtained could therefore to a certain extent account for the high numbers of the study participants who had been identified as potential ED cases. However it would seem as if some of those responses could be explained not by the presence of a full ED, such as AN or BN (even when this was the case for several of the interviewed patients) but by the under-researched EDNOS category. The findings suggest that there was a relatively important presence of subclinical or not obviously diagnosable EDs in this study sample. These findings would be in agreement with Cotton et al. (2003) who also suggested that the EDNOS category could be potentially responsible for an overestimation of the presence of EDs, or even for a true rise in the prevalence of EDs. Additionally, Cotton et al. (2003) acknowledged the need for further clarification via interviews and long-term follow up.

This study has shown that interviews do in fact provide the clarification sought by Cotton et al. (2003). All the participants were open to discussing issues in relation to potential EDs; and although only six of the twenty-five patients seemed to have an apparent ED diagnosis (based on personal accounts), the rest of them presented particular features that would easily qualify them as a potential EDNOS case. These features can only be identified by talking to the participant. This was a somewhat unexpected finding, since secrecy surrounding symptomology is common among ED patients. On the other hand, patients indicated that these topics had rarely been professionally addressed before, which could be explained by the fact that the link between IBS and EDs is not usually tackled during routine visits, or by the fact that the skills to detect those cases appear to be inadequate. This latter point is also

suggested by the findings relating to Strand 3, as well as the nurses' data (see Chapter 5) which are examined in section 7.4.8 of this chapter. Nevertheless, a need for sharing and guidance was noticeable and implicit in the conversations with the patients, which could also explain their openness. A further positive aspect was the development of the study in two stages, which facilitated the contact with the researcher. This may have helped the patient to plan beforehand whether certain issues were to be shared with the researcher.

In view of the findings outlined above, this research seems to corroborate earlier suggestions of an existing link between IBS and EDs in works by Sullivan et al. (1997), Porcelli et al. (1998) and more recent ones, such as the research by Perkins et al. (2005). Both quantitative and qualitative assessment pointed out the fact that potential EDs were particularly prevalent within the female IBS population of this study. As highlighted by McClain et al. (1993), knowledge and familiarity of the GI manifestations of the EDs, and suspicion about one condition masquerading as the other appear necessary for a correct diagnosis and subsequent management of these individuals. In this study, that knowledge or awareness seemed to be missing or simply not applied. However, differentiating EDs from IBS is likely to remain challenging, since, as also suggested by the literature, other GI conditions may resemble an ED (Pritts and Susman, 2003), and therefore further research appears necessary in order to clarify these points.

If a link between IBS and EDs has been established, it would appear beneficial to explore potential EDs in order to prevent further damage. While no conclusive data exist regarding the precise link between these conditions, screening for EDs in IBS seems necessary in order to bring more light to this field. Additionally, the study findings support the need for further clarification of the EDNOS concept and its impact, again in relation to the GI field. Despite supporting the link between EDs and IBS, the problem of whether one condition or the other was first present in the patients could not be determined by this piece of research, as these two examples illustrate:

“Considering the harm that I inflicted on my body⁴ (...), it does not surprise me that my digestive system then became highly sensitive to the food I eat and to my temperament. For me, IBS is the physical manifestation of psychological stress and worry. So too is bulimia. However, IBS provokes useful warning signs that my stress levels are too high, often before I am consciously aware of it.”(Pt 12)

“I suppose I’ve always had a particular relationship with food, ...and that, ... of course IBS made me even more aware of what I was eating at the time (...) from then onwards my experiments with food, restricting food, losing weight...and that nightmare circle was just one.” (Pt 6)

It is the impression of the author that even if a certain predisposition may exist for developing any of these conditions, particular events, stressful situations, and unsettling circumstances appear to be related to onset. Additionally, and this may depend on the individual’s circumstances, support and self-management strategies seem to play a role in determining whether EDs symptoms appear or stay latent, as well as the impact that they may have on the individual.

7.4.2 Use of Screening Tools in the GI Setting

This study took an innovative step by employing two ED screening tools in the GI setting, and this approach proved beneficial. As underlined earlier in this thesis, differences were found between tools, which drew attention to their applicability and soundness. In the researcher’s opinion and with the literature review (Rueda-Jaimes, al., 2005; Cotton et al., 2003; Perry, et al., 2002; Morgan et al., 1999), SCOFF appeared as a better option in order to identify potential EDs cases, since ESP seemed less specific and too imprecise at times. This was also supported by the ROC curve analysis that compared both tools.

As suggested in Chapter 3, screening for EDs in the GI setting appears both pertinent and necessary; however, this is not always achieved. A decade ago, Maradiegue et al. (1996) pointed out the need for screening for EDs in settings other than the psychiatric one; the authors also made reference to the lack of screening instruments that could help to clarify the existence of potential or real problems. Special emphasis was placed on the role that nurses may have in this campaign. This study

⁴ During a period the patient had suffered from BN.

has shown the potential benefits of assessing individuals by using screening instruments, in particular by a nurse. However, one of the problems is that even when identifying patients, a gap appears to be present in daily practice that seems to hinder management since the appropriate management strategies are not in place (Treasure et al., 2005). As an example, when patients in this study were identified as potential cases, they were redirected to the specialists at the clinic who adequately reassessed them and made the necessary adjustments. Unfortunately, this study could not follow up these patients as part of the research due to its cross-sectional nature. Nevertheless, since the researcher was working closely with both specialists at the GI clinic, it is known that all those potential cases were subsequently thoroughly assessed and different routes were taken according to the nature of their problems. A number of them were referred to psychiatric services, or advised to seek psychological help, but this process took a considerable amount of time that may hinder adequate management or even discourage individuals from going for another assessment to different services. To an extent, this could jeopardise the potential benefits of having identified potential cases by using screening tools. A difficult route for further assessment of EDs seems to be present; and the lack of a smooth and more competent transition between services could be seen as another burden for such potential cases.

Finally, on a different level, the use of screening tools in the GI setting proved particularly beneficial for the qualitative stage of this study. By answering both sets of questions preceding the patients' interviews, individuals seemed to engage in the discussion of potential disordered eating habits or problems without difficulty, which assisted conversation and frequently opened new avenues for dialogue within the interviews. It is the impression of this researcher that incorporating the screening tools in the first part of the study saved time and focused attention on the specific topics addressed, which appeared very useful for a busy setting such as this outpatient GI clinic.

7.4.3 Quality of Life, Quantitative and Qualitative Findings

As presented in Chapter 5, participants showed impaired HRQoL when compared to normative data. In general, the quality of life findings are both straightforward and in agreement with the scientific literature that has emphasised the negative effect that IBS may have for most individuals' HRQoL. (Smith et al., 2006; Halder et al., 2004; Gralnek et al., 2002; Hahn et al., 1999; Hahn, et al., 1997). The impact that EDs may have on the individual's quality of life has been also pointed out by the ED literature, as seen earlier in Chapter 3 (Las Hayas et al., 2006; Engel et al., 2005; Rieger et al., 2005; Mond et al., 2005; Kolotkin et al., 2004). Even more markedly, HRQoL appeared notably impaired for those patients with IBS who displayed potential EDs. In this study sample, this finding is relevant since it confirms suspicions of an even more impaired HRQoL for individuals that may struggle with both IBS and a potential ED. Here, the particularly affected dimensions were mental health and social functioning, that together with elevated scores for anxiety and depression for the potential EDs cases portrayed a disabling panorama. Again, qualitative data supported quantitative findings: participants expressing despair regarding their situation which appeared to have an impact on the way they accepted and dealt with the situation they were in. As seen in Chapter 6, numerous remarks were made by the patients concerning how they perceived their situation was affecting their quality of life. A number of specific areas such as family, intimate life, work and interaction with friends were seen by the patients as being negatively affected by their condition. Additionally, anxiety and a certain depressive mood seemed to be present in most individuals, which appeared to be exacerbated by IBS symptomology, uncertainty, and lack of control of the situation that the patients experienced. Specific issues regarding HRQoL questions have been addressed in Chapter 5 for each HRQoL instrument and in Chapter 6 in relation to quality of life as discussed by the participants.

7.4.4 The Individuals' Experiences and Acceptance of the Condition

The experience of symptoms of a particular condition appears to develop over a period of time. In the case of the patients interviewed in this study, most symptoms had mainly evolved over several years and most patients seemed unable to specifically locate their first awareness of the symptoms, suggesting it was somehow inherent to their lives. Additionally, two parallel conditions seemed to be present: IBS and a potential ED, which could have an effect on the realisation and acceptance of what was occurring in the patient. As suggested by McCrae (1984), personal experience of symptoms and the particular way individuals manage the situation may be determined by the person, the situation or the interaction of both.

In this case, the patients' experiences seemed to be determined by a combination of factors which was clarified by the semi-structured interviews. These highlighted the endless routes that patients would take to cope with and manage their symptoms once they had assumed or accepted that a particular condition existed. In many cases, those strategies seemed to be intertwined and added to each other in order to achieve a sense of security, as if by using several strategies at the same time, the condition's management could be made more successful.

Nevertheless, the experience of the patients seemed to be closely influenced by to what extent patients accepted their situation, if they did so at all. As seen in Chapter 6, an element of rejection was present in certain patients, which would determine to an extent the experience of the symptoms, the success of their management and the quality of daily life in general. Other individuals who seemed to have accepted their diagnosis appeared to be more actively engaged in the guidance given or simply in the management of their daily lives.

The intensity of symptoms appeared closely related to the individual's whole experience of their condition. Symptoms' intensity could modulate the patient's perceptions of the whole experience, particularly during periods where these were more intense, or the patient felt unable to manage them appropriately. In general, it

could be said that IBS the overall experience of IBS patients was one of isolation, as they tried to keep their problems from those closest to them, as well as the rest of their acquaintances.

This study finding is in accordance with Meadows et al.'s (1997) research that also noted how patients seemed to self-isolate themselves even from their closest ones, often due to the nature of the symptoms and to the difficulties involved in sharing them, even when in healthy and honest relationships. To a certain extent, this isolating experience appeared to be also related to the patient's contact with healthcare professionals. Patients suggested that professionals often seemed to avoid exploring their feelings, symptoms and progress, which for the individuals seemed to increase their feelings of solitude. Levy et al. (2006) pointed out that since physicians and health professionals in general are usually trained to look for pathophysiological explanations of observed facts, it was possible that they felt uncertain when faced with conditions that may not present in the regular clinical style. In fact, IBS does not fit a simple pathophysiological model, nor do EDs in general. This could provide some explanation for the individuals' feeling of isolation from the professional angle.

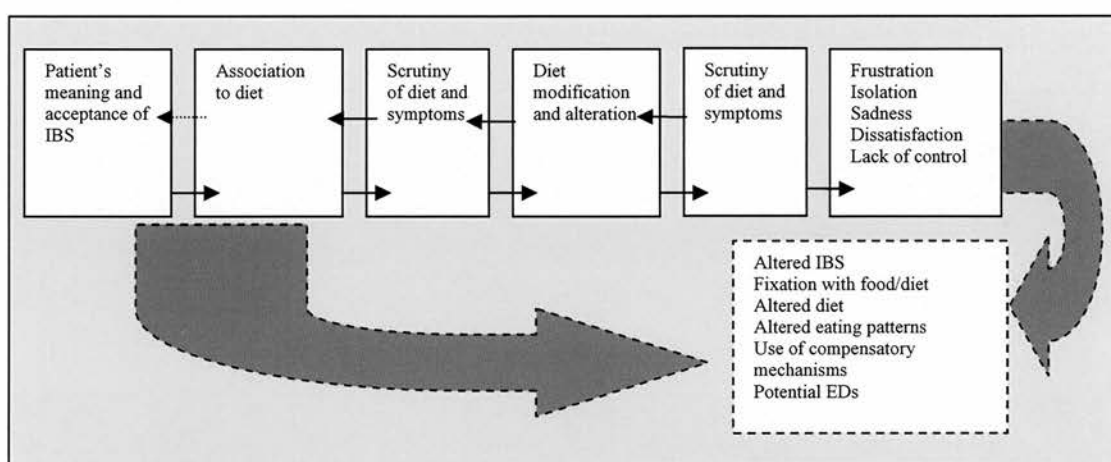
Additionally, according to Shaw (1999), the way in which a condition is socially represented and how far it is seen as socially acceptable may influence illness behaviour and subsequent coping. From the study's quantitative findings and the literature review, the researcher assumed that a major component of illness representation of this group of patients would be related to presence or absence of symptoms and the severity of the same. However, from analysis of the interview data the researcher suggests that it would be symptoms (e.g. severity, presence of "*revolting*" signs), information about diagnosis and treatment, and the uncertainty associated with some of those that are the most influential factors. They affected the way an individual constructed both their diagnosis and also potential outcomes as illustrated by subsequent expectations voiced by the patients. As suggested by Mauksch and Roesler (1990), varied explanations for the cause of a particular condition or illness may determine the way of coping as well as the degree of complying with specific treatments. Therefore, when health professionals do not seek an understanding of the patient's illness interpretation, they may fail to achieve the

patient's compliance or ensure observance of treatment strategies. Participants in this sample frequently complained of lack of time to be listened to at the clinics and subsequent lack of appropriate guidance, especially regarding dietetic advice. As an example, only a few of the study participants had met a (NHS) dietician at some point, which seems clearly insufficient. According to Fletcher and Schneider (2006), female patients with IBS place considerable attention on the relationship between IBS and food. As we saw in Chapter 6, this was very much the case for the interviewed patients who spoke of their repeated attempts to achieve control through food.

Participants' explanations of IBS symptoms were often linked to diet. It was thus reasonable that they should seek greater control of their symptoms by means of diet modification. As described by Neumark-Stzainer et al. (2006), this can lead to an alteration of the normal eating pattern which can be perpetuated by multiple diet experimentation as well as a variety of strategies that in a number of cases may not prove efficient. Therefore, IBS would coexist with an altered eating pattern, accompanied by a particular focus on food and diet. However, most of those participants despite many of them noting "*always being on a diet*", as well as looking for the "*healthy diet*", presented overweight, which would concur with Neumark-Stzainer et al.'s (2006) suggestion that dieting and unhealthy weight-control practices could lead to obesity and EDs. Indeed, as underlined by the literature review, dieting itself has been suggested to trigger symptoms of EDs in women with IBS (Jarret et al., 2001). Jarret and colleagues highlighted the need to accurately address diet and eating behaviours since they seemed to be a starting point for most females in order to manage IBS symptoms. Although food experimentation and dieting would explain certain responses to the screening tools, such as dissatisfaction with eating patterns, and to some extent food dominating the individual's life, the interviews revealed that there were other common responses such as eating in secret, weight affecting self-concept, inducing vomiting as a resource if feeling full, believing oneself to be fat even when others stated the opposite, worrying about losing control of how much was eaten, and significant weight loss over a recent period that could not be explained as a mere focus on diet by the IBS patients. This

would support the existence of a deeper problem, the origin of which remains to be clarified. Even in the cases where patients openly noted having suffered from an ED in the past, IBS symptoms and onset seemed to be present even before developing an ED or a significantly distorted eating behaviour. Despite an apparent fixation with food, deeper issues as suggested before (e.g. low self esteem, poor body image) appeared to be present that may explain some of the findings of this research. These cannot however be thoroughly explored in this research but do open a new line of enquiry within this field. The following picture illustrates some of the findings underlined by data analysis as well as facts associated with them.

Figure 7.1: The individual's experience of IBS & altered eating



* Figure 7.1 illustrates some of the stages related to the individuals' route in relation to IBS and the symptoms scrutiny and dietary experimentation.

Figures 7.1 and 7.2 emphasise and combine different aspects of the qualitative data analysis. Fig. 7.1 offers an integrated view of the main issues regarding the individuals' experience as expressed by the patients. There seemed to be a recurring loop that would perpetuate the presence of symptoms and phases that evolve throughout patients' accounts. Data analysis suggested that a double flow could be hinted from qualitative data examination. Early potential eating problems could lead to an altered IBS pattern, but on the other hand, an existing IBS pattern could lead to develop a manifest disordered eating pattern as represented in Fig. 7.1. This figure, suggests the potential fluctuating nature of ED and IBS symptoms that would make it difficult to specify the nature and/or origin of symptoms, and whether a potential ED

existed first or only manifested itself as a result of IBS symptoms or vice versa. Additionally, and as can be seen in Fig. 7.2 (see section 7.4.6) an intimately related concept to the issue of the individuals' experience is that of support, and associated closely linked to self-acceptance.

As suggested throughout this work, key issues emerged from the qualitative data analyses, which are the concepts of social support, social acceptance related to the individual's own self-acceptance. In this route, those elements seemed to be intimately related to how the person perceived the social backing surrounding her. Individuals made especial emphasis on the significance that social support and assistance would have on the concept of social acceptance as expressed by them. Data analysis highlighted the fact that self-acceptance would be influenced by these two factors and that could ultimately modulate the individual's acceptance of herself.

7.4.5 Gaining control of the situation

A recurrent theme inherent to the patients' account seemed to be control. Independently of whether patients presented an altered eating pattern, or even a potential ED, individuals strove for control in order to cope with their particular situations.

Several authors have emphasised the dangers of using maladaptive ways of coping with a particular situation, since this could adversely affect both physical and emotional health (Arraras et al., 2002; Shaw, 1999). In this study, participants' strategies to cope with their particular circumstances seemed to be varied and peculiar to each individual.

Coping styles were not specifically evaluated but they emerged from the interviews where patients addressed their frustrations regarding a variety of situations that gave IBS or EDs symptomology and its subsequent management an essential position in their lives. A great variety of management strategies were noted by the participants. This is in agreement with research by the International Foundation for Functional Gastrointestinal Disorders (IFFFGD, 2002) that estimated that over two hundred and

eighty different types of management strategies have been identified, of varied effectiveness and expense for patients. Nevertheless, most women described that one of the most important methods of coping with their condition was focused on food intake or controlling their food consumption. The majority of patients also referred to frustration due to the inability to keep symptoms under control, which seemed to increase stress levels and suffering for the patient. Similarly, low mood was found both in the quantitative and qualitative analysis, which could reflect the difficulty and frustration that most of those patients experienced in finding adequate coping strategies. It emerged from the data that patients were trying to gain control over their symptoms as if in a desperate attempt to regain control over their lives, which seemed to be affected in all spheres by their condition. However, it seemed that health care professionals were nearly exclusively addressing those symptoms, which in general were poorly managed by the patient. This imbalance between patients, professionals, and management seemed to be an important source of conflict that emerged repeatedly from the data.

This again underlines the need for guidance that most patients require. For example, helping the patient to realise that expecting symptoms to disappear may be an unrealistic target could help them to find more appropriate coping strategies. Although it is well recognised that both IBS and EDs independently may entail psychological morbidity (Smith et al., 2004; Fairburn and Harrison, 2003), few interventions were in place to manage this, apart from the occasional prescription of psychiatric drugs. Psychological management would appear beneficial for the GI setting in general and seemingly for the IBS patient. Although resources and NHS budgets may limit this suggestion, it would appear logical to manage obvious psychological distress from a non-pharmacological avenue as well.

7.4.6 Lack of Social Support

As a whole, the patients depicted a clear need for support; however they felt that encouragement and assistance were generally limited, and there was a lack of support even from a patient's most intimate circle of friends and relatives, which seemed to affect the entire social network patients had. This included partners, families, friends

and colleagues. It is difficult to state whether the lack of support that patients criticised was somehow related to the individuals' own difficulties in searching for support or help (related to the difficult nature of symptoms), as described by the patients, or the stigma they felt surrounding their condition. However, the loneliness of the patients' journeys was emphasised by individuals and recurrently emerged from the data. Several pieces of research have investigated the relationship between social support and health outcomes (Gable et al., 2006; Uchino and Bert, 2006; Uchino et al., 1996). It is generally agreed that patients presenting higher levels of social support or networks are more likely to have better mental and physical adjustment (Uchino and Bert, 2006). However this group of patients frequently acknowledged the lack of support that they were receiving. In this study, the case of IBS presented a particular disjunctive: social support could be compromised when social acceptance of the condition was not present. This was associated with the patient's own acceptance of the condition, which presented interesting similarities with those presenting potential EDs. In the researcher's opinion, acknowledgement of the symptoms and the condition (either IBS or a potential ED) should exist prior to seeking effective social support. A second dilemma appeared for the patients which related to some of the preconceptions associated with either IBS or EDs within the social spectrum.

As highlighted in the literature review and also through the qualitative findings (see Chapter 6), IBS patients were commonly described as: not able to cope, weak, and attention seeking, amongst others. Similarly, patients with an ED have historically been blamed for being: attention-seeking, selfish, manipulative and so on (Rich, 2006; Gowers and Shore, 1999). Most significantly, the interviewed patients stated that they consciously avoided seeking social support even from those closest to them, since they were worried they would not understand their symptoms or their condition. Therefore, a vicious circle seemed to keep patients from receiving enhanced social support, since it appeared as if patients themselves had difficulties in accepting the nature of their conditions and felt somehow guilty about them. This superseded guilt seemed to involve both IBS and EDs, and therefore sharing symptoms of either nature appeared delicate for patients in most instances, which to

an extent modulated social acceptance as if social support was determined by a social acceptance, which at the same time seemed to be modulated by the individuals' own recognition and endorsement of their condition and the need to ask for assistance. Figure 7.2 next, represents this sequence.

Figure 7.2 Social Support, Social Acceptance and Self-acceptance.



In this case, incomplete social acceptance could subsequently jeopardise social support when patients did not believe that partners, relatives, friends or colleagues would comprehend their situation. Additionally, this fact may increase the psychological burden for the patient who feels unable to share it with others. This element of unsupportiveness has been addressed by the literature (Locke et al., 2004) with suggestions for those patients. In general, patients in this study deliberately tried to be in command of the condition by themselves and in many cases successfully kept symptoms and even exacerbation periods away from their most immediate kin to avoid concern and any strain on the relationships, as some patients expressed it.

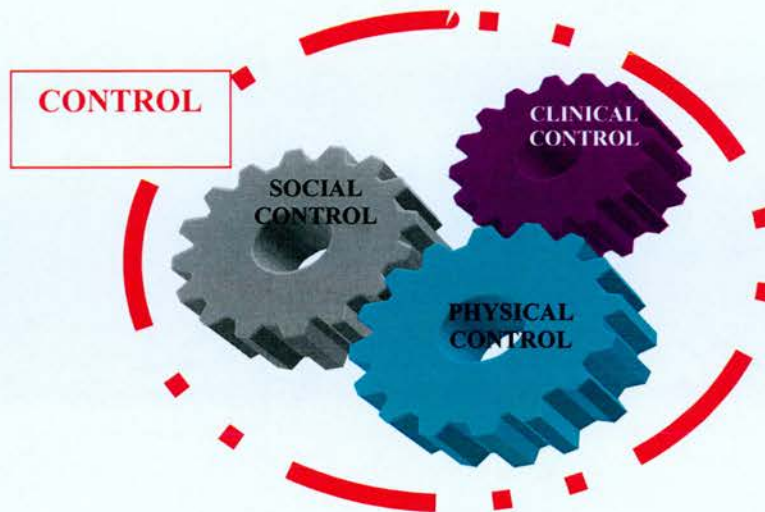
Additionally, patients openly noted not wanting to accept the rules imposed by their condition. Social norms may be severely challenged by IBS, since individuals must devote their attention to the syndrome ahead of any established social norm. Work, social outings, plans, and minimal social routines are constantly challenged by the limitations that IBS may impose on the patient (even if these are minimal). This complicates the patient's situation, as well as the difficulties that certain social norms may jeopardize the patient from adjusted performances. This was particularly noticeable when the individual felt that there were no facilities for IBS management in her most immediate environment and that IBS was not socially accepted on a general level, as highlighted by several of the patients' accounts. Emotions and

perceived barriers interact equally with existing social norms and may affect the final route that individuals choose to follow. Whether that route is taken intentionally or directed by some of the factors discussed here appears to be a last minute decision operated by the patient, modulated by circumstances and unexpected external factors, which makes it very difficult to predict the final outcome.

7.4.7 A Common Element, a Key Issue: Control

The qualitative Strand of the study added a particular depth to the understanding of the patients' experiences, as highlighted in individual accounts. One of the most relevant findings in this study was the fact that an amalgamating element seemed to be present throughout the patients' conversations independently of their circumstances. This common element that emerged from the participants' data was that of control. The physical, social and clinical spheres were constantly readjusted in order to gain control of the situation, and patients expressed frustration since despite intense efforts this was not always achieved. Moreover, the three spheres seemed to be interconnected to create a sense of general control. An illustrative figure (Figure 7.3) representing how the individuals seemed to perceive control regarding their situation, and a short discussion is presented in the following figure.

Figure 7.3: Control Spheres as Expressed by the Patients



Physical control or body control regarding IBS symptoms such as diarrhoea, constipation, bloating, and pain, amongst others, appeared essential for most of the patients. It was felt that the physical management of the body had been lost and regaining command of those aspects would prove beneficial for the individuals, as if achieving life balance again. However, although many strategies were used, control was never guaranteed or secured, thus this was difficult for the patients to accept, and it often generated anxiety and depressive thoughts. As suggested by Seymour (1998, p.156): *“we engage in routine and largely taken for granted bodily surveillance as we monitor the passage of substances in and out of the body and engage in activities designed to prevent the untoward leakage of bodily fluids. While the management of these tasks is seem as a private, personal issue, continence is assumed to be part of the responsibility of adult citizenship. Bodily continence concerns us throughout our lives. We live in fear that our bodies will let us down”*.

Social control of their condition was particularly relevant for the individuals. Partners, family, friends and work environment needed some *“readjustment”* in order to allow patients to achieve control of each particular area. The social aspect of IBS and disordered eating was highlighted by the literature review (Hillege et al., 2006; Bertram et al., 2001; Meadows et al., 1997) but it was made explicit throughout patients’ conversations. Patients openly acknowledged the burden that IBS and potential EDs cases would place on them. Social interaction could be repeatedly

limited by the symptomology as well as by the patients' own perceptions of "safety" when interacting socially or simply not wanting to give any explanations when social circles were extended and individuals did not feel at ease. For example, patients noted being afraid of having an accident, embarrassed by symptoms such as wind or noises, or having to spend prolonged periods in the toilet. Therefore, patients would very carefully monitor toilets and the potential for "trouble" when they were out. Holidays and travelling in general seemed to be jeopardised by their condition, as highlighted by patient 21:

"It is difficult for us to plan holidays, or even going out to a friend's, since that seems to be determined by IBS, and you cannot anticipate how are you going to feel in a month's time"

Patient 24 had had similar experiences:

"When I first went across to meet the in-laws, just my boyfriend at the time... the travelling... I was (sigh), when we got... He lives in Belfast and when we got across to Belfast I had really bad stomach pains. I was bloated, I had really bad pain in the bottom of my stomach and that's really sad, imagine what a mess."

It was also common for patients with disordered eating patterns to refuse to attend certain social gatherings such as dinner parties due to food confrontation and difficult situations that could be generated in those circumstances. Physical control seemed to limit social interaction, and mean a poorer life experience. Although not openly discussed by all the patients, intimate life and sexual relationships also seemed to be severely affected by symptoms and their control. The fact that they felt uncomfortable with their symptoms would lead them to avoid contact with their partners. An element of embarrassment, guilt and shame seemed to be shared, and patients also pointed out how their partners made assumptions about or were affected by these circumstances. Again, it seemed that patients' social interaction was somehow translated into a certain social isolation (imposed by themselves in many cases) that put an extra burden on them to carry out individual strategies without help. Isolation as previously discussed may be related to acceptance and stigma, or the discredit that both IBS and EDs patients and symptomology appear to encompass.

Thirdly, **clinical control** was also constantly sought by the patients. Although individual circumstances were varied, patients required clinical management from their health providers, such as the specialist, GP, or specialist nurses. Not all patients were satisfied with their management, but most of them appeared hopeful that clinical management would translate into physical control of their situation and eventually the social component could be reestablished. However, there was a tendency for disagreements to emerge with their health care providers. This could be motivated by stress, frustration along with unremitting symptoms that on certain occasions were interpreted by the patients as negligence on the part of professionals. In addition to clinical support, as noted in Chapter 6, and motivated by frustration and desperation, many individuals would seek other health alternatives or routes (e.g. herbalist, acupuncture) since they felt they were being inadequately managed.

This appears as a serious vicious circle that may trap the patient and invalidate their attempts to perform certain behaviours that in theory would be beneficial for them. As an example, proposed management strategies by healthcare professionals could entail a certain medication, biofeedback, hypnotherapy, diet adjustments and so on. Although initially compliant, patients may decide to relax their chosen route either as a result of frustration if therapies are not working, or boredom, or simply because they feel a remission period exists. This last option may be particularly dangerous as symptoms could come back with a more severe presentation, to the patient's astonishment. The fact that IBS is a chronic condition (as well as EDs) requires determination to comply with the rules imposed by an unwanted constant companion, and an element of rebellion by altering the expected behaviour from the patient would be understandable. Qualitative results in this study highlighted this aspect repeatedly. Lefcourt (1982) suggested that the perception of control that an individual may have plays a vital role in determining the ways in which people cope with their circumstances. Differences between individuals existed, and whereas some might display more passive styles, others might try to battle against the odds and actively seek help or resources to aid a particular situation. This aspect was quite manifest for this sample (and particularly underlined for the individuals interviewed). Chapter 6 highlighted some of these aspects when patients voiced a variety of hopes

regarding treatment and management, and displayed particular styles that were not always adjusted to the individual's coping styles. This study suggests that individuals may modify their styles when they encounter meaningful experiences that redirect their way of dealing with circumstances (e.g. by using relaxation techniques, autohypnosis or even by severely controlling their intake). However one of the particularities encountered by most individuals is that those strategies seemed to be temporary and soon new strategies should be incorporated into their lives.

Since this study did not particularly study locus of control, nor try to modify the individuals' styles, no further interpretation can be made regarding this point. However, lack of control emerged as an essential element that seemed to impregnate all the qualitative data and seemed destined to undermine the uncertain routes that IBS patients in general and those with added extra disordered eating patterns in particular have to follow. In fact, control could be described as the spinal cord that gave stability to all the findings. Control was implicit and present in the patients' conversations, and individuals were constantly looking for it, as if in an attempt to finally regain their lost balance.

7.4.8 Nurses' Attitudes and Perceptions

As presented in Chapter 5, a sample of 91 GI nurses were selected in order to assess their perceptions towards IBS and EDs and sufferers of IBS and/or EDs. This study was based on the earlier work of Letson and Dancey (1996) who had pointed out important issues in relation to attitudes and knowledge that healthcare professionals and nurses particularly may exhibit in relation to professional care.

Sadly, the results seemed to support the literature in this area that has suggested that healthcare professionals may present certain stigmatic judgments towards a range of conditions, which include IBS and EDs (Longstretch and Burchette, 2003; Boule and McSherry, 2002; Dixon-Woods and Critchley, 2000; Morgan, 1999; Letson and Dancey, 1996). The questionnaire revealed not only limited knowledge of IBS and symptoms recognition, but also limited knowledge about the best strategies for the management of the individuals presenting this condition. Similar results were

obtained for the EDs assessment section, with an even more marked emphasis. The fact that these results regarding IBS were in agreement with the seminal study by Letson and Dancey (1996) suggests that things have changed little over the last decade, despite better infrastructures and more published scientific information regarding the condition.

Furthermore, perceptions of IBS and EDs patients suggested a certain aversion to these types of patients, that was reflected in the statements chosen by the professionals to describe them, such as “*patients are difficult, demanding, waste doctor’s time, unable to cope with life, and crave attention*” both referring to IBS and EDs individuals. As highlighted in section 5.12.1 in Chapter 5, negative comments were more patent towards the patients with EDs. Again, this agrees with recent research by Boule and McSherry (2002) who suggested that even those professionals who are in the front line of detection or treatment of EDs presented behaviours with patients, resulting in less success in identification of individuals as cases, subsequent diagnosis and effective treatment. Similarly, Dixon-Woods and Critchley (2000) criticised the fact that professionals working with IBS patients seemed to hold two different definitions for IBS, a public one and a private one, which seemed to have absorbed particular prejudices in relation to patients. Dixon-Woods and Critchley (2000) did not describe doctors as universally hostile towards IBS or IBS patients, but emphasised that professionals working in the gastroenterology area seemed to hold more negative patient perceptions than those not working in the field, such as GPs. Frustration in relation to IBS care and the effectiveness of healthcare interventions could be responsible to a certain degree for the intolerance that they showed to certain patients. In this study, results showed a certain proportion of nurses that in fact presented marked negative comments in relation to IBS patients, even when working directly in contact with those patients. The sample also highlighted lack of knowledge in relation to EDs and a tendency to describe ED patients pejoratively. As an example, the affirmation “*individuals who suffer from an eating disorder are lazy and crave attention*” was only strongly dismissed by 11% of the sample, whereas the analogous “*individuals who suffer from IBS are lazy and crave attention*” was strongly disagreed with by 24% of the nurses. In this case,

results could suggest that either nurses seemed to be more sympathetic to IBS patients due to the fact that they worked with them on an everyday basis, or that the perceptions nurses had of ED patients were severely negative.

In this respect, it has been pointed out that patients seem more satisfied when taken seriously and are helped to control their symptoms, but many with IBS or a potential ED felt they were labeled neurotic by medical professionals (Dixon-Woods and Critchley, 2000). Although not directly asked about this, the conversations with the patients in this study often brought to light how they felt they were managed and whether the healthcare professionals were dedicating enough time and resources to them to maximise their management progress. It could be argued that certain responses or comments were concealed due to the nature of this investigation and the social position the patients were in, however patients seemed to disclose a certain frustration in relation to how they felt. On the other hand, several patients also pointed out how “*listened to*” they felt whenever they went to visit their specialist, which allows us no further possibility of hypothesis in relation to this topic.

The study findings suggest an “*immature*” professional field where health care professionals may practise with a lack of knowledge that dangerously mixes with certain stigmatised opinions that can ultimately hinder the identification of patients (particularly in the case of EDs). It may even be the case that patients, picking up those attitudes towards their “*difficult*” symptoms, may avoid any attempt to disclose other symptoms not so evidently related to IBS. The patient may feel that family and healthcare professionals disapprove of their symptoms (Donoghue and Siegel, 1994), which (due to the nature of IBS and the lack of medical tests that could confirm the patient’s subjective experience) could make the individual question whether to share her concerns with others, and then inadvertently cease to look for further healthcare support.

It has been suggested that health care professionals that are more knowledgeable about a particular condition are able to provide better care (Grol and Grimshaw, 2003). It would seem logical to presume that if nurses hold such impressions of their patients, education needs to be provided. It cannot be assumed that better knowledge

would fight stigma or presumption, or automatically translate into efficient management, but these aspects should at least be tackled in order to provide accurate information regarding the conditions considered here in an attempt to improve and clarify what those conditions entail and how they should be efficiently managed and addressed, at least from a nursing perspective.

7.5 CONCLUSION

This chapter examined and discussed the study and its findings, which yielded some unexpected results that will be put into perspective in the next chapter.

The use of an extended number of assessment tools generated valuable data from the quantitative point of view, which emphasised an elevated number of females that could be identified as potential ED cases. HRQoL assessment also emphasised impaired QoL that was definitely supported by the qualitative data gathered in the study. Nevertheless, stronger evidence emerged from data that seems to suggest that the efforts that patients make to control and manage these conditions could be compromised to some extent by the lack of support received, as well as a gap in the understanding of the condition from the patients' perspectives when compared to those of the professionals. This concept will be further explored and clarified in the following chapter.

Chapter 8

Conclusions and Recommendations

8.1 CONCLUSIONS

From the discussion of the findings of this study it can be concluded that the detection and management of IBS and potential EDs in the secondary health care setting do not appear as satisfactory as had been anticipated. The innovative approach of using screening ED screening tools proved successful, although several limitations have been addressed, mainly regarding short presentation and the difficulties for further verification of likely cases. HRQoL and well-being seemed to be impaired among the study group, although particularly manifest in those patients who were interviewed, which confirmed most of the quantitative findings. Additionally, nurses' perceptions towards IBS and ED as well as of those who suffer from them suggested important implications for those nurses based in the GI setting in relation to knowledge, education, and certain stereotypical judgements.

From discussing the findings and the elements that this study incorporated, we move to conclude by recognising several concepts that seemed to interact in this study. Three core elements came into view within the research which integrated the elements involved in the journey that the patient faces from onset to diagnosis and management.

The first important element of this picture is **diagnosis**. The difficulties that health care professionals may encounter in ensuring that an adequate diagnosis is given to the patient have been demonstrated. The study findings underlined the long route that patients face before diagnosis, in most cases involving a number of years.

In the case of IBS diagnosis is often complex (see Chapter 2) and to date it is still considered a syndrome with varied presentation that in most cases evolves through time. This uncertainty about the condition adds an element of difficulty to its detection and seemed to create a sense of insecurity in the patient as well, as if their diagnosis were merely a provisional judgement. This study has identified patients that felt unsure about their diagnosis and considered that “*something else*” was happening to them. A range of diagnostic reservations were therefore often put across. The diagnostic process for EDs is also not exempt from controversy. Chapter 3 highlighted some of those difficulties and challenges, and pointed out the imbalance between clear diagnosis and the current diagnostic criteria for these patients.

However, as stated previously, this study did not seek to establish diagnosis but identification of potential cases. It appears to have achieved the latter by using both screening tools and interviews. The use of screening tools were particularly valuable, and to some extent, the prominent presence of potential ED cases in the GI setting was an unexpected finding in this study.

The need for a thorough assessment of the patient from a variety of perspectives emerges strongly from this thesis, in order to obtain a clearer picture of the patient’s needs by looking at the individual in a more complete perspective. While the screening tools played a valuable role in identifying subjects for the interviews, they must be judged to be still somewhat superficial. The evidence from the qualitative data would suggest that the problematic diagnosis¹ leads to an unbalanced treatment: the focus is on the body rather than on the person, and consequently misses relevant information that could contribute towards a more holistic understanding of these conditions. This field appears to be in need of reconstruction, and a more holistic

¹ Faber (1930, pp 162-164) noted: “*everywhere in clinical medicine (...) and in relation to the various etiological entities, there are variations in the clinical manifestations, and the goal, which should be aimed at, is the establishment of sharply defined morbid pictures (...)*” In addition, he remarked: “*...all concepts of disease (...) are human abstractions, not objective entities. Philosophically speaking, everything is fluent, but to the physician, who is to live and act in the world, it is necessary to have definite categories of disease to serve as guides and tools*” (Faber, 1930; pp 207-208).

view is required as its foundation. Despite the usefulness of tools and diagnostic categories, an element is being left aside: the patient as a whole.

Additionally, and influencing the quality of communication and relationships between patients and healthcare professionals, would be the dissimilar **views** or the perceptions that individuals and professionals seemed to have of the condition. There was a clear imbalance between the perspective that patients had of IBS and the effects that it had on them; and those expressed by the nurses in this study, which at times seemed very distant. It could be said that patients and health professionals were looking at the condition (symptoms, presentation, management strategies and the efficacy of those) from very different perspectives, as if they were wearing different pairs of glasses or even speaking different languages. In this study, patients may see health professionals as uncaring, insensible and indifferent to their situation, but on the other hand, specialists would often criticise the patient for being demanding and difficult. The patients' feelings of lack of control and/or inadequate management that led them to repeatedly ask for guidance could explain such behaviour.

Cott (1987) noted that health professionals provide better care when they are completely aware of the patients' fears, expectations and the meanings that they give to their condition. If, as this study suggests, patients and professionals seem to speak a different language to a certain degree, that may lead to misinterpreting signs, symptoms and patients' needs. Nurses may not be aware of the discrepancies between the perceived and actual needs of patients. Related to this, is the fact that they may also be unaware of their own views of the condition and by extension the patient. The image a nurse has of an IBS patient may therefore have been shaped by their views over a process of many years. Therefore, the need for a more comprehensive education is again emphasised. Again, the only way to achieve an accurate picture of the IBS patient may be through a thorough examination; not only of the signs and symptoms, but also of the patients' accounts which would contribute to obtaining a fuller view of the picture that encompasses the whole individual and their needs.

In the case of nurses, that information could be used to better understand their patients' needs and engage in a dialogue with the individual that allows the individual tailoring of management in order to improve results. Consequently, specific signs could be identified (e.g. altered eating patterns, anxiety, and depressive mood) to improve outcomes or to plan cooperative specific strategies that may contribute to an enhanced outcome. Due to the different situations patients face, there is a need for health care professionals in general, and particularly for nurses who closely work with patients, to observe and interpret individual patients' behaviour and to assist them throughout diagnosis and treatment, since these interventions were regarded as inadequate by most of the patients in this study. Maximising the quality of the information that patients have to assimilate and addressing potentially beneficial strategies that could assist individuals throughout this process may prove invaluable.

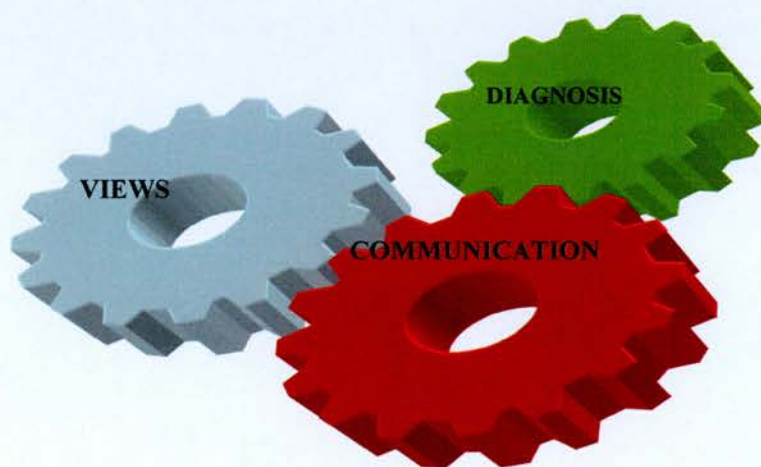
The third element of this model, and one which is intimately related to the idea of the need for a different type of assessment that incorporates the views of the patient, would be the **communication** difficulties that this study has revealed. The communication between patients and professionals seems to be limited. This could be in part related to a lack of time to devote to the patient, as well as to an excessive focus on the symptoms rather than on effectively communicating with the patient and their progress (as previously noted). Communication between patients and professionals also seems to be modulated by the different conceptions that they may have in relation to the condition/s and how best to address them. The literature has emphasised the difficulties that professionals may have in comprehending the severity of the patient's condition, as well as the patient experience, or even disagreement in the perceptions of the causes. Therefore, incompatible perceptions would seem a logical product of this. Some form of bridge for communication between patients and professionals seems required, in order to deal with all the elements that are involved in the journey of this chronic condition.

Patients' communication with relatives or acquaintances seemed to be similarly restricted and inadequate, since there were elements of their condition that they found very difficult to discuss. These were modulated by the invisibility and secrecy

of the condition as previously addressed, and had a significant impact in their relationships and interactions. The particular nature of the symptoms seemed to lead the individual to hide them, since they were seen as embarrassing, dirty and upsetting. Despite the major impact that IBS and/or an ED can have on the life of each individual, as also highlighted in this work, individuals tended to deal with the symptoms themselves, and conceal them, so even those closest to them might be unaware of their situation. Additionally, it should be remembered that EDs in general entail a clear element of secrecy, that may allow patients to keep them as “*secret conditions*” until they are detected or make themselves obvious.

Therefore, it would seem as if the interaction of the difficulties in diagnosing these disorders would also be closely related to the different views that patients, professionals, and even relatives may have of the conditions and the effects on the patient. This panorama is completed by the difficulties in communication that the patient may have, not only in terms of symptoms and the condition as a whole, but with the health professionals that seemed to be incomplete, with frequent misunderstandings.

Figure 8.1: Interacting concepts



A common language that integrates symptoms and the individual (as a whole) appears necessary to enhance successful detection and subsequent management of IBS and potential EDs.

8.2 LIMITATIONS OF THE STUDY

What follows is a discussion of the limitations of the research approach adopted within the study.

Firstly, it should be acknowledged that this study focused only on females, based on the suspicion that both IBS and EDs are conditions that are much more prevalent in women than men. This does not imply that males should not be addressed, in fact quite the opposite, but this study aimed to be a first step towards understanding some of the experiences that women may have with these conditions. It is the intention of the author to include both females and males in subsequent research in order to contribute to the body of knowledge existing in this field.

One limitation of this study was sample size. Despite the fact that 134 participants took place in Strand 1, or the quantitative part, of the study and twenty five individuals were interviewed in Strand 2 of the same, findings cannot be generalised for the entire population. Although participants were selected from a reference hospital which would have a potential for patient heterogeneity, this should not be implied. However, patient numbers and findings appear relevant in that they set up the scene for further investigations. It is recommended that subsequent research should incorporate multisite recruitment. It would also be of interest to establish international research to enquire whether similar results are to be found in diverse geographical and cultural scenarios. To compensate for sample size and recruitment from a singular setting, this study emphasised descriptive data, as well as the use of valuable qualitative information that provided relevant data regarding the phenomena under study. By using data from different sources, findings could be contrasted and compared, which provided further strength to the results.

The validity and reliability of the quantitative assessment tools were examined and discussed earlier in this thesis. It was thought that due to the incorporation of several other tools, using only ESP and SCOFF would be adequate to screen for potential EDs. However, in relation to the assessment of potential EDs, two limitations arise. One is the debate surrounding the definitions of EDs and disordered eating, aberrant eating habits, or disordered eating as addressed in Chapter 3. Considering a case as an ED without a proper diagnosis could not be established. That is why the use of the phrase “*potential case*” was emphasised throughout this study. To some extent, this could limit the strength of the study, if the reader is to judge the findings as per diagnosed ED cases. In the researcher’s opinion, and based on her experience by working with both IBS and EDs patients, screening tools were efficient to detect potential cases and to bring to light certain aspects of cases that could otherwise be considered as difficult to address. On the other hand, and despite the researcher’s familiarity with these conditions, it could not be established that participants were completely honest about their responses, which would introduce an element of bias in the study. When interviewing the patients, responses generally appeared to be sincere and although a guideline was used, conversations flowed which enabled the researcher to readdress issues that may have appeared unclear.

In relation to assessment of IBS-subgroup, classification of patients would have allowed the researcher to identify the impact of specific symptoms. This would be recommended for subsequent studies.

A particular limitation of the questionnaire used to explore nurses’ attitudes and perceptions towards IBS and EDs was the fact that it appeared too lengthy since it incorporated two independent but very similar sections regarding the study. This could have had an impact on completion figures. Unsurprisingly, factor analysis of the EDs nurses’ questionnaires did not support their validity or reliability of this measure in EDs. This relates to the fact that items in this questionnaire were adapted from an IBS scale.

The present study has indicated the need for further research into both the identification of IBS patients with potential EDs and into the experience of the

individual. The following sections offer a number of recommendations for health service managers, policy makers, clinical management, and healthcare planning.

8.3 RECOMMENDATIONS

This thesis has generated as many questions as it has answered and it is clear that further research is needed in several areas as underlined by the research conducted. The recommendations deriving from this study are presented next. These are based on the findings and discussion as well as the conclusions of this thesis. They are inspired by the necessity for nursing advancement towards holistic care and attention in a variety of settings.

The usefulness of ED screening tools in the GI setting has been discussed. However, further research seems necessary in other potentially at risk areas to see whether results in this study are representative of those fields.

There is a need for a more theoretical basis to understand the relationship between IBS and EDs. Future research should consider the need for larger studies that help to clarify the discussed link between such conditions. Additionally, there is a need to incorporate male patients in such researches in order to obtain a clearer picture of the panorama.

Clearer information is required to better estimate HRQoL and “*quality of life*”² in IBS and potential EDs patients. Further assessment of the relationship that IBS and/or a potential EDs may have on such concepts appears necessary. New tools or avenues of assessing this aspect would be highly useful since to date, instruments appear imperfect. This would be of great benefit for the individuals when applied in the GI setting.

This research suggests the need for further education in relation to EDs for those nurses working within the GI setting. The increasing figures for EDs appear to be an important burden for the National Health System, therefore the development of new

² As used by the patients.

policies towards recognition and management by health professionals should be enabled.

A strong need for a new nurse figure in the GI setting emerges. Based on the suspicion that a number of ED patients may go unidentified, and that those who present problems encounter several difficulties with managing them, a clinical specialist nurse who has a background in both areas could be a valuable new resource. In addition, the research clearly suggests the need for specialist skills in communicating with these unpopular patients.

The study findings emphasised the need for clear dietetic guidelines that are presently available for IBS patients in the secondary care setting. There seems to be a lack of consistent or systematic advice given to patients, underlining the importance of revising and discussing dietetic habits with the patient on a regular basis and with clear documentation. This study would also recommend that professionals (working with IBS and EDs patients) should address these issues in order to enhance the adequate management of IBS and EDs. Further research is required to support those interventions since confusion seems to surround this area.

Finally, as one of the aims of the study was to explore the patients' experience of their conditions, the need to carry out further research in this line has been noted. The limited qualitative pieces of research existing in this field so far limit the possibility of comparison, but open an avenue for researchers to become familiar with the patients' views through further studies.

8.4 CONCLUDING REMARKS

This study has added to the literature existing on IBS and EDs from a very specific perspective.

By using an innovative methodology, this research has contributed to underline the potential link between those conditions, assisted by combining quantitative and qualitative methodologies. The precise choice of tools for conducting this study has

generated a comprehensive picture of the study population, which opens new lines of enquiry regarding both IBS and EDs. Particularly the introduction of user friendly screening tools, seems fundamentally relevant for the identification of new EDs. Both ESP and SCOFF tools have shown good properties to detect new cases and it is hoped that both tools can be used in diverse settings to recognize and subsequently manage individuals who may be at risk of developing a potential ED.

This study has also contributed to current knowledge by highlighting the HRQoL impairment that both IBS and/or potential EDs patients may experience; allowing the patients to express their own experiences provided powerful and insightful data. Some of the complexities that patients have to face in relation to detection, diagnosis, management and communication with health professionals and peers have been exposed. The use of qualitative data in order to explore those issues proved very fertile, giving the participants to voice their journeys. It also helped to highlight the suspected link between EDs and IBS, which opens likewise a new line of enquiry for nurses.

Finally, this work highlighted some relevant issues regarding nurses knowledge, education, and attitudes of nurses towards patients suffering from IBS and/or EDs. As indicated throughout this work, the need for further education of GI nurses in relation to EDs has been identified.

A complex picture has been presented, but further research seems needed to clarify and enhance some of the aspects presented in this thesis.

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APPENDICES

List of Appendices

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Appendix 1: HRQoL Assessment

HEALTH RELATED QUALITY OF LIFE MEASUREMENT

HRQoL measurement is growing steadily fast in healthcare research (Fitzpatrick et al, 1992; Deyo, 1991) but several key areas require specific attention when addressing the issue of HRQoL as identified by Aaronson in 1989, such as:

- who should measure HRQoL?
- psychometric properties of the HRQoL measurement tools
- types of measurement
- debate among generic and/or disease-specific instruments

These will be briefly presented next.

Who should measure HRQoL?

This aspect remains controversial, and patient and professional views seem somehow opposed. Bowling (1991) reported consensus among health researchers who believe that incorporate the individual's perspective on a global view in relation to patient's perceived mental and physical well-being. Relatives and physicians ratings can be valued but individual's opinions cannot be taken for granted (Slevin et al., 1988).

Psychometric properties of the HRQoL measurement tools

A growing body of QoL and HRQoL measurement tools exist, although they require rigorous evaluation prior to acceptance as valid diagnostic or evaluative standards for disease assessment. The psychometric assessment of these tools is defined as the evaluation of the instruments, based primarily on the evidence of its validity and reliability (Polit & Hungler, 2004). These terms are briefly defined next.

Validity: relates to the quantitative assessment of how well it measures the phenomenon of interests. Several accepted definitions of validity exist, which substantially overlap:

Criterion Validity: or predictive validity is the comparison of a new index against an accepted reference measure that evaluates the same or similar features.

Construct Validity: is an assessment which relates scores or changes in scores of a new index to a hypothesis, concept or prediction of what the index is measuring.

Content Validity: assesses the degree to which an index measures the full spectrum of problems caused by a particular disease.

Reliability: relates to the consistency of a test, index, or questionnaire when readministered under similar conditions on separate occasions. The reliability of a measuring instrument that yields quantitative data is a major criterion for the assessment of its quality. Essentially, the reliability of an instrument is the degree of consistency with which the instrument measures the attribute under question. Reliability, often relates to two different aspects, external and internal reliability. *External* reliability refers to the degree of consistency of a measure over time. Test-retest reliability, or administering a test on two separate occasions to the same group of individuals, provides assessment of external reliability. *Internal* reliability raises the question of whether a scale is measuring a single idea and is conveniently measured by Cronbach's alpha calculating the average of all possible split-half reliability coefficients of a scale (Bryman & Cramer, 1994).

Responsiveness: Is the facility of an instrument to reflect important changes over time or after an intervention. Although a measure may be responsive to changes it may not accurately reflect these changes.

Sensitivity: refers to the ability of a measurement to reflect degrees or differences.

The components of validity, reliability, responsiveness and sensitivity testing are critical in the evaluation of HRQoL instruments.

Types of HRQoL Measurement

HRQoL assessment tools range from single-item questions to batteries of single-item questions and complete measurement scales. Single item assessment is popular due to its easy administration and subsequent analysis. However, it is debatable whether single questions can effectively measure specific domains and, its reliability is also

difficult to assess. The superiority of multi-item scales over single-item HRQoL evaluation was showed by Manning and colleagues (1982) who used standardised well-tested scales with sound psychometric properties in the assessment of IBS symptoms. On the other hand, Garret et al (1990) illustrated that controversy surrounds the debate as to whether generic or disease-specific measures should be used in the assessment of HRQoL.

Two main avenues therefore exist, generic health status instruments and disease-specific measurement instruments for the assessment of particular conditions. Generic scales implicitly or explicitly aim to measure HRQoL. These have evolved in order to make comparisons between varying conditions, to broaden outcome indicators and because of the time-consuming development of disease-specific questionnaires. According to Hutchinson and Fowler (1992) the main constraint of generic instruments was their inability to identify condition-specific aspects of disease. One of the paradigm generic tools is SF-36, a sound generic test developed for HRQoL measurement. SF-36 is internally consistent, and provides a valid measure of the health status across a wide range of patients. On the other hand, disease-specific HRQoL instruments have been generated from lists of problems identified by patients depending on the condition to be assessed. These provide for a useful comparison among similar groups of patients and measure clinically important changes over time. Disease-specific health status measures tend to be more responsive to change than generic measures and their subjectivity allows for identification of the problems that appear most bothersome to patients. Disease-specific tools are difficult to validate, which may account for a lack of sound specific instruments amongst conditions. However, thorough HRQoL evaluation seems to benefit from using both types of tools. General and specific HRQoL tools combined use may provide a broader picture of the patient situation than when using a single instrument approach.

Appendix 2: Creswell & Plano-Clark Mixed-Methods Classification

THE MAJOR MIXED METHODS DESIGN TYPES (CRESWELL & PLANO-CLARK, P.85, 2007)

Table 4.2 The Major Mixed Methods Design Types

<i>Design Type</i>	<i>Variants</i>	<i>Timing</i>	<i>Weighting</i>	<i>Mixing</i>	<i>Notation</i>
Triangulation	<ul style="list-style-type: none"> • Convergence • Data transformation • Validating quantitative data • Multilevel 	Concurrent: quantitative and qualitative at same time	Usually equal	Merge the data during the interpretation or analysis	QUAN + QUAL
Embedded	<ul style="list-style-type: none"> • Embedded experimental • Embedded correlational 	Concurrent or sequential	Unequal	Embed one type of data within a larger design using the other type of data	QUAN(qual) or QUAL(quant)
Explanatory	<ul style="list-style-type: none"> • Follow-up explanations • Participant selection 	Sequential: Quantitative followed by qualitative	Usually quantitative	Connect the data between the two phases	QUAN → qual
Exploratory	<ul style="list-style-type: none"> • Instrument development • Taxonomy development 	Sequential: Qualitative followed by quantitative	Usually qualitative	Connect the data between the two phases	QUAL → quan

Appendix 3: Ethical Approval

06/S1102/6

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Research governance approval

The study should not commence at any NHS site until the local Principal Investigator has obtained final research governance approval from the R&D Department for the relevant NHS care organisation.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

06/S1102/6	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Professor P. Hayes
Chair

Email: lyndsay.baird@lhb.scot.nhs.uk

Enclosures: *Standard approval conditions*
 Site approval form

SF1 list of approved sites

Appendix 4: Validated Questionnaires Used

ASSESSMENT OF OVERALL HEALTH (SF-36)

1 In general would you say your health is: (Tick one box)

Excellent	Very Good	Good	Fair	Poor
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2 Compared to one year ago, how would you rate your health in general now? (Tick one box).

Much better than 1 year ago

Somewhat better now than 1 year ago

About the same as 1 year ago

Somewhat worse than 1 year ago

Much worse than 1 year ago

3 The following items are about activities you, might do during a typical day. Does your health limit you in these activities? If so how much? (Tick one box on each line).

	Yes limited a lot	Yes limited a little	No not limited at all
a) Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b) Moderate activities, such as moving a table, pushing a vacuum cleaner, or playing golf	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c) Lifting or carrying groceries	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d) Climbing several flights of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e) Climbing one flight of stairs	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

- | | | | |
|----------------------------------|--------------------------|--------------------------|--------------------------|
| f) Bending, kneeling or stooping | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| g) Walking more than a mile | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| h) Walking more than half a mile | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| i) Walking one hundred yards | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| j) Bathing or dressing yourself | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

4) During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of your physical health?

- | | Yes | No |
|--|--------------------------|--------------------------|
| Cut down the amount of time you spent on work or other activities? | <input type="checkbox"/> | <input type="checkbox"/> |
| Accomplished less than you would like | <input type="checkbox"/> | <input type="checkbox"/> |
| Were limited in the kind of work or other activities | <input type="checkbox"/> | <input type="checkbox"/> |
| Had difficulty performing the work or other activities
(for example it took extra effort) | <input type="checkbox"/> | <input type="checkbox"/> |

5) During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of any emotional problems (such as feeling depressed or anxious).

- | | Yes | No |
|---|--------------------------|--------------------------|
| Cut down the amount of time you spent on work or other activities | <input type="checkbox"/> | <input type="checkbox"/> |
| Accomplished less than you would like | <input type="checkbox"/> | <input type="checkbox"/> |
| Didn't do work or other activities as carefully as usual | <input type="checkbox"/> | <input type="checkbox"/> |

6) During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

- | Not at all | Slightly | Moderately | Quite a bit | Extremely |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

7) How much bodily pain have you had during the past 4 weeks?

- | None | Very mild | Mild | Moderate | Severe | Very severe |
|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

8) During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

Not at all	A little bit	Moderate	Quite a bit	Extremely
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9) How much time during the past 4 weeks...

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
Did you feel full of life?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you been a very nervous person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you been so down in the dumps that nothing could cheer you up?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you felt calm and peaceful?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you have a lot of energy?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you felt downhearted and blue?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you feel worn out?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Have you been a happy person?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Did you feel tired?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Has your health limited your social activities (like visiting with friends or close relatives)?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10) During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc)?

All of the time	Most of the time	Some of the time	A little of the time	None of the time
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11) Please choose the answer that best describes how TRUE or FALSE each of the statements is for you.

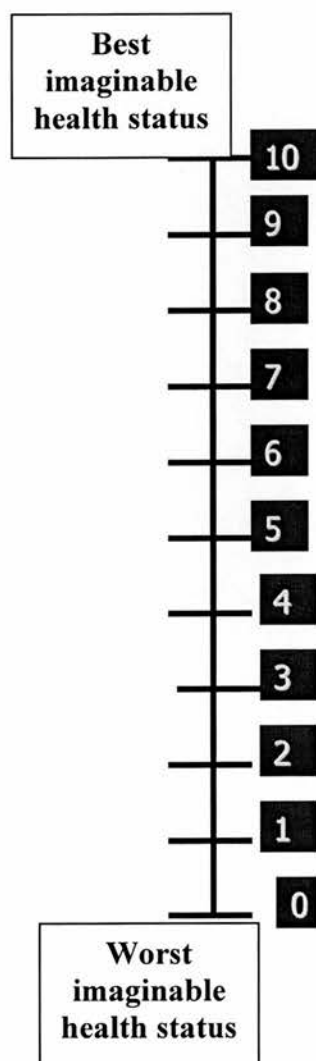
	Definitely true	Mostly true	Not sure	Mostly false	Definitely false
I seem to get sick a little easier than other people	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am as healthy as anybody I know	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I expect my health to get worse	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
My health is excellent	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Your own health state today (Analogue Scale)

To help people say how good or bad a health state is, we have drawn a scale on which the best state you can imagine is marked 10 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today in your opinion.

Please tick the number you feel that indicates how your health state is today!



DESCRIBING YOUR OWN HEALTH TODAY EQ-5D

By placing a tick in one box each group below; please indicate which statements best describe your own health state today.

Mobility

- I have no problems in walking about
- I have some problems in waling about
- I am confined to bed

Self-Care

- I have no problems with self-care
- I have some problems washing or dressing myself
- I am unable to wash or dress myself

Usual Activities (e.g. work, study, housework, family or leisure activities)

- I have no problems with performing my usual activities
- I have some problems with performing my usual activities
- I am unable to perform my usual activities

Pain/ Discomfort

- I have no pain or discomfort
- I have moderate pain or discomfort
- I have extreme pain or discomfort

Anxiety/Depression

- I am not anxious or depressed
- I am moderately anxious or depressed
- I am extremely anxious or depressed

ASSESSMENT OF HOW YOU ARE FEELING (HAD SCALE)

For each question please tick the answer which matches best how you feel

- 1) I feel tense or “wound up”
 - Most of the time
 - A lot of the time
 - Time to time, occasionally
 - Not at all

- 2) I still enjoy the things I used to enjoy
 - Definitely as much
 - Not quite as much
 - Only a little
 - Hardly at all

- 3) I get a sort of frightened feeling as if something awful is about to happen
 - Very definitely and quite badly
 - Yes, but not too badly
 - A little, but it doesn't worry me
 - Not at all

- 4) I can laugh and see the funny side of things
 - As much as I always could
 - Not quite so much now
 - Definitely not so much now
 - Not at all

- 5) Worrying things go through my mind
- A great deal of the time
 - A lot of the time
 - From time to time but not too often
 - Only occasionally
- 6) I feel cheerful
- Not at all
 - Not often
 - Sometimes
 - Most of the time
- 7) I can sit at ease and feel relaxed
- Definitely
 - Usually
 - Not often
 - Not at all
- 8) I feel as if I am slowed down
- Nearly all the time
 - Very often
 - Sometimes
 - Not at all
- 9) I get a sort of frightened feeling like butterflies in the stomach
- Not at all
 - Occasionally
 - Quite often
 - Very often

- 10) I have lost interest in my appearance
- Definitely
- I don't take quite so much care as I should
- I may not take quite as much care
- I take just as much care as ever
- 11) I feel restless as if I have to be on the move
- Very much indeed
- Quite a lot
- Not very much
- Not at all
- 12) I look forward with enjoyment to things
- As much as ever I did
- Rather less than I used to
- Definitely less than I used to
- Hardly at all
- 13) I get sudden feelings of panic
- Very often indeed
- Quite often
- Not very often
- Not at all
- 14) I can enjoy a good book or radio or TV programme
- Often
- Sometimes
- Not often
- Very seldom

DAILY TASKS (IBSQoL)

Please answer all parts of each question.

EMOTIONAL

1) How often in the past month did your stomach symptoms make you feel...

	Always	Often	Sometimes	Seldom	Never
1a. Angry about your this	1	2	3	4	5
1 b. Not as happy as usual	1	2	3	4	5
1 c. Less satisfied with life	1	2	3	4	5
1d. Fed up or frustrated	1	2	3	4	5

MENTAL HEALTH

2) How often during the past month did your stomach symptoms make you feel...

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
2a. More nervous than usual	1	2	3	4	5	6
2b. Worried	1	2	3	4	5	6
2c. Downhearted and blue	1	2	3	4	5	6
2d. Upset	1	2	3	4	5	6

SLEEP

3) During the past month...

	Every night	Most nights	Some nights	A few nights	None
3.a. Have you had trouble falling asleep due to stomach symptoms	1	2	3	4	5
3.b. Have your stomach symptoms caused you to wake up during the night	1	2	3	4	5
3.c. Have your stomach symptoms caused you to wake up earlier than usual	1	2	3	4	5

ENERGY

4) During the past 4 weeks...

	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
Has your IBS made your stomach symptoms made you feel emotionally worn out and tired	1	2	3	4	5	6
Has your stomach symptoms made you feel physically worn out and tired	1	2	3	4	5	6

PHYSICAL FUNCTIONING

5) How often during the last 4 weeks did your stomach symptoms restrict or reduce vigorous physical activities?

None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1	2	3	4	5	6

How often during the last 4 weeks did your stomach symptoms restrict /reduce **moderate** physical activities?

None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1	2	3	4	5	6

How often during the last 4 weeks did your stomach symptoms restrict or reduce **mild** physical activities?

None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1	2	3	4	5	6

DIET

6) How often in the past 4 weeks have your stomach symptoms caused you not to eat at meals time?

None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1	2	3	4	5	6

How often in the past 4 weeks have your stomach symptoms caused you to avoid certain foods/drinks?

None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1	2	3	4	5	6

How often in the past 4 weeks have your stomach symptoms caused you to find foods unappealing?

None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1	2	3	4	5	6

SOCIAL ROLE

7) How often in the past 4 weeks did stomach symptoms make you feel socially uncomfortable?

None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1	2	3	4	5	6

How often in the past 4 weeks did stomach symptoms make you avoid certain social activities?

None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1	2	3	4	5	6

How often in the past 4 weeks did stomach symptoms make you feel socially embarrassed about yourself?

None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1	2	3	4	5	6

How often in the past 4 weeks did stomach symptoms get in way of other activities?

None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1	2	3	4	5	6

ROLE PHYSICAL

8.a How often during the past 4 weeks have stomach symptoms affected your ability to succeed?

None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1	2	3	4	5	6

8.b. How often during the past 4 weeks have stomach symptoms caused you to get less done than expected?

None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1	2	3	4	5	6

8.c. How often during the past 4 weeks have stomach symptoms caused you to avoid certain work activities?

None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1	2	3	4	5	6

8.d. How often during the past 4 weeks have your stomach symptoms affected how well you do your job?

None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
1	2	3	4	5	6

Thank you for taking the time to complete this questionnaire!

Appendix 5: Current Symptom Scale

CURRENT SYMPTOMS

Date: _____

Please indicate which of the indicated <i>symptoms</i> you experience on a regular basis:	Abdominal Pain or discomfort	<input type="checkbox"/>
	Abnormally infrequent motions	<input type="checkbox"/>
	Abnormally hard stools	<input type="checkbox"/>
	Abdominal fullness, bloating or welling	<input type="checkbox"/>
	Urgency (urgent need to pass a motion with very little notice)	<input type="checkbox"/>
	Straining during a bowel movement	<input type="checkbox"/>
	Passing mucus (white discharge) during a bowel movement	<input type="checkbox"/>
	Other (please specify below)	<input type="checkbox"/>
	<input type="checkbox"/>

Thinking about your <i>abdominal pain</i> or <i>discomfort</i> , which of indicated statements apply to you?	Pain is relieved when I pass a motion	<input type="checkbox"/>
	The pain comes on when I have bowel problems (either a change in the frequency of passing a motion, or a change in the consistency the of my stools)	<input type="checkbox"/>
	Neither	<input type="checkbox"/>

Which of the following bowel disturbances are you more prone to?	Constipation	<input type="checkbox"/>	Diarrhoea	<input type="checkbox"/>
	Both	<input type="checkbox"/>	Neither	<input type="checkbox"/>

Which of the statements best describes the pattern of your tummy problems?	Episodes of symptoms occurring at fairly regular intervals	<input type="checkbox"/>
	Episodes of symptoms occurring erratically and unpredictably	<input type="checkbox"/>
	Predictable - I know what sets off my symptoms	<input type="checkbox"/>

How often are you affected by your symptoms ?	Daily	<input type="checkbox"/>	Weekly	<input type="checkbox"/>
	Monthly	<input type="checkbox"/>	Less frequently	<input type="checkbox"/>

How long do your symptoms usually last?	Less than a day	<input type="checkbox"/>	5-7 days	<input type="checkbox"/>
	1-2 days	<input type="checkbox"/>	8-14 days	<input type="checkbox"/>
	3-4 days	<input type="checkbox"/>	All the time	<input type="checkbox"/>

Please list your most bothersome IBS symptoms (most bothersome first)

1.....

2.....

3.....

Are you taking any medication at the moment? If so, please indicate the names below:

.....

Please indicate how you would rate your health IN GENERAL today:

.....

Appendix 6: Eating Disorders Screening Tools

ESP

Are you satisfied with your eating patterns? Yes No

Do you ever eat in secret? Yes No

Does your weight affect the way you feel about yourself? Yes No

- Have any members of your family suffered with an eating disorder?

Yes No

- Do you currently suffer with or have you ever suffered in the past with an eating disorder?

Yes No

SCOFF

- Do you make yourself sick if you feel uncomfortably full?

Yes No

- Do you worry you have lost control over how much you eat?

Yes No

- Have you recently lost more than one stone (7.7 kg) in a 3 months period?

Yes No

- Do you believe yourself to be fat when others say you are thin?

Yes No

- Would you say that food dominates your life?

Yes No

Appendix 7: Interview Schedule for Patient's Interview

INTERVIEW TEMPLATE GUIDE

- Presentation. Thank the patient. Situation.
- Could you please tell me about the origin of your gastrointestinal symptoms?
- Do you have to restrict any foods due to your gastrointestinal symptoms?
- Have you ever been under an “*elimination*” diet?
- Do you usually diet? If so, why?
- Do you find that any specific foods might affect your gastrointestinal symptoms? If so, can you please name them?
- Have you ever experienced any type of eating difficulties? Any eating disorders? If that is the case, would you say they could be related to your IBS symptoms?
- What is your experience in relation to IBS/EDs?
- Any further remarks.
- Concluding the interview. Thank the patient.

Appendix 8: Patient Information Sheet

PATIENT INFORMATION SHEET

Eating Disorders in patients with bowel symptoms

You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The aim of the study is to gather information to explore if there is a link between Eating Disorders and individuals with bowel symptoms (Irritable Bowel Syndrome).

Why have I been chosen?

You have been invited to participate in the study as you attend a Gastrointestinal Clinic which specialises in bowel disorders. It is planned to recruit one hundred patients for this study.

To participate in the study you will be required to complete several questionnaires and to be briefly interviewed by a research nurse. This interview should take no longer than twenty minutes and will not delay the time it takes to see the doctor. The study does not involve any interventions.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

Will my taking part in the study be kept confidential?

All information which is collected about you during the course of the research will be kept strictly confidential. Any information about you which leaves the hospital/surgery will have your name and address removed so that you cannot be recognised from it.

Many thanks for considering taking part in this study.

Contact for further information:

Sandra Tricas Sauras

PhD Student, Gastrointestinal Unit.

****** Hospital, Edinburgh*

*Phone ******

Appendix 9: Contact Letter for Patients Participating in the Interviews

Sandra Tricas-Sauras
Department of N. Research
12, Buccleuch Place
EH8 9LW

Dear Ms *****,

My name is Sandra Tricas Sauras. We recently met at Dr **** Gastrointestinal Outpatient's Clinic at ***** Hospital, Edinburgh.

You participated in our study by completing a set of questionnaires and had a brief meeting with me regarding your symptoms at that time. As you might also remember, we talked about meeting in the future to discuss some of those issues in further detail. I am writing to you today to ask you whether you would still be prepared to meet me. This interview would be arranged at a suitable time for you and it would not take longer than one hour. Special arrangements will be made to minimise any disruption to your time.

I would suggest meeting you on Wednesday the 2nd of **** or alternatively the 9th of the same month at the Gastrointestinal Clinic at ***** Hospital, ***** if any of those dates is convenient for you.

I am enclosing a telephone number where you would be able to reach me so an appointment can be made. Please contact me at: **0131 650 4535** or alternatively **0131 *******.

Thank you very much for your time,

Sandra Tricas Sauras

Appendix 10: Management Guide for IBS Summary

Table: Recommendations for IBS Management

Positive Diagnosis	Dietary Advice	Psychological considerations	Psychological Treatment	Pharmacological Approach
Based on Rome II criteria	Establish habitual fibre intake	Identify features of psychological disorders	Explanation and reassurance	Limited value treatments
Listen to the patient	Increase/decrease fibre intake for constipation/diarrhoea	Disorders of sleep and mood	Relaxation trial	Abdominal pain: Antispasmodics Antidepressants
Explanation and reassurance	Identify excessive lactose, fructose, sorbitol, caffeine, or alcohol intake in patients with diarrhoea	Previous psychiatric disease/history of current past/physical sexual abuse	Biofeedback, hypnotherapy, CBT, Dynamic Psychotherapy	Diarrhoea: Loperamide Codeine Cholestyramine
Healthy lifestyle advice	Trial of lactose/fructose/alcohol exclusion when appropriate		Psychiatric referral for those with serious psychiatric disease	Constipation: Dietary fibre
	Reassurance of rare cases of food allergy			Bloating: Reduce lactose/fibre
	Expert dietetic advice for selected patients			

*Adapted from Jones et al., 2000 (BSG Guidelines)

Appendix 11: Eating Disorders Treatment Guidelines, NICE (2004)



*National Institute for
Clinical Excellence*

Eating disorders

Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders

Summary of identification and management

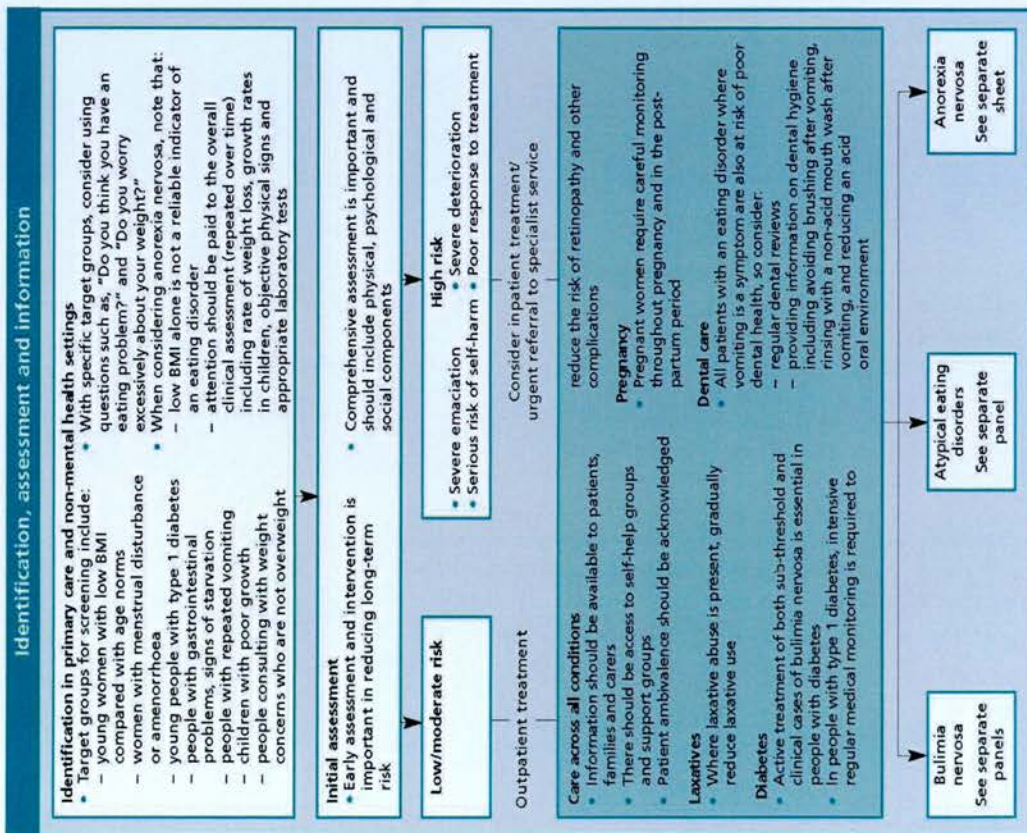
Clinical Guideline 9

January 2004

Developed by the National Collaborating Centre for
Mental Health

Eating disorders: summary of identification and management

January 2004



Bulimia nervosa

Following the initial assessment consider:

- as a possible first step, an evidence-based self-help programme – direct encouragement and support to patients undertaking such a programme may improve outcomes. This may be sufficient treatment for a limited subset of patients

Psychological treatment should form the key element of treatment, so consider:

- for adults: cognitive behaviour therapy for bulimia nervosa (CBT-BN), which should normally be 16 to 20 sessions over 4 to 5 months
- for adolescents: CBT-BN adapted as needed to suit their age, circumstances and level of development
- where there has been no response to CBT or it has been declined, other psychological treatments, particularly interpersonal psychotherapy (IPT). (Note: patients should be informed that IPT takes 8–12 months to achieve results comparable with CBT-BN)

Physical management

- Careful monitoring of risks should be a concern of all health professionals working with people with this disorder
- Assess fluid and electrolyte balance where vomiting is frequent or there is frequent use of laxatives
- If electrolyte balance is disturbed, consider behavioural management as first option
- If supplementation is required, use oral rather than intravenous preparations

Pharmacological interventions may have a role

- Consider a trial of an antidepressant drug as an alternative or additional first step to using an evidence-based self-help programme

Bulimia nervosa – inpatient or day care

- Consider inpatient treatment for patients with risk of suicide or severe self-harm
- Admit patients to setting with experience of managing this disorder

Primary care

- Patients with enduring anorexia nervosa not under the care of a secondary care service should be offered an annual physical and mental health review by their GP
- Where management is shared between primary and secondary care, there should be clear agreement between individual healthcare professionals on the responsibility for monitoring of patients with eating disorders. This agreement should be in writing (where appropriate using the care programme approach) and should be shared with the patient and, where appropriate, families and carers

Atypical eating disorders including binge eating disorder (BED)

General treatment

In the absence of evidence to guide the management of atypical eating disorders (eating disorders not otherwise specified) other than binge eating disorder, it is recommended that the guidance on the treatment of the eating problem that most closely resembles the individual patient's eating disorder is followed.

Psychological treatments for BED

- As a possible first step, consider an evidence-based self-help programme; direct encouragement and support from a healthcare professional may improve outcomes
- In adults, where self-help is not offered or is declined, consider cognitive behavioural therapy for binge eating disorder
- For persistent BED, consider other psychological treatments – interpersonal psychotherapy for binge eating disorder (IPT-BED), and modified dialectical behaviour therapy
- For adolescents with persistent binge eating disorder, consider suitably adapted psychological treatments
- Note that all psychological treatments for binge eating disorder have a limited effect on body weight
- Consider providing concurrent or consecutive interventions focusing on the management of comorbid obesity

Pharmacological interventions for BED

- As an alternative or additional first step to using an evidence-based self-help programme, consider a trial of an SSRI antidepressant

Eating disorders: summary of identification and management continued

January 2004

Anorexia nervosa – outpatient care

- Psychological interventions are the key element in the management of anorexia. The delivery of psychological interventions should be accompanied by regular monitoring of a patient's physical state including weight and specific indicators of increased medical risk.
- Treatment should be of at least 6 months' duration
- When delivering a psychological treatment consider, in conjunction with patient:
 - cognitive analytical therapy (CAT)
 - cognitive behaviour therapy (CBT)
 - interpersonal psychotherapy (IPT)
 - focal psychodynamic therapy
 - family interventions focused explicitly on eating disorders
- Focus of treatment should be on weight gain, healthy eating, and reducing other symptoms related to eating disorders
- Dietary counselling should not be provided as the sole treatment for anorexia nervosa

Pharmacological interventions

Pharmacological interventions have a very limited evidence base for the treatment of anorexia nervosa.

- Medication is not effective as sole or primary treatment; caution should be exercised in its use for comorbid conditions such as depression or obsessive-compulsive disorder, as these may resolve with weight gain alone
- Avoid using drugs that prolong the QTc interval in patients with borderline/prolonged QTc

Note: drugs that prolong the QTc interval include antipsychotics, tricyclic antidepressants, macrolide antibiotics, and some antihistamines

- If medication that may compromise cardiac functioning is essential, ECG monitoring should be undertaken
- Place alert in prescribing record concerning the risk of side effects

Anorexia nervosa – inpatient care

- Consider inpatient treatment for patients:
 - with high or moderate physical risk
 - who have not improved with appropriate outpatient treatment
 - have significant risk of suicide or severe self-harm
- Admit to setting that can provide the skilled implementation of refeeding with careful physical monitoring (particularly in the first few days of refeeding) and in combination with psychosocial interventions
- If uncertain about formal admission, consider seeking advice from an appropriate eating disorder specialist regardless of the age of the patient
- Consider increased risk of self-harm and suicide at times of transition for patients with anorexia nervosa, especially that of the binge-purging sub-type

Psychological treatment

- Psychological treatment is a key element of an inpatient stay but evidence for what kind of treatment is effective is limited
- A structured symptom-focused treatment regimen with the expectation of weight gain should be provided with careful monitoring of the physical status during refeeding
- Provide psychological treatment with a focus both on eating behaviour

Post-hospitalisation treatment in adults

- Following discharge, extend the duration of psychological treatment over that normally provided to those who have not been hospitalised – typically for at least 12 months
- Offer outpatient treatment that focuses both on eating behaviour and attitudes to weight and shape, and on wider psychosocial issues, with regular monitoring of both physical and psychological risk

Anorexia nervosa – physical management

Anorexia nervosa carries considerable risk of serious physical morbidity. Awareness of the risk, careful monitoring and, where appropriate, close liaison with an experienced physician are important in the management of the physical complications of anorexia nervosa.

Managing weight gain

- Aim for an average weekly weight gain of 0.5–1 kg in inpatient settings and 0.5 kg in outpatient settings. This requires about 3500 to 7000 extra calories a week
- Provide regular physical monitoring and consider multivitamin/mineral supplement in oral form for both inpatients and outpatients
- Total parental nutrition should not be used unless there is significant gastrointestinal dysfunction

Managing risk

- Inform patients and their carers if the risk to their physical health is high
- Involve a physician or paediatrician with expertise in the treatment of medically at-risk patients for all individuals who are at risk medically
- Consider more intensive prenatal care for pregnant women to ensure adequate prenatal nutrition and fetal development
- Oestrogen administration should not be used to treat bone-density problems in children and adolescents as this may lead to premature fusion of the epiphyses
- Healthcare professionals should advise people with eating disorders and osteoporosis or related bone disorders to refrain from physical activity that significantly increases the likelihood of fall s.

Additional considerations for children and adolescents

Special considerations apply in the treatment of children and adolescents. The involvement of families and other carers is particularly important. The right to confidentiality of children and adolescents with eating disorders should be respected.

Family members, including siblings, should normally be included in the treatment of children and adolescents with eating disorders. Interventions may include sharing of information, advice on behavioural management and facilitating communication.

Anorexia nervosa

- Family interventions that directly address the eating disorders should be offered to children and adolescents with anorexia nervosa
- Offer children and adolescents individual appointments with a health professional separate from those with their family members or carers
- For children and adolescents, once a healthy weight is reached ensure increased energy and necessary nutrients are available in the diet to support growth and development
- Involve carers of children and adolescents in any dietary education or meal planning

Inpatient care of children and adolescents with anorexia nervosa

- Inpatient care of children and adolescents should:
 - be to age-appropriate facilities (with the potential for separate children and adolescent services), which have the capacity to provide appropriate educational and related activities
 - be balanced the need for treatment and urgent care for the need for treatment and urgent social needs of the young person
 - Consider using the Mental Health Act 1983 or the right of those with parental responsibility to override the young person's refusal to receive treatment that is deemed essential
 - Avoid relying indefinitely on parental consent
 - Seek legal advice and consider proceedings under the Children Act 1989 if the patient and those with parental responsibility refuse treatment, where treatment is deemed essential
 - Consider seeking a second opinion from an eating disorder specialist where issues of consent to treatment are highlighted

Clinical Guideline 9

Eating disorders

Core interventions in the treatment and management of anorexia nervosa, bulimia nervosa and related eating disorders

Issue date: January 2004

This document forms part of the NICE guideline on eating disorders (see above), which is available from the NICE website (www.nice.org.uk/CG009NICEguideline).

An abridged version of this guidance (a 'quick reference guide') is also available from the NICE website (www.nice.org.uk/CG009quickrefguide). Printed copies of the quick reference guide can be obtained from the NHS Response Line: telephone 0870 1555 455 and quote reference number N0406.

Information for the public is available from the NICE website in English (www.nice.org.uk/CG009publicinfoenglish) and Welsh (www.nice.org.uk/CG009publicinfowelsh). Printed copies are available from the NHS Response Line (quote reference number N0407 for an English version and N0408 for a version in English and Welsh).

Information about the full guideline, from which the NICE guideline has been prepared, is given in Section 5 of the NICE guideline.

This guidance is written in the following context:

This guidance represents the view of the Institute, which was arrived at after careful consideration of the evidence available. Health professionals are expected to take it fully into account when exercising their clinical judgement. The guidance does not, however, override the individual responsibility of health professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or guardian or carer.

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Appendix 12: Nurses' Questionnaire

NURSING PERCEPTIONS TOWARDS GASTROINTESTINAL CONDITIONS

Age:

Sex:.....

Job title:

Length of time that you have been working as a Gastrointestinal nurse?:.....

Have you ever suffered from Irritable Bowel Syndrome?:.....

Have you ever suffered from an Eating Disorder?:.....

NURSES' PERCEPTIONS OF PATIENTS SUFFERING FROM IRRITABLE BOWEL SYNDROME (IBS).

Please tick the box that best defines how you feel about the following statements:

1) Patients who suffer from IBS are difficult

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2) People who have IBS have it all in the mind

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3) Patients who have IBS are demanding

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

4) People with IBS are unable to cope with life

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5) People with IBS are lazy and crave attention

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

6) Individuals with IBS waste doctor's time

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

7) People with IBS are neurotic

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

8) People with IBS have a low pain threshold

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

9) My knowledge of IBS is limited

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10) I have a good understanding of IBS

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11) I could confidently explain IBS to a patient

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12) I would recognize the symptoms of IBS

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13) Psychotherapy has been successful in the short term in alleviating the symptoms of IBS

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14) IBS is the result of a variety of causes

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15) Some of the symptoms are abdominal pain, flatulence, and diarrhoea

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

16) Doctors can only speculate about the causes of IBS

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17) IBS causes the muscle of the gut to react

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18) IBS is linked to having abdominal surgery

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

19) There is a self-help group for IBS

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20) There is a cure for IBS

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

21) IBS is a digestive disorder characterized by unexplained abdominal pain

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

22) There is no universal agreement about the cause of IBS

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23) IBS is a common disorder

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23) I am not really interested in IBS

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

24) IBS is not a serious illness

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

25) Health professionals have a poor understanding of IBS

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

26) Doctors have poor knowledge of IBS

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

27) IBS is not taken seriously by health professionals

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

NURSES' PERCEPTIONS OF PATIENTS SUFFERING FROM AN EATING DISORDER (ED).

Please tick the box that best defines how you feel about the following statements:

1) Patients who suffer from an Eating Disorder are difficult

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2) People who suffer from an Eating Disorder have it all in the mind

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

3) Patients who suffer from an Eating Disorders are demanding

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly agree	Agree	Not sure	Disagree	Strongly disagree

4) People who suffer from an Eating Disorder are unable to cope with life

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly agree	Agree	Not sure	Disagree	Strongly disagree

5) People who suffer from an Eating Disorder are lazy and crave attention

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly agree	Agree	Not sure	Disagree	Strongly disagree

6) Individuals who suffer from an Eating Disorder waste doctor's time

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly agree	Agree	Not sure	Disagree	Strongly disagree

7) People with an Eating Disorders are neurotic

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly agree	Agree	Not sure	Disagree	Strongly disagree

8) People who suffer from an Eating Disorder have a low pain threshold

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Strongly agree	Agree	Not sure	Disagree	Strongly disagree

9) My knowledge of Eating Disorders is limited

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

10) I have a good understanding of Eating Disorders

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

11) I could confidently explain what it means to have an Eating Disorder to a patient

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

12) I would recognize the symptoms of an Eating Disorder without too much difficulty

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

13) Psychotherapy has been successful in the short term in alleviating the symptoms of Eating Disorder

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

14) Eating Disorders are the result of a variety of causes

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

15) Some of the symptoms of patients with Eating Disorders are weight loss, visible bingeing and/or purging, low blood pressure

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

16) Doctors can only speculate about the causes of Eating Disorders

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

17) Eating Disorder cause the muscle of the gut to react

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

18) Eating Disorders are linked to having abdominal surgery

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

19) There is a self-help group for patients who suffer from an Eating Disorder

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

20) There is a cure for Eating Disorders

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

21) Eating Disorders are digestive disorders characterized by unexplained abdominal pain

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

22) There is not universal agreement about the causes of Eating Disorders

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

23) Eating Disorders are common disorders

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

24) I am not really interested in Eating Disorders

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

25) Eating Disorders are not serious illnesses

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

26) Health professionals have a poor understanding of Eating Disorders

Strongly agree	Agree	Not sure	Disagree	Strongly disagree
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

27) Doctors have a poor knowledge of Eating Disorders

Strongly agree

Agree

Not sure

Disagree

Strongly disagree

28) Eating Disorders are not taken seriously by health professionals

Strongly agree

Agree

Not sure

Disagree

Strongly disagree