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Factors of importance for health care seeking in irritable bowel syndrome and the use of patient education.

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UNIVERSITY OF GOTHENBURG

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ABSTRACT

Factors of importance for health care seeking in irritable bowel syndrome and the use of patient education.

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Irritable bowel syndrome (IBS) is a common functional gastrointestinal (GI) disorder. The etiology and pathophysiology are incompletely understood and treatment options are limited. IBS is a benign disease, but many patients experience severe GI symptoms and low health related quality of life (HRQOL), leading to health care consumption and high economical costs to the society. Many IBS patients express that they do not receive thorough explanations about their symptoms, and have feelings of not being taken seriously in their contacts with the health care system.

The aims of the present thesis were to identify factors of importance for health care seeking in IBS, to assess how much and what kind of knowledge IBS patients have about their disorder, and to develop and evaluate a structured patient education for IBS patients, an IBS school.

Persons, who did not seek health care for their GI symptoms (non-consulters), and patients who had sought health care, were investigated using questionnaires for comparison of GI and psychological symptoms, HRQOL and coping resources between the groups. Non-consulters had similar GI symptom severity, but less severe psychological symptoms, better HRQOL and coping resources, compared with the patients.

IBS patients, referred from primary care to a gastroenterologist, completed a questionnaire regarding knowledge of IBS. Only a minority of the patients had received enough information and a large proportion was dissatisfied with their knowledge. The patients primarily wanted information about what they can do in order to improve symptoms, treatment options and causes of the symptoms.

In a pilot study, to develop the IBS school, 12 patients were included. The IBS school consisted of six sessions once per week, two hours each time, in groups of five to seven patients. The patients were very satisfied with the construction of the education, as well as with the new knowledge they had received. There were also tendencies towards improved HRQOL and reduced GI symptoms in this small group of patients.

Thereafter we included 143 patients in a study to evaluate the effects of the IBS school compared with written patient information, a guidebook. The patients were randomized to either participate in the IBS school or to receive the guidebook. The effects were evaluated with questionnaires measuring knowledge of IBS, GI and psychological symptom severity and HRQOL. The IBS school group increased their knowledge, and reduced their GI symptom severity and GI-specific anxiety more than the patients in the guidebook group. The patients in the IBS school group also improved their HRQOL after the patient education.

Conclusions: IBS non-consulters have similar GI symptom severity compared with the patients, but manage their symptoms due to better psychological well-being and HRQOL. Many IBS patients have correct knowledge about their disorder, but are not satisfied with that knowledge and mainly want information about what they can do in order to improve their symptoms in daily life. The IBS school is appreciated by the patients and seems to be superior to written information in order to contribute to increased well-being for IBS patients.

Key words: Irritable bowel syndrome; health care seeking; non-consulters; patient education; health related quality of life; GI specific anxiety; GI symptoms.

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Till Bosse, Hannah och Rasmus

Att våga är att förlora fotfästet en liten stund.
Att inte våga är att förlora sig själv.

(Sören Kierkegaard)

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LIST OF PAPERS

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals:

I. **Why do subjects with irritable bowel syndrome seek health care for their symptoms?**
Ringström G, Abrahamsson H, Strid H, Simrén M.
Scandinavian Journal of Gastroenterology (2007) 42; 1194-1203

II. **What do patients with irritable bowel syndrome know about their disorder and how do they use their knowledge?**
Ringström G, Agerforz P, Lindh A, Jerlstad P, Wallin J, Simrén M.
Accepted for publication in Gastroenterology Nursing (2008)

III. **Development of an educational intervention for patients with irritable bowel syndrome (IBS) - a pilot study.**
Ringström G, Störsrud S, Lundqvist S, Westman B, Simrén M.
Submitted for publication

IV. **Structured patient education is superior to written information in the management of patients with irritable bowel syndrome – a randomized controlled study.**
Ringström G, Störsrud S, Posserud I, Lundqvist S, Westman B, Simrén M.
In manuscript

CONTENTS

PAPERS I-IV

ABBREVIATIONS

IBS	Irritable bowel syndrome
GI	Gastrointestinal
HRQOL	Health related quality of life
WHO	World health organization
QOL	Quality of life
SOC	Sense of coherence
CBT	Cognitive behavioral therapy
GSRS	Gastrointestinal Symptom Rating Scale
IBS-SSS	IBS Severity scoring system
VAS	Visual analogue scale
SF-36	Short Form -36
PCS	Physical component score
MCS	Mental component score
IBSQOL	IBS quality of life
SCL-90	Symptom checklist -90
GSI	Global Severity Index
PSDI	Positive Symptom Distress Index
PST	Positive Symptom Total
HAD	Hospital Anxiety and Depression scale
VSI	Visceral Sensitivity Index
CRI	Coping Resources Inventory
IQR	Interquartile range

INTRODUCTION

Irritable bowel syndrome (IBS) is a chronic functional gastrointestinal (GI) disorder, characterized by abdominal pain and/or discomfort related to disturbed bowel habits (1). The prevalence is estimated to 3-20% in the population and the disorder is more common in women compared with men (2-4). Differences in the estimation of the prevalence could partly depend on the use of different diagnostic criteria (5, 6). The disorder was described already in 1871 by Da Costa, although named “membranous enteritis” (7). Even though being a common disorder, the pathophysiology is not clearly understood and there are no biological disease markers for IBS. Various diagnostic criteria have been developed during the years and the latest are the Rome III criteria (1).

Despite being a benign disorder, the IBS symptoms are, for many patients, associated with difficulties in daily life (8). A considerable overlap with other functional GI symptoms is also present in many patients (9, 10), as well as non-colonic symptoms like gynecological and urinary symptoms (11). Moreover, IBS contributes to a substantial economic burden to the society, both regarding direct and indirect costs (12, 13).

Many persons with IBS seek health care for their symptoms and become patients, while others do not attend the health care system at all for their GI symptoms. The reasons behind this are not completely known. Some studies have found that the number of GI symptoms (14) or the severity and duration of abdominal pain (15) are the most important factor for health care seeking. Others have found impaired health related quality of life (HRQOL) (16, 17) or psychological symptoms (18, 19) to be the most important factors for health care seeking.

The limited knowledge of the pathophysiology and the absence of biological markers and effective treatment (20), probably contributes to difficulties in the management of the patients (21, 22). A substantial number of the patients have feelings of not being taken seriously for their symptoms in their contacts with the health care system (23). There also seems to be differences in the perceptions of the disorder between the health care professionals and the patients (24), possibly affecting the management negatively.

During the years of work as a specialist nurse in a gastroenterology out-patient clinic, it has become obvious to me that many IBS patients are disappointed with the management and information they have received in the health care system. Therefore, I wanted to study the reasons for health care seeking, what kind of knowledge that patients have about IBS, what information they need and finally, to develop and evaluate a structured patient education for IBS patients.

1. ETIOLOGY AND PATHOPHYSIOLOGY

The etiological and pathophysiological mechanisms in IBS are not totally understood. Immunological, infective and genetic factors are considered to be important in the etiology of IBS, whereas psychosocial factors are thought to contribute to aggravation of symptoms but are unlikely to be the cause of IBS. A combination of altered gastrointestinal motility and visceral hypersensitivity together with psychosocial factors is proposed to contribute to the symptom generation in IBS (25). Biological disease markers are still missing, which makes IBS, together with other functional GI disorders, a symptom based diagnosis. Over the years different diagnostic criteria have been used, starting with the Manning criteria in 1978 (26), followed by the Rome criteria in 1992 (27), Rome II criteria in 1999 (28) and the most recent Rome III criteria in 2006 (1). Essential symptoms in IBS are abdominal pain and/or discomfort associated with disturbed bowel habits. IBS patients are divided into subgroups based on their predominant bowel habit, i.e. diarrhea, constipation or a combination of these two (1, 28).

There are findings demonstrating disturbed GI motility in IBS patients, although correlations with symptoms, as well as specific GI motility patterns for IBS patients, have been hard to prove (29, 30). However, it has been suggested that normal motor activity within the GI tract, might explain the symptoms in IBS patients through mechanisms of enhanced visceral sensitivity (31). Increased colonic activity after a meal has been a common finding in IBS patients (32-34), and could possibly explain some of the postprandial symptoms in IBS patients. Moreover, disturbed small bowel motility in IBS has also been suggested to be involved in the generation of symptoms like bloating and distension, as a result of impaired transit of intestinal gas in the gut (35).

Visceral hypersensitivity in IBS patients was first demonstrated by Ritchie in 1973 (36). This finding has been reproduced and it has been proposed that rectal hypersensitivity is of importance in symptom generation in IBS patients and a biological marker for IBS (37). However, IBS patients form a heterogeneous group and all patients do not have visceral hypersensitivity. Therefore, it has been questioned whether visceral sensitivity really is a proper biological marker for IBS (38). In a study aimed to investigate factors of importance for the symptom severity in patients with painful functional bowel disorders, it was instead suggested that psychosocial factors are of greater importance than increased rectal sensitivity (39).

The brain-gut axis involves neural pathways, as well as immune and endocrine mechanisms. A dysregulation of the brain-gut axis is, at least partly, believed to explain the symptoms in IBS through an integrated action in the central, autonomic and enteric nervous system (40). Already in 1928 Bockus and Bank named the disorder “neurogenic mucous colitis” and proposed that neurogenic disturbance is an important etiological factor (41). The brain-gut axis regulates and modulates visceral motility, sensitivity and secretion, which probably also is influenced by psychosocial factors that are believed to contribute to IBS symptoms, rather than being a cause of the disorder (42). Moreover, IBS patients have shown an altered perceptual and neuroendocrine response to rectal distensions during mental stress as compared with healthy controls (43).

2. HEALTH RELATED QUALITY OF LIFE (HRQOL)

According to the definition by the World Health Organization (WHO) in 1948, *“health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”*, it would be possible to have a disease, but still feel healthy and vice versa. WHO also defines Quality of Life (QOL) as *“individuals’ 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”*. When the QOL is affected by illness or disease, the term Health Related Quality of Life (HRQOL) is used. Many chronic diseases affect the HRQOL, and comparisons have been performed between IBS subjects and the general population (44) and with groups of patients with other chronic diseases (17, 45, 46).

2.1 Measuring HRQOL

HRQOL comprises several domains or components. Different questionnaires are used in order to measure HRQOL. Single item measure uses one question to assess HRQOL. Since this measure is the simplest questionnaire, it is the measure that is mostly used in daily clinical activities. Health profiles are questionnaires that try to measure all the important aspects of HRQOL with several questions designed to assess the various domains that comprise HRQOL

(47). The measures are further divided into generic and disease-specific questionnaires. Generic measures can be used to measure HRQOL in patients with a wide variety of diseases and allows comparison between groups of patients with different diseases, as well as with the general population. One disadvantage with a generic questionnaire is that small clinically important changes might be missed (47). On the other hand, the disease-specific questionnaires are designed to relate more closely to specific clinical disease aspects, and can be used in a group of patients related to a certain disease, certain function or certain health problem (48).

The questionnaires must have shown to be robust in the assessment, which involves three fundamental concepts: validity, reliability and responsiveness. Validity indicates if the questionnaire measures what it is aimed to measure. Reliability shows if the results from a questionnaire are reproducible. Responsiveness indicates if the questionnaire is sensitive enough to detect a significant change in HRQOL (49).

2.2 HRQOL in IBS patients

HRQOL is reported to be worse in IBS patients compared with the general population (17, 44-46), and as bad or even worse as compared with patients with other chronic diseases like asthma and migraine (17), gastroesophageal reflux disease and diabetes mellitus (45) and inflammatory bowel disease (46). The HRQOL has also been found to be worse in IBS patients compared with subjects with symptoms compatible with IBS who had not sought health care for their symptoms (non-consulters) (16, 17).

HRQOL is considered to be an important outcome measure in clinical trials and evaluation of the health care in IBS patients (47), and there seems to be good evidence that HRQOL scores correlate well with other therapy-associated changes in symptoms and disability in IBS patients (50). However, it has also been suggested that HRQOL in IBS patients primarily is related to extra intestinal symptoms rather than to the GI symptoms (51), and that it therefore would be more helpful to focus on global symptom severity instead of isolated GI symptoms in the management of IBS patients.

Based on this, HRQOL seems to be a key factor in the perception of the disorder in IBS patients. Further evaluation of HRQOL in different subgroups of IBS subjects based on if they have sought health care for their symptoms and if they are managed in primary or secondary/tertiary care is needed. Better knowledge in this area could contribute to an improved management of these patients in the health care system. Moreover, interventions in the form of patient education or providing written information might have the capacity to improve HRQOL, which makes it an important outcome measure when such interventions are evaluated.

3. COPING

Coping can be viewed upon as a response to emotions and as having the function of arousal- or tension-reduction. Coping consists of cognitive and behavioral efforts to manage the demands in the life of persons, which can be problem-focused and/or emotion-focused (52). A coping strategy is what a person does in reaction to a specific stressor occurring in a particular context. Coping resources, on the other hand, act as background factors of behavior (53).

A person's ability to cope with difficulties in life is influenced by different factors like motivation, beliefs about oneself, social and problem solving skills. Individual differences in such areas can explain why different persons respond in different ways on a certain challenge (52). Thus, IBS symptoms could be more or less difficult to live with depending on the person's ability to cope with them. In line with this assumption, it has been shown that psychological symptoms could influence how patients with IBS cope with their illness (54). Moreover, Drossman et al. have demonstrated that among women with GI disorders, certain coping strategies, such as more catastrophizing and less self-perceived ability to decrease symptoms, had significant adverse effects on health outcome (55). In the same study, they also found that women with functional GI disorders were less likely to feel in control of their symptoms as compared with those with an organic GI diagnosis.

Sense of coherence (SOC) is defined by Antonovsky as "*a global orientation that express the extent to which one has a pervasive, enduring although dynamic feeling of confidence that: 1. the stimuli, deriving from one's internal and external environments in the course of living, are structured, predictable and explicable; 2. the resources are available to one to meet the demands posed by the stimuli; and 3. these demands are challenges, worthy of investment and engagement*'" (56). SOC does not refer to any specific type of coping strategy, but to factors that are the basis for successful coping with stressors (56). Moreover, there seems to be a link between HRQOL and SOC, since low scores on the SOC measurement has been found to correlate with worse HRQOL in women both with and without IBS (57).

To conclude, coping seems to be an important factor regarding how people manage difficulties in life. Coping might be an important factor for health care seeking in IBS, which needs to be further evaluated. Enhanced knowledge among health care providers in this area could possibly contribute to a more adequate support to the patients who are consulting in the health care system.

4. HEALTH CARE CONSUMPTION

Symptoms are a part of peoples every day life and some seek health care for them, while others do not. Peoples’ decision for consulting in general seems to be based on a mix of different physical, psychological and social factors (58).

The health care consumption in IBS patients is associated with high costs to the society (12, 13, 59). However, a substantial number of individuals, having IBS according to the diagnostic criteria, do not seek health care for their GI symptoms (60). The reasons for health care seeking in IBS, as well as reasons for not seeking health care, are only partly understood and have most likely more than one explanation.

Some studies propose that the severity and duration of abdominal pain drives the person with IBS to seek health care (3, 15), or that the presence of abdominal pain together with the multiplicity of other GI symptoms are the most important factors (14). Moreover, HRQOL has been found to be worse in IBS patients compared with non-consulters (17, 16), which possibly also could influence health care seeking. Others suggest psychological symptoms to be the most important factor for health care seeking in IBS (8, 18, 19, 61). However, in a Swedish study, there were no differences between patients and non-consulters with IBS according to the psychological measurements (62), but subjects with IBS, both patients and non-consulters, seemed to have more psychiatric distress compared with people without IBS (63). Moreover, it has been suggested that parents with IBS might transmit a pattern of general illness behavior to their children, influencing the health care seeking (64). However, another study did not find any differences between patients with IBS, chronic constipation or Crohn’s disease regarding abnormal illness behavior (65), but they found that abnormal illness behavior was associated to psychopathology, regardless of diagnosis. Interestingly, one study has shown that the combination of the perceived severity of abdominal pain and the patients' worries about the possible seriousness of their symptoms, contributed to health care seeking in IBS (66). On the other hand, some studies demonstrate that non-GI symptoms could be the most important factors for health care seeking in IBS (67, 68), and also sense of coherence could influence the health care seeking, as demonstrated by findings of less sense of coherence in IBS patients compared with IBS non-consulters (69).

Once a person with IBS has become a patient, one question is whether he or she will be managed in primary or secondary/tertiary care. There seem to be some differences between patients handled in primary or secondary/tertiary care, although there are somewhat divergent results from different studies. Tertiary care patients were found to have more anxiety, worse HRQOL, more severe GI symptoms, shorter symptom duration and higher income (70). Another study did not find any differences regarding IBS symptom severity, but a higher number of patients in secondary care reported that they had problems in their usual daily activities (71). Other findings reported in the literature are that diarrhea predominant symptoms, physical fatigue and reduced general health, predicted being a patient in secondary care (72) and that secondary care patients had more severe abdominal pain and more interference with daily activities compared with IBS patients in primary care (73). Moreover, reasons for referral from primary care to a specialist has also been evaluated and found to depend on if the patient denied a role for stress in their symptoms together with multiple tests being performed and the presence of frequent bowel movements (74).

Therefore, health care seeking in IBS seems to be complex and further studies are needed in order to fully understand this phenomenon. Most of the previous studies have only investigated single variables to evaluate reasons for health care seeking. We thought it would be valuable to evaluate the reasons for health care seeking with a wide range of variables (GI symptom severity, HRQOL, coping and psychological factors) in the same population of IBS subjects. Extended knowledge of possible factors behind the patients' decision to seek health care could probably contribute to improvements in the management of IBS patients.

5. PATIENTS' PERSPECTIVE

Many IBS patients express that they have feelings of not been taken seriously for their complaints by health care professionals (75) and they feel insufficiently informed (76). Moreover, a lot of IBS patients have negative emotional experiences of living with IBS overlain by guilt and shame (77). Furthermore, it has been demonstrated that there are differences between IBS patients' and physicians' views about IBS (78-80), which possibly could influence the management of IBS patients in the health care system in a negative way.

Food intake seems to be one of the most important issues in the patients' perspective of the disorder, which negatively affects the daily life among IBS patients. It has been demonstrated that symptom aggravation in relation to food intake contributes to substantial difficulties in social contacts and is associated with feelings of helplessness. Eating behavior has also been shown to be an important factor for many women in their attempts to manage their IBS symptoms (81). However, the pathophysiology behind food hypersensitivity is still poorly understood (82). Worsening of symptoms after a meal does not seem to be related to any specific food item, but rather to a general hypersensitivity to food in the gut (81).

5.1 Disease related knowledge

Having knowledge or not is a complex question. What is useful knowledge? A high level of knowledge does not necessarily lead to better health and a person's beliefs about the efficacy of self-care activities may not emerge until it has been tried and found effective (83). This is in line with the self-efficacy theory, namely the stronger the perceived self-efficacy, the more active the efforts (84). In a group of patients with inflammatory bowel disease, it has been demonstrated that the level of disease-related knowledge per se did not seem to affect the HRQOL (85). On the other hand, it has also been reported that written information in the form of a guidebook for patients with ulcerative colitis both increased knowledge and decreased anxiety (86). Furthermore, knowledge level does not seem to correlate with the duration of disease in patients with inflammatory bowel disease, but patients who were members of the National Association of Crohn's and Colitis had more knowledge compared with non-members (87).

The level of disease related knowledge among IBS patients has been found to be rather high (88). However, in some areas the IBS patients did not have correct knowledge and the authors proposed that future interventions designed to increase knowledge of IBS would be helpful. Moreover, there seem to be a considerable lack of public knowledge about IBS both regarding the prevalence and the impact of the disease (89). Furthermore, it has been suggested that nurses with advanced knowledge related to GI function could be in an ideal position to inform both lay public and colleagues regarding IBS (90). Regrettably, it has also been shown that many nurses had limited knowledge of IBS and that they found it hard to confidently explain the disorder to a patient (91).

Based on this, there seems to be a lack of knowledge of IBS. Further studies are needed to evaluate the knowledge that IBS patients have of IBS and what kind of information they request from their health care providers. Furthermore, interventions purposed to increase the patients’ knowledge of IBS and their ability to use their knowledge is needed. Such interventions need to be developed and thoroughly evaluated.

5.2 Management in the health care system

Already in 1978, Manning and co workers demonstrated that IBS could be a positive symptom based diagnosis and, by taking a careful history, the amount of investigations in many patients with chronic abdominal pain could be reduced (26). A positive symptom based diagnosis, education of the patient, diet and lifestyle advice, as well as psychological support are considered to be of great importance to the patient (92), as well as for cost-effectiveness (93, 94). Establishing a therapeutic physician-patient relationship is considered to be the most important component of the treatment (95), and may be related to less ambulatory health services after the diagnosis in IBS patients (96). The consultation itself can be a therapeutic intervention if it is performed in a structured way including education (97, 98). The doctors’ attention to the patients’ complaints and meeting the same doctor again has been shown to influence both health care consumption and medication in a positive direction (99).

The biopsychosocial model has been described by Engel as a scientific model constructed to take into account the missing dimensions of the biomedical model, i.e. not only biological but also psychological and social factors are important (100). This model is considered to be essential in the management of patients with functional bowel disorders (101, 102). Inclusion of psychosocial factors in the consultation gives a more clinically meaningful picture than the bowel symptoms alone (103). It has also been shown that a collaborative health care model is superior to both medical and psychological as single interventions in the treatment of IBS patients (104).

Medical treatment options exists, but are still limited in IBS (105, 106). Non-pharmacological treatments are available and have proven to have positive long term effects (107). Even though initial costs could be higher compared with usual care, interventions like psychotherapy could be cost effective in the long run (108). Furthermore, the duration of symptoms has an impact on the prognosis, i.e. short symptom duration together with less psychological distress, is found to be associated with better prognosis in IBS (109). IBS patients who are chronic clinic visitors might differ from newly referred patients regarding their perceived severity of both abdominal and non-colonic symptoms, which should be taken into account when evaluating both treatments and interventions (110).

To conclude, education and reassurance are proposed to be two of the most important parts in the management of IBS patients. Further studies are needed to develop and evaluate interventions that can improve and/or complement the traditional patient-physician contacts in the health care system. Structured patient education and written patient information could be such methods to be used in order to increase the patients' knowledge and possibly affect the well-being in a positive way.

6. PATIENT EDUCATION

There seems to be confusion regarding the use of terms in the area of patient education. Information giving is a pure transit of knowledge, whereas teaching emphasizes a change in behavior and education includes both providing information and often involves skills training (111). Moreover, counseling could be considered as a method of withholding advice leading to the discovery of a person's own coping mechanisms and self help groups can serve as counseling activities. A mixture of information giving, teaching and counseling is considered to be needed in patient education (111). When evaluating the effects of patient education, there are several difficulties. It is important that the patient education is flexible enough to fit all patients, but still structured enough to be evaluated (83).

Patient education in group settings have been performed in several different chronic diseases like inflammatory bowel disease (112), diabetes (113,114), chronic musculoskeletal pain (115), and rheumatic diseases (116,117), with satisfied patients although evaluated with different outcome variables.

Educating patients is considered to be an important part of the management also in patients with IBS (118). Both patients and nurses indicate that there is a strong need for better education of both nurses and patients regarding IBS (119). Some studies have been performed to evaluate patient education in group settings (120, 121), and individual settings (122) in IBS with promising results. Moreover, a comparison between a multi-component education and a single-session version for IBS patients, found the multi-component intervention to be superior (122). However, there are studies with somewhat less positive results after patient education in IBS, as compared to cognitive behavioral therapy (CBT) (123), and in CBT compared to a self-help support group, although this self-help support group did not offer any guiding or education from the therapist (124).

Based on the data from the previous studies regarding patient education, further studies are needed in order to evaluate how to organize patient education in IBS. There is a need of randomized control studies for comparisons with adequate control groups in sufficient numbers of patients. The intervention needs to be evaluated with validated questionnaires measuring a wide spectrum of outcome variables that are considered to be important in IBS (14, 47, 51). Also, adequate follow-up periods are needed in order to evaluate the long-term effects of the intervention (108).

AIMS OF THE PRESENT STUDIES

The incomplete understanding of what determines health care seeking as well as the lack of knowledge regarding effects of patient education in IBS evoked the following questions, which formed the basis of the investigations included in this thesis.

1. Why do patients with IBS seek health care for their GI symptoms? Could it be related to GI symptoms, health related quality of life, coping or psychological symptoms?

2. Can differences in symptoms or other factors be detected between those with IBS who seek health care and those who do not, as well as between patients seen in primary versus secondary/tertiary care?

3. How much, and what kind of knowledge do IBS patients, referred from primary care to a gastroenterologist, have of their disorder. What kind of information do they find important to receive?

4. How could a structured patient education in a group setting for IBS patients be organized and evaluated?

5. Are structured patient education and written patient information efficacious in order to improve knowledge of IBS, symptoms and health related quality of life in IBS patients? Is one of these interventions superior compared to the other?

SUBJECTS AND METHODS

The studies were performed during the years of 2003-2006. All subjects in the studies gave informed consent and the studies were conducted according to the Declaration of Helsinki and approved by the ethics committee of the University of Göteborg. In this chapter the methods used are presented and commented on. For further details see the separate papers (I-IV).

1. SUBJECTS

All subjects had IBS according to the Rome II criteria (28) (Table 1). They were recruited through advertisement (paper I), from primary care physicians (paper I, II and IV) and from our outpatient clinic (paper I, III and IV).

Table 1. **Rome II criteria (28).**

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

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

Supportive symptoms of IBS that can also be used to sub classify patients

1. **Fewer than three bowel movements a week**
2. **More than three bowel movements a day**
3. **Hard or lumpy stools**
4. **Loose (mushy) or watery stools**
5. **Straining during a bowel movement**
6. **Urgency (having to rush to have a bowel movement)**
7. **Feeling of incomplete bowel movement**
8. **Passing mucus during a bowel movement**
9. **Abdominal fullness, bloating or swelling**

Diarrhoea predominant; one or more of 2, 4 or 6 and none of 1, 3 or 5
Constipation predominant; one or more of 1, 3, or 5 and none of 2, 4 or 6

Paper I

A total number of 218 subjects with symptoms compatible with IBS according to the Rome II (28) criteria were included. Non-consulters were recruited for inclusion in the study through advertisement in a local newspaper. A non-consulter was defined as a person who had never sought health care for bowel-associated symptoms, but still fulfilled the Rome II criteria for IBS (28). IBS patients managed in primary care were recruited from five primary care physicians and would otherwise not have been referred to a gastroenterologist. IBS patients managed in secondary/tertiary care were consecutively recruited from our GI outpatient clinic for participation in the study. All subjects completed questionnaires to evaluate severity of GI and psychological symptoms, HRQOL and coping resources. The subjects formed three different groups, non-consulters, patients in primary care and patients in secondary/tertiary care, who were compared regarding the scores from the questionnaires.

Paper II

Eighty six IBS patients, who were diagnosed in primary care and referred to a gastroenterologist for further evaluation and/or management, were consecutively included in this study. All patients completed a questionnaire regarding IBS knowledge, which was developed for this study at our unit, purposed to assess how much and what kind of knowledge the patients had of IBS. The questionnaire was completed by the patients before visiting the gastroenterologist.

Paper III

Twelve IBS patients from our GI outpatient clinic were included in this pilot study for development of a patient education, the IBS school. All patients participated in the IBS-school, and completed a course evaluation form at the end of the education, which was the primary aim of the study. Additionally, all patients completed questionnaires for evaluation of perceived knowledge of IBS, GI symptoms and HRQOL at baseline, three, six and twelve months after the start of the education.

Paper IV

The IBS patients were referred from both primary care and GI outpatient clinics in secondary/tertiary care to participate in the study. The patients were individually interviewed by the nurse, who was responsible for the study, before inclusion. All patients received information about both interventions used in the study and the positive results from previous studies using such interventions, i.e. structured patient education (121) and self-help guidebook (86). After the interview, the patients were randomized to either start the education within two to three weeks, or to receive written information about IBS, in the form of a guidebook. All patients who were randomized to receive the guidebook were offered to participate in the IBS school six months later. Likewise, all patients who were randomized to the IBS school were offered to receive the guidebook after the follow-up period. Questionnaires for evaluation of perceived knowledge of IBS, severity of GI and psychological symptoms and HRQOL were completed by the patients at baseline, three and six months after the randomization. The changes in the perceived knowledge of IBS and in GI symptom severity, at follow up relative to baseline, were our primary outcome variables. Changes in HRQOL and psychological symptom severity were secondary outcome variables.

2. QUESTIONNAIRES

All questionnaires used in the studies are self-administered and they have been thoroughly validated.

2.1 Gastrointestinal symptom severity

GSRS

The Gastrointestinal Symptom Rating Scale (GSRS) used in this thesis is a combination of the original GSRS questionnaire (125) and the recently developed GSRS-IBS questionnaire (126), which gives 19 items in total. Six domains; diarrhea, indigestion, constipation, abdominal pain, reflux and satiety, as well as a total score can be calculated to evaluate the perceived GI symptom severity. A seven graded scale is used, where the highest score, 7, denotes very severe symptoms and 1 no symptoms. This questionnaire was used in paper I.

IBS-SSS

IBS Severity Scoring System (IBS-SSS) was developed to rate IBS symptoms and extra colonic features scored on a visual analogue scale (VAS) (0-100 mm). The higher the score, the more severe the symptoms. The overall IBS score is calculated from five items; pain severity, pain frequency, abdominal bloating, bowel habit dissatisfaction and life interference, ranging from 0 to 500. An overall extra colonic score is calculated from ten items, namely nausea/vomiting, early satiety, headaches, backache, excess wind, heartburn, bodily aches, urinary symptoms, thigh pain and lethargy, also ranging from 0 to 500 (127,128). A change of 50 is considered to be adequate to detect a clinically significant improvement (128). This questionnaire was used in paper III and IV.

2.2 HRQOL

SF-36

Short Form-36 (SF-36) was used to assess HRQOL. It is a generic HRQOL measure with eight multi-item subscales (35 items in total), including physical functioning, role limitations due to physical problems, bodily pain, general health perceptions, vitality, social functioning, role limitations due to emotional problems, and mental health. A Physical Component score (PCS) and a Mental Component score (MCS) can be calculated and used as summary scores. Raw scores are transformed into a scale from 0 (worst possible health state) to 100 (best possible health state) on each of the eight subscales (129-131). Methods to calculate a clinically significant change exist for this instrument (132). This questionnaire was used in paper I and III.

IBSQOL

IBS Quality of Life (IBSQOL*)* is a disease-specific HRQOL instrument, including 30 items measuring nine dimensions of health; emotional, mental health, sleep, energy, physical functioning, diet, social role, physical role and sexual relations. Raw scores are transformed into a scale of 0-100, with 100 representing the best possible quality of life scores (133). A minimum meaningful difference can be calculated (134). This questionnaire was used in paper I and IV.

2.3 Psychological symptoms

SCL-90

The Symptom Checklist-90 (SCL-90) is oriented toward the symptomatic behavior in psychiatric outpatients in both clinical and research situations. It is comprised of 90 items, reflecting nine primary symptom dimensions; somatization, obsessive-compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism. Three indices of global psychiatric health can also be obtained. The Global Severity Index (GSI) combines information on numbers of symptoms and intensity of perceived distress. Positive Symptom Distress Index (PSDI) is a pure intensity measure regarding how the patient reports a disorder. Positive Symptom Total (PST) is a count of the number of symptoms that the patient reports as positive. The higher the score, the higher the degree of distress (135- 138). This questionnaire was used in paper I.

HAD

The Hospital Anxiety and Depression Scale (HAD) was developed for non-psychiatric medical patients to detect anxiety and depression. This scale consists of 14 items with seven items relating to anxiety and seven to depression. A four graded scale is used (0-3), giving a range from 0 to 21 on each subscale. The higher the score, the more pronounced the symptom and cut off scores can be used to identify cases with clinically significant depression and/or anxiety with reasonable certainty (139). This questionnaire was used in paper I and IV.

VSI

Visceral Sensitivity Index (VSI) is a questionnaire designed to measure the degree of GI symptom-specific anxiety in IBS. It is a 15 item questionnaire and the higher the score the lower the GI symptom-specific anxiety, with the total scores ranging from 15 to 90 (140). The questionnaire is used with this score calculation in paper I. Recently, a new instruction has been published, resulting in an opposite calculation, namely the higher the score the higher the GI-specific anxiety, with the total score ranging from 0 (no GI-specific anxiety) to a maximum of 75 (severe GI-specific anxiety) (141). The questionnaire is used in paper IV with this latter score calculation.

2.4 Coping

SOC

Sense of Coherence (SOC) scale includes 29 items, measuring the three components; manageability, comprehensibility and meaningfulness as well as a total score. Sense of coherence reflects the ability a person has to cope with difficult situations in life. A seven graded scale is used. The higher the score, the stronger the sense of coherence, which indicates more successful coping abilities and increased likelihood to have good health and quality of life (142-144).
This questionnaire was used in paper I.

CRI

Coping Resources Inventory (CRI) was developed to be a research instrument in order to investigate coping resources in various populations. It comprises 60 statements that measure coping ability on a four graded scale in five areas; cognitive, social, emotional, philosophical and physical, indicating how successfully people deal with environmental stressors. The higher the scale score, the better the resource to cope with stressors (145, 146). This questionnaire was used in paper I.

2.5 Knowledge of IBS

IBS knowledge questionnaire

The IBS knowledge questionnaire was developed at our unit by review of the literature on IBS knowledge and education, with special attention to one previous study (76). The content of the questionnaire was based on the results from interviews with open-ended questions in 15 IBS patients, visiting a gastroenterologist at our clinic, aimed to explore in which areas the patients would like to gain their knowledge of IBS. It was also based on personal knowledge of the authors, gained from a longstanding experience of taking care of IBS patients.

The questionnaire consists of several questions regarding how the patients perceive their own knowledge of IBS, as well as the information/explanation they previously have received. Questions regarding what the patients find important to get information/explanation about and their reasons for seeking health care for their GI symptoms are also included. An additional part of the questionnaire consists of 17 statements, aimed to reveal how much correct knowledge, as well as misconceptions the patients had of IBS.

The questionnaire has been tested at our unit, and found to have good face validity and test-retest reliability. Test-retest reliability was assessed in 22 IBS patients, who completed the questionnaire on two separate occasions, two weeks apart. Eighty-six % of the answers were identical on the two separate occasions. Also content validity was established. We conducted interviews with ten randomly selected patients among those who completed the questionnaire twice. All patients found the questionnaire easy to understand and to complete, and the time spent to complete it was felt to be acceptable, (less then ten minutes). They also considered the questionnaire to cover the most important issues regarding IBS knowledge. This questionnaire was used in paper II.

Knowledge VAS

Two visual analogue scales (VAS) were used to evaluate the degree of the patients' perceived knowledge of IBS, as well as their satisfaction with that knowledge. The scales range from 0 to 100 where 0 represents no knowledge and satisfaction at all, whereas 100 represent best possible knowledge and satisfaction, respectively. This kind of VAS measurement has been used previously in a similar way (76). The knowledge VAS has been tested at our unit, and found to have good test-retest reliability. This was assessed in 22 IBS patients, who completed the VAS on two separate occasions, two weeks apart. The Spearman correlations between scores on the VAS from the two test occasions were $r_s = 0.63$ ($p<0.01$) for perceived knowledge and $r_s = 0.77$ ($p<0.01$) for satisfaction with that knowledge.

We used this VAS in paper II, III and IV.

2.6 Additional questionnaires

Health care seeking among non consulters

A questionnaire confirming that the non-consulters never had sought health care for their bowel associated symptoms was completed by the non-consulters. They were also, with open-ended questions, asked about the reason why they had not consulted, and if they had sought any other kind of help outside the health care system (e.g. relatives, friends or alternative medicine) due to their bowel symptoms. This questionnaire was used in paper I.

Evaluation of the patient education

The patient education was evaluated by the patients. This was done for each session separately, as well as for the entire course. We used a seven graded scale with one question for each session, formulated “How did you experience session one?” where 1 was labeled “bad” and 7 “good”. There was also an opportunity to add comments in relation to each question. Additionally there was one question evaluating the entire course. The evaluation sheet was given to the patients during the first session in order to enable the patients to do their evaluation immediately after each session. The evaluation form was collected anonymously at the end of the last session. This evaluation form was used in paper III.

Individual goal

The patients stated an individual goal with the education at baseline. This was an open-ended question that was evaluated at three months after the start of the education. The patients stated if they believed they had reached their goal totally, partly or not at all. This evaluation form was used in paper III.

3. IBS SCHOOL

The content of the patient education was selected based on the results from the study in paper II. The IBS-school was designed based on the Self-Efficacy Theory (84, 147) and the General Theory of Nursing (148). Moreover, the IBS-school was also performed based on a biopsychosocial model considered to be important in functional GI disorders (101).

The education consisted of six sessions held once per week, two hours each time. In order to cover wide spectra of issues related to IBS, five different health care professionals were involved in the education. The health care professionals held one session each in a group setting with five to ten patients in each group. A lot of space was given for discussion in the group, and the patients also received written information and handouts. The written information was also given to patients who missed a session. A nurse, who organized the education, was responsible for both the first and the last meeting and did also participate in all other sessions in order to answer questions that were outside the topic for the present session.

Session one was organized by a nurse and was an introduction to the entire education and held in a manner aimed to create a comfortable atmosphere. The focus was on improving function rather than curing a disease. Issues like how it is to live with a chronic disease and cope with bothersome symptoms in daily life were discussed, including questions about acceptance and adaptation to the disease. A brief explanation about anatomy and physiology in the GI tract was given, as well as elementary facts about IBS. Since medical treatment options are limited it was stressed that it is of great importance for patients to get reassurance and realize that they have capacities to influence their symptoms. The patients were also informed that lifestyle changes, big or small, can be required in order to improve symptoms. It was clarified to the patients that there are no standard methods to be used for IBS symptoms in general, but the patient has to identify what they can do in their specific situation, and health care providers can support them to achieve this (118, 149, 150).

Session two was led by a gastroenterologist. Information was given about medical and patophysiological mechanisms in IBS and the scientific progress that has occurred during the last years. It was emphasized that IBS, from a medical point of view, is a benign disorder, but that it has profound negative impact on daily life. A symptom based explanatory model was used, with the aim to provide understandable explanations behind the different symptoms, and factors known to improve and/or worsen symptoms were presented to the group. Overlap with other GI and extra intestinal symptoms are common, which was another topic during this session. Some patients experience difficulties in the meeting with health care providers, and reasons for this were explained and discussed. Moreover, information was given about medical and other treatment options, both the ones available today and potential future treatment options. Indications for investigations to exclude other diagnosis than IBS were also clarified (20, 95, 106). Explanations based on well-known pathophysiological alterations (29-37) were presented during this session.

Session three. A dietician discussed food related issues in general and for IBS in particular. It has been reported that a large proportion of IBS subjects limit or exclude food items from their diet (81). General advice was provided and the patients were encouraged not to exclude food. Exclusion diets should only be tried in rare cases where food allergy and/or specific food intolerance are suspected, and under strict supervision. It was clarified that it might be indicated to reduce the intake of some food items, like gas producing food items, including fiber intake. The importance of lactose and fructose intolerance and cooking methods, were also considered to be important issues to discuss in the group (151, 152). The focus was not on what the patients eat, but rather on how and when they eat. Regular eating habits are important, and three main meals and two to three snacks were recommended. Explanations regarding symptoms induced or exaggerated by food intake were provided, and even though a meal might induce GI symptoms, the participants were informed that the GI tract will not be damaged, in contrast to patients with celiac disease, ingesting food containing gluten. The subjects were also informed that probiotics could be tried since they might improve symptoms in subgroups of patients (153).

Session four. A physiotherapist focused on the link between the body and the mind, which includes items like breathing pattern, body awareness, stress and pain. In order to illustrate connections between different parts of the body, a simplified lecture was given about the autonomic nervous system, and it was explained how knowledge about this can help to improve symptoms. Stress is known to increase symptoms in IBS patients (43, 154), and the importance of identifying and eliminating stressors in daily life was discussed within the group. There are also some evidence that IBS patients can benefit from physical activity (155), which was argued for during this session. Moreover, since relaxation can improve symptoms in IBS patients (156), a short relaxation practice was performed during this session.

Session five was held by a psychologist and the title of this session was “Despite IBS, is it possible to live a good life?” Difficulties to talk about GI symptoms with relatives and friends are common. This session was held in an open manner to allow spontaneous discussions between the patients in order to share experiences for more successful coping strategies. Many patients are frustrated about the limitations they experience in their daily life due to GI and extra intestinal symptoms. The importance of verbalizing these feelings of frustration in order to manage symptoms in daily life was discussed, and the focus of this session was how to reach acceptance of having a chronic disorder. Psychological treatment is known to be efficient for symptom improvement in IBS (101), and the patients were provided with information about different forms of psychological treatment.

Session six. The final meeting was led by the same nurse as in the first session. This session was aimed to summarize the entire course. The patients were asked to recall and reflect about what they have learnt and how they thought that they could use this new knowledge. Identifying the knowledge one has and the implementation of it into practical use in daily life is an active process, which is supposed to continue for a long time after the education. The patients were also asked if there was anything that needed to be explained more thoroughly. The last session also served as a forum to answer questions for patients who had missed a session. Many patients are interested in participating in self-help groups (77), and information about the Swedish patient support group (Riksförbundet för magtarmsjuka, RMT), working in the entire GI field was also provided.

This patient education was performed in paper III and IV.

4. GUIDEBOOK

The guidebook consists of two booklets, written for IBS patients by one of the gastroenterologists at our unit. The booklets are detailed and cover the same areas of issues related to IBS as are covered in the structured education, namely pathophysiological mechanisms, GI and extra intestinal symptoms, the diagnostic workup, treatment options, food related issues as well as psychological and lifestyle factors. This guidebook was used in paper IV.

5. STATISTICAL METHODS

All statistical analyses were made with the SPSS version 14.0. Since data from questionnaires should be considered ordinal data, and can not be assumed to have Gaussian distribution, all analyzes were made with non-parametric methods. The following statistical methods were used: Mann Whitney *U* test for comparisons between groups (I, IV), Wilcoxon signed rank test for comparisons within groups between baseline and the follow-up evaluations (III, IV). In order to find independent predictors for health care seeking, we also used a forward stepwise multiple logistic regression model (I). All variables with a p-value of less than 0.1 in the univariate comparisons were entered. Only results on subscales, not total scores, were entered into this analysis. Significance was accepted at the 5% level ($p<0.05$).

RESULTS

1. HEALTH RELATED QUALITY OF LIFE (HRQOL) (I, III, IV)

1.1 HRQOL related to health care seeking (I)

HRQOL was worse among those who had sought health care for their IBS related symptoms, i.e. patients who were managed in primary care and in secondary/tertiary care (consulters), compared with those who had not sought health care (non-consulters). This was demonstrated with both HRQOL questionnaires used in study I, namely IBSQOL and SF-36. According to IBSQOL the consulters had, compared with the non-consulters, significantly lower scores in six out of nine dimensions, indicating worse HRQOL (Table 2). Also on the generic measurement, the SF-36, there were differences in the same direction for both the physical component score (PCS) [45 (40-51) (Median (IQR)) vs. 50 (41-53); p=0.006] and the mental component score (MCS) [44 (31-52) vs. 48 (38-54); p= 0.07].

Table 2. Comparison between consulters and non-consulters regarding disease-specific HRQOL as measured by IBSQOL.

Dimension	**Non-consulters** (*n*= 70) Median (IQR)	**Consulters** (*n*= 148) Median (IQR)	**P-value**
Emotional	62 (44-87)	56 (44-75)	0.03
Mental health	85 (65-95)	70 (30-85)	< 0.001
Sleep	83 (58-100)	83 (58-100)	0.18
Energy	75 (50-87)	62 (50-87)	< 0.001
Physical function	92 (83-100)	67 (25-92)	< 0.001
Diet	73 (60-87)	60 (42-80)	< 0.001
Social role	69 (56-87)	69 (45-81)	0.05
Physical role	81 (62-100)	62 (37-87)	< 0.001
Sexual relations	67 (50-100)	75 (50-90)	0.81

Also between the two groups of consulters there were differences according to the HRQOL measurements. Those who were patients in secondary/tertiary care had significantly worse HRQOL compared with the consulters in primary care as measured with the disease-specific IBSQOL (Table 3). However, the measurement with the SF-36 showed no significant differences between patients in primary care and secondary/tertiary care, PCS [44 (37-50) vs. 46 (42-53); p=0.1] and MCS [43 (29-53) vs. 44(31-52); p=0.7].

Table 3. Comparison between consulters in secondary/tertiary care and consulters in primary care regarding disease-specific HRQOL as measured by IBSQOL.

Dimension	**Consulters primary care** (*n*= 53) Median (IQR)	**Consulters secondary/tertiary care** (*n*= 95) Median (IQR)	**P-value**
Emotional	62 (50-87)	50 (37-66)	0.02
Mental health	85 (70-95)	45 (20-75)	< 0.001
Sleep	92 (67-100)	75 (50-92)	0.005
Energy	75 (62-87)	50 (37-75)	< 0.001
Physical function	92 (83-100)	42 (12-79)	< 0.001
Diet	80 (53-87)	53 (27-67)	< 0.001
Social role	75 (44-87)	69 (50-81)	0.05
Physical role	75 (50-94)	56 (31-75)	< 0.001
Sexual relations	75 (58-92)	67 (50-83)	0.2

1.2 HRQOL related to patient education (III, IV)

The HRQOL improved after the patient education, which was demonstrated both in the pilot study (III) and in the randomized control study (IV). In the pilot study the patients had better HRQOL, indicated by higher scores on SF-36, at all follow-up evaluations according to MCS compared to baseline [three months: 32 (21-42) vs. 44 (33-55); $p<0.05$; six months: 32 (21-42) vs. 40 (32-55); $p<0.05$; twelve months: 32 (21-42) vs. 36 (21-54); $p=0.2$]. The PCS increased at three and six months but was unchanged at twelve months compared to baseline [three months: 37 (32-42) vs. 42 (33-47); $p<0.05$; six months: 37 (32-42) vs. 41 (32-49); $p=0.6$; twelve months: 37 (32-42) vs. 37 (26-49); $p=0.7$].

In the comparison of change in HRQOL between the IBS school group and guidebook group at follow-up relative to baseline (IV), statistical significance was reached only in two out of the nine dimensions. This was seen for diet at three months ($p=0.02$) and physical functioning at six months ($p=0.02$), where the improvement in the IBS school group was greater (Table 4). In the within-group comparisons, the patients in the IBS school group demonstrated significantly higher scores on several of the nine dimensions on IBSQOL at the follow-up evaluations compared with baseline, indicating improved HRQOL. This was not the case in the guidebook group where only one dimension was significantly improved at the six month follow-up (Data not shown).

Table 4. Comparisons between the IBS school group and the guidebook group regarding the change of HRQOL score according to IBSQOL at three and six months relative to baseline.

	Three months		**Six months**	
Dimension	**IBS school** (n=72) Median (IQR)	**Guidebook** (n=71) Median (IQR)	**IBS school** (n=72) Median (IQR)	**Guidebook** (n=71) Median (IQR)
Emotional	6.2 (-0.2, 15.6)	0 (-12.5, 18.7)	6.2 (0, 12.5)	6.2 (-12.5, 12.5)
Mental health	0 (-5, 10)	0 (-10, 10)	5 (0, 10)	0 (-15, 12.5)
Sleep	0 (-12.5, 8.3)	0 (-8.3, 8.3)	0 (-0.3, 8.3)	0 (-8.3, 8.3)
Energy	0 (0, 12.5)	0 (-12.5, 12.5)	0.5 (0, 25)	0 (-12.5, 25)
Physical function	0 (0, 8.3)	0 (-8.3, 8.3)	8.3 (0, 16.7)	0 (-16.7, 8.3)*
Diet	6.7 (0, 13.3)	0 (-13.3, 6.7)*	0 (-6.7, 13.3)	0 (-6.7, 13.3)
Social Role	0.5 (-0.2, 12.5)	6.2 (-12.5, 12.5)	0 (-6.2, 12.5)	6.2 (-6.2, 12.5)
Physical Role	6.2 (0, 18.7)	0 (-6.2, 12.5)	0 (-6.2, 18.7)	0 (-12.5, 25)
Sexual relations	0 (0, 8.3)	0 (-8.3, 12.5)	0 (0, 16.7)	0 (-8.3, 16.7)

* p<0.05

2. GASTROINTESTINAL (GI) SYMPTOM SEVERITY (I, III, IV)

2.1 GI symptom severity related to health care seeking (I)

There were no significant differences regarding the severity of GI symptoms between the patients who had sought health care for their IBS symptoms and those who had not, as demonstrated by similar scores in both groups on GSRS (Table 5). However, patients who were managed in secondary/tertiary care had somewhat more severe GI symptoms compared with patients seen in primary care. This was demonstrated by a significantly higher total score on GSRS, as well as higher scores for two subscales, namely abdominal pain and indigestion (Table 6).

Table 5. Comparison between consulters and non-consulters regarding GI symptom severity as measured with GSRS.

Variable	**Non-consulters** (*n* = 70) Median (IQR)	**Consulters** (*n* = 148) Median (IQR)	**P-value**
Abdominal pain	3.0 (2.4-3.7)	3.0 (2.5-3.8)	0.32
Diarrhea	3.0 (2.0-4.4)	3.0 (2.0-4.3)	0.65
Indigestion	3.6 (2.8-4.6)	3.6 (3.0-4.6)	0.43
Constipation	2.3 (1.6-3.7)	2.7 (2.0-4.0)	0.07
Reflux	1.5 (1.0-2.5)	1.5 (1.0-2.5)	0.61
Satiety	1.7 (1.0-3.0)	2.0 (1.0-3.0)	0.23
Total	2.8 (2.4-3.6)	3.0 (2.5-3.7)	0.24

Table 6. Comparison between consulters in secondary/tertiary care and consulters in primary care regarding GI symptom severity as measured with GSRS.

Variable	**Consulters primary care** (*n*= 53) Median (IQR)	**Consulters secondary/tertiary care** (*n*= 95) Median (IQR)	**P-value**
Abdominal pain	2.8 (2.3-3.4)	3.3 (2.8-4.0)	<0.001
Diarrhea	3.0 (1.7-4.0)	3.5 (2.0-4.4)	0.14
Indigestion	3.4 (2.6-4.5)	4.0 (3.1-5.0)	0.02
Constipation	2.7 (2.0-4.0)	2.7 (2.0-4.0)	0.97
Reflux	1.5 (1.0-2.0)	1.5 (1.0-2.6)	0.27
Satiety	1.5 (1.0-3.0)	2.0 (1.0-3.5)	0.46
Total	2.8 (2.3-3.5)	3.2 (2.8-3.8)	0.008

2.2 GI symptom severity related to patient education (III, IV)

According to the IBS-SSS the GI symptom severity was reduced after the patient education in both the pilot study (III) and the randomized control study (IV). This was demonstrated by lower IBS-scores at all follow-up evaluations compared to baseline in the pilot study [three months: 284 (233-369) vs. 253 (183-337); p=0.03; six months: 284 (233-369) vs. 240 (178-326); p=0.05; twelve months 284 (233-369) vs. 269(159-346); p=0.06].

In paper IV, the between group comparison showed a more pronounced reduction of GI symptom severity in the IBS school group compared with the guidebook group at three months [-21(92) vs. -6(65); p= 0.06] and at six months [-32(102) vs. -13(80); p= 0.04] (Figure 1). Within-group comparisons showed that the IBS-score was significantly decreased at both three and six months relative to baseline in the IBS school group [three months: 316 (261-395) vs. 282 (211-394); p< 0.001; six months: 316 (261-395) vs. 289 (197-374); p< 0.001]. GI symptom severity was slightly, but not significantly, affected in the guidebook group [three months: 297(230-386) vs. 314(223-369); p= 0.3; six months: 297(230-386) vs. 291(231-357); p= 0.06].

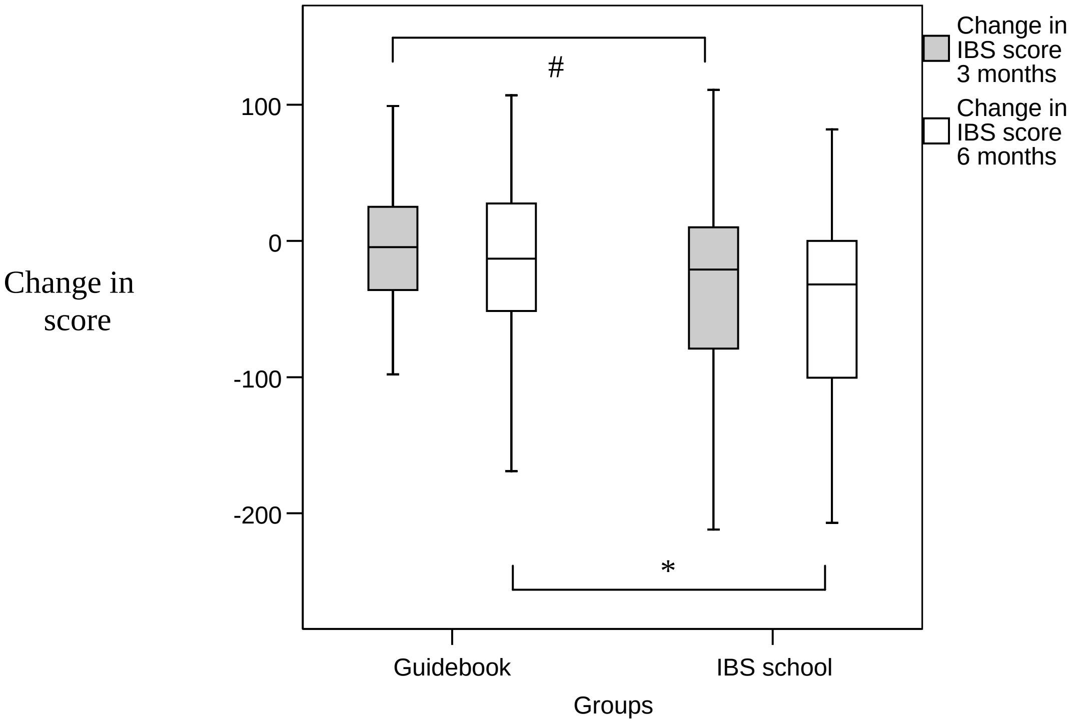

Figure 1. The change in GI symptom severity according to IBS-SSS. The patients in the IBS school group reduced the GI symptom severity more than the patients in the guidebook group, with a statistically significant difference at 6 months. * p<0.05; # p=0.06.

3. PSYCHOLOGICAL SYMPTOMS (I, IV)

3.1 Psychological symptoms related to health care seeking (I)

More severe psychological symptoms, including GI-specific anxiety, were found in the group of patients who had consulted health care for their IBS related symptoms compared with the non-consulters. This was demonstrated on HAD, SCL-90 and VSI (Table 7). The only significant difference found between consulters in primary care and consulters in secondary/tertiary care regarding psychological measurements was on the VSI. GI-specific anxiety was significantly more pronounced in the secondary/tertiary care patients, as indicated by lower scores on the VSI [50 (40-66) vs. 63 (47-71); p=0.03].

Table 7. Comparisons between consulters and non-consulters regarding psychological variables.

Psychological variable	**Non-consulters** (n=70) Median (IQR)	**Consulters** (n=148) Median (IQR)	**P-value**
HAD Anxiety	5 (3-8)	7 (3-11)	0.005
HAD Depression	3 (1-6)	4 (2-8)	0.006
SCL-90 GSI	0.4 (0.2-0.8)	0.5 (0.3-1.0)	0.004
SCL-90 PST	26 (14-40)	33 (21-49)	0.02
SCL-90 PSDI	1.4 (1.2-1.7)	1.5 (1.3-1.9)	0.004
VSI	63 (53-75)	56 (42-68)	0.004

3.2 Psychological symptoms related to patient education (IV)

The severity of GI-symptom specific anxiety, as measured with the VSI, was more reduced in the IBS school group than in the guidebook group, both at three [-5(10) vs. 1(10); p<0.001] and six months [-5(13) vs. -1(18); p=0.02] (Figure 2). The within group comparison in the IBS school group showed a significant reduction of the VSI score at the follow-up evaluations compared to baseline [three months: 44 (27-59) vs. 34 (22-52); p<0.001; six months: 44 (27-59) vs. 30 (17-50); p<0.001]. This was not the case in the guidebook group [three months: 37 (24-52) vs. 34 (25-50); p=0.3; six months: 37 (24-52) vs. 33 (23-49); p=0.7].

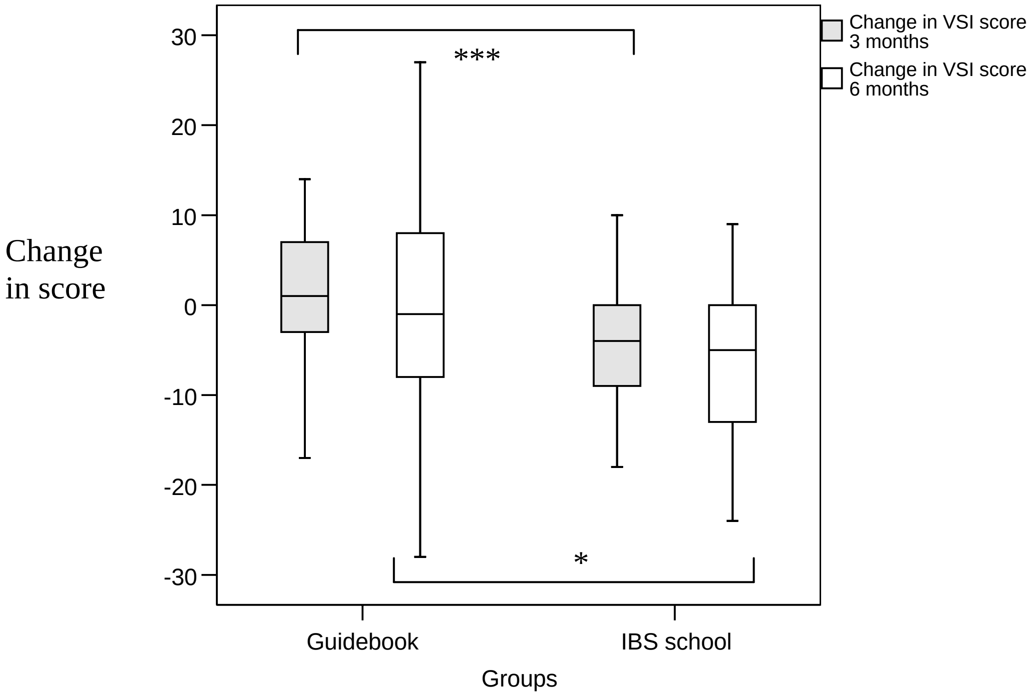

Figure2. The between group comparison revealed that the improvement in GI-specific anxiety according to VSI was significantly more pronounced in the IBS school group at both three and six months compared with the guidebook group. * p<0.05 *** p<0.001.

When comparing changes in general anxiety and depression according to the HAD scale no differences between the groups could be detected (p>0.2). However, general anxiety, as measured with HAD improved significantly after the IBS school (Figure 3a), but not after receiving the guidebook (Figure 3b). There were no significant differences regarding depression score in any of the within or between group comparisons.

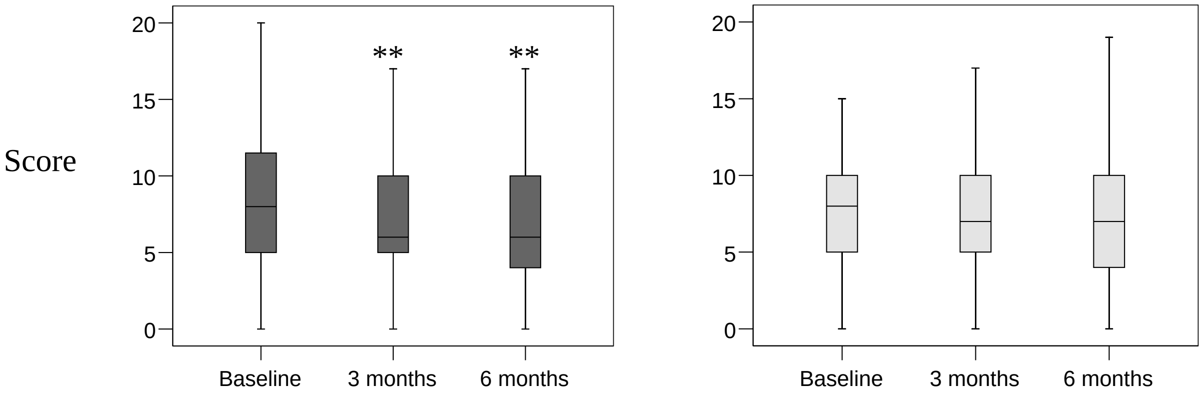

Figure 3a. IBS school group

Figure 3b. Guidebook group

Figure 3. Anxiety according to the HAD scale. General anxiety scores were significantly reduced in the IBS-school group (a), but not in the guidebook group (b), at follow-up. ** p < 0.01 vs. baseline.

4. COPING (I)

Non-consulters had somewhat higher scores on the SOC scale, indicating better ability to cope with difficulties in life, compared with those who had consulted health care for their IBS symptoms. This was significant in two out of three component scores: manageability [54 (47-59) vs. 51 (42-57); p=0.04], meaningfulness [45 (40-51) vs. 44 (36-48); p=0.04], comprehensibility [47 (40-50) vs. 44 (39-50); p=0.52], and total SOC score [144 (131-158) vs. 139 (118-156); p=0.11]. Likewise, according to the CRI non-consulters scored somewhat higher compared with consulters, also indicating better resources to cope with stressors. This was significant on the total score [177 (158-191) vs. 166 (152-184); p=0.02], and in two out of five subscales: cognitive [28 (26-32) vs. 27 (23-31); p=0.03] and physical [29 (25-34) vs. 27 (24-30); p=0.01]. According to the three other subscales, social, emotional and philosophical, we did not find any statistical differences (Data not shown). There were no statistical differences between primary care patients and secondary/tertiary care patients according to neither SOC, nor CRI.

5. HEALTH CARE CONSUMPTION (I, II)

In order to find independent predictors for health care seeking, we performed a forward stepwise multiple logistic regression analysis. All variables with a p-value of less than 0.1 in the univariate comparisons were entered. Only results on subscales, not total scores, were entered into the analysis. Four factors, all related to HRQOL measurements, were in the logistic regression analysis found to be independently associated with being a consulter. These were social functioning of the SF-36 and three dimensions of the IBSQOL (Physical functioning, Emotional and Mental health). These factors explained 41 % of the variance (Table 8). Likewise, three dimensions of the IBSQOL (Physical functioning, Physical role and Diet) together with a higher degree of anxiety on both HAD and SCL-90, were found to be independent predictors of being a consulter in secondary/tertiary care compared with a combined group of non-consulters and consulters in primary care. This model explained 65 % of the variance (Table 9) (I).

Table 8. Predictors for being a consulter (multiple logistic regression analysis).

Step	**Predictor**	**R^2 after each step Nagelkerke %**	**p-value**
1	IBSQOL Physical Functioning	25	0.01
2	SF-36 Social Functioning	34	<0.001
3	IBSQOL Emotional	38	0.003
4	IBSQOL Mental Health	41	0.034

Table 9. Predictors for being a consulter in secondary/tertiary care (multiple logistic regression analysis).

Step	**Predictor**	**R^2 after each step Nagelkerke %**	**p-value**
1	IBSQOL Physical Functioning	46	<0.001
2	IBSQOL Physical Role	55	0.005
3	HAD Anxiety	58	<0.001
4	SCL-90 Anxiety	63	0.002
5	IBSQOL Diet	65	0.035

Those who had not sought health care for their IBS symptoms stated three different types of reasons for not doing so. Mild symptoms and/or ability to control symptoms was stated by 31 subjects (44 %), fear of possible findings and/or undergoing invasive tests by 8 subjects (11 %) and that other factors than GI disease was an obvious explanation for their IBS symptoms by 4 (6%) of the subjects. The remaining 27 subjects (39 %) did not state any reason at all for not seeking health care (I). Moreover, difficulties in daily life due to GI symptoms were stated as the main reason to seek health care by 60 of the patients (70%) (II). Another 16 patients (19 %) sought health care in order to be investigated and/or receive a diagnosis, and 8 patients (9.3 %) were afraid of having a serious disease. The remaining two patients stated that cramping abdominal pain forced them to seek health care (II).

6. PATIENTS' KNOWLEDGE OF IBS (II, III, IV)

The patients who had IBS according to a primary care physician, and were referred for further evaluation and/or management in secondary/tertiary care, had to a large extent correct knowledge of IBS, as evaluated with the 17 statements in the IBS knowledge questionnaire (II). The median number of correct answers was 15 (IQR 13-16). Six patients, out of a total of 86, responded correctly to all the 17 statements, and only six patients had less than ten correct answers. However, there were some statements, where 30 % or more of the patients either responded falsely, or did not respond at all. These statements were associated with pain/discomfort being important in the diagnosis of IBS, the role of food intake/diet in IBS, the risk that IBS will turn into a serious disease, and the diagnostic work up (II). However, according to VAS the patient did not perceive their level of knowledge of IBS as high and they were dissatisfied with their level of disease related knowledge (Figure 4).

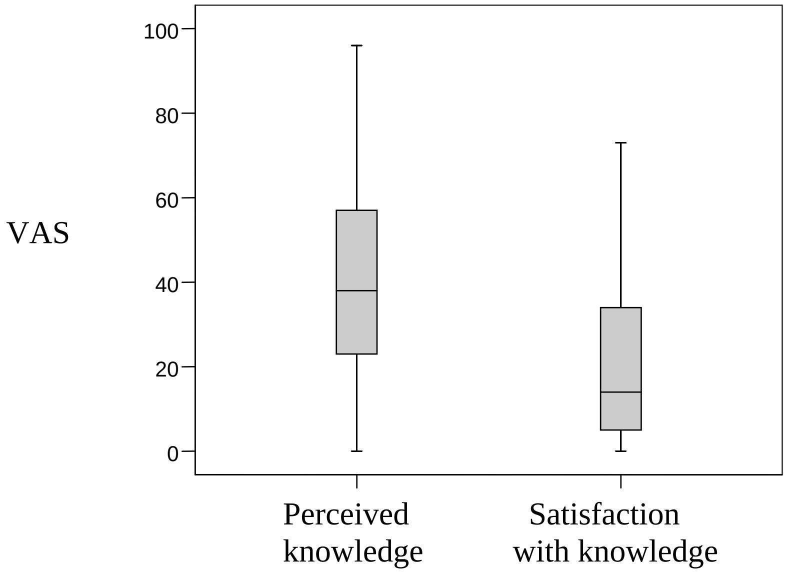

Figure 4. Perceived knowledge of IBS and satisfaction with that knowledge. Results from VAS ranging from 0 to 100 assessing perceived knowledge and satisfaction with that knowledge.

Furthermore, as demonstrated by the answers on the first question in the IBS knowledge questionnaire, only 25 % of the patients answered that they 'absolutely' had knowledge about IBS and 20 % stated that they did not have knowledge about IBS (Figure 5).

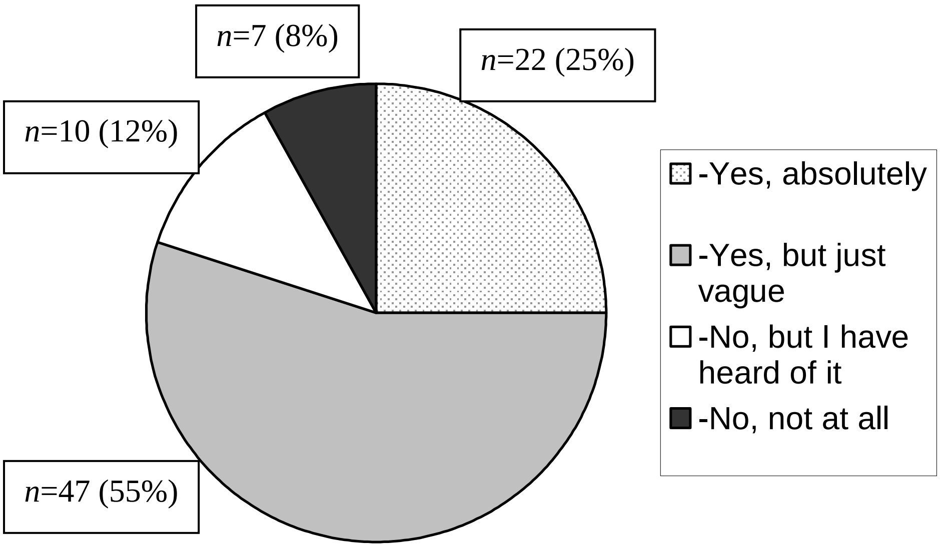

Figure 5. Knowledge of IBS.
Question 1. “Do you consider that you have knowledge about IBS?”

Moreover, 37 (43%), of the patients rated “information about what they can do in order to improve their symptoms” to be the most important issue to receive information from the health care system about. Furthermore, 29 patients (34%) rated knowledge about treatment options as second most important and for 27 patients (31%) information about causes of the symptoms was rated as the third most important issue (II).

6.1 Knowledge of IBS related to patient education (III, IV)

The level of perceived knowledge and satisfaction with that knowledge was significantly increased after the patient education compared to baseline as measured with VAS. This was demonstrated in the pilot study with an increase of perceived knowledge of IBS [three months: 47 (14-60) vs. 75 (72-88); p=0.006; six months: 47 (14-60) vs. 81 (54-84); p=0.03; twelve months: 47 (14-60) vs. 75 (69-87); p=0.005], as well as satisfaction with the knowledge [three months: 43 (11-47) vs. 79 (68-93); p=0.003; six months: 43 (11-47) vs. 72 (50-82); p=0.004; twelve months: 43 (11-47) vs. 81 (60-92); p=0.002].

In the randomized controlled study, the patients in the IBS school group reported significantly greater improvement of their knowledge and the satisfaction with that knowledge than the patients in the guidebook group both at three and six months follow-up compared with baseline (p<0.001 for all comparisons) (Figure 6). Also in the within-group comparisons this improvement was found in the IBS school group, but not in the group who received the guidebook (Table 10).

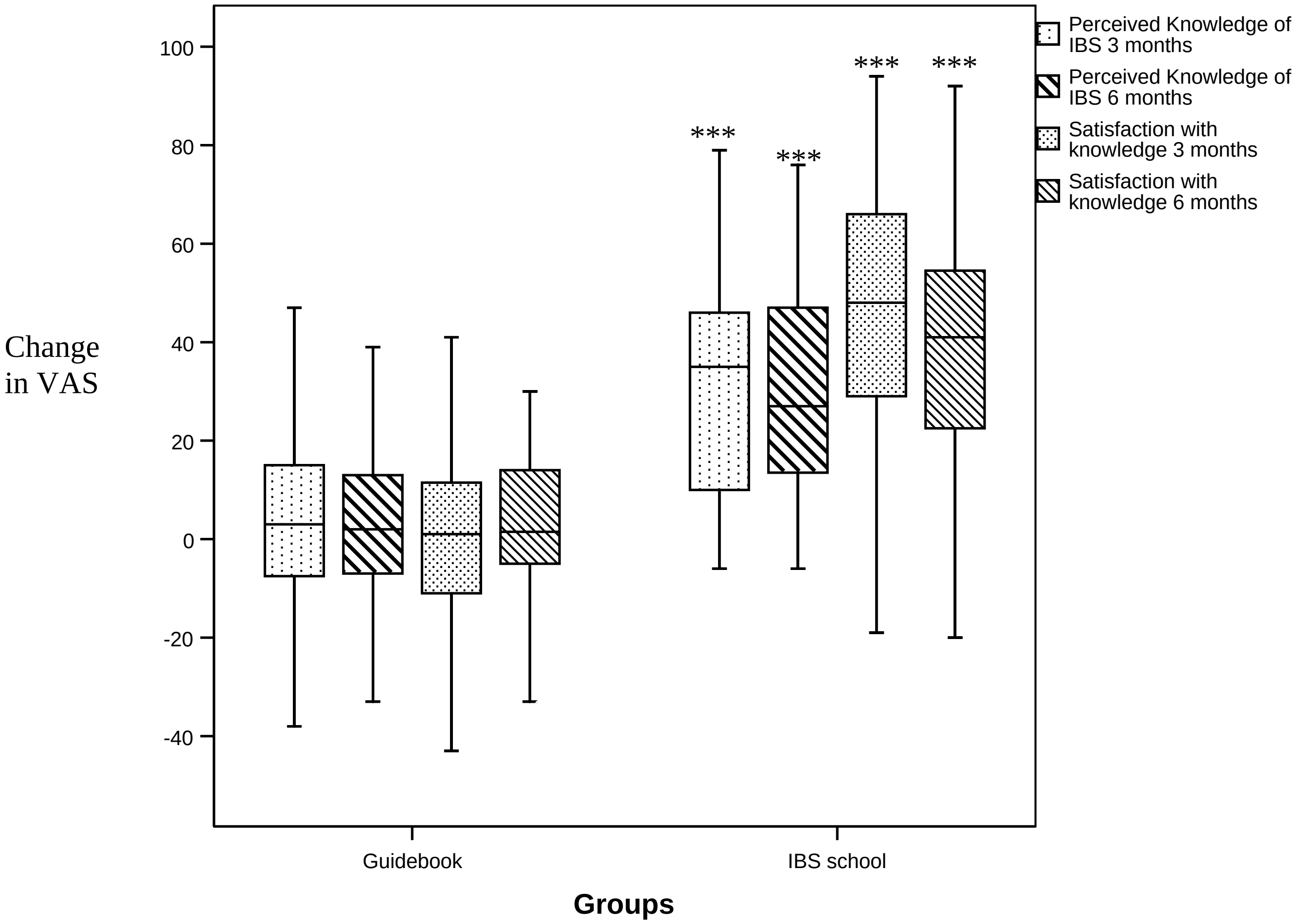

Figure 6. The change in knowledge and satisfaction with that knowledge at three and six months relative to baseline, which was significantly higher in the IBS school group than in the guidebook group. *** p< 0.001

Table 10. Perceived knowledge and satisfaction with that knowledge as measured with VAS.

	IBS school group (*n*= 72) (Median (IQR)	**Guidebook group** (*n*= 71) (Median (IQR)
Perceived Knowledge		
Baseline	40 (24-53)	40 (27-62)
3 months	74 (66-82) ***	46 (28-60)
6 months	73 (63-81) ***	50 (31-61)
Satisfaction with Knowledge		
Baseline	20 (4-42)	29 (7-51)
3 months	77 (61-84) ***	31 (14-46)
6 months	70 (48-80) ***	27 (14-52)

*** p<0.001 relative to baseline.

7. EVALUATION OF THE PATIENT EDUCATION (III)

In the pilot study each session of the IBS school, as well as the entire education was evaluated by the patient on a seven graded scale. The patients were overall satisfied with the content and how the course was organized and performed (Table 11). The majority of the patients also made positive comments on the mix of professionals involved in the IBS school. Moreover, some patients expressed that meeting other IBS patients was very useful, and they felt that they could view their situation from a different perspective after the education. Some negative criticism was given from some of the patients, regarding too little time for questions and that some participants occupied too much time for individual issues.

Table 11. Evaluation of the structured patient education on a seven graded scale.

Session	**Mean (±SD)**	**Median**	**Minimum**	**Maximum**
1. Introduction	6.75 (0.7)	7	5	7
2. Pathophysiology/symptoms	6.58 (0.8)	7	5	7
3. Dietary advise	6.38 (1.1)	7	4	7
4. Stress and relaxation	5.64 (2.0)	7	1	7
5. Psychological factors	5.64 (1.7)	6	2	7
6. Summary	6.40 (1.1)	7	4	7
Entire course	6.42 (0.7)	6.5	5	7

The patients formulated individual goals before the start of the education. Those goals were evaluated by the patients at three months after the start of the education, i.e. approximately six weeks after the end of the education. The goals were formulated like, ‘An opportunity to meet other in a similar situation’, ‘To learn about facts regarding diet, physical activity and understand what happens in the gut’, ‘To get knowledge leading to confidence and ability to explain to friends and relatives about IBS’, and ‘To get control over symptoms’. Six, out of twelve patients (50%), experienced that they reached their individual goal totally, five patients reached their goal partly and one patient did not reach the goal at all.

GENERAL DISCUSSION

The main results in the present studies will be discussed briefly below and compared with other findings in the literature.

1. HEALTH RELATED QUALITY OF LIFE (I, IV)

As shown in this thesis, IBS is associated with poor HRQOL, which supports the findings in some previous reports (44, 157). Poor HRQOL has also been shown to correlate with other factors like the GI symptom severity (158-161), psychological factors (159, 162, 163) and also with the time since onset of symptoms (164). Furthermore, in a recent population study, poor HRQOL was identified as a predictor of new onset of IBS (165), and having IBS was recently shown to be associated with negative interference at work (166, 167).

We also found differences between different groups of IBS subjects regarding HRQOL (I). Despite similar GI symptom severity in the groups, the non-consulters had better HRQOL compared with the consulters. This is in line with previous findings (16, 17), although these studies did not evaluate the GI symptom severity. Our findings were demonstrated in both the univariate and the multivariate analyses. It reached statistical and, according to the work of Watson et al.(134), also clinical significance on several of the nine dimensions on IBSQOL. It seems logical that if a person has GI symptoms and due to them experience major impairments in multiple situations of daily life, it is not surprising that HRQOL is affected. On the other hand, having GI symptoms but not experiencing any or just little impairment in daily life, might characterize a person who does not need to seek help in the health care system. This could, at least partly, explain the health care seeking, and emphasize the importance of understanding our patients from a multi component approach including HRQOL (168).

After the patient education, but not after receiving the guidebook, statistically significant improvements were observed on several of the nine dimensions on IBSQOL (IV). However, the comparisons between the groups for change in HRQOL were mainly non-significant. Although this improvement did not quite reach what is considered to be clinically significant (134) and the comparisons between the groups for change in HRQOL were mainly non-significant, the trend seemed to be clear. It could be assumed that consulters, who do seek help due to their GI symptoms, experience considerable impairment in HRQOL and therefore might have difficulties to manage their symptoms in daily life. An intervention like the IBS school where understandable explanations, together with the opportunity to discuss and reflect together with others are given, seems to have the potential to positively affect this aspect of life. This line of argument is supported by the results from a previous evaluation of patient education in IBS (122). In that study it was demonstrated that both a multi session and a single session version of the education improved HRQOL. The authors also found that the improvement was more pronounced in the multi session version (122).

To conclude, HRQOL seems to be a key factor in terms of how symptoms, related to IBS, affect the daily life of the patients. Our results emphasize the importance of acknowledging this in the meeting with the patients. Structured patient education in the form of an IBS school was found to be a promising intervention in terms of improving HRQOL in this group of patients, but further studies in larger groups of patients and with longer follow-up seem warranted to prove this.

2. GASTROINTESTINAL SYMPTOM SEVERITY (I, IV)

As there were no differences between consulters and non-consulters regarding GI symptom severity as measured with GSRS (I), the GI symptom severity alone was probably not the reason for the decision to seek health care in this cohort. However, patients in secondary/tertiary care had higher scores, indicating more severe GI symptoms, compared with the patients in primary care. This, together with even worse HRQOL and more GI symptom specific anxiety, as demonstrated in the secondary/tertiary group, might indicate a more profound impairment of the disorder in some patients and might be a reason for referral to a gastroenterologist. Our findings are in line with the literature describing the IBS population as a very the heterogeneous group (72-74, 169), and emphasize the importance of a multi component approach in the meeting with the individual patient. A move from a pure biomedical model toward a biopsychosocial model is considered to be appropriate in the management of IBS patients (170, 171), i.e. the focus should not be on single physiological epiphenomena (51).

According to the IBS-severity scoring system the GI symptoms improved more after the patient education compared with after receiving written information, even though this reached statistical significance only at the six-month follow-up evaluation (IV). This questionnaire has been found to have good psychometric and methodological qualities compared with other GI symptom measures (172) and is sensitive to changes (128). Some of the patients in the IBS school stated that receiving an understandable explanation about how it is possible to have abdominal pain, without having a medically serious disease, was very helpful for them. Thus, the GI symptom improvement after the education might be a matter of perception of symptoms rather than a decrease of the GI symptom per se. In other worlds, when the patients did not worry about their symptoms, the symptoms became less frightening and easier to tolerate, which confirms previous reports (66, 75, 76). This could, at least partly, be explained by the fact that there seems to be a relation between GI symptoms and stress, although the causality is not certain (173) and that GI-specific anxiety mediates the relationship between general psychological distress and GI symptom severity (141).

The results in this thesis suggest that GI symptoms per se might be of minor importance for many of the IBS subjects in their decision to seek health care. Much more important seems to be how the GI symptoms are perceived by the patients and to which extent the symptoms interfere with their daily activities. The IBS school seems to be an effective method to reduce the perception of GI symptoms in daily life for IBS patients.

3. PSYCHOLOGICAL SYMPTOMS (I, IV)

Psychological factors seem to be of importance for peoples’ decision to seek health care due to their GI symptoms. Non-consulters expressed less psychological distress compared with the consulters according to all measures, i.e. HAD, SCL-90 and VSI, used in paper I, which is in line with earlier findings (18, 61) and also more recent studies (174). Especially the anxiety scores differed between the groups. This was demonstrated by more GI-symptom specific anxiety (VSI) in consulters compared with non-consulters, which was even more pronounced in secondary/tertiary care patients compared with primary care patients. Also, general anxiety was found to be one of the predictors for being a consulter in secondary/tertiary care according to the multiple stepwise logistic regression analysis (I).

A recent qualitative study reveals that an anxiety reaction often is followed by an attack of illness both in patients with IBS and patients with inflammatory bowel disease (175). This indicates that psychological factors are of importance for symptom generation in patients with both functional and organic GI disorders. Moreover, somatic comorbidity has been shown to be more common in IBS patients compared with both controls and patients with inflammatory bowel disease and seems to be influenced by psychiatric illness (176). Remarkably, it has also been reported that psychological factors could be associated with higher rates of surgery in IBS patients (177).

The GI-symptom specific anxiety was more reduced after the IBS school compared with after receiving written information. It has recently been shown that psychological illness increases the risk of more severe GI symptoms in functional GI disorders (174), and that psychological distress seems to modulate the effects of stress on GI symptoms (178). It seems reasonable to assume that by presenting simple and understandable explanations about the pathophysiology behind certain GI symptoms in functional disorders, GI specific anxiety, which might be the link to the improvement of GI symptoms (141), could be reduced.

To conclude, psychological factors are of great importance in the symptom generation in IBS. Anxiety also seems to be a key factor for health care seeking. We have also demonstrated that patient education in the form of an IBS school is efficacious in order to reduce GI-specific anxiety in IBS patients. We hypothesize that this might be of great importance in order to improve the long-term outcome in IBS patients, and we plan follow-up studies in order to evaluate this further.

4. COPING (I)

In these studies coping aspects, as measured with the SOC scale and CRI, differed somewhat between consulters and non-consulters, but not between patients in primary care and secondary/tertiary care. This was not a very strong finding and might not be as important as other factors like the HRQOL and psychological distress, as discussed above.

5. PATIENTS' KNOWLEDGE OF IBS (II, III, IV)

Patients' knowledge of IBS in general was good, which was indicated by a high number of correct answers on the 17 true-or-false-statement part of the IBS knowledge questionnaire (II). However, on a direct question, only a quarter of the patients answered that they 'absolutely' had knowledge about IBS. Also the ratings of perceived knowledge and satisfaction with the knowledge by using the VAS showed that knowledge was quite poor. These results indicate that having disease related knowledge per se not necessarily means that the patient feels confident with that knowledge. This was shown in a group of IBS patients referred from primary care to a gastroenterologist, but remains to be evaluated in other groups of IBS patients

By using the same VAS measurement, we found that the patients' perceived level of knowledge was markedly increased after the patient education (III), and increased more in the IBS school group than in the guidebook group relative to baseline (IV). This most likely reflects that the patients found their knowledge to be useful in a different way after the patient education. Self-management programs has been shown to improve the patients confidence to deal with disease related problems (179), and might be the explanation behind this distinct increase in satisfaction with knowledge after the IBS school.

Most of the patients stated that they first of all wanted information about what they can do in order to improve their symptoms in daily life, followed by treatment options and what causes their symptoms (II). This is in line with another recent study (180) and is also confirmed by a study reporting that IBS patients found more confidence in getting advice about lifestyle modifications than they would from drugs (181). One area where most patients lacked correct knowledge was associated to food (II). A substantial number of the patients did not believe that food intake in general would worsen their symptoms but that specific food items would do so. Also in a recent study it has been reported that IBS patients first of all want to learn about what food item to avoid (182). For some patients, this approach probably leads to a desperate search for food items to avoid in order to reduce their GI symptoms. However, no associations between perceived food intolerance and tests for food allergy and malabsorption in IBS patients have been found (183). Instead, worsening of symptoms in relation to meals seems to be associated with female sex and higher levels of anxiety (184) and a general hypersensitivity to food in the gut together with feelings of helplessness (81). Therefore, including information about possible pathophysiological mechanisms regarding food intake and symptom generation seems to be of great importance when providing information to IBS patients.

Other areas where the patients did not have correct knowledge of IBS were about the diagnostic work-up, the importance of pain/discomfort in the diagnosis and the risk that IBS will turn into a serious disease (II). This is in line with a recent study where the IBS patients had significant misconceptions in the same areas (185). Such misconceptions could possibly lead to anxiety and fear, and these findings underline the importance of providing information designed to relieve the fears and concerns of IBS patients in these areas.

Since there was no available questionnaire to use to measure knowledge of IBS, the IBS knowledge questionnaire was developed at our site for the study. It was found to have good test-re-test reliability. Good content validity was also demonstrated by interviews with ten randomly selected patients, who found the questionnaire easy to understand and to complete, as well as covering the most important issues regarding IBS knowledge. Based on this, we think it is reasonable that the results from the questionnaire are valid and reliable in the group of patients included in our studies. However, in order to further prove the credibility of this questionnaire more studies are needed.

6. HEALTH CARE CONSUMPTION (I, II)

It is probably not possible to find one single explanation for why people seek health care for their IBS symptoms. As shown in our study (I) and in some other studies (8, 18, 19, 61, 174), health care seeking was predicted by psychological factors and poor HRQOL rather than GI symptoms. This is also corresponding to our results as the majority of the patients stated difficulties in their daily life due to GI symptoms to be the main reason for seeking health care (II). Moreover, mild symptoms and/or ability to control symptoms was stated by 31 subjects (44 %) to be the main reason for not seeking health care (I). To our knowledge, this has not been investigated before in IBS patients and could serve as valuable information also in order to understand those who do seek health care. Furthermore, others have shown that health care seeking mainly is predicted by the GI symptoms (14, 15, 186, 187). However, few studies have investigated both HRQOL and GI symptom severity in the same population. In our study (I) we used questionnaires to measure GI and psychological symptom severity, HRQOL and coping in the same population. When including all these factors psychological symptoms and HRQOL were the most important factors for health care seeking. Most likely, the reason for health care seeking is a combination of different factors. Some recent studies have shown that psychological factors together with the frequency of bowel movements seemed to influence the frequency of visits to the general practitioner (163), and that the presence of medical comorbidity and affected HRQOL determined the health care seeking behavior (188). Furthermore, the patients' perception about the possible seriousness of the GI symptoms seems to influence the health care seeking (66). This is in line with another study where maternal fears about abdominal symptoms in children with recurrent abdominal pain predicted the health care seeking (189). Finally, a recent Swedish study has shown that psychological illness increases the risk of more severe GI symptoms in functional GI disorders, and is also associated with a greater need for health care consultation (174).

Several guidelines for management of the IBS patient have been published (20, 190, 191) and one of the most recent is from 2007 (169). It is suggested that identifying the patients concerns and explaining symptoms in simple terms will improve the outcome. IBS is a heterogeneous condition and treatment should be chosen individually for each patient, based on the predominant symptom (169). Unfortunately, a substantial number of patients do not seem to get this management according to a study reporting that on average 25 % of the patients made five or more visits to health care professionals before they received their IBS diagnosis (192). Also in our study a large proportion of the patients had not received the diagnosis of IBS, even though the primary care physician stated so in the referral letter (II). Furthermore, the knowledge about IBS seems to be limited among non-gastroenterologists (193), possibly affecting the management in a negative way. On the other hand, a positive diagnosis, information, reassurance and lifestyle advices, including dietary advice from a dietician, has been shown to reduce symptoms (194), and thorough explanation and reassurance during the first consultation decreased the self-perception of impairment in daily life in IBS patients (195).

The results from our studies, together with the data from the literature, emphasize the importance of listening to the patients and using a multi component approach, including education, in the meeting with the patients.

7. PATIENT EDUCATION (III, IV)

A nurse, specialized in functional GI disorders, was responsible for the IBS school. This is in accordance with a recent review confirming that nurses can play a positive role in the management of IBS patients (196). The concept of the IBS school was first evaluated in a pilot study in a small number of patients (III), with promising results. The patients were very satisfied with the contents and how the patient education was organized. Especially, the patients appreciated the meeting with other patients in a similar situation, which confirms other findings in the literature (75, 77, 196, 197) The meeting with others opened up for new solutions and contributed to feelings of relief that they were not alone. A recent qualitative study concludes that there is a need of establishing support network within the IBS community (175). Such network could be organized in the form of the IBS school as described in this thesis, including information giving, teaching and counseling that is proposed to be necessary in patient education (111). Moreover, support network could also be organized on the internet, which many IBS patients have found to be useful (198). Interestingly, patient education in migraine patients performed by special trained patients has also been shown to have positive effects on symptoms and health care utilization (199).

Our patients made positive comments on the opportunity to get information from the health care providers together with the possibility to ask questions during the sessions. Additionally, the patients often brought a question (raised at home since last session) to the next session, which was an opportunity most patients appreciated. Despite the small number of patients, we found some significant improvements on perceived knowledge, GI symptoms and HRQOL after the education. This, together with the positive evaluation of the IBS school from the patients, encouraged us to perform the randomized control study (IV).

Our results demonstrated positive effects on perceived knowledge of IBS, GI symptom severity, anxiety and HRQOL after the patient education (IV). A finding worth to highlight is the reduced GI-symptom specific anxiety after the participation in the IBS school, since this could be a key factor for the experience of GI symptoms in IBS (141). It seems reasonable to assume that the presence of GI symptoms without an understandable explanation could worsen the symptoms. In line with this, having GI symptoms but receiving reliable and understandable explanations could instead ease the symptoms. This link could very well be through the reduction of GI-symptom specific anxiety.

In the guidebook group, we found some minor improvements, although very few variables reached statistical significance. However, written information in the form of a guidebook has recently been shown to reduce health care consultations and symptom severity in IBS patients, evaluated both with a quantitative method (200) and a qualitative method (201). Reasons for the modest improvement in the guidebook group in our study could, at least partly, depend on that our patients mainly were recruited from secondary/tertiary care. According to the differences, demonstrated in paper I, between patients in primary care and secondary/tertiary care, it seems reasonable to assume that the need of information and education differs between these groups of patients. Patients in secondary/tertiary care could be more affected by the disorder and might therefore require more support together with receiving the written information, compared with primary care patients. In the study of Robinson et al. and Rogers et al. (200, 201) all patients were recruited from primary care, and could have been less affected by the disorder, compared with the patients in our study. A similar comparison between patient education in a group setting and written information has recently been performed in patients with asthma (202). That study showed that patient education was superior to written information on disease related knowledge and HRQOL.

Some other Swedish studies have evaluated patient education in patients with inflammatory bowel disease (112, 203, 204). The patients in those studies were very satisfied with the performance of the education, but few disease related variables were improved. However, in our studies (III, IV), we found positive effects on both symptoms and HRQOL after the IBS school. There are probably several explanations for this discrepancy. One of these could be different management in the health care system, depending on if the patient has an organic or functional GI disorder. It has been reported that physicians perceive that patients with organic GI diagnoses have more serious problems compared with IBS patients (79). Is it possible that patients with inflammatory bowel disease therefore do receive more thorough information in the general health care, compared with the IBS patients? If so, this might result in different needs of information after the meeting with the physician. This assumption is in line with a previous finding reporting that patients with inflammatory bowel disease had more disease related knowledge compared with IBS patients (76).

Moreover, this also corresponds well to the literature describing that many IBS patients have feeling of not being taken seriously for their symptoms (23, 75, 76), and emphasize the importance of providing information and education to IBS patients.

Since patient education is associated with economical costs, and all patients do not respond favorable it is of great importance to investigate if there are factors predicting a positive outcome. In gastro-esophageal reflux disease it has been reported that only patients with a lower level of formal education seemed to profit from the patient education in terms of HRQOL (205). In patients with inflammatory bowel disease, patients with shorter symptom duration were those with the most positive response after the patient education (203). We have recently in abstract form (206), presented predictors for being a responder after the IBS school in a larger group of patients. A responder was defined as reporting satisfactory relief of the GI symptoms at three months after the start of the education. According to this definition, 45 % of the patients were responders. These patients had significantly less severe GI symptoms and significantly better HRQOL at baseline compared with the non-responders. However, still the responders had moderate IBS symptoms according to IBS-SSS and significantly impaired HRQOL according to IBSQOL. Otherwise there were no statistical differences between responders and non-responders. Our results suggest that patients with the most severe GI symptoms and most impaired HRQOL probably are less likely to benefit from the IBS school. These patients will probably need more support than what is offered in a patient education in a group setting. Continuing follow-up evaluations after the IBS school at our site will shed further light on this issue.

Even though patient education could be regarded as being time consuming and costly, it will most likely be paid back in the long run if the patients will consume less health care afterwards. This has to be evaluated in future studies. However, the total time spent for one IBS school is 12 hours. A calculation of the time spent on one patient in a group of eight patients will give 90 minutes spent on each patient. One could assume that this will turn out to be a cost effective treatment in the long run. This assumption is supported by the fact that even if the initial costs can be higher compared to usual care, interventions like psychotherapy has been shown to be cost effective in a long-term follow-up (108). Furthermore, non-pharmacological interventions could have additional positive long-term effects, which seemed to depend on lifestyle changes that were made long time after the end of the intervention (107).

According to our results, the IBS school has the capacity to improve several important aspects involved in the experience of IBS (IV). Since our results are based on a population with the majority of the patients being managed in secondary/tertiary care, this remains to be evaluated also in primary care patients. Many of the factors found to discriminate between consulters and non-consulters (I) were significantly improved after the IBS school. This suggests that patient education is an adequate complement in the usual care, i.e. providing what consulters are missing, but non-consulters already seem to have in terms of psychological well-being and HRQOL. As a positive consequence of our experiences and results with the IBS school, the intervention has been implemented in the clinical routine at our outpatient clinic. We are now following the patients over time and include cost benefit analyses. Moreover, in order to find an optimal method of patient education, from a cost benefit perspective, we are investigating if other forms of patient education can be as positive as the one presented in this thesis.

SUMMARY AND CONCLUSIONS

1. Differences between subjects with IBS who had sough health care for their symptoms (consulters) compared with those who had not consulted (non-consulters) were demonstrated. Consulters had worse HRQOL and more pronounced psychological distress, compared with non-consulters, but the GI symptom severity was similar in the two groups. These findings emphasize that the management of the patients needs to be holistic and not only focus on single GI symptoms.

2. Also between IBS patients who were managed in primary care and secondary/tertiary care, some differences were demonstrated. Primary care patients had less severe GI symptoms, better HRQOL and less pronounced psychological distress compared with secondary/tertiary care patients. These findings indicate that the IBS population is a heterogeneous group, which has to be considered both in the usual care as well as in clinical trials.

3. Most of the patients had to a large extent correct knowledge of IBS, but they were not satisfied with their knowledge. Issues where many patients had lack of knowledge were in areas dealing with the diagnostic work-up and the importance of food generating GI symptoms. The patients mainly wanted information about what they can do in order to improve their symptoms. This stresses the importance of providing useful knowledge in an understandable way to IBS patients.

4. We have developed a structured patient education (IBS school) and evaluated this intervention in a pilot-study. The IBS school was highly appreciated by the patients. Especially, positive comments were made on how useful they found the opportunity to discuss IBS related issues with other patients, with simultaneous guidance by health care professionals. This proposes that self help groups are valuable complements in the management of IBS patients.

5. The IBS school was superior to written information. Especially, the perceived knowledge of IBS improved more and the GI symptom severity and GI specific anxiety was more reduced in the IBS school group compared

with the guidebook group. This indicates that providing knowledge in the form of an IBS school is a proper method to enhance both knowledge and well-being in IBS patients. It is probably not just a matter of which information that is provided, but it seems to be of great importance how the information is provided.

SUMMARY IN SWEDISH

Svensk sammanfattning

Irritable bowel syndrome (IBS) är en funktionell mag-tarmsjukdom, med en förekomst av ca 10-20 % i västvärlden. Vad som orsakar IBS är endast delvis klarlagt och behandlingsmöjligheterna är begränsade. Sjukdomen är ur medicinsk synvinkel ofarlig, men många drabbade har utomordentligt svåra mag-tarmsymtom och låg livskvalitet. Detta är ofta förenat med hög sjukvårdskonsumtion och sjukfrånvaro, vilket leder till stora kostnader för både individ och samhälle. Många IBS-patienter upplever dessutom att de blir otillräckligt informerade och inte tagna på allvar för sina symtom i sina kontakter med sjukvården.

Vårt syfte var att identifiera faktorer som påverkar sjukvårdskonsumtion vid IBS, hur mycket och vilken kunskap patienter med IBS har om sin sjukdom, samt att utveckla och utvärdera en strukturerad patientutbildning för patienter med IBS, en s.k. IBS-skola.

Vi undersökte 218 individer med IBS, dels personer som inte sökt sjukvård för sina mag-tarmsymtom (non-consulters), dels patienter som sökt sjukvård. Frågeformulär för värdering av svårighetsgrad av mag-tarm- och psykologiska symtom, livskvalitet och copingresurser fylldes i av alla för jämförelse av dessa faktorer mellan grupperna. Skillnader som sågs mellan grupperna var att de som inte hade sökt sjukvård för sina mag-tarmsymtom hade bättre livskvalitet och copingresurser samt lägre grad av psykologiska symtom, jämfört med patienterna som hade sökt sjukvård. Däremot var svårighetsgraden av mag-tarmsymtomen likvärdig i de båda grupperna.

Åttiosex patienter som fått diagnosen IBS av en primärvårdsläkare och remitterats vidare till mag-tarmspecialist, fyllde i ett frågeformulär angående sin kunskap om IBS. Avsikten var att utvärdera vilken information patienterna hade fått, hur nöjda de var med sin kunskap, samt vilken information de önskade få om IBS. Endast en liten andel av patienterna upplevde att de hade fått tillräckligt med information. Majoriteten av patienterna hade nästan alla rätt på ett kunskapstest om IBS, men många kände sig trots detta missnöjda med den kunskap de hade om IBS. Patienterna ville i första hand få information om: vad de själva kan göra för att lindra symtom följt av vilka behandlingsmetoder som finns samt information om vad symtomen beror på.

En patientutbildning, s.k. IBS-skola, utvecklades och prövades i en liten studie med 12 patienter. IBS-skolan bestod av sex träffar á två timmar, en gång per vecka, i grupper om fem till sju patienter. En sjuksköterska, mag-tarmläkare, dietist, sjukgymnast och psykolog ansvarade för varsin föreläsning med ett stort utrymme för diskussion. Frågeformulär för värdering av hur patienterna upplevde utbildningen fylldes i efter IBS-skolan. Patienterna var mycket nöjda med utformningen och innehållet i IBS-skolan och den nya kunskap de kunnat tillgodogöra sig. Vi såg också tendenser till förbättrad livskvalitet och minskade mag-tarmsymtom efter IBS-skolan.

Vi gick därefter vidare med en större studie för att utvärdera effekterna av denna IBS-skola och jämföra detta med effekterna av att enbart få skriftlig information om IBS, s.k. Guidebok. Effekterna mättes med frågeformulär för värdering av upplevd kunskap om IBS, mag-tarmsymtom, livskvalitet och psykologiska symtom. Sammanlagt 143 patienter deltog och hälften lottades till att delta i IBS-skolan och den andra hälften till att få den skriftliga informationen. Patienterna som deltagit i IBS-skolan ökade sin kunskap, minskade sina mag-tarmsymtom och ångest samt förbättrade livskvaliteten i högre grad än vad patienterna som fått skriftlig information gjorde.

Slutsatser: Personer med IBS som inte söker sjukvård för sina mag-tarmsymtom har likvärdiga mag-tarmsymtom jämfört med dem som söker sjukvård. De har däremot bättre livskvalitet och psykologiskt välbefinnande, vilket troligen bidrar till att mag-tarmsymtom upplevs mindre svåra och att behovet av att söka sjukvård blir mindre uttalat. Många IBS-patienter har mycket korrekt kunskap om sin sjukdom, men de känner sig inte nöjda med kunskapen, och önskar i första hand information om hur de själva kan lindra sina symtom. IBS-skolan förbättrade patienternas kunskap om sin sjukdom och påverkade mag-tarm- och psykologiska symtom och livskvalitet i positiv riktning. Dessa studier visar sammantaget att individers upplevelse av sina mag-tarmsymtom i hög grad är kopplat till livskvalitet och psykologiskt välbefinnande. Riktade insatser för att informera och utbilda IBS-patienter om sin sjukdom, såsom IBS-skolan, kan bidra till ett ökat välbefinnande för den enskilde. Dessutom, om behovet av sjukvårdskonsumtion och sjukfrånvaro kan minskas, kan det även bidra till ekonomiska besparingar för samhället. Det är därför viktigt att fortsätta denna utveckling och utvärdering av patientutbildning i ett längre perspektiv och inkludera analyser för att även värdera långtidseffekter och kostnadseffektivitet.

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