

A gender perspective on irritable bowel syndrome

Symptoms, experiences and the development of a person-centred support intervention

Ida Björkman

Department of
Internal Medicine & Clinical Nutrition,
Institute of Medicine
Sahlgrenska Academy
University of Gothenburg

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ida.bjorkman@gu.se

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*This body that's only done me wrong.
That always proved weak when I needed it strong.*

*That lays down to rest when I need to run.
That refuses to just go on.*

*It finally spoke out, said
-We need to see what this is about.*

*Lyrics from the song This Body by A. Norlin, on the album The Fox,
The Hunter and Hello Saferide.*

Abstract

Irritable bowel syndrome (IBS) is a common functional gastrointestinal disorder which affects approximately ten percent of the world's population and which is more prevalent among women than men. The hallmark symptoms of IBS are abdominal pain and disturbed bowel habits and a number of differences between men and women with IBS have been reported. Only a smaller number of studies have explored the patients' perspective on everyday life and health care encounters in IBS, and never from a gender perspective.

The present thesis aimed to explore symptoms, experiences from daily life and health care encounters in IBS from a gender perspective, and to develop and in a pilot study evaluate a nurse led intervention in IBS. A multimethod design was applied where questionnaires on self-reported health were combined with interviews with patients.

Among 557 patients diagnosed with IBS it was found that there were more similarities than differences when men and women were compared. However there was a pattern of difference disfavoring the women especially regarding health related quality of life. An interview study including 19 patients revealed that the experience of living with IBS was gendered, meaning that social norms on masculinity and femininity affected the experience of symptoms.

A subsequent qualitative study including 10 patients with severe IBS showed that their experiences of health care encounters were mostly negative and that they struggled to protect themselves from stigmatizing labeling. The findings from the mentioned studies were then used in the systematic development of an intervention for person-centred support in IBS. The intervention was found to be feasible, appreciated by the participants, and efficient in reducing IBS symptom severity in a pilot study including 17 patients, whilst there were no significant changes for general self-efficacy or gastrointestinal-specific anxiety.

This thesis contributes to the existing knowledge on IBS through adding a sociocultural perspective on gender/sex and by introducing person-centred care as a viable part of the clinical management of the disorder.

Keywords: irritable bowel syndrome, functional disorder, gender, sex, person-centred care, nurse, intervention, self-efficacy, symptoms, self-management.

List of papers

This thesis is based on the following studies, referred to in the text by their Roman numerals:

- I. Björkman, I., Jakobsson Ung, E., Ringström, G., Törnblom, H. & Simrén, M. 2015. More similarities than differences between men and women with irritable bowel syndrome. *Neurogastroenterology & Motility* 27(6), 796-804.
- II. Björkman, I., Dellenborg, L., Ringström, G., Simrén, M. & Jakobsson Ung, E. 2014. The gendered impact of Irritable Bowel Syndrome: a qualitative study of patients' experiences. *Journal of Advanced Nursing* 70(6), 1334–1343.
- III. Björkman, I., Simrén, M., Ringström, G. & Jakobsson Ung, E. 2016. Patients' experiences of health care encounters in severe irritable bowel syndrome: an analysis based on narrative and feminist theory. *Journal of Clinical Nursing* 25(19-20), 2967-2978.
- IV. Björkman, I., Simrén, M., Ringström, G., Myrgren, J. & Jakobsson Ung, E. The role of the nurse in the management of irritable bowel syndrome: development and pilot study of a person-centred support intervention. *In manuscript*.

Content

List of papers	6
Abbreviations	9
Populärvetenskaplig sammanfattning	11
Preface	14
Background	15
<i>Previous research on irritable bowel syndrome</i>	15
IBS diagnostic criteria, prevalence and pathophysiology	15
Gender/sex differences and IBS	18
Patients' experiences of IBS	18
Health care encounters in IBS	19
<i>Interventions in IBS led by or involving nurses</i>	20
<i>Person-centred care and self-management</i>	21
Person-centred care	21
Self-management and self-efficacy	22
Theoretical framework	23
<i>Gender medicine</i>	23
<i>Intersectional gender/sex</i>	25
<i>Standpoint theory</i>	27
Aims	30
Methods	31
<i>Methodological viewpoints and design</i>	31
<i>Participants and context</i>	32
<i>Quantitative approaches (study I & IV)</i>	34
Questionnaires	34

Statistical procedures	36
<i>Qualitative approaches (study II-IV)</i>	36
Interviews	37
Hermeneutic approach (study II)	37
Narrative approach (study III)	38
General inductive approach (study IV)	40
<i>Method for the intervention development (study IV)</i>	41
Ethics	43
Results	45
<i>Men and women with IBS</i>	45
Living with symptoms	45
Experiences and impact on quality of life	47
<i>Health care encounters in IBS</i>	49
Patients' experiences of health care encounters	49
An intervention for person-centred support	52
Discussion	57
<i>Discussion of methods</i>	57
Methodological pluralism	57
Critical reflection, fairness and responsibility	58
<i>Discussion of results</i>	60
Gendered experiences	60
Gendered health care encounters	62
Person-centred care and power sensitivity	64
Conclusion and future perspectives	66
Acknowledgements	68
References	71

Abbreviations

BSFS Bristol stool form scale

CNS Central nervous system

ENS Enteric nervous system

FGID Functional gastrointestinal disorder

GI Gastrointestinal

GSES General self-efficacy scale

HADS Hospital anxiety and depression scale

IBS Irritable bowel syndrome

IQR Interquartile range

MRC Medical Research Council

PCC Person-centred care

PHQ Patient health questionnaire

QOL Quality of life

SOC Sense of coherence

VSI Visceral sensitivity index

Populärvetenskaplig sammanfattning

Irritable bowel syndrome förkortat IBS, även kallad kolon irritabile eller irritabel tarm är en mycket vanlig åkomma som drabbar cirka tio procent av befolkningen och är något vanligare hos kvinnor än hos män. Vad som orsakar IBS är inte helt klarlagt men det verkar vara en kombination av en mängd orsaker som stort rörelsemönster och ökad känslighet i tarmen, avvikande bakterieflora och möjligen inflammatoriska processer. Psykosociala faktorer som stress, depression och ångest är också av betydelse liksom kostvanor. Det finns inga tester eller undersökningar som kan bekräfta diagnosen som därför ställs genom diagnoskriterier varav de senaste kallas ROME IV. En del könsskillnader har identifierats gällande IBS som mer förstoppning, ökad känslighet i tarmen och lägre livskvalité hos kvinnor. Många av de tidigare studierna baseras på små material och fynden är ibland motsägelsefulla.

Ett fåtal studier har undersökt IBS utifrån patientens perspektiv och de visar att leva med IBS kan vara mycket besvärligt trots att sjukdomen i medicinsk mening är ofarlig. Intervjustudier med patienter visar att de kan uppleva en förlust av kontroll över kroppen när symptomen uppträder och det i sin tur kan leda till känslor av hjälplöshet och skam. En del patienter beskriver också mötet med vården som svårt och att de inte alltid känner att de blir lyssnade till eller tagna på allvar av sin vårdgivare. Intervjustudier med vårdgivare har visat att läkare och sjuksköterskor också tycker att vårdmötet vid IBS kan vara svårt och väcka känslor av otillräcklighet och frustration. Inga studier har ännu undersökt huruvida erfarenheten av att leva med IBS samt vårderfarenheter skiljer sig mellan män och kvinnor.

Det finns idag ingen botande behandling vid IBS så vårdinsatser fokuserar på att lindra symptom och att på olika sätt stödja patienterna att leva ett gott liv trots sjukdom. Ett antal icke-medicinska behandlingar så som mag-tarminriktad hypnoterapi, kognitiv beteendeterapi och patientutbildningar har visat god effekt vid IBS men dessa är i nuläget inte tillgängliga för flertalet patienter. Sjuksköterskor är en underutnyttjad grupp vid behandling av IBS vilka skulle kunna öka både tillgänglighet och variation av interventioner

Det övergripande syftet med detta forskningsprojekt var att undersöka symptom, erfarenheter från dagligt liv och mötet med vården vid IBS ur ett

genus/könsperspektiv samt att utveckla och i en pilotstudie utvärdera en sjuksköterskeledd intervention för IBS.

Ett genus/könsperspektiv innebär i detta sammanhang att förstå IBS ur ett större samhällsligt perspektiv, där människor utsätts för olika stressorer och hälsorisker och har olika möjligheter till en hälsofrämjande livsstil, baserat på kön, socioekonomisk tillhörighet och andra sociala kategoriseringar. En teoretisk utgångspunkt är ståndpunktsteori som menar att den som har egen erfarenhet av ett fenomen, i detta fall IBS, har ett unikt och speciellt värdefullt perspektiv. Därför har patienterfarenheter varit i centrum för projektet som innefattar fyra delstudier med både kvalitativ och kvantitativ metod.

Ett flertal metoder för datainsamling och analys användes som självskattningsinstrument (enkäter) kring fysiska och psykologiska symtom, känsla av sammanhang och hälsorelaterad livskvalité och intervjuer både i grupp och enskilt. Interventionen utvecklades systematiskt utifrån en litteraturstudie och efter konsultation av en expertgrupp och utvärderades i en pilotsstudie. Alla studier genomfördes vid Mag-tarmlab som är en öppenvårdsmottagning vid Sahlgrenska universitetssjukhuset i Göteborg, specialiserad på funktionell mag-tarmsjukdom.

Studie I syftade till att undersöka eventuella skillnader mellan män och kvinnor med IBS gällande fysiska och psykiska symtom, känsla av sammanhang (ett mått på förutsättningar för bemästrande/coping), och hälsorelaterad livskvalité. Femhundrafemtiosju personer diagnostiserade med IBS varav 152 var män svarade på enkäter om självskattad hälsa och resultaten visade att män och kvinnor var mer lika än olika. Sammantaget fanns dock ett mönster av skillnad, framförallt gällande avföringsvanor där kvinnorna rapporterade mer förstoppning, och även för hälsorelaterad livskvalité där kvinnorna skattade lägre nivåer. I en uppföljande intervjustudie omfattande nitton personer, varav tio var män, följdes temat om könsskillnader vid IBS upp som syftade till att ge en fördjupad förståelse ur ett genusperspektiv. Vi fann att män och kvinnor gav olika betydelse till att leva med symtom och att de därmed fick olika konsekvenser för vardagslivet. Dessa skillnader kan sannolikt förklaras genom olika köns- och genuskodade normer som reglerar vad som är socialt accepterade beteenden, attityder och utseenden för män och kvinnor; en ständigt pågående process som ibland kallas att ”göra kön”.

I studie III följde vi upp ett tema som lyfts av patienterna själva i studie II, nämligen det problematiska vårdmötet. Tio personer med svår IBS intervjuades och det var tre aspekter av den professionella diskursen¹ som upplevdes som

¹ En diskurs kan bestå av samtal och yttranden men kan också hänvisa till hela system av förklaringsmodeller och begrepp. En diskurs kan kommuniceras på olika sätt till exempel i text och tal.

särskilt problematiska i patientrollen; att IBS inte är en allvarlig sjukdom, att IBS beror på stress och/eller psykologiska faktorer samt att de drabbade själva bär huvudansvaret för tillfrisknandet. Patienterna motsatte sig den professionella diskursen genom att formulera en motdiskurs bestående av en utförlig beskrivning av sitt lidande, genom att hävda att symtomen vid IBS har kroppsliga orsaker och genom beskrivningar av sjukvårdens tillkortakommanden. Denna motdiskurs kan ses som ett försök att hålla fast vid en positiv självbild under hotet av misstro och stigmatisering från sjukvårdens sida.

I den sista delstudien utvecklades en intervention för personcentrerat stöd vid IBS som sedan utvärderas i en pilotstudie där sju personer deltog. Utvärderingen bestod av självskattningsinstrument som fylldes i före och efter deltagandet samt telefonintervjuer med deltagarna som genomfördes efter interventionen. Resultatet visade att interventionen var praktiskt genomförbar, mycket uppskattad av deltagarna och mag-tarmsymtomen var lindrigare efter deltagandet. Det fanns dock ingen statistiskt signifikant skillnad gällande tilltro till egen förmåga eller mag-tarmspecifik oro och ångest när mätningarna före och efter deltagandet jämfördes. Resultaten från interventionen är endast vägledande och behöver bekräftas i större studier.

Detta forskningsprojekt bidrar med viktig kunskap om IBS genom att introducera ett sociokulturellt perspektiv på kön/genus samt genom att presentera en intervention för personcentrerat stöd som en del av omhändertagandet av denna patientgrupp.

Preface

I situate this thesis in the area of gender medicine, broadly defined as a research field trying to put health and illness into context (Vetenskapsrådet 2004). By doing in gender medicine I believe I'm 'sitting on a fence' (to paraphrase the biologist Linda Birke 2000), that is: the fence between gender studies and medicine.

Gender medicine situates the body into its sociocultural context, where health and illness is seen as partly structured by power relations in a system where resources, risks and stressors are unevenly distributed between men and women and other social categories. However, in contrast to gender studies, the body within gender medicine must be attended to in all its materiality; as being something more than a cultural and discursive phenomenon.

By practicing gender medicine I am also 'sitting on the fence' between critical and positivistic epistemological claims. One important agenda within gender medicine has been to put the research process in context by pointing out how questions asked, methods used and interpretations favoured within academic medicine not easily can be isolated from the societal context in which they occur. Thus, the research process is seen as infused by social values, an insight which differs from the objectivist ideals of most medical research, honouring detachment and neutrality.

In these positions of apparent tensions I have produced knowledge on irritable bowel syndrome that I hope to be communicable and usable to clinicians, researchers and patients; methodologically sound and socially responsible to those for whom it matters the most: people suffering from IBS.

Background

Previous research on irritable bowel syndrome

The following section introduces IBS diagnostic criteria, prevalence and pathophysiology, and summarize previous research on IBS regarding gender/sex differences, patients' experiences and health care encounters.

IBS diagnostic criteria, prevalence and pathophysiology

IBS is a functional disorder meaning that it has no known structural pathology. Regardless of not showing any objective signs, the subjective, individual suffering is profound and well documented. IBS has a major impact on quality of life (QOL) comparable to other chronic disease like diabetes and end-stage renal disease (Coffin et al. 2004; Gralnek et al. 2000).

The hallmark symptoms of IBS are abdominal pain or discomfort associated with diarrhoea or constipation or a mix of both, but other symptoms such as flatulence, bloating, urgency to defecate and nausea are also common (Lacy et al. 2016; Longstreth et al. 2006).

IBS is a diagnosis set by symptom criteria which are defined based on evidence and consensus by a large group of clinicians and researchers from all over the world comprising the ROME foundation. As the research field proceed the criteria is updated, the current being the fourth update from the foundation and accordingly referred to as ROME IV which were launched in May 2016. See box 1 for the ROME IV diagnostic criteria for IBS.

BOX 1. ROME IV diagnostic criteria for IBS

Recurrent abdominal pain, occurring on average, at least 1 day/week in the last 3 months, and associated with two or more of the following:

- related to defecation
- associated with a change in frequency of stool
- associated with a change in form (appearance) of stool.

Criteria fulfilled for the last 3 months with symptom onset at least 6 months prior to diagnosis.

(Lacy et al. 2016)

Extraintestinal symptoms or comorbidities like headache, fibromyalgia, back pain, fatigue, urinary urgency and gynaecological symptoms are more common in IBS than in general populations (Riedl et al. 2008). The prevalence of IBS is high in community samples; a meta-analysis of 80 studies reports a pooled prevalence of 11.2 %. It varies among countries and IBS is more common among women than men (14 % vs. 8.9 % in a meta-analysis of 55 studies); younger people are more likely to be affected than those older than fifty years whilst the effect of socioeconomic status on prevalence is less clear (Lovell & Ford 2012).

Proposed pathophysiological pathways involved in symptom generation in IBS are disturbed GI motility, low-grade inflammation, disturbed functioning of the nervous system (local and/or central processes), visceral hypersensitivity and a disturbed microflora of the gut (Drossman 2016). However, it has been difficult to establish objective signs that correlate with the symptoms that patients report. For example Törnblom et al. (2012) found that a majority of patients diagnosed with IBS had a normal colonic transit time (believed to reflect motility). Regarding visceral hypersensitivity there has also been difficulties in relating symptoms to presence of hypersensitivity; hypersensitivity has been suggested to explain symptoms of pain in IBS, but not everyone that reports severe pain presents with visceral hypersensitivity, and vice versa (Drossman 2006).

The inflammation hypothesis is supported by many reports that onset of IBS symptoms is associated with a gastrointestinal infection and also that the symptoms partly mimics those of inflammatory bowel disease. However, it has proven difficult to find unambiguous inflammatory markers in IBS (Öhman & Simrén 2007).

The difficulties in establishing any clear-cut aetiology in IBS in accordance with the traditional biomedical model has led to the introduction of the biopsychosocial model. This is described as a ‘paradigm shift’ since it leaves the reductionist and dualist thinking behind, in favour of a more holistic understanding, acknowledging the interaction between biological and psychosocial factors in IBS (Drossman 1996). See figure 1 for an overview of the biopsychosocial model.

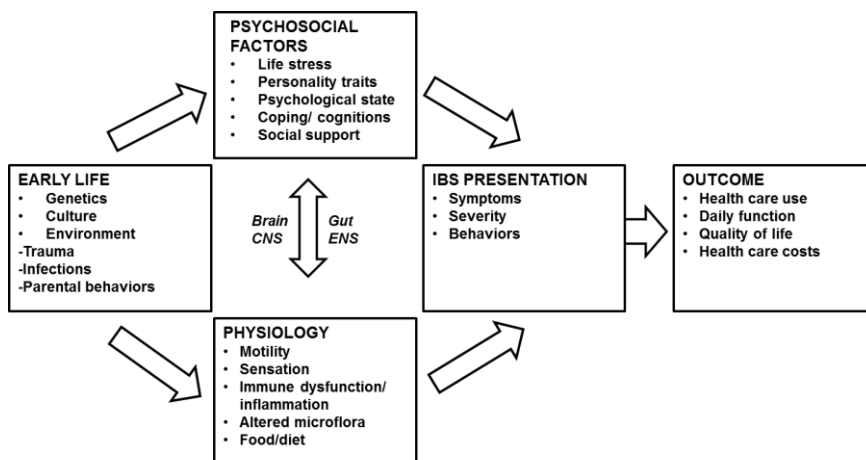


Figure 1. Overview of the biopsychosocial model

Modified after Drossman 2016 & 1996. CNS= Central Nervous System, ENS= Enteric Nervous System

The introduction of the biopsychosocial model has led to an increased focus on the psychological state of patients and anxiety and depression are prevalent in patients with IBS that seek health care (Whitehead et al. 2002). A meta-analysis of ten studies showed that people with IBS had significantly higher scores of depression and anxiety than healthy controls (Fond et al. 2014). It is unclear however, in what direction these associations work and both top-down and bottom-up processes has been suggested. Creed et al. (2006) suggests that psychological symptoms modulate the experience of symptoms in IBS and thus illness behavior such as for example the decision to seek medical attention. However, Drossman (2006) suggests a bidirectional association where psychological symptoms intensify gut related symptoms, which in turn intensifies the psychological stress, i.e. a vicious circle. Nicholl et al. (2008), found that exposure to sleep problems, anxiety, depression and other psychological distress in a cohort free of IBS predicted IBS symptoms at 15 months follow-up, which suggests that psychological factors precedes IBS, but there is also a more recent follow-up study implicating the importance of bidirectional interaction between the brain and the gut regarding the development of IBS symptoms (Koloski et al. 2012).

Furthermore, patients often report that stress worsens their symptoms, and chronic stress affects both gastrointestinal function and central stress response systems (Chang 2011), and being subjected to different kinds of trauma, such as violence and abuse, have been linked to IBS (Salmon et al. 2003).

Gender/sex differences and IBS

Regarding gender/sex differences in IBS the data are conflicting. Women with IBS are proposed to have a lower QOL than men with IBS (Amouretti et al. 2006), however Dancy et al. (2002) found no gender differences in quality of life levels among a smaller number of IBS patients.

Chang et al. (2006) found that women with IBS more often had visceral hypersensitivity compared to men with IBS and Labus et al. (2008) found gender/sex differences in brain activation in response to visceral stimuli in men and women with IBS, but the practical implications of such findings are not altogether clear. Studies regarding gastrointestinal motility (as reflected by transit time) implicate that men have a faster transit than women (Frissora & Koch 2005). Törnblom et al. (2012) have in a large IBS population shown that men with IBS in general have faster and to a higher extent pathological colonic transit time than women with IBS.

Gonadal hormones are often referred to as a possible explanation for gender/sex differences in IBS. In support of the influence of hormones it has been reported that symptoms fluctuate during the menstrual cycle and that women with IBS reports increased symptoms at the time of menstruation (Adeyemo et al. 2010; Frissora & Koch 2005). Houghton et al. (2000) suggests that 'female hormones' might predispose for IBS and that 'male hormones' have a protective effect. Heitkemper & Jarrett (2008) suggests that estrogen and progesterone might influence sensitivity to pain. However, the specific influence of these hormones in IBS remains unclear (Adeyemo et al. 2010; Frissora & Koch 2005).

Exploring the concept of gender roles in IBS a survey study by Voci & Cramer (2009) found that agency, a trait that is traditionally associated with a masculine gender role, was related positively to quality of life in women suffering from IBS. Ali et al. (1998) found that communion, a feature traditionally associated with the feminine gender role, correlates with preoccupation with symptoms among both women and men with IBS.

Patients' experiences of IBS

Qualitative studies reflecting the patients' experiences of IBS constitute a small part of the research field; the group is described as being heterogeneous and the impact of symptoms can range from being an 'uncomfortable nuisance to persons being virtually housebound from pain and fear of a public accident' (Casiday et al. 2009). Håkanson (2013) conducted an integrative review including 23 qualitative studies on patients' experiences in IBS and found that

challenges faced were managing everyday life, negative health care encounters and how to self-manage successfully. Regarding self-management in IBS, diet and stress have been recognized by patients as important triggers for symptoms (Casiday et al. 2009; McCormick et al. 2012). People diagnosed with IBS experience a lack of control of one's body due to the episodic and unpredictable nature of symptoms (Bertram et al. 2001; Farndale & Roberts 2011; Lu et al. 2009; Rønnevig et al. 2009). The symptoms often invades the private sphere (Håkanson et al. 2009; Rønnevig et al. 2009), and can lead to feelings of embarrassment and helplessness (Schneider & Fletcher 2008). It often includes an altered self-image (Håkanson et al. 2009) and some experience feelings of guilt for bringing the disorder on themselves (Casiday et al. 2009).

Patients with IBS also make great efforts learning to live with the disorder (Jakobsson Ung et al. 2013), not letting it rule their life (Casiday et al. 2009) and they have even been described as 'stoic'. However, the disorder often demands a reorientation of life (Casiday et al. 2009).

Health care encounters in IBS

A number of qualitative studies report that patients experience an unsympathetic attitude from health care providers, and that they are not understood and taken seriously (Bertram et al. 2001; Dixon-Woods & Critchley 2000; Håkanson et al. 2010; Meadows et al. 1997). Physicians interviewed by Dixon-Woods and Critchley (2000) were found to have 'private' views of patients with IBS as typically being a woman, quite neurotic and stressed. Some, however, expressed the view that psychological explanations were unfair to patients and the last recourse, as medical science had not come up with any other explanations yet. IBS was a source of frustration not only because of the medical ambiguity surrounding the diagnosis and treatment, but also because of the alleged personality characteristics of patients. A survey showed that a majority of nurses also held negative views of patients with IBS as 'demanding, unable to cope with life, lazy, attention craving and wasting the doctor's time' (Letson & Dancey 1996).

A more recent study found much more positive attitudes in physicians who stated that IBS is a legitimate diagnosis and that the patients are not difficult to neither diagnose nor manage (Harkness et al. 2013).

One study reports that patients with IBS want their physician to give information, directions on where additional information can be retrieved, to answer questions, listen and to offer support and hope (Halpert et al. 2010a). In that study relational skills and empathy on behalf of physicians was as highly

valued as their ability to give information and answer questions. Ninety-four percent of the patients expected their physician to listen to them; however, recalling their last encounter only 64 % felt that he/she did this, and 89 % percent expected their physician to provide support, but only 47 % felt that he/she did this.

Interventions in IBS led by or involving nurses

In lack of curative treatments in IBS, interventions focus on symptom control and helping patients to cope with symptoms. Several non-medical and alternative treatments in IBS have been tested with favourable results, for example gut-directed hypnotherapy (Lindfors et al. 2012), cognitive behavioural therapy (CBT) (Vollmer & Blanchard 1998), and expressive writing (Halpert et al. 2010b).

A common reason for people with IBS to seek care is that they want information on how they can improve their situation through self-care (Ringström et al. 2007). Preferably they want information on pathophysiology, treatment, diet and general lifestyle advice, and it has been suggested that nurses can play an important role in providing such information and support (Bengtsson et al. 2010; Heitkemper et al. 1995; Ringström et al. 2007). Interventions in IBS led by nurses that have shown positive effects are, for example: educational programs (Bengtsson et al. 2006; Håkanson et al. 2011; Ringström et al. 2010), multi-component programs with elements of teaching, cognitive behavioural therapy (CBT), relaxation exercises and support (Heitkemper et al. 2004; Jarrett et al. 2009), and nurse-led hypnotherapy (Lövdahl et al. 2015). However, Bengtsson et al. (2010) evaluated a nursing intervention based on Leininger's Sunrise model for holistic care, but could not demonstrate any effects.

Two interventions found men to be less likely to respond to the treatment: Kennedy et al. (2006) for CBT, and Lövdahl et al. (2015) for gut-directed hypnotherapy.

Qualitative evaluations of nurse-led interventions in IBS are sparse, but Håkanson et al. (2012) found that an educational program facilitated learning about oneself through others, being part of a community, understanding illness as part of a whole and employing new strategies. However for those participants who could not recognise their own illness experience among the others in the group it could be a disempowering experience. In open items in questionnaires evaluating similar programs patients stated that their experience of participating was positive (Ringström et al. 2009b) and that they had enjoyed sharing experiences with others and the interest shown by the professionals leading the

program (Bengtsson et al. 2006). One study evaluated cost-effectiveness and it was found that an addition of nurse-led CBT to medical treatment with antispasmodics did not reduce overall costs (Kennedy et al. 2006).

Person-centred care and self-management

The following section introduces the theoretical frameworks used in the intervention development in Study IV: person-centred care (PCC) combined with critical theory and self-efficacy theory. It also presents the concepts of self-care and self-management.

Person-centred care

PCC focus on the person with a disorder rather than on the disorder itself and starts from the patient's lived experience of illness (Wolf 2012), which is communicated through a patient narrative (Ekman et al. 2011).

The core principles for person-centred care as presented by the Gothenburg group are: patient narrative, partnership and documentation (Ekman et al. 2011). Emphasized is the patient's own knowledge, abilities, capacities and ownership of decisions and to support autonomy then becomes a central goal (McCormack & McCance 2010), as well as striving to empower patients (Morgan & Yoder 2012). How to operationalize such ideas into clinical practice is unfortunately less clear and it might even be that the organization of health care opposes such strivings (Wolf 2012).

PCC has not been evaluated as part of the clinical management of IBS, but has shown effects in other long-term or chronic disorders. In persons with acute coronary syndrome it has improved self-efficacy (Fors et al. 2015), and in chronic heart failure it has lessened uncertainty regarding disorder and treatment (Dudas et al. 2013), and improved quality of life (Brännström & Boman 2014).

There has been a need to further strengthen the sensitivity to power in relation to PCC, which has then been combined with critical theory (see p. 27 on critical theory). Hollnagel and Malterud (1995) combine PCC with critical theory in relation to medically unexplained symptoms in women, Trede (2012) in relation to physiotherapy and Walseth and Schei (2011) in relation to life-style consultations between physician and patient in primary care. Walseth and Schei (2011) present an important contribution by operationalizing PCC through introducing Habermas' theory of communicative action.

Self-management and self-efficacy

How to self-manage successfully is a major concern to people suffering from IBS and an important part of the clinical management of the disorder, especially since there is no curative treatment available (Håkanson 2013; Ringström et al. 2007). For effective self-management, patients with chronic disorders typically need some kind of professional support and health care professionals should provide support that is adjusted to the person's life context (Auduly et al. 2012). PCC is a suitable framework for supporting self-management since it focuses on the patients' individual needs, preferences, capabilities and active participation in care (Bengtsson 2015).

Self-management and self-care are two concepts with no universal definition which are often used interchangeably. The concept of self-care has its origin in the American Civil Rights and Women's Liberation movements in the 1960s which were critical of the medical establishment. However, by now the concept is supported by and integrated into health care agendas (Brodin 2006). Barlow (2010) defines self-management as 'the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a long term health condition or disability'. Self-care on the other hand refers to the actual activities people do to self-manage, for example adapting their diet or exercising. Self-management then encompasses a much broader concept which also includes social, cognitive and emotional processes in which self-care is only one part.

Self-efficacy is an important factor in the process of self-management and describes a person's general belief in hers/his ability to respond differing stress and strains (Bandura 1995). So it is not enough to know what to do in response to different challenging situations but it is also about trusting oneself to be able to take action. For example, one study showed that patients with IBS have adequate factual knowledge on IBS but lack the confidence to use it in everyday life (Ringström et al. 2009a). Thus increased self-efficacy is an important outcome for interventions supporting self-management in IBS.

Theoretical framework

In the present thesis applying a gender perspective situates it in the area of gender medicine, includes an intersectional understanding of gender/sex and the epistemological stance of standpoint theory as outlined in the following section.

Gender medicine

Gender medicine is a research field that seeks to put health and illness into a societal context, and points to the influences of social structures and relations of power for health status (Vetenskapsrådet 2004). One example is the conceptualization of ‘Constrained Choice’ in figure 2, introduced by Bird and Rieker.

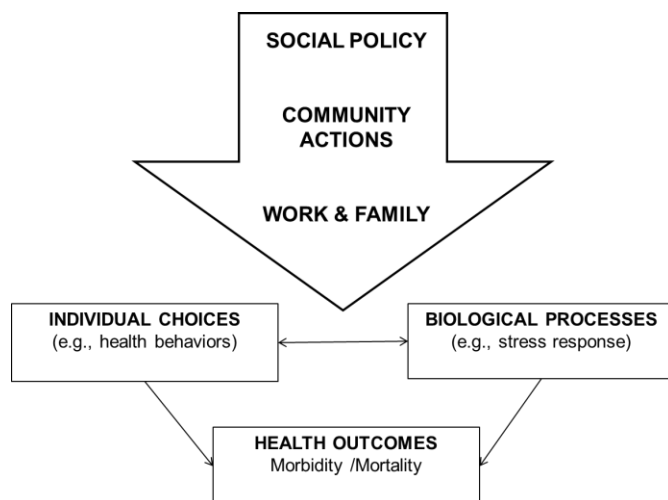


Figure 2. Conceptualization of Constrained Choice

Modified after Bird & Rieker (2008).

The model describes how social policies, community actions and issues at the workplace and within the family affect biological processes and constrains the individuals possibilities for healthy living (Bird & Rieker 2008).

Hammarström et al. (2004) describes the development of gender medicine in Sweden since the 1980s. This research field grew out of a critique of medical research and practice for not being as value-neutral and objective as it set out to be, but based on conservative and stereotypical understandings of men and women; examples of such critique are Fausto-Sterling (1992), and more recently Jordan-Young (2010). Vidali (2013) presents with a similar critique on how the medical literature on IBS is full of assumptions regarding women which risks representing the (female) patient ‘as having unjustified anxiety and is to blame for her condition’.

The early critique from the proponents of gender medicine targeted the scientifically irrational and socially unfair practice of doing clinical research on only (white) men, and then generalizing the findings to women. Such critique led to substantial changes in how clinical trials were conducted and by now it is considered good practice to include also women and ethnic minorities (Bosch & Klinge 2005). Making women visible in medical research and doing research on women where there had only been knowledge on men, for example in heart disease, became an important first goal for gender medicine (Hammarström et al. 2004). For IBS the situation is the opposite with most research in the field being conducted on women and accordingly our knowledge about IBS in men is limited (Toner & Akman 2000), a research practice that risks framing IBS as a ‘woman’s disorder’.

In a later phase of gender medicine the epistemological grounds of biomedical research were critiqued such as positivistic and overly reductionist frameworks and dichotomous² thinking. The field then moved from discussing the proper object of research to the actual conduction of research. Theoretical development within gender studies³ was, and still is, an important influence both through constructionist understandings of gender/sex and other social categories and critical, epistemological grounds for socially responsible research. Following the tradition of gender studies, gender medicine often has had both a deconstructive and reconstructive agenda. That means that it often scrutinizes and critiques mainstream research for gender conservative discourse and gender biases. The

² Dichotomous thinking understands a phenomenon through opposing it to another phenomenon and constructing the two as mutually exclusive and exhaustive. Dichotomies typically do not emerge from empirical observation but often refer to points on a continuum (Sprague, 2016). Examples of common dichotomies are gender/sex, man/woman, body/mind, culture/nature and healthy/sick.

³ In Sweden the academic field is called ‘Gender Studies’ but in other countries the corresponding part of Academia can be called ‘Women’s Studies’ or ‘Feminist Studies’.

reconstructive agenda focus on doing research differently, asking new questions and exploring new ways to answer them.

Intersectional gender/sex

Usually a distinction is made between *sex* and *gender* where sex refers to the biological body, hormonal status, sex organs and genetics. Gender on the other hand refers to the socially constructed such as gendered behaviour or body language⁴. The concept of gender was introduced to counteract biological determinism⁵ but has later on been critiqued for leading to cultural essentialism⁶ instead. Therefore it might be more useful to view both sex and gender as open and ongoing processes as suggested in the popular phrase ‘doing gender’.

Traditionally the sexed body has been understood as that which is stable, the given on which the cultural workings of gender are written. This is in line with a dichotomous understanding of nature/culture as two separate domains in which nature is always the primary. In the earlier days of gender studies the interest was culture (gender) and no attention was given to nature (sex/body). Medicine, on the other hand, traditionally aims to understand the nature/body paying little or no attention to culture.

By ‘sitting on a fence’ (see preface) and practicing gender medicine neither of these positions is acceptable so there must be a way of theorizing bodies as both materiality (nature/sex) and social construction (culture/gender). Philosopher Judith Butler offers one such ‘in between position’. Butler is often misread as a ‘somatophobic’⁷, however in her book ‘Bodies that matter’ she distances herself from a radical constructionism which ‘refutes the reality of bodies [...] the alleged facts of birth, aging, illness, and death’ (Butler 2011).

So what is the relation then between sex and gender according to Butler? Central to Butler, is the concept of performativity (Butler 2006 [1999]). Gender is performative and what might appear as essential and natural is in fact the repetition of certain acts, already defined as masculine and feminine (Butler 2006 [1999]). Butler sets gender prior to sex and offers an understanding of how repetitions of cultural norms actually help materialize the type of bodies they

⁴ In Swedish the word ’kön’ already has wider meaning than the English ‘sex’.

⁵ Biological determinism constructs biology as a determining factor for the social, cultural and psychological character and social position of a person. It can be used to legitimize inequality, exclusion and subordination between women and men, different ethnicities, classes, sexualities and other social categories (Lykke, 2010).

⁶ Cultural essentialism constructs culture as the determining factor for a person and the effect is the same as for biological determinism; it naturalizes and universalizes inequality (Lykke, 2010).

⁷ Thanks to anthropologist Lisen Dellenborg for pointing this out to me. Somatophobia= fear of (theorizing) the body.

claim to describe. Following Foucault, Butler also links the describing of bodies (signification processes) to issues of power. Butler's understanding of gender/sex thus denaturalizes nature/bodies as something given. Accordingly nature/bodies are not something 'out there' to be discovered but something which materializes through signification processes. One such signification process is gender dichotomies where cultural understandings of men and women are read onto biology rather than being the outcome of empirical observations of nature (Birke 2000). Dichotomous gender/sex is a cultural construction since all measurements of gender/sex are actually 'wide-ranging distributions' (Condit 1996).

So why then, one might ask, is there a cultural construction of two sexes instead of three or perhaps five? Butler draws this back to a prevailing heteronormative ideal, she calls it the heterosexual matrix, where women and men are assigned differing life domains in a complementary way (Butler 2006 [1999]).

As opposed to the cultural essentialist idea of socially learned gender roles, which are supposedly internalized into stable identities, an understanding of gender as performance implies a process of ongoing interaction between the individual and her/his social context. Gender/sex is constantly recreated but also negotiated in the interaction between the individual and her/his environment (Butler 2006 [1999]). The repetition of cultural norms however is never perfect; there is always a change in the meaning of what constitutes 'proper' bodies. There is also room for resistance; one can perform what Butler calls 'subversive acts' to undermine the dominant social norms.

In accordance with Butler's understanding of gender as inextricably woven together with and primary to sex I will use the expression gender/sex. However, I also acknowledge that gender/sex needs to be understood as one of many important social positions such as ethnicity, sexual orientation, mother tongue, class and bodily ability (Lykke 2010). Such a perspective is called intersectionality. So when I use the concept of gender/sex this should be read as intersectional gender/sex.

There is another implication of Butler's theory concerning bodies as applied to IBS. Bodies are often framed medically and medical science and practice gets to define what counts as normal and abnormal, healthy and sick. Medical diagnoses, definitions and categorisations thus can be understood as signification practices which help make 'real' that which it claims to describe (Foucault 2003 [1973]). Psychiatrist and gastroenterologist Douglas Drossman writes on the constructed nature of the diagnosis of IBS which

has varied based on societal perspectives of illness and disease over time, on the scientific evidence, and on the clinician's training and personal biases [...] the definition has changed from the absence of

organic disease to a stress-related or psychiatric disorder to a motility disorder, and [...] to a disorder of GI functioning

(Drossman 2016, p. 1268)

Standpoint theory

Epistemology (meaning criteria for what constitutes scientific and scholarly knowledge) is usually a non-issue in medical research where the focus is on methodology (procedures for the production of knowledge) (Lykke 2010). The unwillingness in such research production to attend to epistemology has been traced to positivistic assumptions (Harding 2015).

Positivism relies on the assumption that there is a reality ‘out there’ and that we can effectively know it through our senses. At the other end of the spectrum lies the constructionist paradigm. According to that paradigm reality is not something out there, but a construction, which implies that reality can be understood and described from many perspectives that are all real and equally true (Polit & Beck 2012). Such postmodern epistemological claims, sometimes referred to as ‘the death of truth’, have had a major impact on social sciences and the humanities. Medical science, on the other hand, has remained quite unbothered by this epistemological paradigm shift.

The difference between positivism and constructionism can be described as understanding scientific knowledge as discovery or construction (Condit 1996). The criticism of constructivism is that you will end up in a relativism where ‘anything goes’ which makes truth claims, scientific or other, impossible or at least meaningless.

Butler’s view of sex/gender offers an ‘in between’ position between materialism and constructionism (Butler 2011); one can also assume an ‘in between’ position between positivist and constructionist epistemological claims. That is what standpoint theory offers, which is an epistemology that has its origin in critical theory⁸ (Hartsock 2003). In contrast to quantitative, positivist traditions who seek to explain phenomenon and qualitative, hermeneutic traditions who seek to understand phenomenon; critical research often has an emancipatory agenda of social change.

Standpoint theory is post-positivistic and does not argue that researchers can have unmediated access to reality. It is influenced by constructionist thought, but distincts itself from it through arguing that there is a world out there,

⁸ Critical theory is the philosophical tradition of the ‘Frankfurt School’, which builds on Marxist philosophy.

independent of our knowledge of it. However, the knowledge we can gain of it is always socially mediated and flawed. Just like Butler acknowledges the link between gendered/sexed bodies and power (Butler 2011), standpoint theory links knowledge production to (gendered) power relations (Harding 2015; Hartsock 2003). Research production cannot be separated from the societal context of sociocultural and historical power inequalities (Haraway 1988; Harding 2015). In such a system gender/sex intersects with other power differentials and identity markers such as ethnicity, class, sexual orientation and other social categories. Those which are excluded, dominated and/or stigmatized by such social systems are the ‘Others’⁹ (Lykke 2010). Standpoint theory allows researchers to search out the unique position of ‘Others’ by starting from their life experience.

Biologist and theorist of science Donna Haraway, one proponent of standpoint theory, contests traditional notions of objectivity put forward in positivist research traditions. Her starting point is the question of responsibility for the knowledge researchers produce. The traditional view of objectivity she refers to as the ‘God-trick’ where the researcher views ‘everything from nowhere’ and therefor escapes being held responsible for the material effects of the research (Haraway 1988). According to standpoint theory, good research is not objective, at least not in the traditional meaning of the word, but responsible. Responsibility implies paying close attention to the interests of marginalized groups and those who can be personally affected by a particular piece of research (Harding 2015). It is reasonable that such groups get a say in how research about them should proceed. Applied to IBS, that would be the patient perspective and furthermore, it is possible that certain subgroups of patients are particularly vulnerable.

Traditionally within Marxist theory the appropriate standpoint is that of the working class and in feminist theorizing that of women (Hartsock 2003). Following critique on the concept of woman (for example by Butler (2006 [1999]), and how it excludes many experiences¹⁰, I would argue, as does Swigonski (1994) in the case of social work, that the categories need to be extended for medicine and health research to include also for example patients. An important standpoint of relevance to present thesis is the patient position, since suffering from a disorder, especially a medically unexplained and functional disorder, could in itself be an ‘Othered’ position (Wendell 1996).

Such an extension of what constitutes an appropriate standpoint is also in line with an intersectional understanding of sex/gender where gender is solely one important social position among others (Swigonski 1994). The standpoint sought

⁹ The ‘Other’ is a concept from de Beauvoir’s classic ‘the Second Sex’ describing how woman is always situated as the other to man who thus get to represent the primary/human/norm.

¹⁰ See Lykke (2010) for a summary of the critique.

here is therefor at the intersection of gender and patient, however in line with my intersectional understanding of gender/sex I have strived to be open also to other social categories.

Aims

The present thesis aims to explore symptoms, experiences from daily life and health care encounters in IBS from a gender perspective, and to develop and in a pilot study evaluate a nurse-led intervention in IBS.

Specific aims:

- I. Investigate gender differences in gastrointestinal, extra-intestinal and psychological symptoms: sense of coherence and quality of life in a large group of patients diagnosed with IBS
- II. Explore the impact of IBS on daily life from a gender perspective
- III. Explore patients' experiences of health care encounters in severe IBS
- IV. Systematically develop a nurse-led intervention in IBS and evaluate this in a pilot study

Methods

Methodological viewpoints and design

How should one evaluate the quality of research and what is it that separates research from other forms of knowing? Harding (2015) writes that such questions are as old as Galileo and the enlightenment and still by no means resolved. One important dividing line goes between quantitative and qualitative research traditions. The methodological position taken in the present thesis is, again, ‘sitting on the fence’ (see preface) agreeing with Malterud (2001) who argues for a methodological pluralism. The rationale for that being that different methods can give us a broader and more nuanced picture of a phenomenon.

Quantitative methods in general have the advantage of giving the opportunity to include a higher number of participants; findings are often generalizable and can have an impact in both public and scientific discourse (Sprague 2016). On the other hand, quantitative methods have the disadvantages of possibly objectifying participants by turning people into numbers, phenomenon are often decontextualized and standardized measures account for the researchers perspective and thus might not reflect participants actual experiences (Sprague 2016).

Qualitative methods allow for context to be more visible, can account for a more nuanced picture of a phenomenon, but can only represent a small number of participants and the analysis might not always be as systematic or transparent as for statistics (Malterud 2001; Sprague 2016). Against this background a multi-method design was employed, acknowledging the strengths and weaknesses in each approach.

Study I builds on patient reported outcomes questionnaires and aims to investigate gender differences in gastrointestinal, extra-intestinal and psychological symptoms, sense of coherence (SOC) and quality of life (QOL) in patients diagnosed with IBS. Study II builds on interview data and aims to explore the impact of IBS on daily life from a gender perspective. Study III is an interview study employing a narrative method and explores patients’ experiences of health care encounters in severe IBS, while study IV describes the development and piloting of a person-centred intervention. See table 1 for overview of study designs, data and analyses.

Table 1. Overview of study designs, data and analyses

Study	Participants	Design	Data	Data analysis
I	557 participants Consecutive sampling	Quantitative cross- sectional	Questionnaires	Descriptive statistics Mann-Whitney U-test
II	19 participants Purposeful Sampling	Qualitative	Group and individual interviews	Hermeneutic method
III	10 participants Purposeful sampling	Qualitative	Individual Interviews	Narrative method
IV	17 participants Purposeful sampling	Multimethod Evaluative before and after	Questionnaires Individual interviews (phone)	Descriptive statistics Wilcoxon signed rank test General inductive method

Participants and context

The participants for all the studies were recruited from the gastroenterology outpatient clinic for functional bowel disorders at Sahlgrenska University Hospital. Patients were referred to the clinic from primary care or by self-referral. See table 2 for overview of participant characteristics.

Table 2. Overview of participant characteristics

	Inclusion criteria	Exclusion Criteria	Age range (mean)	Number of participants (male)	IBS-severity¹	Other characteristics
I	Age ≥ 18 Rome II/III criteria for IBS	Other serious somatic ² or psychiatric ³ disorder. Insufficient in Swedish.	18–76 (40)	557 (152)	50 (9%) mild 234 (42%) moderate, 273 (49%) severe	Psychological comorbidities ⁴ anxiety 21% depression 8%
II	Age ≥ 18 Rome II criteria for IBS	Other serious somatic ² or psychiatric ³ disorder. Insufficient in Swedish.	30-70	19(10)	-	From differing socioeconomic groups/occupations/household constellations. 3 from ethnic groups other than Swedish.
III	Age ≥ 18 Clinical diagnosis of IBS	Other serious somatic ² or psychiatric ³ disorder. Insufficient in Swedish.	20-67	10(6)	-	1 retired, 1 on full-time sick leave, 1 unemployed, 7 students or employed. 7 with comorbidities ⁵
IV	Age ≥ 18 Clinical diagnosis of IBS	Other serious somatic ² or psychiatric ³ disorder. Insufficient in Swedish.	21-72 (39)	17(4)	2 (12%) mild 9 (53%) moderate 6 (35%) severe	2 retired, 2 on full-time sick leave, 2 unemployed, 11 students or employed.

¹Cutoff points <150=mild, 150-300=moderate, >300 severe. ²Organic GI, respiratory or cardiac disease. ³Psychotic or bi-polar disorder, current alcohol or substance abuse. ⁴Measured by HAD, cutoff point= 11. ⁵Myalgic encephalomyelitis, rectal prolapse, candida albicans overgrowth, allergies, depression and fibromyalgia.

Quantitative approaches (study I & IV)

The aim in study I was to investigate gender differences in gastrointestinal, extra-intestinal and psychological symptoms, SOC and QOL in patients diagnosed with IBS and thus a quantitative approach was applied. Furthermore, a quantitative approach was used in the evaluation of the person-centred intervention. Self-reported questionnaires were completed at inclusion (study I), and at baseline and after 3-5 months (study IV).

Questionnaires

The IBS Severity Scoring System (IBS-SSS) is a multidimensional rating scale assessing overall IBS severity on a Visual Analogue Scale (VAS) (0-100 mm). An overall IBS score, ranging from 0 to 500, is calculated from five items: pain severity, pain frequency, abdominal bloating, bowel habit dissatisfaction and life interference. There are also ten items referred to as an extra-colonic score measuring nausea, early satiety, headaches, back pain, lethargy, excess wind, heartburn, urinary symptoms, thigh pain and bodily pain. The extra-colonic score ranges from 0-500 and the higher the score, the more severe the symptoms. IBS-SSS can be used to classify IBS symptom severity as mild (<150), moderate (150-300) and severe (>300). IBS-SSS has been validated and found to be responsive to changes in symptom severity and a change of 50 is considered to be adequate to detect a clinically significant improvement (Francis et al. 1997). The overall IBS score and the extra-colonic score were used in study I and the overall IBS score in study IV.

The Generalized Self-Efficacy Scale (GSES) reflects the general belief in one's ability to respond to and control the stress and strain of daily life. It is a ten item scale where each item has four response alternatives, ranging from 1 ("Not at all true") to 4 ("Exactly true"). The scores from all items are summarized to give a total score ranging from 10-40 where a higher score indicate a higher sense of self-efficacy. The scale has been validated for different cultural contexts (Luszczynska et al. 2005; Scholz et al. 2002). This questionnaire was used in study IV.

The Hospital Anxiety and Depression Scale (HAD) was developed to detect anxiety and depression in non-psychiatric patients (Zigmond & Snaith 1983). The questionnaire consists of seven items each for anxiety and depression. It uses a 4-point Likert scale (0-3), which provides a minimum score of zero and a maximum score of 21 on each subscale. The higher the score, the more

pronounced the symptom. A score of seven or less on each subscale denote a non-case, 8–10 a doubtful case and 11 or more a definite case of anxiety or depression. The HAD scale has been found valid for assessing severity of anxiety and depression through diverging populations (Bjelland et al. 2002). This questionnaire was used in study I.

The IBS Quality of Life (IBSQOL) is a disease-specific questionnaire that measures 9 different dimensions of health that have been found relevant to persons suffering from IBS. These include emotional functioning, mental health, physical functioning, energy, sleep, food/diet, social role, physical role, and sexual relations. To facilitate score interpretation, the summed total score is transformed to a 0–100 scale ranging from 0 (poor quality of life) to 100 (maximum quality of life). The scale has been found reliable, valid and responsive (Hahn et al. 1997). This questionnaire was used in study I.

The Visceral Sensitivity Index (VSI) is a 15 item questionnaire designed to measure the degree of GI-specific anxiety in IBS. The total score ranges from 0 (no GI-specific anxiety) to 75 (severe GI-specific anxiety), and the higher the score, the higher the GI-specific anxiety (Labus et al. 2004). This questionnaire has been tested for validity with excellent results (Labus et al. 2007) and it was used in study I and IV.

The Sense of Coherence (SOC) scale reflects a person's ability to cope with difficult stressors and situations in life. The SOC scale measures three domains of coping ability: manageability, comprehensibility and meaningfulness, as well as a total score. It consists of 29 items and a 7-graded scale is used; the higher the score the stronger the sense of coherence, which indicates better coping resources (Antonovsky 1993). The SOC scale has been found valid and reliable in different cultural settings (Eriksson & Lindström 2005). The scale was used in study I.

The Bristol Stool Form Scale (BSFS) assesses stool form based on a seven-point scale (from 1 to 7), where 1 = separate hard lumps, like nuts; 2 = sausage shaped but lumpy; 3 = like a sausage or snake, but with cracks on its surface; 4 = like a sausage or snake, smooth and soft; 5 = soft blobs with clear cut edges; 6 = fluffy pieces with ragged edges, a mushy stool; 7 = water, no solid pieces (O'Donnell et al. 1990). Patients completed a one-week diary where all bowel movements were registered and the stool form noted, and based on this information the stool frequency (stools/day) and mean stool consistency were calculated. This questionnaire was used in study I.

The Patient Health Questionnaire (PHQ-15) comprises 15 somatic symptoms, each scored from 0 (not bothered at all) to 2 (bothered a lot). PHQ-15 scores of 5, 10, 15, represents cutoff points for low, medium, and high somatic symptom severity, respectively. It is a well validated, brief questionnaire for monitoring somatic symptom severity in clinical practice and research (Kroenke et al. 2002; Kroenke et al. 2010). Since the present evaluation regards gender differences the item about menstrual problems was excluded. This questionnaire was used in study I.

Statistical procedures

In study I non-parametric Mann-Whitney U tests were conducted to compare median total scores, as well as individual items/symptom scores from the different questionnaires between men and women. False discovery rate (FDR) was then conducted to adjust for multiple comparisons (Benjamini et al. 2006), and Cohen criteria was used to evaluate effect size. According to Cohen criteria .1 equals small effect, .3 medium effect and .5 large effect (Cohen 1988). To compare differences in age between groups t-tests were used.

For study IV non-parametric Wilcoxon Signed Rank Test was conducted to compare median total scores before and after the intervention.

Significance was accepted at the 5% level (p -value <0.05) and for all statistical analysis the SPSS statistical package, version 19.0 (SPSS, Chicago, IL) was used.

Qualitative approaches (study II-IV)

Qualitative methods were applied to gain a deeper understanding of the patients' experiences in relation to their everyday life, health care encounters and participating in the person-centred intervention. Three different qualitative approaches were chosen based on the nature of the data and the specific aims of the respective studies. All qualitative methods belong in a hermeneutic tradition and therefore share a common ground and accordingly interpretation is necessary for all understanding (Gadamer 1989 [1960]). Although all qualitative methods rely on interpretation it could be useful to refer to them as more or less interpretative as opposed to descriptive.

Interviews

The data was collected through semi-structured interview (study II and III) and through structured interviews, and by reviewing medical records (study IV). All interviews were recorded and transcribed verbatim.

For study I the interviews were conducted individually or in groups with the men separated from the women. Open-ended questions were asked, such as: 'Can you tell us about your experience of IBS' and 'What are the consequences of IBS in daily life?' The group interviews lasted 90-120 minutes and the individual interviews 40-60 minutes.

For study III all the interviews were done individually. Open-ended questions were asked about the participants' experiences of healthcare encounters in IBS, both positive and negative. A couple of times during each interview the interviewer summarized what had been said so far, in order to give the narrator a chance to correct any misunderstandings or to add more information. The interviews lasted for 45-90 minutes. One participant was interviewed at home and all the remaining interviews were conducted at the clinic.

For study IV the interviews were structured according to certain areas of interest for the evaluation and conducted by phone. The questions focused on the participants' perceptions of the intervention as a whole, as well as of the different parts, and the perceived changes regarding symptoms and self-management. Occasionally probe questions were asked such as: 'Can you please tell me more about...?' The interviews lasted for 10- 25 minutes. The review of medical records was done to identify documented personal goals, resources and health plans.

Hermeneutic approach (study II)

Fleming et al. (2003) describes a model for Gadamerian hermeneutics consisting of five steps: 1) deciding on the research question: 2) identifying preunderstandings: 3) entering into dialogue with participants: 4) entering into dialogue with the text: 5) establishing trustworthiness. Central concepts in Gadamerian hermeneutics is prejudice, tradition and dialog. Prejudice in the Gadmerian sense is mostly a positive feature, not only referring to a negative bias but as something needed for understanding; it is what we take in to the hermeneutic situation and which forms our horizon.' Truth' stems from a fusion of horizons which is made possible through dialog and is thus not a property of something but rather the process as such. So the truth that emerges is dependent on that specific, unique situation and is not a universal, timeless truth (Gadamer 1989 [1960]).

Analysis study II

The interview texts were analysed in two steps; first with an inductive approach and then with a deductive approach using a gender theoretical framework (Butler 2006 [1999]; Schippers 2007). The entire text was read individually with notes made during the reading, which were then discussed in the research group.

The procedure was then repeated with the women's account separated from the men's. Our impression of the whole guided a division of the statements, which were then put together to form a new whole. In the next phase, we moved from the whole to the parts by reading the text line by line and then referring back to the whole.

Themes began to emerge, forming an in-depth picture of the participants' experiences. These themes were then examined in the light of our preunderstandings. It was found that women and men generally spoke differently about and gave different meanings to the various aspects of living with IBS. A gender theoretical framework was thus used to guide understanding of the findings and we moved between the text, concentrating on relating the meaning of each section of the transcript back to the text as a whole and the theoretical framework, so that a new, expanded understanding could be achieved.

Narrative approach (study III)

In study III the aim was to explore the patients' experiences of health care encounters and a narrative approach was chosen. Narrative methodology separates itself from other qualitative methods because it is 'less about founding themes and more about asking what stories do' (Frank 2010). It takes the insight from Gadamer that 'truth' is dependent on the context a step further by understanding the interviews/narratives of participants as performative acts¹¹. This method thus has more of a postmodern inclination by stressing the instability of identities and meanings. Accordingly we do not only tell stories about ourselves, but the stories we tell also shape our identities (Baldwin 2005).

These narrative selves or identities are not stable over time but change and are highly influenced by narratives others tell about us and by overarching cultural narratives (Baldwin 2005; Hydén & Brockmeier 2008). Baldwin's ideas regarding counterstories/narratives (Baldwin 2004), narrative tactics (Baldwin 2003) and narrative repair (Baldwin 2007) was used to understand what the narratives attempted to do. Baldwin (2004) argues that when two stories

¹¹ Narratives as performative acts should be understood such as that identity and meaning is not necessarily the primary which is expressed through narrative (Hydén & Brockmeier 2008). Rather identity and meaning are also the outcome of the narrative.

compete, each side uses different tactics to open up their own story and close down the other. Thus, we read the narratives as counterstories to a professional discourse that had been communicated to the patients in different clinical settings.

Analysis study III

The analysis of the transcribed narratives again was a two-step process. Firstly the analysis was inductive, and secondly deductive, using a feminist and narrative theoretical framework. The analytical process began through conventional modes of categorising and coding the transcripts to identify underlying themes across the interviews (Polit & Beck 2012). We read interview transcripts separately in the research group, and then discussed in group meetings emerging themes until a consensus was achieved on what the stories were about.

In contrast to the hermeneutic analysis in study II, the narratives were never cut up to form a new whole, but each participant's narrative was kept intact. Another difference was that we paid close attention to the order of each theme in the narratives and which question each answer referred to. Notes made by the first author during interviews regarding emotional impact, body language, and so on were also taken into consideration. In the second step we encountered the material deductively using Baldwin's framework and feminist theory, analysing what the narratives intended to do. See table 3 for an illustration of the analytical process in study III.

Table 3. Illustration of the analytical process in study III

Excerpt from narrative	Code	Interpretation based on interview text. Analytical question: What is this about?	Theme	Interpretation based on interview text and theoretical understandings. Analytical question: What does it do?
<p><i>-I went to get help but I don't think I got any. It was more like, well, you're probably stressed. I got an explanation but no help.</i> <i>-How do you feel about getting that explanation?</i> <i>- Well, I guess stress has something to do with it because there has been a lot of stress. But it was obvious that something physical was going on as well, caused by the antibiotics.</i></p>	<p>What causes IBS?</p>	<p>He does not accept the explanation that symptoms are only due to stress but has an alternative organic explanation.</p>	<p>Organic aetiology</p>	<p>The question of aetiology interpreted as linked to blame and responsibility. He engages in narrative repair through presenting a counternarrative.</p>

General inductive approach (study IV)

The general inductive approach separates itself from the hermeneutic and the narrative method by being more descriptive and less interpretative. The general inductive approach presents with a way to analyse data using predefined research questions and is thus well suited for evaluation of interventions (Thomas 2006). The questions posed were derived from the theoretical model guiding the intervention and the approach was mainly descriptive. Qualitative evaluations of interventions should be able to identify surprising and unexpected themes (Craig 2008), so even if the focus is determined by the evaluation objectives, the general inductive approach can be both inductive and deductive (Thomas 2006).

Analysis study IV

The initial coding and categorising was performed by one researcher who was external to the main research group. Two researchers thereafter individually sorted the categories under different themes, all relating to the overarching theme of 'Perceptions of participating in a person-centred intervention for IBS'. In group discussions the categories and themes were then discussed until a consensus was reached.

Method for the intervention development (study IV)

The aim of study IV was to develop and evaluate an intervention for IBS and the Medical Research Council (MRC) presents with a revised framework for developing complex interventions which was applied (Craig 2008). Nursing interventions are often complex since they include multiple components, can be individualized and call for a number of different skills in both patient and provider.

The MRC states that best practice is to develop interventions systematically, use the best available evidence and a firm theoretical base and the framework describes a number of steps for the development, piloting, evaluation and implementation phase (Craig 2008). Study IV reports only from the development and pilot phase which included identifying the existing evidence, identifying/developing theory and modelling of processes and outcomes. Strategies used for the development phase were literature review, multi-professional expert group and extended expert group. The evaluation phase of the intervention can be reviewed under the headings quantitative and qualitative approaches.

The literature review addressed interventions in IBS led by or involving nurses which were reviewed for content and mode of delivery, theoretical frameworks and outcomes used (Craig 2008). An overview of the studies included in the review can be found in appendix 1. Additional theoretical literature was then sought to further orient the content of the intervention, possible mechanisms of change and suitable outcomes.

Based on the literature, theory and clinical experience, a multi-professional group developed the person-centred support in IBS (PS-IBS) intervention and a draft version was presented to an extended expert group. The multi-professional and expert group represented different professions and all had experience from meeting patients with IBS in contexts such as research, diagnostic work-up, medical treatment, patient group education and individual support, hypnotherapy and from giving dietary advice.

Ethics

The research conducted in the present thesis was conducted in accordance with the World Medical Association Declaration of Helsinki (2003). To protect the confidentiality and privacy of the participants identifying details were removed and tape recordings, questionnaire data and transcripts were kept in a locked area. Autonomy of participants was protected through informed consent and they were informed about the purpose of the study and the data collection procedures. They were also told that they had the right to withdraw at any time without it influencing their future care. Consent, both verbal and written, was given at inclusion and participants had the opportunity to ask questions about the studies.

Eventual risks and burdens for participants identified were that the interviews and/or questionnaires could induce disturbing thoughts or memories. Health care professionals were present to support the participants in the case that would occur. We tried to minimize participant burden through restricting the number of questionnaires in study IV and to conduct the interviews by phone. There could be a conflict between the researcher's interest in qualitative research reporting to give enough information on context and participants whilst protecting confidentiality. In that case research interests must never overshadow the rights of the individuals participating. Another ethical issue is representation of vulnerable groups in research and we strived for a variety regarding age, gender and to a certain extent ethnicity. Unfortunately we did not have demographic data on other social categories besides that. The Regional Ethical Review Board in Gothenburg has approved all the studies included in this thesis.

According to the epistemological stance taken in the present project one cannot easily separate ethical from methodological issues, thus parts of the discussion of methods, for example study designs, are also ethical issues.

Results

Men and women with IBS

Living with symptoms

Study I aimed to investigate gender differences in patients diagnosed with IBS and we found that women had harder stools than men ($q=0.033$, $r=.14$) and reported a higher total IBS symptom severity ($q=0.042$, $r=.13$). In the following interview study it was revealed that IBS symptoms forced the informants to transcend strong taboos associated with gastrointestinal function and especially women found such matters very ‘embarrassing’. Passing wind, burping and making loud sounds while in the toilet was seen as unacceptable. The men, on the other hand, had a more relaxed attitude towards such symptoms (Study II). The women also discussed the symptom of bloating as troublesome and feared it made them look ‘fat’. Study I also showed that bloating was rated as more severe by the women ($q=0.020$, $r=.16$).

I'm so ashamed walking around with this huge belly. Oh my God, she's become so fat! That's what everybody must think. And then I become obsessed about what to wear. If I wear this or that, for example, it might not show my belly (Woman study II).

Study I showed no significant gender/sex differences for stool frequency, bowel habit dissatisfaction, abdominal pain severity or frequency or for the extra-colonic symptoms measured by IBS-SSS. However, the total somatic symptom burden measured with PHQ-15 (excluding menstrual symptoms) were higher for women ($q=0.035$, $r=.18$). See table 4 for an overview of gastrointestinal and extra-intestinal symptoms for women and men.

Table 4. Gastrointestinal and extra-intestinal symptoms for women and men presented as median (IQR)

	Women	Men	p-value	q-value ⁴	r-value ⁵
Impact on daily life¹	69(50-84)	66(49-82)	0.67	0.73	0.023
IBS severity score¹	301(234-365)	263(195-350)	0.021*	0.042*	0.13
Bloating severity¹	64(39-78)	50(27-70)	0.003*	0.020*	0.16
Bowel habit dissatisfaction¹	73(54-90)	67(42-85)	0.035*	0.059	0.11
Average stool frequency/day²	1.8(1.2-2.7)	2.0(1.3-3.3)	0.036*	0.059	0.11
Average stoolform²	4.2(3.3-5.1)	4.5(3.5-5.5)	0.008*	0.033*	0.14
Abdominal pain severity¹	50(25-68)	43(18-60)	0.062	0.095	0.10
Abdominal pain frequency¹	60(30-85)	60(20-90)	0.75	0.78	0.017
Total somatic symptom burden³	12(9-15)	9(7-13)	0.012*	0.035*	0.18
Extra-intestinal symptoms¹	141(91-210)	136(81-189)	0.35	0.43	0.051

¹Measured by IBS-SSS (N=252 Women/87 Men). ²Measured by BSFS (N=290 Women/95 Men).

³Measured by PHQ15excl.menstr.(N=137 Women/40 Men). ⁴FDR-adjusted p-value. ⁵Effect size. *p or q-value <0.05

Anxiety and depression was present in 21 % and 8 % of the patients in study I (measured by HADS, cut off point=11). Women reported more severe general anxiety (HAD) (q=0.017, r=.13) and GI-specific anxiety (VSI) (q=0.042, r=.12) than men. There were no gender/sex differences for depression (HAD) nor for the mental domain of IBSQOL. See table 5 for an overview of psychological symptoms and sense of coherence in women and men.

Experiences and impact on quality of life

In the interview study, the men's accounts were characterized by leisure activities, sports and a hectic working life (study II). Women also spoke of working life but mainly about topics such as relationships, home and family. The women described how they suffered when they could not live up to high expectations in relation to loved ones. They felt considerable responsibility for the welfare of others such as children, partners and friends. When IBS symptoms prevented them from living up to their ideal image of being supportive to others, they felt guilty. Taking a short rest because of the pain, or long periods spent in the restroom due to constipation, could trigger such feelings of guilt. The men talked more about the practical rather than the emotional consequences of living with IBS (Study II). The women also reported their QOL in the emotional domain to be lower than the men ($q=0.026$, $r=.12$) table 6 (Study I). Prerequisites for coping also differed, with women reporting a lower overall sense of coherence than males ($q=0.042$, $r=.16$) table 5.

Table 5. Psychological symptoms and sense of coherence in women and men presented as median (IQR)

	Women	Men	p-value	q-value ⁴	r-value ⁵
General anxiety¹	7(4-10)	5(3-8)	0.002*	0.017*	0.13
General depression¹	5(2-8)	5(2-8)	0.57	0.67	0.024
GI-specific anxiety²	34(23-51)	31(18-45)	0.024*	0.042*	0.12
Sense of coherence total score³	138(121-155)	149(136-160)	0.019*	0.042*	0.16

¹Measured by HAD scale (N=405 Women/152 Men) ²Measured by VSI (N=277 Women/102 Men)

³Measured by SOC scale (N=155 Women/62 Men). ⁴FDR-adjusted p-value. ⁵Effect size. *p or q-value <0.05.

The men suffered in the sense of being forced to take sick leave and work part time and they expressed 'feelings of uselessness' and a 'fear of losing control'.

I'm considered useless to employers and that's why I'm unemployed. At this stage I'd rather work for free. That's what happens when you've been unemployed for as long as I have (Man study II).

They often struggled to maintain the image of themselves as reliable employees and they felt they had primary responsibility for family finances. The consequences of intrusive symptoms were most apparent at work and they described how they missed out on career opportunities and suffered from loss of income.

I lose a load of money because of this (IBS). The limit for sickness benefit is about 26,000, so that's no fun (Man study II).

In contrast to such qualitative accounts, the QOL domain reflecting work performance, physical role, did not show any significant differences between men and women ($q=0.73$, $r=.020$).

Regarding sexual relationships both men and woman stated that the symptoms often had a negative effect on their desire to engage in intercourse. However, whilst women expressed guilt toward their partner for refraining from sexual activities, the men felt that they compensated their partner by being especially kind and affectionate (Study II).

I discovered that my gut starts when we have sex. And then I think, no, it's not worth it. Then I start to play an ugly game where I start to avoid (intercourse). I pretend to be busy. And then I hear him breathing deeply (he's fallen asleep). Why am I doing this? Shame, shame on you! (Woman study II)

You can't focus solely on it (intercourse). There are other things that are important as well ... like giving each other attention and just being there (Man study II).

The most pronounced gender/sex difference in QOL was seen for the domain of sexual relations where women reported lower levels ($q=0.00$ $r=0.24$).

Other domains of QOL where the women reported lower scores were energy ($q=0.033$, $r=.12$) and food ($q=0.017$, $r=.14$), whereas no differences between men and women were seen for sleep or social role, table 6.

Table 6. Quality of life in women and men presented as median (IQR)

	Women	Men	p-value	q-value¹	r-value²
IBSQOL Emotional	50(38-69)	63(38-75)	0.005*	0.026*	0.12
IBSQOL Mental	80(60-90)	80(65-90)	0.108	0.16	0.071
IBSQOL Sleep	75(52-92)	75(50-92)	0.92	0.92	0.0045
IBSQOL Energy	50(38-75)	63(50-75)	0.009*	0.033*	0.12
IBSQOL Physical functioning	73(53-92)	80(59-92)	0.021*	0.042*	0.10
IBSQOL Food	60(47-80)	67(53-80)	0.002*	0.017*	0.14
IBSQOL Sexual	58(50-83)	69(50-81)	0.000*	0*	0.24
IBSQOL Social role	63(44-81)	69(50-81)	0.30	0.38	0.046
IBSQOL Physical role	56(36-81)	62(34-84)	0.654	0.73	0.020

All measured by IBSQOL(N=376 Women/138 Men). ¹FDR-adjusted p-value. ²Effect size. *p or q-value <0.05.

Health care encounters in IBS

Patients' experiences of health care encounters

Interview study II showed that women strived to be 'good patients' and they felt awkward and uncomfortable when they were only able to describe a number of symptoms to their physician without any confirmatory tests. They often felt trivialized in healthcare encounters and feared being dismissed as 'whiny' and neurotic.

I went to a third doctor, who said: I'm just telling you, it's a case of pulling yourself together. Just sit up and pull yourself together (Woman, study II).

Such encounters could make them doubt their own experiences or that they were imagining their symptoms. Some women, however, described that they did express anger and made demands on their health care professionals (Study II).

The men suffered because they felt that the disorder was seen as psychosomatic and a ‘woman’s disorder’, somehow labelling them as emotional and weak (Study II). They also referred to IBS as being a ‘rubbish diagnosis’ and expressed feelings of distrust and anger toward healthcare professionals (Study II).

No, I'm not going to bloody accept it. They (the physicians) must accept that there are patients who don't put up with certain things. There are those who accept everything and they get nothing for it. It's a pity that you need to fight when you're supposed to receive help (Man study II).

Again in study III, interviewing patients with severe IBS, we found that their experiences of health care encounters in IBS were mostly negative, and often induced feelings of confusion and self-doubt. The patients found it especially problematic when health care professionals described IBS as a minor disorder

No matter whether it (IBS) is dangerous or not, it's really difficult and disabling, you know, and that to me is just as important as whether it's dangerous. I would rather live with something that would kill me at 55 that didn't cause any symptoms. You would just, you know, 'bam', die 30 years early. I would rather have it that way than live 40 years with these symptoms. So, to me, that's a really strange attitude that dangerous would be worse than difficult symptoms. I don't think... well, that way of thinking is only possible if you've never experienced it yourself. Then you think like, well, it can't be that bad, since it's not deadly or anything. Well, try living with it yourself and then we'll see if you think it's dangerous or not (Man, study III).

... with primarily stress or psychological aetiology.

It's so easy for them to say that it is all psychological – that is what I've been told: you are burned out. It was very fashionable a few years back to be burned out, so they put me on antidepressants ... I run a company, so they told me my abdominal problem was because of stress and anxiety from working, but I don't experience it like that. Sure, I have had my ups and down in life, feeling anxious at times, but this is not related to that (Woman, study III).

In study II the women reported that such a psychosomatic explanatory model could lead to feelings of guilt about not living as one should, and therefore that they have themselves to blame for being ill (Study II).

The patients actively negotiated the professional discourse by presenting a counter-narrative describing their own suffering and strengths, experienced health care shortcomings, and possible organic aetiology of IBS (Study III).

Supportive encounters were described as being listened to and having ones' point of view acknowledged as valid and important as well as continuity

Wanting to be taken seriously was a phrase that appeared often in the narratives and had two different aspects. First, it concerned relational aspects of the encounter, and second, it was about getting access to resources (e.g. referral, prescriptions, and investigations). Receiving a diagnosis could help with the confusion, but was even more important as a proof of rightful suffering: that one was not weak in character but 'really, objectively ill'.

[A] doctor's diagnosis has authority, you know. And self-diagnosing, well it's not, not scientific. It doesn't have the same authority, or people don't take it seriously, anyway. So I would say it's very important (diagnosis) ... It just feels better to have something backing you up, something that's not just based on your own point of view... but when I think about it, it shouldn't have to be like that. Every person is the expert on their own body, right? ... So my opinion should be worth as much as a doctor's opinion, but it's not. And if my opinion had been taken seriously by them, it would be taken seriously by my friends and family as well. They're the experts, after all (Man, study III).

The issue of aetiology was positioned in relation to responsibility for recovery, as lifestyle or psychological issues were understood to be the responsibility of the patients, and bodily problems the responsibility of health care professionals. The therapeutic option most wanted was medication. Those who had experienced psychological treatment options found them helpful, but did not think they addressed the 'underlying problem'.

Narrators also described their healthy lifestyles, how they managed stress, followed complicated diets, and exercised. Two narratives stood out from the rest regarding the amount of time these patients engaged in discussing how they themselves had overcome IBS through lifestyle changes. These persons were also notably the ones who were most satisfied with the health care professionals. Health care professionals were seen as good, but the real heroes of their narratives were themselves. They had 'won over IBS'.

Somewhat paradoxically, narrators shared accounts of extensive health care utilization, stressful life events, and often a history of psychological problems. However, they refused to see themselves as 'typical IBS patients' and distanced

themselves from being that ‘type of person’, namely stressed, psychologically fragile, and attention seeking.

An intervention for person-centred support

In the following part I will present the findings from the piloting phase of the PS-IBS intervention. The results of the development phase and a full description of the intervention can be seen in Study IV and appendix 1 and 2.

Perceptions of participating in the PS-IBS intervention

Findings from the pilot phase of study IV supported the protocol as being feasible, acceptable to patients and potentially efficient in reducing symptom severity. The findings from the questionnaires and the interviews are grouped under six different themes which all relate to the overarching theme of: ‘Perceptions of participating in a person-centred intervention for IBS’. The six themes are; learning about oneself and about IBS, being part of a supportive patient-nurse relationship, engaging in self-care, using a health diary and written information, exploring personal resources, formulating a health plan and setting goals, and managing symptoms.

Learning about oneself and about IBS

The interviews revealed that the intervention induced learning, consisting of factual knowledge about IBS such as pathophysiology, but also learning about oneself, such as trigger factors for symptoms and ways to cope with symptoms. Thus, the fact that the information and support was personalized and tailored was seen as a crucial element by the participants.

Being part of a supportive patient-nurse relationship

The participants stated that they had felt listened to and involved in the planning of the care and felt that they had formed a supportive relationship with the nurse. The supportive and relational aspect of the intervention was seen as important as the actual learning and self-care activities. The participants felt that it was positive to meet the same nurse over an extended time period, and some stated that they had shared issues with the nurse they could hardly speak to others

about. Some felt that they would have needed additional meetings. They described the support as having ‘someone being at my back’ or ‘carrying me forward’. They also stated that it was important that the nurse had specific knowledge about IBS and ‘knew what she was talking about’.

Engaging in self-care

The participants reported that the intervention had induced changes in their self-care, although all of them had already developed some self-care strategies through trial and error. The self-care advice given by the nurse was more important for those who were newly diagnosed with IBS, than for those with long illness trajectories. Food-related strategies were the most commonly used strategies, and included how to eat (smaller portions, chew well etc.), and trigger food elimination, but also reintroducing food items in those who had very restricted diets. Those who already exercised regularly felt supported to continue, and of those who did not exercise at the start of the intervention, some started taking long walks during the study. The least appreciated self-care activity was relaxation practices, which were seen as ‘odd’ and ‘taking too much time’.

Using a health diary and written information

The evaluation of using a health diary and the written information were mixed. Regarding the health diary, some felt that it was an important tool to give a good overview over situations and food that might trigger symptoms and also induced a sense of control. Some patients, however, found it to be too burdensome or even ‘controlling’ to complete. Some participants also explored other creative ways for documentation such as personal notebooks or drawings, and also found the written information to be crucial to the understanding of IBS, whereas others felt that it did not provide any new knowledge.

Exploring personal resources, formulating health plans and setting goals

In the interviews not all participants remembered setting personal goals or reflecting on personal resources, but most of the participants had such goals and resources documented in their medical records. The goals that were documented included: to understand why symptoms occur, improvement of symptoms,

knowledge about what to eat, take control of IBS, feel freer, happier and less anxious, and to stop refraining from activities.

The personal resources documented included: having a strong social support system, being knowledgeable, a strong will to overcome symptoms, high self-awareness, a positive attitude, a good relationship with your GP, being creative: already leading a healthy life-style, being good at sticking to routines and focusing on solutions. The quantitative evaluation showed a small numerical increase in self-efficacy at follow-up compared with baseline, but this was not statistically significant (table 7).

The health plans included relaxation exercises, increased physical activity, dietary changes, and less often psychosocial issues (such as being more open about symptoms and seeking more social support).

Managing symptoms

A majority of the participants stated that the intervention had led to a reduction of symptom severity, or at least to another way of coping with symptoms.

However, two participants denied experiencing any symptom improvement or a different way of coping with symptoms. These two had the longest illness trajectories, extensive comorbidities and difficult social situations. However, they did not regret being a part of the intervention, since they found it valuable to get the chance to talk to someone about their life and illness. These two patients were also among the participants, who did not use the health diary or read the written information, and for one of them no health plan or resources were documented.

Those who had experienced a different way of coping with symptoms described it as a different way 'to think about symptoms', and that the symptoms were 'less frightening' and 'not causing so much stress'.

There was also a significant improvement in overall IBS symptom severity measured by IBS-SSS (table 7). Out of the 14 participants who provided follow up data 7 (50 %) had a clinically relevant symptom improvement (≥ 50 points reduction in IBS-SSS total score). There was no change in GI-specific anxiety measured by VSI (table 7).

Table 7. Pre- and post-intervention levels of self-efficacy, GI-specific anxiety and IBS symptom severity (Median, IQR)

	Baseline N=14	Follow up N=14	p-value
General self-efficacy¹	28(26-31)	30(26-33)	0.106
GI-specific anxiety²	35(25-47)	35(18-42)	0.187
IBS symptom severity³	253(176-367)	208(133-291)	0.019*

¹Measured by GSES ² Measured by VSI ³ Measured by IBS-SSS * p-value <0.05

Discussion

Discussion of methods

In the following section I will discuss choice and application of methods in relation to the idea of methodological pluralism and some of the strengths and weaknesses in the different study designs used. I will also discuss choices made during the research process in relation to quality criteria for research according to standpoint epistemology: critical reflection, fairness and responsibility.

Methodological pluralism

Historically there has been skepticism within medical research and practice on whether findings generated by qualitative methods are really scientific (Malterud 2001). Proponents of the qualitative paradigm in turn sometimes tend to romanticize their own practices as more holistic and accuse the quantitative methods of reductionism. Qualitative and quantitative methods both have their weaknesses and strengths, so rather than asking if a research finding is true or not we can ask what it is true about (Malterud 2001).

So what can the present findings possibly be true about? There are some limitations due to the sampling and design of the different studies to be discussed. Recruiting participants from secondary/tertiary care settings means that the findings might not be transferable to non-seekers or primary care populations. Due to the cross-sectional design of study I one cannot evaluate any causality in what the sources are of the differences found. Because there was no control group in study IV, it is uncertain if the demonstrated changes in symptom severity are actually due to the intervention or to a natural fluctuation of symptoms.

Interviews, although remaining closer to patients' experiences than questionnaire data, have their drawback. This is especially true for unstructured interviews, which can favour articulate people and thus can be seen as elitist (Sprague 2016). One example from the present project is one of the participants in study III who presented what could be regarded as a rather 'broken' narrative (Hydén & Brockmeier 2008). I had much trouble following the logic of it as the narrator jumped between contexts and time points and were not native Swedish speaking. Such narratives risks being given less weight in the analysis and I did

not use any quotes from that participant in writing up the result. Another drawback of interview data is that what might be considered to be an attempt to give voice to a certain group can in fact end up supporting the dominating discourse (Sprague 2016). An example of this is study II where the respondents rather uncritically endorsed stereotypical understandings of men and women. If I had stayed closer to their accounts, and refrained from doing a theoretically driven interpretation, I would have reproduced a gender conservative discourse.

Critical reflection, fairness and responsibility

There are other issues besides instrumental ones related to method, that need to be reflected about; where quantitative research traditions can learn from qualitative research traditions. Dahlberg et al. (2001), situated in a qualitative research tradition, state that as researchers we need to be critical of and reflect on our preunderstandings to gain a critical attitude. To achieve a critical attitude, openness is necessary, and ‘to be open means to conduct one’s research on behalf of the phenomenon’ (Dahlberg et al. 2001).

One way to conduct research ‘on behalf of the phenomenon’ could be to let the nature of the data guide the choice of method and the theoretical framing. One example of this from the present project is the choice of using a narrative method instead of a hermeneutic method in study III. While conducting the interviews for study III, I noticed that participants were not abiding to my research agenda and I was frustrated that interviewees departed from my questions. After the third interview, where I tried to steer my informants back to the subject (as I perceived it), I decided to let them elaborate more freely, still using the same introductory question. It then appeared to me as though the narratives were pleas of something, and that they found it important to present themselves in a certain way, or even: to defend themselves. The choice of changing the hermeneutic method for a narrative method was to be able to capture these narratives as such performative acts (see p. 38 on narrative as performative act).

The idea of openness expressed by Dahlberg et al. (2001) seems to correspond to the idea of ‘fairness’ as expressed in standpoint theory as a criterion for good research. The fairness doctrine implies that research should ‘be fair to all existing evidence and to its severest critics’ (Harding 2015). Being fair to the evidence (or ‘to be open’) could mean to not read my own preconceptions into the data. Being fair to the severest critics’ means transparency, which I have tried to accomplish through thick descriptions: by providing quotes from interviews, and by being open with choices made to make it as easy as possible for the reader to evaluate the quality of interpretations.

Reflection on my own role, interests and influence in the project is also important to ensure transparency. My closeness to the project, for example being the person actually providing the intervention, could be seen as both a weakness and strength. Shifting between roles as a nurse and a researcher has also been challenging at times. I was especially worried that my close relationship to the participants in study IV would make them overestimate the effects of the intervention. In the end I got the opportunity to let another nurse, external to the research group and context, perform and transcribe the interviews and collect the questionnaire data. However, seeing my closeness to the participants also as a resource I did want to be part of the analyses of the material.

My personal experience of being female, a nurse and from a working class background probably has made me more receptive to gender/sex and class aspects of my material and less receptive to issues of for example ethnicity and disability.

Fleming et al. (2003) suggests, on the behalf of doing Gadmerian hermeneutics, that group discussions within the research team could be helpful to identify preconceptions and that analysing both individually and collectively is one way to ensure that the interpretation is truly based on the data. This has been a strategy used in all three qualitative analyses and we do have different professional backgrounds and epistemic holds within the research group which should be regarded as strength. However, since we are all similarly situated as white, middle class, able bodied and educated, we might share the same preconceptions, making it difficult for some shared, deeply rooted prejudice to hit the surface.

From the perspective of critical theory, critical reflection has a somewhat different meaning compared to in the hermeneutic tradition. The focus then changes from individual characteristics and interests of the researcher to her/his relationship to societal power dynamics. A way to handle the problem of 'being open' or 'fair' could be to think of ones characteristics and interests also historically, embedded in a web of power relations where certain voices and interpretations are systematically privileged on the expense of others (Lykke 2010). Having such a critical perspective as a researcher would imply asking questions like: What could be the material effects of our interpretations? Who benefits from such an interpretation and who does not? Are there other possible interpretations that would benefit a different group of people? Who has not been heard regarding this issue? Is our research reproducing oppressive categorizations and/or stereotypes? (Harding 2015). These are also issues with implications for ethical considerations in a research project.

Another criterion for good research according to standpoint theory is responsibility (Harding 2015). I will give some examples of choices made in an

effort to be responsible. In study I, the findings are framed as more similarities than differences. In study II, we interpreted the interviewees' gender conservative discourse as performative acts rather than an expression of 'natural' differences. For study III we decided to be open to other potentially vulnerable positions than gender/sex and pursue a research topic raised by patients themselves which is salient to them and in their direct interest. In study IV there is an added value for research participants since they get to be part of an intervention rather than just providing data.

Another important point of discussion in relation to responsibility is the design of study I and II. Does it not perpetuate gender dichotomies and gender conservative discourse to start out with dividing men and women as separate and distinct categories? Is it not so that a focus of difference actually produces difference? One could argue that such research designs supports stereotypical ideas of men and women as being fundamentally different. It could thus be that some of the gender/sex differences found in study I and II is an artifact from the initial design of the studies.

One way to counteract the risk of such bias, which was used in study III, is to not have any social categorizations from the start but to let them grow out of the material. Still, depending on context, I believe there is a value in using social categories such as men and women as *analytical* categories. However, in doing so, it is important to be mindful of how findings are framed and interpreted not to naturalize potential differences found. As Butler states on using the term woman: 'surely, it must be possible both to use the term, [...] and also to subject the term to critique' (Butler 2011).

Discussion of results

I introduced this thesis by situating it in the area of gender medicine, a research field aiming to put health and illness into context. In the following section I will discuss my main findings in relation to research representing a diverse discourse from gender medicine, through medical sociology and previous research on IBS. I will also relate the findings to the theoretical understandings outlined in the background.

Gendered experiences

In a large sample of patients diagnosed with IBS we found that men and women were more similar than different (Study I). However, there was a pattern of modest, but significant differences regarding symptom profiles, quality of life

and sense of coherence. More severe health impairment in women with IBS has been reported in the literature before, although the data is sometimes conflicting and difficult to interpret (Frissora & Koch 2005, Adeyemo et al. 2010). The pattern with women reporting more severe symptoms and lower quality of life seems to be present also in the general Swedish population and not specific for IBS (Krantz & Östergren 1999).

Interview study II suggested that cultural beliefs and ideals about how men and women should look and behave led to suffering and forced the informants to abandon gender illusions and that this was true for both men and women.

The women described how IBS disrupts them from fulfilling relational responsibilities as partners and mothers and they felt responsible for the welfare of others. Sociologist Ulla-Britt Lilleaas has done research on gender/sex in relation to ill-health in Norwegian men and women and came to similar conclusions. She found that many women had a habit of being in a state of bodily preparedness for others and that they often related to their body as an object or machine (Lilleaas 2003). Strömbäck et al. (2014) found that among young Swedish women with stress-related illness, objectifying and distancing oneself from the body was a strategy to negotiate gendered social norms. Ali et al. (1998) found that communion (a relational focus), a feature traditionally associated with the feminine gender, correlates with preoccupation with symptoms among both women and men with IBS. Such a relational focus, being a major aspect of femininity, was described by the philosopher Simone de Beauvoir in the phenomenological classic 'The Second Sex' already in 1949. She described this way of relating to the world as 'being-for-others' and also argued that women, due to being the 'Other' (see p. 28 on the Other), more often than men relate to their own body as an object (de Beauvoir 2002 [1949]).

One study investigated Taiwanese women's experiences of IBS and also found that cultural and gender norms affect the way women perceived their IBS. They felt it detracted from their feminine image, where women are supposed to be 'clean, modest and reserved' (Lu et al. 2009). They preferred to refer to their symptoms in terms of diarrhoea rather than constipation as they associated diarrhoea with cleanliness, weight loss and a slim body. The gendered norm of slenderness was evident also in the accounts of our participants who suffered from how bloating made them look 'fat'. Men are not indifferent to how their bodies look, but it has been suggested that it is a more central concern to women (Lips 2004).

We found that men are affected by how IBS disrupts their 'doing' masculinity by preventing them from being reliable family providers. Again, in a Norwegian context, where women were found to have a bodily preparedness for others, the men often had a bodily preparedness for work (Lilleaas 2003). Being prepared

for work means being available at all times in a fast paced and continuously changing labor market (Lilleaas 2003). In my material collected more than 10 years later, being prepared for work was a theme in both men's and women's accounts supporting the idea that gendered norms are constantly in a flux (Butler 2006 [1999]). The distribution of paid and unpaid work in heterosexual relationships can also be related to the heteronormative matrix described by Butler, where men and women are expected to take on complementary roles (Butler 2006 [1999]). The kind of paid work women and men do is also partly structured by gender/sex and one study found that women with IBS have lower authority over decisions at work compared to men with IBS (Faresjö et al. 2007).

Although women are nowadays very much part of the workforce, men's participation in household duties has not increased to the same extent (Statistics Sweden 2010/11). Thus, many women face a second shift¹² of unpaid work as they come home from their employment. Such strains possibly take their toll on both physical and mental health, and Hammarström & Phillips (2012) found an association between gender inequity in the couple relationship and depression in Swedish women.

Men were troubled by the 'female health concern' label attached to IBS (Study II). Masculine norms can, in general, hinder men from disclosing pain or other symptoms (Courtenay 2000). Suffering from a disorder understood as a 'women's disorder' could in itself be perceived as stigmatizing for men (Dancey et al. 2002). According to Butler gendered norms are both enabling and restraining (Butler 2011). Some masculine norms might thus protect from symptoms having any major impact on the daily life of men, and Voci & Cramer (2009) found that agency, a trait that is traditionally associated with masculine gender, was related positively to quality of life in women suffering from IBS. On the other hand masculine norms might hinder those men who do suffer from IBS from disclosing that and reach out for help

Gendered health care encounters

In study III we pursued a topic raised by patients themselves in study II: the challenging health care encounter. The problematic encounter in IBS has been discussed before (for example by Dixon-Woods & Critchley, 2000 and Håkanson et al. 2010), but not from a gender perspective.

In study II we found that women were more vulnerable in the clinical encounter. One study also indicates that the medical management of patients

¹² The Second Shift is the title of a book by sociologist Arlie Hochschild from 1989 which describe the double burden of many employed mothers.

with IBS might suffer from a gender bias. In a fictitious case about IBS in a national exam, Swedish residents suggested different investigations and treatment depending on whether the patient was introduced as a woman or a man. For example, more x-rays of the colon were suggested for men, while more tranquilizers and life style advice were suggested for women (Hamberg et al. 2004).

In study III the men and women were equally disappointed with health care. But how could the discrepancy between findings in study II and III be understood? It could be that participants in study III were more severely affected by IBS and comorbidities making social disadvantage based on gender secondary. That would be in line with an intersectional understanding of gender/sex where it is solely one of many social positions. It could also be a question of study design since study II was designed to search for gender differences which study III was not (see discussion of methods). The conclusion in study II that health care practices should be gender sensitive need to be understood in light of the intersectional view of gender/sex guiding this thesis, where gender is one of many vulnerable social positions and should probably be read *power* sensitive. Malterud (1992) has previously described that health care encounters can have an unintentional iatrogenic nocebo effect (detrimental effect caused by health care) in medically unexplained and functional disorders.

We interpreted the findings from study III as patients trying to protect themselves from potentially stigmatizing labelling. They refused to see themselves as ‘typical IBS patients’ and distanced themselves from being overly stressed or psychologically fragile (Study III). Interview studies with nurses and physicians indicate that there might be some stereotypical understandings of patients with IBS amongst health care professionals (Dixon-Woods & Critchley 2000; Letson & Dancey 1996). However, a more recent study reports that general practitioners do not find the management of patients with IBS particularly difficult and that they do consider it being a legitimate disorder (Harkness et al. 2013). That raises the question whether the changed understanding of IBS within the research literature (recall Drossman 2016: ‘the definition has changed from the absence of organic disease to a stress-related or psychiatric disorder to a motility disorder, and [...] to a disorder of GI functioning’), has had an impact on health care professionals’ attitudes to patients? Standpoint theory stresses that research findings has ‘material effects’ and this could be an example of that (Harding 2015).

We suggest that what might be regarded a difficult patient is rather a question of a difficult disorder and the working of cultural myths and norms. For one, medical research and practice tend to differentiate between symptoms (subjective experiences) and signs (objective facts), favouring the latter. We

found that this was true also for the patients who craved medical evidence that they were really sick (Study III). In another interview study patients with IBS believed that biomedical evidence would have strengthened their position in the clinical encounter (Håkanson et al. 2010).

The distinction between symptoms and signs is not in support of people suffering from functional disorder, who fails to present with signs. Malterud (1999), however, tries to overcome this dichotomy (see p. 24 on dichotomies) by reminding us that what kind of signs that can emerge is closely tied to available technology and that someone interpret and make them understandable. Thus, signs are always based on subjectivity and not more 'real' than symptoms (Malterud 1999).

Person-centred care and power sensitivity

Study IV showed that a person-centred support intervention in IBS was feasible, appreciated by patients and potentially efficient in reducing symptom severity. The participants uniformly stressed the importance of the supportive partnership and felt that they had been heard. The theoretical frameworks guiding the intervention were self-efficacy theory, person-centred care (PCC) and critical theory. These were chosen to be able to provide self-management support in IBS, while not reproducing clinical patterns identified in study II and III, whereby patients would feel trivialized and not taken seriously.

I understand person-centred care as a potentially radical paradigm that could well suit the specific challenges posed by functional disorders. By stressing the importance of patient narrative and lived experience, it reverses the traditional hierarchy that favours the objective over the subjective. Working in partnership with the patient and practicing shared decision making could also destabilize the power asymmetry between the health care professional and the patient.

So, what does it mean for clinical practice to be power sensitive? It must be beyond our control as health care professionals to attend to issues of social justice? Malterud (2010) states, that what we can do is to make sure not to reproduce social injustice in the clinical encounter, for example by 'ruling the rhetorical space' and by favouring signs over symptoms.

To approach patients with IBS in a power sensitive way would include to: 1) avoid possibly stigmatizing labels, 2) make sure not to dominate the clinical interaction, 3) understand that symptoms are as 'real' as signs, 4) not to reproduce stereotypical understandings of men and women or of patients with IBS.

We found that patients did not accept individual responsibility for recovery (study III). The question of responsibility for recovery needs to be addressed further, especially since the intervention entails self-management support in IBS. Opposed to what the word implies, self-management can never mean to truly self-manage, as in doing it all on your own (Bengtsson 2015). This is important to stress in a cultural context dominated by a healthism paradigm where the body is seen as an object to be controlled by making rational lifestyle choices. This paradigm tends to overestimate the amount of control one can have over one's body and health, for example by overlooking social factors restraining the possibilities for healthy choices (Bird & Rieker 2008; Lupton 1995). So the keyword here is support, as in health care professionals supporting their patients in their endeavour to self-manage IBS.

Conclusion and future perspectives

Among patients diagnosed with IBS it was found that there were more similarities than differences when men and women were compared. However there was a pattern of difference disfavoring the women, especially regarding health related quality of life but also regarding bowel habits where women reported more constipation and bloating. In a consequent interview study it was found that the experience of living with IBS was gendered meaning that social norms on masculinity and femininity affected the experience of symptoms. Interviewing patients with severe IBS their experiences of health care encounters were mostly negative and they described how they struggled to protect their positive identities from stigmatizing labeling. Thus patients with IBS need to be approached in a power sensitive way which include to: 1) avoid stigmatizing labels, 2) make sure not to dominate the interaction, 3) understand that symptoms are as 'real' as signs, 4) not to reproduce stereotypical understandings of men and women or of patients with IBS.

An intervention for person-centred support in IBS was developed and found to be feasible, appreciated by the participants and efficient in reducing IBS symptom severity in a pilot study, whereas there were no significant changes for general self-efficacy or GI-specific anxiety. These findings are only preliminary and need to be further evaluated controlled studies including larger samples.

The present thesis only gives limited knowledge on IBS and social categories apart from gender/sex such as socioeconomic status, educational degree or ethnicity. This thus presents with an important subject for further research.

There are also several ontological issues that could be attended to in future research, regarding what kind of theoretical understandings of the body we need to guide research on symptom generation in complex disorders such as IBS. Interdisciplinary collaborations between scholars of gender studies, medicine and health care sciences are thus warranted.

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