Self-care: the way to find balance in life

Development and evaluation of a self-care questionnaire for patients with inflammatory bowel disease

Ulrica Lovén Wickman

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Dedicated to all the patients living with inflammatory bowel disease

Knowledge will bring you the opportunity to make a difference.

–Claire Fagin

Vigilans et fidelis

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ABSTRACT

Introduction: Inflammatory bowel disease (IBD), ulcerative colitis (UC), and Crohn's disease (CD) occur worldwide and are life-long chronic conditions. The symptoms, which include abdominal pain and frequent diarrhea, cause limitations in life. Thus, patients with IBD need self-care in accordance with their symptoms, their own commitment to maintaining health, and decisions on symptom management. To strengthen self-care, there is a need for a tool that assesses self-care in patients with IBD, which aims to support the patient dialogue about self-care.

The overall aim of this thesis was to develop and evaluate a questionnaire for the clinical assessment of self-care, and to explore self-care in relation to disease activity and to health-related quality of life (HRQOL) in patients with IBD.

Design and method: The thesis includes four studies, where studies I, II and IV were conducted in Sweden, and study III was conducted in the United States (U.S.). In study I, a descriptive design, interviews were conducted with twenty adult patients, in order to explore self-care in patients with IBD. In study II, the self-care questionnaire was developed and tested with 193 patients with IBD in Sweden. In study III, a cross-sectional descriptive design, the self-care questionnaire was translated into English, and the responses of 67 patients in the U.S. were evaluated. Finally, in study IV, a cross-sectional exploratory design was used to explore self-care in relation to patient characteristics, disease activity, and HRQOL among 234 patients. For a total of 421 patients, the data was analyzed using content analysis, and descriptive and analytic statistics (studies I, II, III and IV).

Results: Among patients with IBD, self-care relates to symptom recognition, handling symptoms, planning life, and seeking new options. Self-care varied according to how the patient managed daily life with regard to the symptoms of the disease (study I). Based on the results from study I, the self-care questionnaire was developed in Swedish, resulting in a valid and reliable questionnaire comprising 22 items (study II). The questionnaire was translated to English, and performed self-care activities were associated with a lower degree of well-being in relation to age and gender (study III). The patients were taking medication for IBD, paying attention to their

intestinal symptoms, adapting their diet, managing their stress, planning their day and avoiding activities (studies III and IV). Self-care was more frequent in patients with CD when it came to paying attention to psychological symptoms; diet adaption; avoiding various activities including sex; and looking for new approaches to living with IBD. A greater degree of self-care activities was associated with a lower degree of HRQOL (IV).

Conclusion: The results indicate the importance of identifying the total symptom experience, and of the patient's need to discuss self-care, in order to strengthen self-care and achieve better treatment. The self-care questionnaire can be a useful tool to benefit the discussion of self-care for the patient, and to secure health literacy, medication adherence, and HRQOL. The valid and reliable self-care questionnaire is available for patients with IBD at gastroenterology clinics or out-patient clinics, as primary care. Disease activity affects self-care, and consequently the self-care activities.

Keywords: disease activity, inflammatory bowel disease, instrument development, health-related quality of life, questionnaire, reliability, self-care, symptoms, translation, validity, well-being

LIST OF PAPERS

This thesis consists of four studies, two of them published in international peer-reviewed scientific journals. In the text, the studies are referred to by Roman numerals. Studies I and II are reprinted with the permission of the publisher. Studies III and IV have been submitted for publication.

- I. Lovén Wickman U, Yngman-Uhlin P, Hjortswang H, Riegel B, Stjernman H & Hollman Frisman G (2016). Self-care among patients with inflammatory bowel disease: An interview study. *Gastroenterology Nursing*, 2016, 39(2):121–8. doi: 10.1097/SGA.0000000000000120.
- II. Lovén Wickman U, Yngman-Uhlin P, Hjortswang H, Wenemark M, Stjernman H, Riegel B & Hollman Frisman G (2019). Development of a self-care questionnaire for clinical assessment of self-care in patients with inflammatory bowel disease: A psychometric evaluation. *International Journal of Nursing Studies*, 2019, Jan; 89:1-7. doi: 10.1016/j.ijnurstu.2018.08.016.
- III. Lovén Wickman U, Yngman-Uhlin P, Hjortswang H & Hollman Frisman G. Questionnaire-based evaluation of self-care in inflammatory bowel disease. Manuscript submitted.
- IV. Lovén Wickman U, Hollman Frisman G, Hjortswang H & Yngman-Uhlin P. Self-care, disease activity and health-related quality of life in patients with inflammatory bowel disease: A cross-sectional exploratory study. Manuscript submitted.

ABBREVIATIONS

AGA	American Gastroenterological Association
CAM	Complementary alternative medicine
CD	Crohn's disease
CRP	C-reactive protein
CVI	Content validity index
ECCO	European Crohn's and Colitis Organisation
EIMs	Extra intestinal manifestations
GI	Gastrointestinal
HCP	Health-care professional
HRQOL	Health-related quality of life
IBD	Inflammatory bowel disease
MRI	Magnetic resonance imaging
SMT	Symptom management theory
TOUS	Theory of unpleasant symptoms
UC	Ulcerative colitis
VAS	Visual analogue scale

PREFACE

In 2012, my former manager director Ann-Kristin Kempe asked if I was interested in participating in a doctoral project. After several meetings with my main supervisor, I was accepted for doctoral studies in March, 2013. As a primary care nurse for decades, I saw that self-care was common, and necessary in order to manage day-to-day life with a chronic disease. Self-care may be the key to living a balanced life; it can lead to decreased complications and a healthier lifestyle. To improve the daily life of patients with inflammatory bowel disease (IBD), supportive efforts are required.

My interest in research has evolved during these years, with a lot of enthusiasm, curiosity, patience, thinking, and investigation. I have made new insights, I have learned a great deal, and I have developed as a researcher. In the beginning, when the interviews were conducted, many stories were entrusted to me, and these gave me an insight into the value of self-care in the patient's daily life. Therefore it is important to develop self-care research, for the benefit of the patients. There is a need for support in the assessment of self-care, and this thesis will provide insight into questionnaire development and self-care in patients with IBD, both in Sweden and the U.S. The truth exists out there, and design, planning, and an evaluation process are the keys to development.

Ulrica Lovén Wickman

INTRODUCTION

This doctoral thesis is an inquiry into and an analysis of patients' self-care when living with inflammatory bowel disease (IBD). There is no clear evidence that self-care programs for patients with IBD improve health or increase well-being. Still, nurses in the field of IBD are encouraged to facilitate self-care (1, 2).

IBD involving ulcerative colitis (UC) and Crohn's disease (CD) is a chronic life-long condition. It normally has its onset early in life but can arise at any age (3). In industrialized countries worldwide, the incidence of IBD is increasing (4). Living with IBD requires the understanding of people in one's surroundings (5).

Research concerning self-care in patients with IBD has previously focused on medication adherence, diet adaptation, self-efficacy, and social support (6-8). The symptom experience is often unpleasant and affects patients, with consequences for their daily life (9). Patients manage the symptoms in daily life with medical treatment and other self-care activities. It is important for patients to receive knowledge about IBD and its treatment at the time of diagnosis. Self-care relies on the patient's knowledge, support from health-care professionals (HCPs), web-based information and forums, social contacts and patient organizations (7, 10). Self-care in patients with IBD is valuable, and includes a healthy lifestyle that involves a nutritious diet, sufficient sleep, and regular exercise. These are all important factors for the long-term HRQOL of patients, and of people in general (2, 11). Self-care in IBD often aims to avoid symptoms and maintain health (12).

This thesis focuses on the development and evaluation of a self-care questionnaire for patients with IBD, and may help increase our knowledge of self-care in these patients.

BACKGROUND

Epidemiology

The incidence and prevalence of IBD varies around the world. Since the 1990s, the incidence of both CD and UC have increased in Africa, Asia and South America (4). For CD, the incidence per 100,000 adults is 10 in Sweden, 0.3 to 12.7 in Europe, 0 to 20.2 in North America and 0.04 to 6.4 in Asia (13). For UC the incidence per 100,000 adults is 19 in Sweden, 0.9 to 24.3 in Europe, 0 to 19.2 in North America and 0.1 to 6.3 in Asia (14). In Europe the highest prevalences per 100,000 adults are (for CD) 322 in Germany and (for UC) 505 in Norway. In North America, the highest prevalences are found in Canada, with 319 for CD and 286 for UC (4, 15-17).

Pathogenesis

The pathogenesis of IBD is not fully understood. Several factors appear to be involved in the development of IBD, such as dysfunction of the intestinal barrier and of the immune system, as well as patient genetics and environmental factors (18). Both CD and UC are associated with gene defects, including genes related to maintenance of the intestinal barrier and to immune regulation (19). The immune system is complex, with both the innate immune system that is unspecific but that activates rapidly, and the adaptive immune system that is more specific. Immunological tolerance is affected by the impaired intestinal barrier and microbiome (20, 21). Twin studies have shown evidence for the heredity predisposition of IBD. One theory is that a barrier dysfunction is a primary defect in CD, since changes were predominantly seen in monozygotic twins (22, 23). Other theories are that gene defects lead to an immunological dysfunction and lost immunological tolerance, resulting in an abnormal immune response to harmless antigens, or that IBD can be triggered by a virus or bacteria (24, 25). Gene defects in patients with IBD are associated with functions such as cell cycle and growth, fluid balance in the colon, lipid and lipoprotein metabolism, and the mucosa barrier dysfunction (26, 27). Genome-wide association studies identify over 230 genetic loci known to be associated with IBD (28, 29). The explainable genetic risk is only 20-25% of the expected heritability in IBD (30).

A number of environmental factors have been associated with development of IBD, such as enteric infections, certain foods, and changes in nutritional behavior (31). The impact of nutrition varies, but so far there is no evidence that any food has effect (32-34). Smoking is a risk factor, because nicotine negatively affects the microcirculation, reducing the blood flow to the mucosa, the microbiome, the smooth muscles, and the intestinal permeability (35). Continued smoking increases the risk of a more complicated course of CD, and is associated with a poorer prognosis. The reverse applies for UC, with a lower risk of illness (36). Other increasing risk factors are antibiotics and anti-inflammatory medication, which can trigger relapse in IBD (31). To date, still there is no answer to why more patients develop IBD, and environmental factors are further discussed (25).

Diagnostics

IBD is diagnosed based on clinical signs and on physical examination of the clinical picture, including the symptoms, endoscopy, magnetic resonance imaging (MRI) and histology. Laboratory parameters including measurement of C-reactive protein (CRP) and fecal calprotectin are important tools for the initial diagnosis of IBD. The appearance of inflammation and the localization and identification of extra-intestinal manifestations (EIMs) are important in the diagnostic evaluation, and intestinal infections with similar symptoms must be excluded (37-40).

CD can affect all parts of the gastrointestinal (GI) tract, including all the layers of the intestine. The intestinal mucosa may become thickened due to edema, fibrosis, or hypertrophy (41). UC affects only the mucosa, not the underlying layers. Regenerative mucosa may occur between the ulcers, which are called post-inflammatory polyps. Abscesses, atrophy, and fibrosis can be seen in the mucosa (42, 43).

Symptoms in inflammatory bowel disease

IBD causes a variety of symptoms, and its course is unpredictable, including periods of remission and relapse. Patients describe continuing and variable symptom experiences (38, 44, 45). Physical symptoms include bowel-related symptoms such as abdominal pain and cramping, loose stools, increased stool frequency, urgency, incontinence, bloody diarrhea, fever, and anemia. In severe diarrhea, the inflamed mucosa and the resection of parts of the intestines lead to an inability to absorb nutrients, and with time, nutritional deficiencies may occur (38). Common psychological symptoms are worry, anxiety, and depression. Stress can often exacerbate the symptoms of patients with IBD, but more symptoms does not necessarily mean increased inflammation (46). There is no proven association of a causal relation between psychological symptoms and the development or progression of IBD (47).

Disease severity and complications

The course of IBD is variable and the detection of complications requires continuing clinical follow-up (48). EIMs are common in patients with IBD, with a prevalence of 25 to 40%, including joint inflammation and dermatologic and ocular problems (49). The most common EIMs are musculoskeletal (such as arthritis and osteoporosis), dermatological (such as erythema nodosum, pyoderma gangrenosum, aphthous ulcers, necrotizing vasculitis), and eye disorders (uveitis/iritis, episcleritis, scleromalacia, corneal ulcers or retinal vascular disease) (49, 50). With CD, there is a risk of complications such as stenosis or fistulas in the intestine. Perianal disease may be developed with fistulas and/or abscesses (51). Primary sclerosing cholangitis in CD and UC is a chronic cholestatic disease affecting predominantly males with a median age of ~40 years. Primary sclerosing cholangitis is a chronic and asymptomatic cholestasis, which encompasses icteric cholangitis with pruritus and cirrhosis, which in turn can cause cancer. Serious complications in UC include toxic mega colon, bowel perforation and excessive bleeding (52). Development of colon cancer is increased among patients with CD and UC. Patients with UC have an increased risk of dysplasia and adenocarcinoma (39). Immune modulators protect against cancer development by controlling the inflammation that can cause cancer. On the other hand, the risk of lymphoma, non-melanoma skin cancers and bladder cancer is increased by medication with thiopurine (53). A risk of developing cancer has also been shown on the skin, kidneys, prostate, and pancreas (54).

Treatment

Medical treatment

In patients with IBD, medical treatment is directed at the inflammatory process. The aim is to treat the acute disease, in order to induce clinical remission and then to maintain remission. The step-up method is usually used, but patients with a poorer prognosis or complications may use biological treatment and/or immune modulator treatment at an earlier stage. The choice of treatment is individual, and based on disease location, severity, medication side effects, EIMs, multi morbidity, and individual aspects (37, 55).

Current guidelines for the treatment of IBD, as well as the disease location and its severity, should be evaluated based on endoscopy, MRI, and laboratory parameters such as CRP and fecal calprotectin (12). Anti-inflammatory drugs are used in IBD for local effect in the intestines. Oral aminosalicylates (5-ASA) are available with different modes of administration to achieve high concentration in the colon; these include sulfasalazine, mesalamine, balsalazide, and olsalazine. Rectal medication such as suppositories, foams, and clyisma can be given, in order to reach different segments in the rectum and the left colon (56). Corticosteroids are primarily used for patients with CD, to induce remission. Corticosteroids have side effects and patients who do not respond to corticosteroids are considered for other options such as biological treatment or immune modulators (38). For UC, corticosteroids are given as treatment if aminosalicylates do not respond or in case of high disease activity. Immune modulators reduce inflammation by targeting the immune system, with the aim of maintaining remission in patients with IBD. Immune modulators such as thiopurines include 6-mercaptopurine, azathioprine, cyclosporine, tacrolimus, and methotrexate, and are efficient in more severe disease or steroid dependency. For CD with complications, patients are given biological treatment with or without simultaneous immune modulators. Biological treatment in tumor necrosis factors (TNF)- α inhibitors such as infliximab and adalimumab neutralize a protein produced by the immune system, and are used for patients with moderate to severe CD or UC (57). Methotrexate is effective for the maintenance of remission in patients with CD. Novel treatments such as janus kinase inhibitors (JAK) inhibitors (tofacitinib) and biological treatments such as vedolizumab and ustekinumab have recently been approved (58). Antibiotics including metronidazole and ciprofloxacin are recommended for cases of septic, bacterial or perianal disease complications (38). Many patients will need further treatment such as cancer treatment, chemotherapy, radiation, hormonal therapy, or surgery (53).

Surgery

In CD, surgery is mostly performed on patients who do not respond to medical treatment, and in case of complications such as strictures, stenosis, abscesses and fistulas (59). Surgical treatment is not a curative option for patients with CD, because the inflammation tends to recur (48). Surgery for severe UC includes proctocolectomy with ileostomy or restorative proctocolectomy, with an ileal pouch-anal anastomosis. Reconstruction can also be performed with ileorectal anastomosis or a Kock pouch (59). The only treatment for primary sclerosing cholangitis is liver transplantation (60, 61).

Self-care

Most patients with IBD have maintenance medical treatment; as the disease is chronic it is important that they adhere to the prescription even if there are no symptoms (38, 62). Self-care for patients with IBD may also consist of support groups (63). IBD schools with patient education are often available at gastroenterology clinics, on the internet, on podcasts and on cell phone apps (64, 65). This is available in Sweden on the internet and on cell phone apps. There are also psychological interventions such as cognitive behavioral therapy, mindfulness-based therapies, hypnosis, and stress management (34).

Self-care as regards medical treatment, exercise, diet management, stress management, and information on tobacco and alcohol must be provided to the patient, and is especially important for patients with IBD (34). For patients with CD, tobacco cessation is the most effective way to reduce relapse. Among patients with UC, the recommendation is also tobacco cessation, in order to enhance overall health aspects. Alcohol often irritates the gastrointestinal tract (66). Higher levels of stress are associated with relapse (67). However, among patients with depression in IBD, there is limited support for the use of stress management (34). To reduce stress, enhance nutritional status, and improve mental and physical health, exercise is recommended (34, 68). Dietary recommendations include regular meals and a balanced diet every day. Individual recommendations relating to dietary content, surgery, and exercise levels must be discussed. Onions, leguminous plants, fruit, juice, dairy products, and carbonated drinks are examples of dietary content that can be reduced. Patients with IBD may have difficulty maintaining adequate nutrition in periods of relapse (34).

Living with inflammatory bowel disease

Patients with IBD face a wide range of challenges including medication side effects, symptoms, and social isolation (69). Living with IBD impacts on daily life, with effects such as exhaustion, a damaged body image, not being believed, secrecy, limitations, and fear of complications (70). The symptom experience, with abdominal pain and diarrhea, varies individually and over time, and may be very debilitating for the patient. Self-image, social relations, attitude to life, and sense of well-being have been described as crucial (9). Studies have shown an increasing sickness and reduced health status and HRQOL among patients with IBD when the patients are unemployed or on sick leave (71-73). Adults are affected by loss of productivity as a result of sick leave, unemployment, and early retirement (74).

Reproductive health

Patients with IBD are affected in their reproductive age, when raising a family, and in social relations. Medical treatment can decrease fertility in men with reversible oligospermia. Surgery can reduce fertility among men and women. Proctocolectomy and ileoanal anastomosis may affect men with impotence, ejaculatory problems, and decreasing fertility. After surgery, fertility often decreases for women who undergo an ileal pouch-anal anastomosis. The effects of medical treatment and the risk of relapse during pregnancy influence health (62, 75, 76). Many patients feel uncomfortable sharing their concerns, and live alone with their concerns and anxiety (5).

Health-related quality of life

In patients with IBD, HRQOL refers in this thesis to *“the patient’s experience of how illness or treatment interferes with daily life”* (77) p. 1196. This definition applies to the World Health Organization (WHO) definition of a multi-dimensional concept including domains related to physical, mental, emotional, and social functioning (78). Patients with a longer disease duration experience a better HRQOL than patients with a shorter disease duration, and CD patients with a short disease duration are reported to have the lowest HRQOL and are in greatest need of education and support (77, 79). HRQOL varies depending on how patients with IBD manage limitations related to the IBD symptoms (80). At the worldwide level, HRQOL is impaired for patients with both CD and UC (81, 82). Symptom severity, relapse, and not working are seen as factors associated with lower HRQOL (80).

THEORETICAL FRAMEWORK

Symptom theories

Symptom theories describe different views of the symptom experience (85, 86). There is no consensus on the definition of symptoms. However, symptoms can be defined as a subjective experience from the patient's point of view, "*a subjective experience reflecting the bio-psycho-social functioning, sensations and cognition of an individual*" (83) p. 669. Symptoms differ over time and several symptom dimensions can be experienced (84).

The *Symptom Management Theory (SMT)* describes symptoms as a dynamic process with individual outcomes. Influencing factors are the patient, health/illness, and the environment. The symptoms do not have to be experienced by the patient; they may be at risk of developing as a result of an influencing context variable. All chronic and acute symptoms must be managed in relation to a specific individual, group, family, or work environment (83, 85, 86). In IBD, symptoms may affect the patient's psychological and social lives due e.g. to difficulties in maintaining employment (87).

The Theory of Unpleasant Symptoms (TOUS) has three components: the individual symptom experience, the influencing factors that affect the symptoms, and the consequences of the symptoms (84). The symptom experience is described in terms of *intensity*, i.e. the strength or severity of the symptoms; *timing* in duration and frequency of the symptoms; the level of *distress*, i.e. the patient reaction and how bothered the patient is by the symptoms; and *quality* – how the patient characterizes the symptoms. These dimensions can be separate or related to each other, and multiple symptoms can co-occur (84). With IBD, the majority of the symptom experience is unpleasant, including e.g. abdominal pain, bloody stools, and EIMs. In the symptom experience, intensity is individual and varying. Distress in IBD is often related to worry and anxiety (87).

The influencing factors are psychological, physiological, and situational factors (84, 88). Psychological factors such as fatigue are frequent in patients with IBD, both in remission and active disease (89). Mood disorders such as worry, anxiety, and depression may also be influencing factors (87). Patients with IBD have poorer mental health, and perceive their health as

worse than people without chronic disease (69). Physiological factors such as bloody diarrhea affect the patient's life situation. Situational factors can be referred to social support. Social support is reliant on the knowledge and discourses of the chronic illness, and how it is mediated by ethnicity, group history, and experiences within the family (8). With IBD, increased social support is associated with improved HRQOL (8).

The consequences of the symptoms depend on how the symptoms appear and their effect on the psychological, physiological, and situational factors (84). Bowel problems in IBD affect the patient's professional life, and their ambition to reach personal goals (91).

Self-care theories

Symptoms interact with self-care and are integrated in the middle-range theory of self-care. Symptoms are known to influence self-care and various elements of the self-care process (92). Self-care has become more important and increasingly, efforts are made to educate and support patients' self-care in managing their health. Evidence shows implications of improved self-care through improved consultation quality, fewer health-care visits, reduction of hospital admissions, and improved medicine use (93).

There is no consensus on the definition of self-care; several definitions exist. Self-care includes care of oneself, family, and friends. The definitions include words that imply active choices or actions of the patients and HCP (94, 95). The ways in which patients perform self-care are described in the middle-range theory of self-care in chronic illness (96).

This thesis uses the definition from the middle-range theory of self-care: "Self-care is a process of maintaining health through health promoting practices and managing illness" (96) p. 195. The theory evolves from studies of self-care in heart failure, and expresses self-care in terms of maintaining health, being alert to symptoms and choosing the ultimate self-management (97, 98). Engaging in self-care makes the patient an active participant in the management of the illness, and self-care is not identical for all patients or fixed over time. Self-care, when living with a chronic illness, is often related to recommendations from HCPs. When living with a stable condition, one is often able to maintain health. In an active chronic illness, self-care becomes a priority, and self-care is vital to the maintenance of health (96).

The self-care theory includes three key concepts:

- *Self-care maintenance*: behavior that the patient uses in order to adhere to treatment and advice, with the aim of maintaining health by way of positive health practices. The behaviors can be either self-determined or by recommendation from the HCP (96).
- *Self-care monitoring*: activities that involve the process of paying attention to oneself and to the symptoms that arise, by way of body listening. Observing, interpreting and responding to bodily changes are essential to an awareness of changes in signs and symptoms. Monitoring activities must change clinically over time, and for self-care management to be effective, changes in symptoms must be monitored, because one cannot make decisions regarding adjustments if the symptoms have not been evaluated (92, 96).
- *Self-care management*: evaluation of symptom recognition; evaluation of the importance of the change in signs or symptoms; implementation of a treatment option; and monitoring of the effectiveness of the chosen treatment (96).

The self-care process for patients with chronic illnesses such as IBD can be described as daily challenges to maintain health by way of positive health practices in self-care maintenance. Paying attention to the symptoms and interpreting changes in them influences self-care management (92, 96).

RATIONALE

Studies of symptoms among patients with IBD, and studies related to HRQOL, are available. Several of these express the multitude of self-care activities that patients with IBD perform, as well as the consequences of living with IBD. When this project started there existed a knowledge gap regarding the assessment of self-care in clinical health care, as well as regarding self-care in relation to disease activity and to HRQOL among patients with IBD.

For many years there has been evidence that self-care is associated with both better treatment outcomes and higher patient satisfaction. Positive self-care includes a healthier lifestyle, managing medication, using services, and being able to understand and respond to symptoms (95). The patients manage their conditions according to their experience of living with the chronic condition, socioeconomic circumstances, and the context and family situations. HCPs can learn to become experts on managing diseases while the patients are experts at handling their life situation. Active participation is a prerequisite for self-care, and self-care is a process that gradually evolves during the patients' life span (96).

Patients need to routinely reflect on their self-care, so they can discuss it with HCPs in line with the recommendations of the Swedish National Board of Health and Welfare (99, 100). Therefore, the purpose of this thesis was to develop a structured assessment tool for self-care in patients with IBD. The purpose of this thesis was to support patients in their day-to-day lives, in order to enhance their HRQOL.

AIMS OF THE STUDY

The overall aim of this thesis was to develop and evaluate a questionnaire for the clinical assessment of self-care, and to explore self-care in relation to disease activity and to health-related quality of life in patients with IBD (studies I-IV).

The specific aims were:

- To explore self-care among patients with inflammatory bowel disease
- To develop and evaluate the self-care questionnaire for assessment of self-care among patients with inflammatory bowel disease
- To investigate self-care practices in adults with inflammatory bowel disease with a newly developed questionnaire, which was developed in Swedish and translated to English in a U.S. sample of patients with IBD, and further to determine if these practice are related to well-being
- To explore self-care in relation to disease activity and health-related quality of life in patients with inflammatory bowel disease

METHOD

Design

This thesis is based on various designs, with the aim of developing and evaluating a self-care questionnaire. In study I, a descriptive design was used. Study II consisted of a questionnaire development; study III comprises a cross-sectional descriptive design; and in study IV, a cross-sectional exploratory design was performed.

Setting

In studies I, II, and IV, the participants were recruited from gastroenterology clinics in southeastern Sweden during a period between June 2012 and April 2017. Study I included patients from two county hospitals. Studies II and IV were conducted with patients from two county hospitals and one university hospital. Study II also included HCPs from five gastroenterology clinics in southeastern Sweden. Study III was conducted in the U.S, and the participants there were recruited in October and November of 2015.

Sample

Inclusion criteria for all studies were adults ≥ 18 years and language knowledge. Exclusion criteria for study I were surgery within the last six months or another severe symptomatic chronic disease. In study I, patients with IBD were selected with a variation in age, gender, diagnosis, and duration of disease from two gastroenterology clinics. Recruitment of patients in study II and IV was performed from three gastroenterology clinics in southeastern Sweden. Patients who answered the final questionnaire with 22 items ($n=93$) in study II were also included in study IV. In study III the participants were recruited and identified by ResearchMatch.org, an online database in the U.S. For a comprehensive description of study design and methods in all studies, see Table 1.

Table 1. Design, methods and analysis

Study	I	II	III	IV
Design	Descriptive design	Questionnaire development	Cross-sectional descriptive design	Cross-sectional exploratory design
Data collection	Individual interviews	Questionnaires Cognitive interviews	Questionnaires in a web survey	Questionnaires
Inclusion criteria	≥18 years, knowledge of Swedish language	≥18 years, knowledge of Swedish language	≥18 years, knowledge of English language	≥18 years, knowledge of Swedish language
Samples	Purposeful sampling.	Consecutive sampling	Convenience sampling	Consecutive sampling
Settings	Two county hospitals in Sweden	Two county hospitals and one university hospital in Sweden	Web survey on ResearchMatch in the United States	Two county hospitals and one university hospital in Sweden
Data analysis	Content analysis	Descriptive and analytical statistics	Descriptive and analytical statistics	Descriptive and analytical statistics

Data collection

Patient characteristics

In study I, patient characteristics were obtained after each interview. In studies II and IV, patient characteristics were obtained in the form of demographic data. In study III, patient characteristics were obtained in the web survey.

The flow chart shows the patients and HCPs participating in the studies, and the numbers of items (Figure 1).

Figure 1. Flow chart of patients with IBD, and health-care professionals

Interviews (Study I)

In study I, data was collected in individual semi-structured interviews. The interviews were performed face-to-face, except for one telephone interview. The location of the interview was decided by the patient: at the patient's home, in a room near the hospital or at the patient's workplace. An interview guide was formulated by the author, and was used to explore self-care in patients with IBD. Three pilot interviews resulted in one added question. The interviews started with introducing the author and creating a relaxed atmosphere. Thereafter came an opening question: "Please tell me what self-care means for you?".

The participants were then given three open-ended questions (Table 2).

Probes and follow-up questions were used, such as “Can you tell me more about?”. The interviews were audio-recorded and transcribed verbatim.

Table 2. Interview guide

<ul style="list-style-type: none"> • Tell me what you do to influence your disease in order to feel well? • Tell me what you particularly attend to related to your disease? • Tell me what you do to manage symptoms of your disease?

Development of the self-care questionnaire (study II)

The development of the self-care questionnaire was done in three phases: item generation, early evaluation, and final evaluation (Figure 2).

Figure 2. Development and evaluation process in item generation, early evaluation, and final evaluation

Phase 1, item generation

Items were constructed to describe self-care in patients with IBD, based on a review of the literature and analysis of the interviews in study I. A literature search was initially performed in the databases Pubmed and Cinahl with the search string self-care/self-management AND inflammatory bowel disease. The literature search was updated throughout the development process and the evaluation of the self-care questionnaire (101). Based on the literature review and the interviews, the first version of the self-care questionnaire consisting of 51 items was developed and evaluated by three nurses and one physician in the research group.

Phase 2, early evaluation

Health-care professional validation

The HCPs, three physicians, and three nurses from various hospitals in Sweden, all with extensive clinical experience in gastroenterology (11-37 years), were asked to participate. Four of them had academic experience. They were given an information letter about the study, the items in the questionnaire and instructions on how to assess each item. They were asked to consider whether each item was relevant or not and whether the questionnaire measured every dimension of the content area. The items were rated on a categorical scale: “not relevant”, “sometimes relevant”, “often relevant”, and “always relevant”. The HCPs were also asked to suggest improvements to the existing items, and to suggest new items. Each HCP assessed the items individually, and a content validity index (CVI) was computed for each item and for the total questionnaire (102, 103, 105). The item-CVI (I-CVI), for each item was calculated, giving a rating of either 3 or 4, divided by the total number of HCPs. The CVI for the entire scale, scale-CVI (S-CVI), was calculated as the average value of all the I-CVI values (102, 103, 105). After the HCP validation, one item was added (I avoid sex) and two items were combined to a single item.

Cognitive interviews with patients

Three patients with IBD, who had already given their informed consent to participate in the study, were asked to participate in cognitive interviews. Oral and written information was provided before the cognitive interviews. The interviews were performed in a health-care setting with the author as interviewer. The patients were asked to speak out loud when answering the 51-item questionnaire. The cognitive interviews were audio-recorded and transcribed verbatim, and analysed by way of discussions among the research group (104). After the cognitive interviews, two items were reformulated and one item on smoking was deleted.

Content validation assessed by patients

The questionnaire (50 items) was thereafter sent to 100 patients with IBD for validation. The items were rated on a categorical scale: “never”, “sometimes”, “often”, “always” and “not relevant item”. The patients were asked to rank the items, to suggest new items, and to suggest improvements to the items. For each item, the percentage of “often” and “always” responses was calculated.

The 22 items were thereafter compiled into 9 questions and 22 items, making up the final form of the questionnaire (Table 3).

Table 3. The final self-care questionnaire

1. Do you pay attention to symptoms of inflammatory bowel disease?

Items: a) I pay attention to intestinal symptoms/b)physical symptoms unrelated to the intestines/c) psychological symptoms

Scores: from 1 (never) to 4 (always) or 5 (not applicable)

2. How often do you feel confident that you are able to determine whether intestinal symptoms are due to inflammatory bowel disease?

Score: from 1 (never) to 4 (always) or 5 (not applicable)

3. How often do you adapt your day to problems caused by inflammatory bowel disease?

Items: a) I adapt my diet/ b) I avoid various activities/ c) I avoid sex/ d) I avoid alcohol/ e) I plan my day so that I am always near a toilet/ f) I plan my day in view of the fact that I have IBD

Scores: from 1 (never) to 4 (always) or 5 (not applicable)

4. How often do you practice self-care to prevent or relieve symptoms of inflammatory bowel disease?

Items: a) self-care to make sure to sleep well/ b) self-care to manage stress/ c) I find out more about IBD/ d) I look for new approaches to living with IBD/ e) I use natural remedies/ f) I perform other self-care activities (open ended).

Scores; from 1 (never) to 4 (always) or 5 (not applicable)

5. Do you take medication for inflammatory bowel disease as prescribed by a doctor?

Score: from 1 (never) to 4 (always) or 5 (no prescription medication),

6. Do you know whom to contact if you experience symptoms of inflammatory bowel disease?

Score: 1 (no) or 2 (yes),

7. How familiar are you with symptoms that require contact with a healthcare provider?

Score: from 1 (not familiar) to 4 (totally familiar)

8. Tobacco use: Do you smoke?/ Do you use snuff?

Score: from 1 (daily use) to 4 (I never have)

9. How often does self-care help you relieve symptoms of inflammatory bowel disease?

Score: from 1 (never) to 4 (always) or 5 (not applicable)

Phase 3, final evaluation

The self-care questionnaire measured self-care with 22 items. Responses were scored on a categorical scale: “never”, “sometimes”, “often”, “always” (range 1-4) or “not relevant”. Higher values indicate more often performed self-care, except for the item “not relevant”.

Pilot study

A pilot study including 93 patients with IBD was performed. The patients were asked to answer two global questions on Visual Analogue Scales (VAS), in order to evaluate content validity:

- To what extent do you perform self-care?
- How effective is your self-care to support you in daily life?

Test-retest

In test-retest, 50 of the 93 patients responded to the self-care questionnaire within an interval of 3 to 4 weeks. In retest, patients responded to an additional question asking if they had changed their self-care after answering the questionnaire the first time. Percentage agreement was used to assess test-retest stability using frequency and percentage for test and retest (106, 107). A percentage agreement of >70% was considered acceptable (117). An intraclass correlation coefficient was used to account for systematic error (108). An intraclass correlation coefficient of more than 0.6 was considered acceptable (109).

In study III, the self-care questionnaire was translated into American English, using both forward and backward translation. The items were categorized in relation to the theoretical concepts of the middle-range theory of self-care by the developer of the middle-range theory, Professor Barbara Riegel (96).

Questionnaires on symptoms and disease activity

Symptoms and disease activity

Symptoms were registered on a diary card used daily in the clinical care of this patient group. If the following symptoms had appeared during the previous days, they were registered: number of bowel movements during daytime/nighttime and soft stools, number of stools per day, degree of urgency for defecation, presence of visible blood in stools and abdominal pain (Likert type scale 0-3, a lower score means fewer symptoms), general well-being (Likert type scale 0-4, a lower score means better well-being), and extra intestinal symptoms (fever, mouth ulcers, joint pain, skin rash, ocular inflammation and rectal symptoms). The symptom and disease activity questionnaire is used in clinical care from validated indices (110, 111).

Harvey Bradshaw Index (HBI)

Disease status was measured using clinical disease activity indices. A modified version of HBI for patients with CD, a 5-item disease activity index, excluding abdominal mass (scores <5 indicating remission) with maximum score of 22, was used. Scores between 5 and 7 indicate mild activity, 8 to 16 moderate activity and >16 severe activity. The HBI showed excellent correlation to the Crohn's Disease Activity Index (CDAI) ($r=0.93$, $p<0.001$) (110).

Simple Clinical Colitis Activity Index (SCCAI)

The SCCAI for patients with UC, a 6-item disease activity index, scored ≤ 2 , indicating remission with a maximum score of 19. The SCCAI showed excellent correlation to the Powell-Tuck Index ($r=0.959$, $p<0.0001$) and the complex index ($r=0.924$, $p<0.0001$) (111, 112). The index is validated for assessing disease activity in UC (113).

Short Health Scale (SHS)

Patient-reported HRQOL is a four-item questionnaire developed to measure the patient's subjective experience of how disease affects four major health dimensions in patients with IBD. In SHS, the dimensions were symptom burden, social function, disease-related worry, and general well-being. Responses were scored on a 100 mm visual analog scale and presented in individual scores for each of the four questions. The SHS was developed for Swedish patients with UC, and is also used for patients with CD. A lower score indicates better HRQOL. Test-retest reliability has shown $r=0.69-0.82$ and an ICC between 0.66-0.77 (77, 114).

Data analysis

Conventional content analysis

Conventional content analysis was chosen to explore self-care as a phenomenon in patients with IBD (115). Content analysis is detailed and systematic, in order to assess the variations that occur in the data (116). The interview text was analyzed with conventional content analysis in the five following steps. Data were read word by word and exact words or phrases from the text were highlighted, in order to capture key thoughts or concepts. Notes were made in the margins of the documents, in order to record initial impressions about the data and developing codes. The codes were sorted independently into categories, and grouped conceptually by linked codes within the categories. The differences in coding and category development were discussed until consensus was reached. Finally, labels for codes, subcategories, and categories were developed (115). An example of the analysis process is presented in table 4.

Table 4. Analysis process in study I

Meaning unit	Condensed meaning unit	Code	Sub-category	Category
“If I know that I’m going to some kind of event, and if there aren’t toilets available, I try, I always think about it, planning a bit” (Informant 1, CD)	“If I’m going to some event and if there aren’t toilets available, I try to think about it, and plan”	Planning access to toilets	Planning due to hobbies and activities	Planning life

Statistical analysis

Descriptive statistics in the self-care items and symptom registration were presented as number, percentages, median, interquartile range, or range. “Often” and “always” performing self-care were presented in percentages in the content validity by patients. Percentage agreement was used to assess test-retest stability in custom tables, with number and percent for each item (106). Intra-class correlation coefficient (ICC) was calculated for each item, to account for systematic error (108). Differences within the same group in disease activity were analyzed with the Wilcoxon sum rank test. Each single item of the self-care questionnaire was analyzed separately (study II, study IV).

To analyze differences in self-care in relation to general well-being, age, gender, marital status, and disease activity, a Mann-Whitney U-test was used in a two-group comparison. Well-being was grouped as: well or slightly below par/poor; very poor; or terrible. Age was dichotomized at the median (45 years). Disease activity was grouped as remission or active disease. Raw median scores were calculated in study III for self-care maintenance, self-care monitoring, and self-care management (98, 117, 118). The Spearman rank correlation coefficient was used to assess bivariate associations between the self-care items and general well-being. Rho values >0.30 were considered as a cut point (study III)(101).

To explore differences between groups, Student’s t-test was used for the continuous variables of age and duration of IBD. A chi-squared test was used for the category variables gender, diagnosis, marital status, education,

and surgery. Fisher's exact test was used to calculate the difference between dichotomous variables of self-care and diagnosis. Spearman's rank correlation coefficient was used to analyse associations between self-care, patient characteristics, disease activity, and HRQOL. To determine correlation, a value of 0.1-0.29 was classified as a weak correlation, 0.3-0.49 was classified as a moderate correlation and 0.5-1.0 was classified as a strong correlation (119). To explore the relationship between self-care, patient characteristic, disease activity, and HRQOL, a multiple logistic regression was calculated. The multiple logistic regression analysis was performed to investigate log odds for patients with IBD planning their day (120). The dependent variable "planning the day" was dichotomized into "no planning" and "planning the day". The independent variables were the self-care items, patient characteristics, and HRQOL such as symptom burden, social function, worry and well-being. The self-care items were dichotomized into "no self-care activity" and "performed self-care", except for "Do you know whom to contact if you experience symptoms of IBD?" (No/Yes). Also, "How familiar are you with the symptoms for which you should contact a healthcare provider?" was dichotomized, into "not familiar" and "familiar" (study IV). A Mann-Whitney U-test was also used in a two-group comparison between the Swedish and U.S. sample. Study-specific statistical analyses are shown in Table 5.

Table 5. Study-specific statistical methods

	Study II	Study III	Study IV
Measurements	Self-care questionnaire ^a Symptom registration ^b	Self-care questionnaire ^a Symptom registration ^b	Self-care questionnaire ^a Symptom registration ^b Short Health Scale ^e
Data analysis	Content validity index Percentage agreement Wilcoxon rank sum test	Spearman rank correlation Mann-Whitney U test	Spearman rank correlation Fisher's exact test, Chi-squared test Student's t-test Multiple Logistic regression

^a Category scale, "never", "sometimes", "often", "always", and "not relevant", one open-ended item

^b Likert type scale and tick-boxes

^e Visual analog scale, 100 mm, for dimensions of symptom burden, social function, worry, and wellbeing

Statistical analyses were performed using SPSS 24 (121). The level of significance was set at $p < 0.05$ for all analysis (studies II, III and IV).

Trustworthiness

There are several methods for ensuring the trustworthiness of qualitative studies. In study I, trustworthiness was secured through credibility, confirmability, dependability, and transferability. A purposeful sampling was used to achieve different aspects of the patients' view of self-care, and to capture a wide range of perspectives related to the phenomenon of self-care. The same questions were asked of all participants after the pilot interviews. To establish credibility, the recorded interviews were transcribed verbatim and read from beginning to end, over and over, to get a good overall picture. All interviews were transcribed verbatim and were read in full text, to address confirmability. Increased credibility was achieved by the co-assessment of all the authors, who read the interview texts and were involved in the analysis process. The interview transcripts were analyzed sep-

arately, to maximize transparency, accuracy, and concordance, when developing codes, sub-categories, and categories. Continuous discussions were held regarding coding and categorization, until consensus in the research was reached. The co-assessment was performed to ensure the credibility of the codes and categories. The coding process has been provided, as well as an explanation of how interpretations were made and a conclusion was reached, to illustrate that similarities and differences in the findings are based on the data. To be able to repeat the study, the entire method was described clearly. The interviews took place between June 2012 and May 2013.

Validity

A questionnaire development includes several aspects. In the questionnaire development (study II), face validity was represented by the literature review, participation of patients with IBD, the research group, and how the HCPs perceived the items (122). To enhance content validity, the questionnaire was first evaluated by six HCPs – three physicians and three nurses, all with many years' experience of gastroenterology. To further strengthen content validity, the items were assessed by three patients in cognitive interviews. After minor adjustments (the re-wording of three items), the questionnaire was tested in content validation assessed by 100 patients with IBD. The higher the content validity of the questionnaire, the broader the inferences we can draw for a wider range of situations (122). Our sample is representative, from three different gastroenterology clinics, and the patients were considered to be important to judge the items. We decided to use one item on confidence, which is related to the middle-range theory of self-care (96). To strengthen construct validity, an underlying theory may help to develop a better questionnaire (122). It was not possible to assess criterion validity described as concurrent validity, as no other self-care questionnaire existed for patients with IBD at the time of data collection (122). In study III, the self-care questionnaire was translated using a forward and backward process by two different bilingual American-English translators. No preunderstanding of the self-care questionnaire existed among the translators (Appendix II). Cross cultural validity was performed in the U.S. by an American researcher, Professor Barbara Riegel, to get a result that was equivalent and comparable to the original (123).

Reliability

An intra-class correlation coefficient (ICC) was measured, to account for systematic error. Test-retest reliability was used, to test stability within a three-four week interval with the same patients (n=50) in study II (122).

Transferability and generalizability

Information has been provided, so the reader can determine whether the findings in study I are applicable to other social environments. To increase transferability, the context was described, and the analysis process explained (116, 124). In the quantitative studies, the research was reported so that readers can follow the performance, the results, and the conclusions. In studies II, III and IV, the Guidelines for Reporting Observational Studies has been used to Strengthen the Reporting of Observational Studies in Epidemiology (STROBE) (125). The sampling in studies II and IV was from three gastroenterology clinics, which implies generalizability of the results of these two studies. The questionnaire was evaluated in both Sweden and the U.S., in order to facilitate implementation and to explore its clinical relevance. Professionals have been involved in order to strengthen the study design and analysis.

Ethical considerations

Ethical considerations have been considered for all the studies in the thesis. Ethical approval for data collection by way of interviews with patients with IBD (study I) in Sweden (study code: 2011/288-32 and 2012/161-32), and ethical approval to develop and to evaluate the questionnaire (studies II and IV) were approved by the Regional Ethical Review Board at Linköping University (study codes: 2014/366-31 and 2015/269-31). Ethical permission for the study in the U.S. (study III) was approved by the Institutional Review Board (IRB) at Pennsylvania University (code: 823418). Ulrica Lovén Wickman and main supervisor Gunilla Hollman Frisman were certified by the National Institutes of Health's (NIH) Office of Extramural Research, upon completion of the web-based course "Protecting Human Research Participants", which concerns ethical principles and guidelines for the protection of human subjects of research (certification nos. 1853437 and 1834663). This protection includes respect for the person and beneficence, i.e. that all patients are treated ethically, that their decisions are respected, that they are protected from harm, and that efforts are made to secure their well-being (126). All the studies were designed and conducted in accordance with the World Medical Association Declaration of Helsinki (127, 128). The studies are based on the code of ethics for nurses, i.e. that the author as a nurse acts with respect for every person's dignity, worth, and uniqueness. The nurse's commitment is to the patient, and to promote and protect the rights, health, and safety of the patient (129).

All participants in studies I, II, III and IV were sent written informed consent forms. For studies II and IV, an informed consent form was sent by post together with the questionnaire. The form stated that participation was completely voluntary and that the participants were free to discontinue participation without consequences, at any time, and without providing a reason. Data was to be presented on a group level, so individuals could not be identified. For studies II, III and IV, all participants completed their consent form and the questionnaires at home or where they chose to fill in the questionnaires. Study participation was free of charge, and patients were expected to send questionnaires in pre-stamped envelopes to the author. Data collection included several questionnaires (II, III, IV), which could be perceived as burdensome to some participating patients, and may have caused late response (130). Being asked to participate can be perceived as stressful. Physical and psychological risks are fatigue and thoughts about a lack of self-care. A realization of one's lack of knowledge could emerge, and lead to negative thoughts. If integrity is threatened, this

can result in discomfort. There was a preparedness to provide patients with support if needed. Contributing to the development of a questionnaire for assessment of self-care could be experienced as positive (131). In the U.S, a web-based questionnaire was used, and a raffle ticket valued at USD 250 was sent to a randomly selected respondent, as a thank-you for completing the questionnaire (study III). All data collection (studies I-IV) was carried out by the author, who was not involved in the clinical care of the patients involved.

RESULTS

The results are presented below, firstly as development of the self-care questionnaire, and secondly as self-care and health-related quality of life. In total, 421 patients participated in all the studies, the median age of patients in Sweden and the U.S. was between 43 and 54 years, and gender distribution was rather equal, except for study III (Table 6).

Table 6. Participant characteristics

	Study I n=20	Study II n=193*	Study III n=67	Study IV n=234
Age years, Md (range)	43(25-66)	54 (18-83)	45 (21-80)	48 (19-87)
Women, n (%)	10 (50)	93 (48)	48 (72)	122 (52)
Crohn's disease, n (%)	12 (60)	91(47)	39 (59)	93 (40)
Ulcerative colitis, n (%)	8(40)	102(53)	27 (41)	141 (60)
Married/cohabit, n (%)	17(85)	137(71)	43 (64)	175 (75)
Single living, n (%)	3(15)	45 (23)	24 (36)	59 (25)
University, n (%)	8(40)	70(36)	63 (94)	83 (36)
Working full-time, n (%)	9(45)	85(44)	31 (46)	121 (52)
Working part-time, n (%)	6(30)	21(11)	8 (12)	24 (10)
Retired, n (%)	1(5)	59(31)	14 (21)	68 (29)
Sick-leave, n (%)	2(10)	9(5)		10 (4)

*Studies II and IV, n=93, are based on the same cohort

Development of the self-care questionnaire (I, II)

The analyses of the interviews in study I, review of the literature, and clinical expertise were used to devise the initial items. The findings in study I consisted of the following categories and subcategories (Figure 3):

Figure 3. Categories and subcategories in study I

Symptom recognition

Physical sensations were considered symptoms of IBD, such as stomach symptoms, nausea and joint pain, and side-effects of medical treatment. The psychological sensations reported were loneliness, aggressiveness and symptoms of depression.

Handling symptoms

The patients varied widely in their descriptions and considerations regarding dietary content. They tried to think of what to eat and on what occasions to eat. In terms of adapting their diet, they mentioned portion size, and were prepared to try anything that might alleviate their symptoms. The patients took the medication that their physician prescribed, and followed their medical treatment plan. Physical activities were said to affect the whole body and enhance general well-being. Resting during the day and using a routine to manage day-to-day life, including regular sleeping habits, was cited as a way to avoid stress and to think about what helps the patients feel good. They used complementary alternative methods (CAM) such as heating pads to relieve the pain, so they could fall asleep. The patients also reported daily intake of alcohol with spices to relieve symptoms, as well as household remedies.

Planning life

“Planning when to do activities” included the need to always know the location of a toilet. “Planning” concerned having access to appropriate food when traveling. “Planning when to refrain from activities” related to avoiding social activities.

“To always know where the toilets are when you’re out somewhere. If I’m on a train or bus, and had to go to the toilet, well, then I needed to go immediately. I wasn’t able to wait four minutes, because then there was, in principle, no hope. Now it’s much better. Now I get, now I know, a slight feeling that it’s time now I have to start looking, because it’ll soon be time, you know. It’s a great deal better now, but it’s still that I think a bit, maybe – Where am I going? How long will I be out?”
(Informant 10, CD)

Seeking new options

The participants expressed a need for information about the consequences of diet intake, which they obtained from the internet, reading, and lectures. The patients responded that it was important to find out what they were interested in, such as listening to books, listening to music, or playing an instrument. They facilitated their self-care by way of personal contacts with friends and HCPs.

Content validity index assessed by HCP

In total, 51 items were generated from the literature search and interviews. Twenty-two items had higher or equal I-CVI of 0.83 after the first assessment. The 51 items were discussed in the research group and it was decided to retain them further into the cognitive interviews (105) (Table 7). However, the item “I make sure that I get sufficient sleep” was combined to an item with similar content and one item (avoid sex) was added.

Cognitive interviews with patients

Three patients participated in the cognitive interviews, age range 53-74 years. It emerged that they had difficulties understanding four items, so two items were reworded and one item was deleted:

“I take all medication as prescribed” was reworded as “Do you take medication for IBD as prescribed by a physician?”

“I change my medical treatment alone when it comes to my IBD” was discussed but was further used.

“I know who I will turn myself to when I do not feel good” was reworded to “Do you know whom to contact if you experience symptoms of IBD?”

“I have quit smoking” was deleted.

Table 7. Content validity index (I-CVI) assessed by healthcare professionals (51 items) and content validation assessed by patients (50 items)

Items	I-CVI	Percent	Included
I pay attention to symptoms of IBD	1.00	75	x
I keep notes of my bowel symptoms	0.67	8	
I pay attention to physical symptoms unrelated to the intestines	0.83	53	x
I find it difficult to interpret my symptoms	0.67	7	
I have no sexual desire	0.33	20	
I avoid sex - <i>added</i>		22	x
If I have problems with the leakage of urine or faeces, I contact my clinic	0.17	42	
I am continuously aware of the locations of toilets	0.67	63	x
If I experience debilitating tiredness, I contact my clinic	0.67	30	
I pay attention to psychological symptoms	0.50	39	x
I am aware of my own need to sleep	0.50	60	
I am aware of the side effects of medication	0.67	45	
I am aware of my own level of stress	1.00	43	x
I have strategies to ensure that I do not forget to take medication	1.00	64	
I take all medication as prescribed- into <i>Do you take medication for IBD as prescribed by a physician?</i>	0.83	92	x
I change my medical treatment alone when it comes to my IBD	1.00	10	
I adapt my diet	0.83	55	x
I eat vegetables and/or root vegetables every day (fresh, frozen or cooked)	0.67	66	
I eat fruit and/or berries every day (fresh, frozen, preserved, juice etc.)	0.33	68	
I eat fish or shellfish as a main course, in a salad or as sandwich topping every week	0.33	71	
I avoid stressful situations	0.17	34	
I take measures, such as meditation or yoga, to reduce stress	1.00	5	
I take measures to enable me to deal with stress	0.50	18	
Self-care to make sure to sleep well	0.83	72	x
I make sure that I get sufficient sleep –into <i>I experience that I get enough sleep</i>	0.83		

I experience that I get enough sleep	0.83	29	
I sleep during the daytime, to ensure that I get sufficient sleep	0.50	13	
I carry out physical activity to reduce stress	0.67	37	
I carry out physical activity every day	0.50	42	
I carry out physical training, such as running, aerobics or ball games, every week	0.67	31	
I use tobacco products	1.00	14	x
I have quit smoking- <i>deleted</i>	1.00		x
I consume alcohol	0.67	11	
I avoid alcohol in order to alleviate my symptoms	0.50	23	x
I take other drugs, such as cannabis, to alleviate my symptoms	0.67	3	
I use natural remedies	0.67	6	x
I take dietary supplements and vitamins	0.67	25	
I avoid dairy products in order to alleviate my symptoms	0.67	33	
I avoid fatty foods in order to alleviate my symptoms	0.67	31	
I avoid certain foods in my diet in order to alleviate my symptoms	0.83	48	x
I plan situations in everyday life in order to alleviate my symptoms	1.00	42	x
I avoid activities in everyday life	0.83	20	x
I contact the nurse at my clinic for advice when I'm not feeling well	0.83	39	
I contact my physician for advice when I'm not feeling well	0.67	35	
I contact online medical care services when I'm not feeling well	0.83	6	
I contact my clinic when I'm not feeling well	0.67	41	
I contact close friends when I'm not feeling well	0.5	14	
I actively seek new pathways to ensure that I feel well	0.83	38	x
I actively seek information to ensure that I feel well	0.83	37	
I know who I should turn to when I'm not feeling well-into <i>Do you know whom to contact if you experience symptoms of IBD?</i>	0.83	83	x
I seek knowledge about my disease	1.00	40	x

Content validation by patients

The validation showed number and percent of the patients' ranking of the items "often" or "always" where a frequency of the most common items was considered and compared to I-CVI of 0.83 from the expert panel. The most common self-care activities had a frequency of $\geq 38\%$ (Table 7).

The final questionnaire

The HCPs answered 51 items and the patients answered 50 items. Two items were combined, two items were reworded. One item deleted and one added item; "I make sure that I get sufficient sleep" (among the items assessed by HCP) was combined with a similar item, "I take all medication as prescribed" and "I know who I will turn myself to when I do not feel good" was reworded. The item "I have quit smoking" (among the items assessed by HCP) was deleted. One item was added: I avoid sex (low frequency assessed by patients 22%).

High I-CVI (≥ 0.83) and high frequency ($>38\%$) by patients, and included in the questionnaire:

- I pay attention to symptoms of IBD
- I pay attention to physical symptoms unrelated to the intestines
- Do you take medication for IBD as prescribed by a doctor?
- Self-care to make sure to sleep well
- I adapt my diet
- I plan situations in everyday life in order to alleviate my symptoms
- I actively seek new pathways to ensure that I feel well
- Do you know whom to contact if you experience symptoms of IBD?
- I seek knowledge about my disease

High I-CVI (≥ 0.83) and high frequency ($>38\%$) by patients, and included in the questionnaire in another formulation:

- I am aware of my own level of stress
- I have strategies to ensure that I do not forget to take medication
- I avoid certain foods in my diet in order to alleviate my symptoms
- I contact the nurse at my clinic for advice when I'm not feeling well

High I-CVI (≥ 0.83) and low frequency ($< 38\%$) by patients and included in the questionnaire:

- I use tobacco products
- I avoid activities in daily life

Low I-CVI (< 0.83) and high frequency ($> 38\%$) by patients and included in the questionnaire:

- I am continuously aware of the locations of toilets
- I pay attention to psychological symptoms

Items included after discussion in the research group:

- How often do you feel confident that you are able to determine whether intestinal symptoms are due to IBD?
- How familiar are you with the symptoms for which you should contact a healthcare provider?
- Do you use snuff?
- Other kinds of self-care
- How often does self-care help you relieve symptoms of IBD?

Low I-CVI (< 0.83) and high frequency ($> 38\%$) by patients and not included in the questionnaire:

- If I have problems with the leakage of urine or feces, I contact my clinic
- I am aware of my own need to sleep
- I am aware of the side effects of medication
- I eat vegetables and/or root vegetables every day (fresh, frozen or cooked)
- I eat fruit and/or berries every day (fresh, frozen, preserved, juice etc.)
- I eat fish or shellfish as a main course, in a salad or as sandwich topping every week
- I contact my clinic when I'm not feeling well
- I carry out physical activity every day

Low I-CVI (< 0.83) and low frequency ($< 38\%$) by patients were not included in the questionnaire except for:

- I avoid alcohol
- I use natural remedies
- I avoid sex (not assessed by HCP)

The final questionnaire consisted of 22 items with a content validity index of ≥ 0.83 from HCPs and the most commonly occurring self-care by patients ($>38\%$). The items also came from the literature review and from the experiences of the research group. In the final questionnaire, more detailed items were replaced by more overarching items, for example items addressing diet adaptation. The research group judged that items on using snuff and natural remedies, and on avoiding alcohol and sex, should remain in the questionnaire even if these were relatively uncommon among the patients. The item on confidence in determining whether intestinal symptoms are due to IBD was added. The research group also decided to keep the two items about being near a toilet and paying attention to psychological symptoms, since these were common among patients. The final revision focused on getting the questions to work together as a comprehensive questionnaire. Items were therefore added on “Other kinds of self-care” and “How often does self-care help you relieve symptoms of IBD?”. The research group discussed the results until consensus was reached regarding item selection for the final questionnaire (Appendix I).

Pilot study

All patients in the pilot study answered two questions in order to validate the self-care questionnaire:

To what extent do you perform self-care?

Median 62 (0-100 mm)

How effective is your self-care to support you in daily life?

Median 55 (0-100 mm).

Test retest reliability

In the test-retest, 50 patients responded to the self-care questionnaire, resulting in 75-100% conformity for each item. The items with the highest conformity were: “Do you know whom to contact if you experience symptoms of IBD?” (100%), and “I use natural remedies.” and “Do you use snuff?” (both 96%). The lowest conformity was shown for “I pay attention to physical symptoms unrelated to the intestines.” (75%), and “How often do you feel confident that you are able to determine whether intestinal symptoms are due to IBD?” (79%).

For each item, ICC showed $r=0.426-1.000$. The lowest value was shown for “I plan my day in view of the fact that I have IBD” ($r=0.426$) and “I pay attention to physical symptoms unrelated to the intestines.” ($r=0.667$). The highest values were shown for: “Do you know whom to contact if you experience symptoms of IBD?” ($r=1.000$) and “Do you smoke?” ($r=0.954$). The questionnaire has been proven valid and reliable, according to content validity, face validity and test-retest reliability.

Self-care and health-related quality of life (studies III, IV)

Self-care in daily life (studies III and IV)

In total, 301 patients answered the final version of the self-care questionnaire (Appendix I). Self-care maintenance in daily life was expressed as adapting the diet (82%), taking medication (91%), planning the day so that I am always near a toilet (71%), planning the day in view of the fact that I have IBD (65%), and avoiding activities (61%). According to self-care monitoring, the patients paid attention to their intestinal symptoms (95%), physical symptoms unrelated to the intestines (86%), and psychological symptoms (69%). Self-care management was described as making sure to sleep well (62%), stress management (73%), finding out more about IBD (79%), and looking for new approaches living with IBD (68%) (Table 8).

Table 8. Self-care in daily life among patients with inflammatory bowel disease (n=301)

Survey question	Never	Sometimes	Often	Always	Not relevant
	n (%)	n (%)	n (%)	n (%)	n (%)
Self-care maintenance					
I adapt my diet	50 (17)	107 (36)	82 (27)	58 (19)	3 (1)
I avoid various activities	109 (36)	124 (41)	49 (16)	12 (4)	4 (1)
I avoid sex	126 (42)	96 (32)	26 (9)	13 (4)	36 (12)
I avoid alcohol	84 (28)	83 (28)	58 (19)	44 (15)	19 (6)
Plan my day so that I am always near a toilet	80 (27)	103 (34)	54 (18)	56 (19)	5 (2)
I plan my day in view of the fact that I have IBD	100 (33)	120 (40)	44 (15)	31 (10)	4 (1)
Do you take medication for IBD as prescribed by a doctor?	2 (1)	17 (6)	33 (11)	224 (74)	24 (8) ^a
Self-care monitoring					
I pay attention to intestinal symptoms	10 (3)	91 (30)	85 (28)	112 (37)	1 (0)
I pay attention to physical symptoms unrelated to the intestines	31 (10)	105 (35)	89 (30)	62 (21)	11 (4)
I pay attention to psychological symptoms	69 (23)	105 (35)	65 (22)	35 (12)	20 (7)
Self-care management					
Self-care to make sure I sleep well	101 (34)	96 (32)	53 (18)	36 (12)	11 (4)
Self-care to manage stress	72 (24)	130 (43)	64 (21)	26 (9)	5 (2)
I find out more about IBD	59 (20)	135 (45)	66 (22)	35 (12)	3 (0)
I look for new approaches to living with IBD	87 (29)	125 (42)	46 (15)	32 (11)	7 (2)
I use natural remedies	217 (72)	51 (17)	13 (4)	14 (5)	4 (1)

Scored "never", "sometimes", "often", "always" (range 1-4) or "not relevant". Internal data missing 1-15, ^ano medication

Differences in self-care between the Swedish and U.S. sample

In the Swedish sample, the gender distribution was relatively equal: women (n=234/122, 52%), while the U.S. sample consisted mainly of women (n=67/48, 72%). A majority of the patients were in employment: 65% in Sweden and 58% in the U.S.

The overall most common self-care activity was adapting one's diet, with 71% of patients in Sweden and 88% of patients in the U.S. stating that they adapted their diet "sometimes", "often" or "always". In Sweden, 80% and 58% (U.S.) reported that they always took their medication. For avoiding activities in daily life, the figures were 58% for Sweden and 75% for the U.S, with 44% (Sweden) and 48% (U.S.) stating they avoided sex, and 67% (Sweden) and 60% (U.S.) stating they avoided alcohol. In Sweden, 74% reported that self-care helped to relieve symptoms of IBD while for the U.S. this figure was 88%.

The results were calculated for the Swedish sample and the U.S. sample (Table 9). Patients in the U.S. sample had higher median scores, and significant differences appeared for self-care maintenance, self-care monitoring, and self-care management.

Table 9. Self-care subscales, scale total points, median raw scores, and comparison in the Swedish sample to the U.S. sample

	Items	Scale Total points	Median Raw Score (Range)		
			Swedish sample	U.S. sample	P-value
Self-care maintenance	7	28	17 (7-27)	19 (10-26)	0.004
Self-care monitoring	3	12	8 (3-12)	10 (4-12)	<0.001
Self-care management	5	20	9 (5-20)	13 (6-20)	<0.001

Self-care and health-related quality of life

A higher level of self-care activities in “paying attention to intestinal symptoms”, “I avoid various activities”, “I plan my day so that I am always near a toilet” and “I plan my day in view of the fact that I have IBD” was significantly associated with HRQOL in greater symptom burden, less social function, more worry, and worse well-being (Table 10). “Making sure to sleep well”, “managing stress”, “finding out more about IBD” and “looking for new approaches to living with IBD” were associated with lower social function and more worry (Table 10).

Table 10. Self-care in association to health-related quality of life in patients with inflammatory bowel disease (n=234)

	Md (IQR)	Symptom burden		Social function		Worry		Well-being	
		Rho	p-value	Rho	p-value	Rho	p-value	Rho	p-value
Do you pay attention to symptoms of IBD?									
I pay attention to intestinal symptoms	3(2)	.348	<.001	.411	<.001	.429	<.001	.319	<.001
I pay attention to physical symptoms unrelated to the intestines	2(1)	.155	.019	.310	<.001	.259	<.001	.248	<.001
I pay attention to psychological symptoms ^a	2(2)	.143	.033	.210	.002	.257	<.001	.321	<.001
How often do you feel confident that you are able to determine whether your symptoms refer to IBD?	3(0)	-.131	.048	-.112	.192	-.130	.049	-.068	.309
How often do you adapt your day to problems caused by IBD?									
I adapt my diet	2(1)	.205	.002	.305	<.001	.262	<.001	.161	.015
I avoid various activities	2(1)	.388	<.001	.604	<.001	.418	<.001	.470	<.001
I avoid sex	2(1)	.271	<.001	.377	<.001	.270	<.001	.435	<.001
I avoid alcohol	2(2)	.121	.070	.220	.001	.104	.119	.187	.005
Plan my day so that I am always near a toilet	2(1)	.451	<.001	.609	<.001	.494	<.001	.437	<.001
I plan my day in view of the fact that I have IBD	2(1)	.378	<.001	.575	<.001	.473	<.001	.406	<.001
Do you take medication for IBD as prescribed by a physician?	4(0)	-.040	.548	-.107	.108	-.097	.144	-.150	.023
How often do you administer self-care to prevent or relieve symptoms of IBD?									
Self-care to make sure to sleep well	2(2)	.169	.011	.317	<.001	.295	<.001	.186	.005
Self-care to manage stress	2(2)	.217	.001	.355	<.001	.371	<.001	.194	.003
I find out more about IBD	2(1)	.243	<.001	.346	<.001	.375	<.001	.228	.001
I look for new approaches to living with IBD	2(4)	.262	<.001	.373	<.001	.366	<.001	.244	<.001
I use natural remedies ^d	1(0)	.025	.709	.106	.112	.106	.111	.030	.654
Do you know whom to contact if you experience symptoms of IBD?	2(0)	-.062	.351	.018	.791	.060	.369	-.037	.579
How familiar are you with the symptoms for which you should contact a health care professional?	4(1)	-.138	.037	-.034	.605	-.048	.469	-.110	.097
Do you smoke?	4(1)	-.075	.263	-.178	.008	-.166	.013	-.131	.050
Do you use snuff?	4(1)	.017	.805	.015	.831	.061	.378	-.103	.132
How often does self-care help you relieve symptoms of IBD?	2(1)	-.096	.151	-.059	.376	.028	.680	-.045	.501

DISCUSSION

The overall aim of this study was to develop and evaluate a questionnaire for the clinical assessment of self-care, and to explore self-care in relation to disease activity and to HRQOL in patients with IBD. The thesis is, as far as we know, the first to describe the development process of a disease-specific self-care questionnaire for patients with IBD. The main findings resulted in a valid and reliable self-care questionnaire for clinical use among patients with IBD. Using the self-care questionnaire may help improve the self-care of patients living with IBD, because self-care is a key component in disease management. Based on results of the self-care questionnaire, a discussion between the patient and HCP may improve awareness of self-care activities aimed at maintaining health. As a result of discussions on self-care, patients are becoming more aware of their health, and are expected to take a greater part in caring for themselves (132).

Discussing self-care may help to increase participation in health care. Health literacy and medication adherence may also improve, in line with the Swedish National Board of Health and Welfare's regulations for self-care (99,100). The self-care regulation stipulates that: HCPs should make individual assessments; analyse risks; consult and plan; make new assessments if conditions change; establish procedures for cooperation with other actors; and ensure that the management system contains self-care procedures (99, 100). Guidelines are provided in the European Crohn's and Colitis Organisation's (ECCO) Consensus Statements (133) and by the American Gastroenterological Association (AGA)(134).

Several steps were used in the process of developing and evaluating the self-care questionnaire. Self-reported questionnaires were used, and we tried to inquire not only about self-care, but also about self-reported symptoms and dimensions of HRQOL in daily life. Previously developed questionnaires on self-care in other chronic illnesses exist for example for diabetes and heart failure (98, 135). Plural self-care questionnaires are often disease specific, but recently a generic measure of self-care based on the middle-range theory, the Self-Care of Chronic Illness Inventory, including three separate scales, has been developed for further evaluation (118).

Self-care for patients with inflammatory bowel disease

Our study revealed categories of self-care including “symptom recognition”, “handling symptoms”, “planning life”, and “looking for new options”. “Symptom recognition” and “handling symptoms” entail daily challenges for the patients. “Planning life” and “looking for new options” are necessary in making everyday decisions. The result in study I shows that a decision to actively participate in the care of IBD is a prerequisite for self-care. When patients seek health care, the interaction with the HCP will motivate them to be engaged in self-care. However, all of them engage in some level of self-care, and their motivation and engagement may vary (96). The results of study I were also important as the basis for the item development. Study I, a qualitative study, gave a deeper understanding of the phenomenon of self-care. Most patients play an active role in their health care when living with IBD. The way that patients manage life with IBD varies according to their socioeconomic level and personal experience of living with a chronic condition, as well as the local context and social relations (136). Evidence-based self-care activities include health literacy in the capacity of the patient to obtain, process, and understand health care information. To be able to make health-care decisions, the patient must have some self-awareness of their physical and psychological condition. Healthy behaviors are healthy eating, including a balanced diet, good personal hygiene, responsible use of medical treatment and risk avoidance or mitigation, such as quitting tobacco and limiting alcohol use (137).

The prevalence of self-care in studies III and IV were found to be high. Activities include taking medication, adapting diet, planning life, and avoiding activities. Our study indicated that the patients always took their medication between 58% (study III) and 80% (study IV) of the time. Valid medication adherence scales to assess and discuss adherence could be useful to combine if the medication adherence are low (138). Several studies indicate the importance of medication adherence, and many studies report low medication adherence with a risk of decreased disease activity among patients with IBD (139, 140). Known predictors for the risk of relapse are younger age, longer periods without clinical follow-up, and limited knowledge of medical treatment (141). There were differences in the items. Some items concerned measures to reduce symptoms such as adapting diet and taking medication or dealing with daily life despite the symptoms by planning activities, while other items were more consequences of the symptoms for instance avoiding activities such as sex.

The patients' perspective on their diet is individual, and dietary changes are mostly made in order to alleviate symptoms. One recommendation is for the patients to record their daily intake, so they can discuss it with the HCP (142). The results showed that the patients tried to think about what they eat, but they either go on living as usual, without seeing any obstacles, or could not do anything because of IBD. The patients preferred more home-made cooking: soups and stews rather than fast food. Respondents in study I stated that generally, a balanced life was good for the stomach. There is still a need for research aimed at developing scientific evidence that can guide HCPs when giving dietary advice (143).

"I plan my day in view of the fact that I have IBD" was shown to be a common response for patients with IBD. More symptom burden, and the bowel interfering with daily life, meant that patients had to plan their days more carefully. Planning life included deciding when to do activities, and when to refrain from activities. In study I, avoiding activities referred to social activities such as hobbies, travel and overnight stays. Critical situations in daily life, such as loss of bowel control that includes leakage, odor, and incontinence, result in avoidant behavior in intimate situations and in relationships, as well as in social and leisure activities (91).

Self-care guidelines for patients with IBD vary, and are not always evidence-based. IBD Home, a new mobile-based service for patients with IBD that is under development, will allow patients to monitor their disease from home (144). Several studies focus on medication adherence and diet adaptation (139, 143). Use of technology in promoting self-care could be the next generation for patients with IBD. More mobile apps are being developed for patients with IBD, with useful features such as a toilet finder. However, there is a need for more professional medical involvement and evidence-based guidelines. Self-care guidelines can be useful complements when the patient meet their HCP (145).

Questionnaire development

The questionnaire development literature for self-care can be divided into different types of studies depending on the data in the questionnaires (118, 146, 147). In studies I and II, the key to finding manageable and valid questions was that patients participated in the construction of the questionnaire. Our questionnaire was developed from the patients' point of view, and resulted in a reasonable number of items (148). Many questionnaires are too extensive, which can result in a low response rate as the respondents may lose patience. The content of the questionnaire has been shown to be more important than the length of the questionnaire (149). To ensure

that the items were related to different aspects of self-care, one can refer to the literature review, the interviews, the HCP's content validity index, and the content validation made by patients. The stepwise approach and careful preparation were essential in designing the questionnaire. The 51 items were developed from the interviews with patients and the literature search, for the initial exploration of the content validity. The advantage of a four-point category scale is easily quantifiable for statistical analysis (122). In our study, the items were scored "never", "sometimes", "often", and "always" (1-4) and "not applicable".

Promoting health-related quality of life

Debilitating symptoms were noted to affect the self-care activity. Paying attention to symptoms, avoiding activities, and planning daily life affect HRQOL. Increased symptoms, more worry, and less social function lead to poorer HRQOL and greater need of self-care. Measuring HRQOL provides important knowledge of how the illness affects daily life. Increased understanding of the patient's life situation can make it easier to identify difficulties for the patient. Following up patients with IBD requires regular contact with HCPs in order to maintain remission, and is important in the detection of complications. Self-care discussions must be integrated in the follow-up. The patients describe the need to be seen when they are feeling well, as well as when they are feeling ill, and that self-care is integrated with the care from the HCP (150). The disease-specific self-care questionnaire may be useful in strengthening self-care and improving patients' HRQOL.

Final remarks on the theoretical framework

High frequencies of symptoms and disease activity were reported in the analysis, and the symptoms must be managed in daily life. There is always a need for improved symptom management in line with the SMT that all symptoms must be assessed and handled (85).

The TOUS can help HCPs assess both individual symptoms and how these are related to factors for managing the total symptom experience of the patients. The theory is useful in practice and research (84). In IBD, the unpleasant symptoms are numerous. The influencing factors that have an effect include psychological factors such as anxiety and depression. In study II, 47% of the patients were retired, worked part-time or were on sick leave, and in study IV, the figure was 43%. It is well known that productivity loss and sick leave are common in patients with IBD. Working life is important in securing healthy personal finances and a good HRQOL. Factors that affect worry and anxiety are psychological stress, increasing age, active disease, surgery, stoma, and socioeconomic status (87). Studies have shown

that disability ranges from 24% to 100% (151, 152). The severity of disability and burden affecting the capacity to work are shown to be higher in CD than in patients with UC (151, 152). Critical and social incidents cause patients to avoid social togetherness (91). Social isolation and exclusion are overarching for patients with IBD. Social networks play an important role in managing IBD (69). In our results, respondents expressed firstly a loneliness in that they are unable to share their feelings, and secondly avoidance in that they refrain from social activities such as hobbies, restaurant visits, and overnight stays.

The meaning of the symptom for patients with IBD is very important, and not clearly addressed in TOUS. Cultural differences and migration may increase the complexity of self-care for patients with IBD in terms of reaction and meaning of the symptoms. The meaning of the symptoms may influence the patient's daily life (avoidance and planning behavior). For patients with IBD, symptom experience also changes over time. The intestinal symptoms vary between mild, moderate, and severe. In TOUS, it is recommended that outcomes are assessed regularly, in order to monitor changes (153).

The middle-range theory of self-care in chronic illness was chosen as a framework with terms of the self-care concepts to understand the self-care process with a clearly described terminology. The theory guides HCPs in all work situations, and for all chronic illnesses. When patients seek healthcare, they are in need of guidance. HCPs and patients interact, and the theory influences the role of HCPs in supporting self-care (96). Applying the theory to patients with IBD in study III was discussed, because adapting diet and taking medication can be related to both self-care maintenance and self-care management. However, in collaboration with the author of the theory, Prof. Barbara Riegel, the items were ordered into the theory. In the newly developed Self-care of Chronic Illness Inventory, items have been included in self-care management: "When you have symptoms, how likely are you to" ... "change what you eat or drink to make the symptom decrease or go away?" and "take a medicine to make the symptom decrease or go away?". These items can be useful in the further evaluation of the self-care questionnaire (118). The items of "adapting diet" and "taking medication" were, in our study, applied in self-care maintenance. The U.S. sample had higher median scores for self-monitoring and self-care management. Lower scores in the Swedish sample may reflect behaviors known to vary in patients with IBD over time. The Self-care of Chronic Illness Inventory involves self-care maintenance in health-promoting behavior in sleep management, physical activity, and managing stress. Illness-related behavior involves trying to avoid getting sick (e.g., flu shot, washing

hands), eating a special diet, seeing one's HCP for routine health care, and taking prescribed medicines. Symptom management is arranged into autonomous and consulting behaviors (118). In our evaluation in study III, managing stress and sleep management were applied in self-care management.

Methodological considerations

This thesis is based on four studies. The strength of the studies is the subjective response from 421 patients and the choice of methodologies. Qualitative and quantitative methods were used to develop the self-care questionnaire. Quantitative methods were used to evaluate the self-care questionnaire and self-care in relation to disease activity and HRQOL.

Sample

For all the studies, the inclusion criterion was that participants were adults. The only exclusion criterion was in study I: having another severe disease or having undergone surgery within the past six months. The samples in studies II, III and IV consisted of patients in any stage of the disease, or with multimorbidity. This strengthens the use of the self-care questionnaire with all patients with IBD. In study I, the patients varied in age, gender and marital status, and the data material was collected in various contexts, which facilitates transferability to other western countries. In study II, both patients and HCPs participated. Study III included mostly well-educated women and it is a small selected sample, which implies a low degree of generalizability. We had difficulty recruiting patients for study III, and the over-representation of well-educated women is a limitation that affects the results. A small sample entails the risk of selection of participants (106). A known barrier for participation in study III was that no reminders were sent. The ethical approval in Sweden and the U.S. did not allow reminders to be sent for studies II, III and IV. Also, some patients might have been excluded due to difficulties understanding or speaking Swedish (studies I, II, IV) and English (study III). Patients participating from gastroenterology units represented the accessible population. Larger samples are more representative, and the samples of patients in studies I, II and IV are suggested to be a representative sample of patients with IBD in Sweden as the patients were recruited from different geographical areas. The consecutive sampling in study II may have benefited patients with higher disease activity.

The item non-response rate was rather low, up to 5%. The higher item non-response rates were for: “I avoid alcohol”; “I avoid sex”; and “I pay attention to psychological symptoms”. It is known that items relating to alcohol, sex, and psychological issues are sensitive (148), however it is relevant to discuss them with patients with IBD. Item non-response was lower than similar IBD-related questionnaire surveys (154).

In cross-sectional design, all measurements are used at a specific point in time (155). Recruitment took place during a long period, except for study III where recruitment was limited to two months. A longer period of data collection may have increased the response rate. When recruiting patients in Sweden and the U.S, the response rate was 73% in study III and in 49% in study IV. There were non-responders in studies II, III and IV. There were various reasons why it was difficult to participate. For study III, the patient response rate was lower than expected. In studies II, III and IV, no reminders were sent out, which could have reduced patient participation. However, response rates in questionnaire surveys are said to be declining in many countries (156).

Trustworthiness, validity, and reliability

Statistical methods were used, depending on the type of data, sample size, and data distribution. To enhance the credibility of the interview study (study I), the process was clearly described and for confirmability, quotes were provided to strengthen compliance with the data. Qualitative data can provide rich details of self-care among patients with IBD, for broader understanding. The author took into account the preunderstanding in order to minimize the author’s own influence. Patient experiences were described based on Swedish conditions. One telephone interview was conducted based on the critical situation that the patient experienced, with a desire to participate in the study. When using qualitative content analysis, transferability can be discussed (116). However, our results may be transferred to similar contexts for patients living in Western cultures. In study I, the author and main supervisor analyzed the data independently. Identifying and condensing meaning units, coding, and categorization is a back-and-forth process that is used to reflect the raw data (115, 157). When devising categories, at least two researchers should be independently involved, to minimize the risk of unconsciously reaching desirable results (101). Patient characteristics, data collection, and data analysis strengthen the dependability and transferability of study I.

In study II, both patients and HCPs participated. For usability, it was important to limit the questionnaire without losing validity and reliability.

With postal questionnaires, the risk of social desirable bias, where the respondent adjusts the responses in order to appear “better” in some way, is often considered smaller than with interview studies (148). In questionnaire development, validity refers to the degree to which the questionnaire measures what it is intended to measure (122). The items in our questionnaire, in study II, are supposed to be well worded, so that every participant interprets the question the same way. In our questionnaire, face validity was considered by patients to enhance the item “understanding”. External validation was performed by patients with IBD, and by HCPs with strong credentials regarding gastroenterology. Nurses and physicians from various Swedish counties participated, and as the questionnaire was intended for broad use, it could have been useful to recruit expertise also from other countries (122).

For a questionnaire to have excellent content validity, there is a need for outstanding experts, strong items, and detailed instructions for the experts (101). In our study, CVI was used early in the development phase. In the development procedure, we used the CVI method and all items remained in the cognitive interviews for future use, which is a deviation from the methodology (103, 105). We decided to maintain the items, in order to find out the patients’ view in the cognitive interviews. Cognitive interviews provided time for discussion and evaluation of the item “understanding”.

Items with high I-CVI ≥ 0.83 and low frequency among patients, such as “use of tobacco products” and “I avoid activities in daily life”, were included in the questionnaire according to their levels of influence in patients with IBD. Some items with low I-CVI (<0.83) and high frequency among patients ($>38\%$), were not included in the questionnaire. The items were discussed, and problems with the leakage of urine and feces, and awareness of the side effects of medication can be related to symptom recognition. ; eating vegetables and/or root vegetables every day (fresh, frozen or cooked); eating fruit and/or berries every day (fresh, frozen, preserved, juice etc.); and eating fish or shellfish as a main course, in a salad or as sandwich topping every week were considered in the item “I adapt diet”. The items “I am aware of my own need to sleep” and “I contact my clinic when I’m not feeling well” were also discussed, and found to be already in the questionnaire, in another formulation.

Criterion validity is often used to correlate the questionnaire with another measure, ideally a gold standard for patients with IBD. However, this was not possible because as far as we know, no other questionnaire existed for

IBD when we developed the self-care questionnaire. The response alternatives used were on a category scale. As a minimum number of categories, five to seven has been suggested, because reliability may decrease if there are fewer (122). In this study, self-reported questionnaires were used for evaluation. Many questionnaires are too extensive, leading to the risk of a lower response rate. It has been found that the content of the questionnaire is more important than the length (149).

Reliability can be measured in different ways, depending on the study design, and can relate to the consistency of the questionnaire. In study II, reliability was confirmed in test-retest. An acceptable value of >0.70 was considered (117). We judged our self-care questionnaire to be reliable after we excluded the two participants who had changed their self-care activity and with knowledge that self-care is changeable over time. The ICC varied between $r=0.426$ and $r=1.000$ for each item. "Planning the day when living with IBD" had the lowest ICC values, which implies that planning the day may vary among the patients over time.

In the thesis, the data was not normally distributed, and because of this, non-parametric analysis was used. To determine the number of patients required for studies II, III and IV, we discussed the number of patients required to be able to perform statistical calculations, and the possibility of generalizing the results and drawing reliable conclusions. The results must be interpreted with caution, especially those in study III, which included predominantly well-educated women. Study III did not contain a representative sample of patients with IBD. Patients with other severe diagnoses were excluded in study I, but not in subsequent studies. The purpose was, when developing items, to eliminate confounding factors for self-care.

Clinical implications

The results of this thesis contribute to increased knowledge of self-care among patients with IBD. Using the questionnaire in clinical health care may increase patients' compliance to advice and treatment, to managing their lives in a safer way, and to increasing their chances of living a healthier life. Medication adherence may increase, which ultimately can reduce the frequency of relapses, of illness, and of absenteeism. Patients' knowledge of the prescribed medical treatment is an important predictor for adherence to treatment (141).

Actively involved nurses and physicians are given the opportunity to facilitate the assessment of self-care, and to provide self-care counselling, when patients visit gastroenterology clinics or primary health care. To support the patients in the discussion of self-care, it is important to individualize their health care plans.

What this thesis adds

This thesis adds a self-care questionnaire for clinical use for patients with IBD and knowledge of self-care in daily life in relation to disease activity and to HRQOL for patients with IBD.

Future research

This thesis generated some implications for future research about self-care and supporting patients with IBD. Future research should continue, in order to gain a deeper understanding of the benefits of self-care, and to identify the predictors for self-care in patients with IBD, as well as the benefits of self-care for their families. Further implications for research are:

- Further utility testing of the self-care questionnaire in clinical care.
- Validation of the self-care questionnaire in other languages.
- To further investigate self-care in patients with IBD, as our study indicates an avoidant behavior with negative influence on HRQOL. An intervention using self-care may increase knowledge about self-care, bringing positive outcome for patients.
- Further exploration of self-care in relation to self-efficacy.
- There should be further research into the need for social support to families, with the aim of enhancing self-care among patients.

CONCLUSIONS

Self-care is central to improving HRQOL in chronic illness. To enhance the HRQOL of patients with IBD, it is necessary to reduce worry, symptom burden, and bowel interference in daily life. The results of this thesis indicate the importance of self-care for patients with IBD. The findings of this thesis highlight the importance of a valid and reliable self-care questionnaire for clinical use that strengthens self-care in patients with IBD. Self-care for patients with IBD includes a broad range of self-care activities and is commonly used. HCPs need to discuss self-care with the patients, and document it in an individual health care plan. Self-care is more frequent in patients with CD. Patients with CD planned their day to a higher degree when their bowel symptoms interfered with daily life. Support for self-care in patients with IBD is necessary in relation to disease activity, in order to maintain or increase HRQOL.

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SVENSK SAMMANFATTNING

Det övergripande syftet med den här avhandlingen var att utveckla en enkät och utvärdera enkäten för klinisk bedömning av egenvård (Studie I, II, III, IV). Syftet var även att utforska egenvård i relation till sjukdomsaktivitet och hälsorelaterad livskvalitet bland patienter med inflammatorisk tarmsjukdom (Studie IV).

Inflammatorisk tarmsjukdom (IBD), inkluderar ulcerös kolit (UC) och Crohn's sjukdom (CD). De förekommer i hela världen och är livslånga kroniska tillstånd. Symtomen orsakar begränsningar i livet och egenvård bland patienter med inflammatorisk tarmsjukdom hänvisar till patientens eget engagemang att bibehålla hälsa och ta beslut om att hantera symtom.

Avhandlingen är baserad på fyra delarbeten och studiematerialet till artiklarna består av intervjuer och enkäter till patienter från gastroenterologiska kliniker vid tre sjukhus i sydöstra Sverige och från en databas av personer med inflammatorisk tarmsjukdom från USA. Läkare och sjuksköterskor har också deltagit.

I den första studien användes kvalitativ metod, med intervjuer utförda med tjugo vuxna för att utforska egenvård bland patienter med IBD (studie I). I studie II, utvecklades och testades en enkät om egenvård bland 193 patienter med IBD, tre läkare och tre sjuksköterskor. I studie III, översattes enkäten om egenvård. Enkäten besvarades av 67 patienter i USA och egenvård utvärderades i förhållande till ålder, kön och allmänt välbefinnande (studie III). Egenvård utforskades i relation till sjukdomsaktivitet och hälsorelaterad livskvalitet bland 234 patienter (studie IV). Totalt deltog 421 patienter och data analyserades med innehållsanalys, beskrivande och analytisk statistik (studie I, II, III, IV).

Resultatet visade att patienter med inflammatorisk tarmsjukdom utövar egenvård beroende på hur de hanterade det dagliga livet i samband med sjukdomens symtom. Egenvård identifierades i fyra kategorier; de uppmärksammar symtom, hanterar symtom, planerar livet och söker nya alternativ. Att anpassa sig till symtom och hantera symtom är vanligt förekommande (studie I). En enkät om egenvård är utvecklad på svenska och bedömts som valid och reliabel (studie II). Enkäten är översatt till engelska

och patienter med lägre grad av välbefinnande utövade mer egenvård (studie III). Patienterna beskrev att den egenvård som de utövar omfattar att ta mediciner, anpassningar av kosten, undvikande av aktiviteter, planera dagen och åtgärder för att hantera stress (studie III, IV). Egenvård var vanligare hos patienter med Crohns sjukdom när det handlade om att uppmärksamma psykologiska symptom, anpassa kosten, undvika olika aktiviteter och leta efter nya vägar för att leva med sin sjukdom (studie IV).

Att patienter med inflammatorisk tarmsjukdom utövar egenvård är betydelsefullt. Patientens val och självbestämmande skapar delaktighet i hälso- och sjukvård. I avhandlingens resultat presenteras en enkät som är avsedd att användas som stöd vid samtal för bedömning av egenvård bland patienter med IBD. Sjukvårdspersonalen ges möjlighet att med hjälp av enkäten som stöd, kunna göra en individuell bedömning av patientens egenvård. Enkäten är utvecklad på svenska och översatt till engelska för att kunna användas i engelskspråkiga länder och patienterna ska kunna bemötas på sjukhus och primärvård för att samtala kring egenvård utifrån aktuell evidens.

ENKÄT OM ANPASSNINGAR OCH EGENVÅRD I VARDAGEN

Vid inflammatorisk tarmsjukdom

Här är ett antal frågor om anpassningar och egenvård, med egenvård menas vad du själv gör för att må bra i ditt dagliga liv. Markera med ett kryss vad som stämmer bäst för dig.

1. Uppmärksammar du symtomen från din inflammatoriska tarmsjukdom?

	Aldrig	Ibland	Ofta	Alltid	Ej relevant
Uppmärksammar mina tarmsymtom.	☐	☐	☐	☐	☐
Uppmärksammar kroppsliga symtom som inte gäller tarmen	☐	☐	☐	☐	☐
Uppmärksammar mina psykiska symtom.	☐	☐	☐	☐	☐

2. Hur ofta känner du dig trygg i att kunna tolka om dina tarmsymtom beror på inflammatorisk tarmsjukdom?

Aldrig	Ibland	Ofta	Alltid	Ej relevant
☐	☐	☐	☐	☐

FRÅGOR OM ANPASSNINGAR OCH EGENVÅRD

3. Hur ofta anpassar du ditt vardagsliv när det gäller problem orsakade av din inflammatoriska tarmsjukdom?

	Aldrig	Ibland	Ofta	Alltid	Ej relevant
Anpassar min kost	☐	☐	☐	☐	☐
Undviker aktiviteter.	☐	☐	☐	☐	☐
Undviker sexuell aktivitet.	☐	☐	☐	☐	☐
Undviker alkohol.	☐	☐	☐	☐	☐
Planerar aktivitet med tanke på var det finns toaletter	☐	☐	☐	☐	☐
Planerar vardagen utifrån sjukdomen	☐	☐	☐	☐	☐

**4. Hur ofta gör du
egenvårdsåtgärder för att
undvika eller lindra symptom
på din inflammatoriska
tarmsjukdom?**

	Aldrig	Ibland	Ofta	Alltid	Ej relevant
Åtgärder för att sova bra.	☐	☐	☐	☐	☐
Åtgärder för att hantera stress.	☐	☐	☐	☐	☐
Söker mer kunskap om sjukdomen	☐	☐	☐	☐	☐
Söker nya vägar att leva med sjukdomen	☐	☐	☐	☐	☐
Använder naturläkemedel	☐	☐	☐	☐	☐

Annat slags egenvård _____

LÄKEMEDEL OCH KONTAKT MED HÄLSO- OCH SJUKVÅRDEN

**5. Följer du ordinerad
läkemedelsbehandling**

	Aldrig	Ibland	Ofta	Alltid	Har ingen ordinerad medicin
	☐	☐	☐	☐	☐

**6. Vet du vem du ska/kan
vända dig till om du får
symtom från din
inflammatoriska
tarmsjukdom?**

	Nej	Ja
	☐	☐

**7. Hur väl känner du till vid
vilka besvär/symtom du bör
kontakta sjukvården?**

	Känner inte alls till	Känner inte till särkilt väl	Känner till ganska väl	Känner väl till
	☐	☐	☐	☐

8. Tobaksvanor

Röker du?

- ☐ Ja, röker dagligen
☐ Ja, händer att jag röker då och då
☐ Nej, jag slutade röka år _____
☐ Nej, jag har aldrig rökt.

Snusar du?

- ☐ Ja, snusar dagligen
☐ Ja, händer att jag snusar då och då
☐ Nej, jag slutade år _____
☐ Nej, jag har aldrig snusat

**9. Hur ofta upplever du att
egenvårdsåtgärder hjälper dig
att lindra symtom från din
inflammatoriska
tarmsjukdom?**

	Aldrig	Ibland	Ofta	Alltid	Ej relevant
	☐	☐	☐	☐	☐

QUESTIONNAIRE CONCERNING ADAPTING YOUR LIFE AND ADMINISTERING SELF-CARE

Inflammatory bowel disease

The following questions concern ways that you adapt your life and administer self-care (methods of making yourself feel better). Tick the box that best describes your situation.

1. Do you pay attention to symptoms of inflammatory bowel disease?	Never	Occasionally	Often	Always	Not applicable
I pay attention to intestinal symptoms	☐	☐	☐	☐	☐
I pay attention to physical symptoms unrelated to the intestines	☐	☐	☐	☐	☐
I pay attention to psychological symptoms	☐	☐	☐	☐	☐
2. How often do you feel confident that you are able to determine whether intestinal symptoms are due to inflammatory bowel disease?	Never	Occasionally	Often	Always	Not applicable
	☐	☐	☐	☐	☐

ADAPTING YOUR LIFE AND ADMINISTERING SELF-CARE

3. How often do you adapt your day to problems caused by inflammatory bowel disease?	Never	Occasionally	Often	Always	Not applicable
I adapt my diet	☐	☐	☐	☐	☐
I avoid various activities	☐	☐	☐	☐	☐
I avoid sex	☐	☐	☐	☐	☐
I avoid alcohol	☐	☐	☐	☐	☐
I plan my day so that I am always near a toilet	☐	☐	☐	☐	☐
I plan my day in view of the fact that I have inflammatory bowel disease	☐	☐	☐	☐	☐

4. How often do you administer self-care to prevent or relieve symptoms of inflammatory bowel disease?

	Never	Occasionally	Often	Always	Not applicable
Self-care to make sure I sleep well	☐	☐	☐	☐	☐
Self-care to manage stress	☐	☐	☐	☐	☐
I find out more about inflammatory bowel disease	☐	☐	☐	☐	☐
I look for new approaches to living with inflammatory bowel disease	☐	☐	☐	☐	☐
I use natural remedies	☐	☐	☐	☐	☐

Other kinds of self-care _____

MEDICATION AND CONTACTING HEALTHCARE PROVIDERS

5. Do you take medication for inflammatory bowel disease as prescribed by a doctor?

Never	Occasionally	Often	Always	No prescription medication
☐	☐	☐	☐	☐

6. Do you know whom to contact if you experience symptoms of inflammatory bowel disease?

No	Yes
☐	☐

7. How familiar are you with the symptoms for which you should contact a healthcare provider?

Totally unfamiliar	Relatively unfamiliar	Relatively familiar	Totally familiar
☐	☐	☐	☐

8. Tobacco use

Do you smoke?

- ☐ Yes, every day.
☐ Yes, occasionally
☐ No, I quit in _____(year)
☐ No, I never have

Do you use snuff?

- ☐ Yes, every day
☐ Yes, occasionally
☐ No, I quit in _____(year)
☐ No, I never have

9. How often does self-care help you relieve symptoms of inflammatory bowel disease?

Never	Occasionally	Often	Always	Not applicable
☐	☐	☐	☐	☐

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