

Use of complementary and alternative medicine,
fatigue, and personal resources in patients with
inflammatory bowel diseases

Two cross-sectional descriptive studies

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1 Preface

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List of papers

- I. Opheim R, Høivik ML, Solberg IC, Moum B. Complementary and alternative medicine in patients with inflammatory bowel disease: The results of a population-based inception cohort (IBSEN). *Journal of Crohn's and Colitis* 2012; 6:345-353.
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- III. Opheim R, Fagermoen MS, Bernklev T, Jelsness-Jørgensen LP, Moum B. Fatigue interference with daily living among patients with inflammatory bowel disease. *Quality of Life Research* 2013. In press, DOI: 10.1007/s11136-013-0508-4.
- IV. Opheim R, Fagermoen MS, Jelsness- Jørgensen LP, Bernklev T, Moum B. Sense of coherence in patients with inflammatory bowel disease. *Submitted Nov2013*.

List of abbreviations

AdjOR	Adjusted Odds Ratio
Anti-TNF α	Tumor Necrosis Factor α Inhibitor
AZA	Azathioprine
CAM	Complementary and Alternative Medicine
CD	Crohn's Disease
CI	Confidence Interval
ECCO	European Crohn's and Colitis Organisation
FI	Fatigue Interference
FSS	Fatigue Severity Scale
FSS-5	The Five-item Fatigue Severity Scale
GSE	General Self-Efficacy Scale
HBAI	Harvey-Bradshaw Activity Index
HRQOL	Health-related Quality of Life
IBD	Inflammatory Bowel Disease
IBSEN	Inflammatory Bowel Disease South Eastern Norway
I-CAM-Q	International CAM Questionnaire
IPAA	Ileal Pouch Anal Anastomosis
MTX	Methotrexate
N-ECCO	Nurses-European Crohn's & Colitis Organisation
OR	Odds Ratio
SCCAI	Simple Clinical Colitis Activity Index
SOC	Sense of Coherence
SOC-13	13-Item Short Version of the Sense of Coherence Scale
SD	Standard Deviation
UC	Ulcerative Colitis
WHO	World Health Organization
5-ASA	5-aminosalicylic acid
6-MP	6-mercaptopurine

2 Introduction

Crohn's disease (CD) and ulcerative colitis (UC) are chronic relapsing inflammatory bowel diseases (IBD) of unknown etiology, that affect 2.5 – 3 million people in Europe [1]. IBD affects children, adolescents, and adults, with a peak incidence between 15 and 34 years [2,3]. Diarrhea, bloody stools, and stomach pain are characteristic symptoms. The disease course is characterized by periods with symptom flares and periods of remission [3,2,4,5], but it is highly individual and variable, even in individual patients at different times during their illness. A high proportion of patients is on lifelong medication regimens and need frequent contact with the health care system [6]. Medical treatment includes the use of anti-inflammatory medications, but these may cause adverse drug reactions. The symptom severity, an unpredictable disease course, adverse drug reactions, loss of bowel control and knowing that the disease has no cure, may cause significant daily challenges and impact health-related quality of life (HRQOL) [7-12]. Thus, living with a chronic illness such as IBD involves complex cognitive, physical, emotional, psychological, and behavioral processes [13]. Patients must manage and adjust to life-long medication use, lifestyle changes, find meaning in and adapt to unstable life conditions, relate to concerns about how their life will unfold, and discover how they can remain as healthy as possible [14].

Several studies have addressed the use of complementary and alternative medicine (CAM) among IBD patients [15]. CAM involves several therapies, products, and practices that are not normally part of conventional health care. Research has shown that IBD patients use CAM for reasons such as symptom relief, to ameliorate adverse drug reactions from conventional medicine, and to gain control over their disease [15]. However, CAM use is not unique to IBD patients. Systematic reviews have documented that the use of CAM has increased in the industrialized western world in recent decades, and it is currently regarded as common among the general population [16,17]. The Norwegian population spent a total of approximately 3.8 billion NOK on alternative practitioners in 2012 [18]. CAM use has rarely been assessed in non-selected IBD populations internationally, and the frequency of CAM use among IBD patients in Norway is not known.

Fatigue has been identified as one of the leading concerns for IBD patients [11,19,20]. Studies assessing fatigue in IBD have found that it is a common experience, even

when the disease is quiescent [21-23] and that fatigue is associated with reduced HRQOL [24,25]. Although fatigue is common among IBD patients, the interference of fatigue with daily living has not been systematically investigated. Further, fatigue is a common reason for CAM use in other chronic diseases [26,27]. This relationship has not been adequately studied in the IBD population.

Adjustment to chronic disease such as IBD is affected by different psychosocial factors. The medical sociologist Aaron Antonovsky studied why some people are able to stay healthy despite hardship and strain [28]. His answer was the concept “sense of coherence” (SOC): people who assess the world as meaningful, understandable, and manageable seem to adjust better to their situation and are healthier than those who not. In addition, a person’s belief about how capable he/she is to do what is needed to influence own health and deal with challenges (self-efficacy) has been related to self-management [29-31]. Thus, given the complexity of living with a chronic disease, personal resources appear to be important for well-being, quality of life, and the ability to cope with disease.

3 Aims of the thesis

The overall aim of this thesis was to increase the knowledge about certain aspects of living with inflammatory bowel disease: the use of CAM, the experience of fatigue interference with daily living, sense of coherence and self-efficacy. The specific aims were:

1. To determine the proportion of CAM use in a population based cohort of IBD patients followed for ten years and to describe the associations between CAM use and socio-demographic and disease-related factors (paper I)
2. To determine the overall and specific use of CAM among IBD patients attending outpatient clinics in Norway and to describe the associations between CAM use and socio-demographic and disease-related factors (paper II).
3. To examine fatigue interference with daily living in IBD patients, to explore the relationships between severe fatigue interference and socio-demographic and disease-related factors, as well as CAM use (paper III).
4. To describe the sense of coherence among IBD patients and to explore the relationships between socio-demographic and disease-related factors, fatigue interference, self-efficacy, and SOC (paper IV).

4 Background

4.1 Inflammatory bowel diseases

Inflammatory bowel diseases are characterized by chronic, relapsing inflammation of the gastrointestinal tract. The two main entities are ulcerative colitis and Crohn's disease, which differ in localization and behavior. UC is characterized by mucosal inflammation of the colon, affecting the rectum and a variable extent of the colon in continuity [32]. CD is characterized by transmural and granulomatous inflammation that can be located at any site in the gastrointestinal tract from the mouth to the anus. The transmural inflammation in CD may cause a more mutilating disease behavior, with complications such as strictures, abscesses, and fistulas [33]. The diagnoses are confirmed by a combination of specific clinical, endoscopic, histological, and radiological criteria [34]. Both UC and CD can be complicated by extra-intestinal manifestations, which most commonly affect the joints, skin, eyes, liver and bile ducts [35]. In both diseases, inflammation causes intestinal symptoms, such as frequent and urgent diarrhea, sometimes with blood, pus, mucus, abdominal pain, tenesmus, and general symptoms including fever, fatigue, and weight loss [3,2].

4.1.1 Epidemiology and etiology

In adults, the highest incidences of CD and UC have been reported in northern Europe and North America [36]. The latest incidence rates in Norway are 5.8 per 100,000 persons/year for CD and 13.6 per 100,000 persons/year for UC in the IBSEN study performed from 1990-1993 [3,2]. The prevalence of CD in Europe is 213 cases per 100,000 persons, whereas the prevalence for UC is 294 cases per 100,000 persons [1]. Incidence has been increasing in recent decades, especially for CD and in the pediatric population. Changes in dietary habits and environmental factors, such as improved sanitation and industrialization toward a western lifestyle, are some of the explanations postulated [37,36]. The prevalence of IBD is expected to increase further due to the early age of onset of the disease and the low mortality of IBD patients [36]. CD most frequently presents between 15 and 25 years of age, whereas UC most frequently presents between 25 and 34 years [2,3].

The etiology and pathogenesis of the diseases are not well understood. Genetic, microbial, and environmental factors are believed to play a role in the dysregulation of intestinal immunity, leading to gastrointestinal injury [38,39].

Family and twin studies have demonstrated a genetic predisposition for IBD, although more so in CD than in UC [40-44]. Environmental factors, such as changes in diet, antibiotic use, cigarette smoking, hygiene status, microbial exposures, and pollution, have been proposed as potential triggering factors and are associated with an increased westernized lifestyle worldwide [45,46]. However, causality between environmental factors and development of IBD has not been established.

4.1.2 Disease course

Crohn's disease

Defining specific disease phenotypes in CD is important for research constancy, patient management, and the assessment of disease prognosis. Several sub-classification systems have been used to classify CD. The most common are the Vienna classification [47] and the Montreal classification [48]. Disease location seems to remain stable over time, whereas disease behavior changes with an increasing number of patients progressing from non-penetrating, non-structuring disease to stricturing or penetrating disease [49]. Population-based studies have demonstrated that approximately one third of patients experienced a relapse within the last year and underwent intestinal surgery within the first five years [50,8]. After 20 years, the cumulative surgery rates lie between 40% and 80% [51]. Stenoses, fistulas, and abscesses are the primary reasons for bowel resection. Approximately 25%-46% of patients will experience extra-intestinal manifestations [50]. CD patients have an increased risk for colorectal cancer and small bowel cancer [52]. In a Norwegian population based-study (the IBSEN study), there was no significant difference in the overall mortality between CD patients twenty years after initial diagnosis and the general population [53].

Ulcerative colitis

In the Montreal classification, UC are sub-classified into three categories according to disease extent. Ulcerative proctitis is involvement limited to the rectum, left-sided colitis is involvement limited up to the splenic flexure, and pancolitis/extensive colitis involvement extends proximal to the splenic flexure [48]. Originating in the rectum, the inflammation may progress proximally during the disease course [4]. Severity of flares and their response to treatment vary from minor symptoms to life-threatening fulminant colitis that does not respond to treatment and requires colectomy. Approximately one third experience a relapse within a year [9]. Extensive colitis at diagnosis is an important risk factor for colectomy, and

the probability of colectomy is highest during the first year after diagnosis. Approximately 10 % of patients undergo colectomy within the first ten years since diagnosis [4]. During the disease course, extra-intestinal manifestations are observed in approximately one third of patients [54]. A possible increased risk of colorectal cancer among UC patients is debated, but the most recent studies have shown a decreasing trend during the last decade [55]. New therapeutic options and the implementation of surveillance strategies may be some of the causes of the reduction [55]. The overall mortality risk is not increased compared to the general population [56].

4.1.3 Medical and surgical treatment

The main treatment goals are to induce and maintain disease remission and improve HRQOL [6]. To promote a European perspective on the management of IBD, the European Crohn's and Colitis Organisation (ECCO) has developed consensus guidelines [57-60]. Medical treatment is directed by several factors: type of disease, localization of lesions, severity, clinical predictors of severe disease course, complications, and medical response and tolerance of the patient [58,57]. The inflammatory manifestations of UC and CD are mostly treated with a spectrum of the same medications, including 5-aminosalicylic acid (5-ASA), corticosteroids, immunosuppressive agents, biological agents, and antibiotics.

5-ASA has a central role in the treatment of UC, particularly in patients with mild to moderately active disease [57]. In addition, it is used as a maintenance treatment to sustain remission [57]. 5-ASA is still used to some extent in CD treatment, but the clinical rationale and documentation for this is weak [58,61].

Corticosteroid has a central place in the treatment of acute active UC and CD. Prednisolone has an immediate effect in 70 %-90% of the patients. Corticosteroids are not an option in maintenance therapy, because of serious long-term adverse effects, such as osteoporosis, increased risk for infections, and myopathy. The corticosteroid budesonide is an option when the inflammation is located in the terminal ileum in CD [61,62].

The thiopurines azathiopurine (AZA) and 6-mercaptopurine (6-MP) are the most common immunomodulating agents used to maintain remission in UC and CD. Due to their slow onsets of action, they are not an option for single therapy in disease relapse. Thiopurines are

also used in combination with anti-TNF therapy [62]. Methotrexate (MTX) is an immunomodulating agent introduced to CD patients who are resistant or intolerant to thiopurines, and it is effective at both inducing and maintaining remission. The role of MTX in the induction or maintenance of remission in UC has not been addressed [62]. Cyclosporine is an option in the treatment of patients with severe UC who do not respond to corticosteroids and are considered for urgent colectomy. The effect of cyclosporine in the treatment of CD has not been documented [61].

Antibiotics are used to treat secondary complications in IBD, such as fistulizing disease [58,61]

Tumor necrosis factor- α (TNF- α) is an important pro-inflammatory cytokine known to be important in the immune pathogenesis in IBD. TNF- α inhibitors neutralize the biological effect of the cytokine. Several different anti-TNF agents are available and they are commonly introduced to IBD patients with moderate to severe disease that are not responding to other therapies, have experienced serious adverse drug reactions, or who are not eligible for surgery [61].

Medical treatments for IBD may have adverse effects. General adverse effects, such as nausea, stomach pain, tenesmus, diarrhea, skin rash, and fatigue are reported in relation to all the medication types and are difficult to differentiate from disease symptoms. However, in most cases these adverse effects cease upon withdrawal of the drug. Treatment with corticosteroids may induce short-term adverse effects, such as fluid retention and weight gain, hypertension, high blood glucose levels, and sleep and mood disturbances. Among the long term adverse effects are increased risk for infections, osteoporosis, cataracts, and muscle atrophy. Use of immunosuppressants can affect the skin, liver, kidneys, pancreas, and cause malignancy, bone marrow suppression, and leucopenia. These risks increase with accumulated doses, and thus, patients need to be monitored for leucopenia with regular blood-count measurements. Patients treated with anti-TNF have an increased risk for infections, but the risk for cancer is unclear. Allergic reactions under infusion may occur [61,62].

In addition, iron deficiency and anemia are reported to occur frequently in both UC and CD [63-65]. Monitoring IBD patient hemoglobin levels, hematological status, iron status, vitamin

12, and folic acid levels are recommended in the ECCO guidelines for the management of disease [59].

Surgery is performed in cases of medical treatment failure, during acute severe disease or if high-grade dysplasia is present [60]. In UC, proctocolectomy with ileal-pouch-anal-anastomosis (IPAA) is the procedure of choice for most patients requiring colectomy [60]. Surgery in CD may include small bowel resections and treatment of fistulas and abscesses [58].

4.1.4 Psychosocial support

ECCO consensus guidelines states that psychosocial consequences of living with IBD should be taken into account during the regular clinical practice. Adequate time at consultancy, individual education of patients, patient-centered information, patient education programs and work with health-promoting strategies are suggested methods to meet these patient needs [6,59,60]. Nurses with special competence in IBD are suggested to have a key role in this work [66-68]. Recently, the N-ECCO (Nurses-European Crohn's & Colitis Organisation) proposed statements for the nursing role in caring for IBD patients [68].

4.2 Core Concepts

4.2.1 Complementary and alternative medicine

In the western world and in the academic literature the term *complementary and alternative medicine* (CAM) is the most commonly used term to cover health care practices and products used primarily outside the formal health care system [69]. Subcategories of health-care seeking behaviors fall under the umbrella of CAM, such as the use of *CAM services*, which includes visits to alternative health care providers such as, acupuncture, homeopathy, spiritual healing, and reflexology, the use of *CAM products* such as, herbal medicine and dietary supplements, and different types of *CAM self-help practices* such as, yoga, meditation and relaxation techniques [70].

CAM is heterogeneous, and this is exemplified by the national legal status and regulation of alternative health care providers and the terminology used. In most countries, CAM is not covered by national insurance systems, and users pay almost all costs out of pocket. In

addition, CAM constantly changes as some CAM modalities gradually become accepted and integrated into conventional medicine. For example, chiropractors are authorized health care personnel in Norway but not in Sweden. In contrast, naprapaths are authorized personnel in Sweden but not in Norway [71]. Further, although acupuncture is not legalized in Norway, it is accepted as a treatment in 50% of Norwegian hospitals [72]. Hence, the individual CAM modality that is included as CAM relies on tradition, culture, and context [73,74,71]. In addition, the term CAM includes two mutually exclusive terms: “complementary”, which indicates CAM modalities that are used *alongside* conventional medicine, and “alternative”, which indicates CAM modalities that are used *instead of* conventional medicine. Moreover, the term CAM borrows terminology from conventional medicine. Therefore, CAM is simultaneously comparable to conventional medicine while defined as something completely different [75]. Research on CAM is affected by the lack of a universal agreement on how it should be defined.

In Norway, alternative treatment is regulated by law. In § 2, in Lov om alternativ behandling [Alternative treatment act of illness] alternative treatment is defined as:

“Alternative treatment is understood to mean health-related treatment which is practiced outside the established health services and which is not practised by authorised health personnel. However, treatment practised within the scope of the established health services or by authorised health personnel is also covered by the term alternative treatment when the methods used are essentially methods that are used outside the established health services” [76,77].

CAM subcategories are generally based on several different theoretical models. However, unifying aspects within CAM therapies, products, and practices are that the primary explanation of illness is a disturbance in an individual’s energy balance. Different traditions use different names for this, such as Qi, energy, prana, yin-yang, or dynamis [78]. This balance is understood as crucial for self-healing and the ability to regenerate [79]. CAM practitioners often hold a holistic view of health, emphasizing that health is a product of biological, psychological, social, and spiritual dimensions. Emphasis in treatment is often placed on individual resources and efforts. An important therapeutic element is the quality of the interaction and the communication between the patients and the therapist [71,80].

4.2.2 Fatigue and fatigue interference

Fatigue is defined as a “sense of physical tiredness and lack of energy, distinct from sadness or weakness” [81]. The etiology of fatigue is poorly understood, but it is considered to be a subjective experience embracing physical, cognitive, as well as affective components [21]. It is associated with a sense of loss of control over one’s environment, low positive affect, and psychological distress [82]. Hence, fatigue interference of daily living is an important aspect of the fatigue experience. The Fatigue Severity Scale used in this dissertation was developed with the aim of measuring the impact of fatigue on daily living, i.e., fatigue interference [83].

4.2.3 Sense of Coherence

The medical sociologist Aaron Antonovsky raised the question of why some people stay healthy despite stressful situations while others do not. To respond to the question he introduced the concept of *sense of coherence* (SOC) in his theory of Salutogenesis in 1979 [84,28]. The concept “salutogenesis” originates from the Latin *salus*, which means health, and the Greek *genesis*, which means origin. Together, this term signifies the creation of health. Health is regarded as a continuum, a movement between total ill health (dis-ease) and total health (ease) rather than healthy versus unhealthy [85]. This positive health approach focuses on predictors for a positive health outcome.

According to Antonovsky, the SOC concept reflects a person’s resources and dispositional orientation, which enables them to manage tension, reflect on internal and external resources, and deal with stressors in a health-promoting manner [86]. The resources are any characteristic of a person and their environment, such as personal control, self-identity, culture, social support, and socio-economic status [87]. SOC consists of a cognitive component (comprehensibility), a behavioral component (manageability) and a motivational component (meaningfulness) [85]. The stronger the SOC, the more likely the person will assess the situation as understandable and predictable (comprehensibility), to have the resources and capacity to manage the situation (manageability) and to be motivated to move in a health promoting direction (meaningfulness) [85]. To measure one’s SOC, Antonovsky developed the Sense of Coherence questionnaire [88,89]. Systematic reviews on SOC research conclude that the SOC is strongly related to a person’s mental health and HRQOL [86,90]. Antonovsky assumed that a person’s SOC develops from life experience during

childhood and young adulthood, and to be relatively stable around the age of 30 [28]. However, intervention program research focusing on salutogenic treatment principles has shown that SOC is positively affected by interventions [85,91].

4.2.4 Self-efficacy

Self-efficacy is a core concept in Albert Bandura's social-cognitive theory [29]. In the context of this theory, individuals are simultaneously agents and objects. We are proactive, reflective, and self-regulative and can influence our actions. Self-efficacy refers to the "belief in one's capabilities to organize and execute the courses of action required to produce a given attainment" [29] (p 3). In other words, self-efficacy is belief in one's ability to succeed in a particular situation. Self-efficacy develops from early childhood through the experience of positive outcomes from one's behavior and personal agency in situations. The reactions in one's environment can promote or inhibit self-efficacy. Self-efficacy continues to evolve throughout life as people acquire new skills, experiences, and understanding. A review article evaluating intervention programs focusing on modifying a person's self-efficacy concluded that enhanced self-efficacy could be of importance for improving chronic illness outcome, such as adherence to prescribed medical regimens and improved health status. Thus, self-efficacy may serve as a predictor for health-related behavior and self-management [92].

4.3 Previous research

4.3.1 CAM use in the general population and in IBD patients

CAM use in the general population

In Norway, the use of CAM in the general population has been documented several times in the past 25 years [93-95,18,96]. The prevalence rates in these studies are difficult to compare due to the variability of CAM modalities included in the studies. However, in this period the use of *CAM services* (defined as receiving alternative therapy from a CAM practitioner, such as acupuncturist, homeopath, or healer) increased from 8% to 37% [95,93,94,18,96]. The latest study was conducted in 2012 by the National Research Center for Complementary and Alternative medicine (NAFKAM). They found no significant changes in the prevalence of CAM service use from 2007 to 2012 [18], and thus, the prevalence appears to have stabilized. This trend is comparable to Scandinavian countries and other western countries [97-99,17].

Acupuncture and massage are the CAM modalities most frequently reported in Norway [18,96,94], and the majority use CAM for symptom relief or to promote health [94]. Fifty percent of the Norwegian hospitals and one-third of the Danish hospitals offer alternative therapies [72]. In both countries, acupuncture was the most common CAM modality offered. In the NAFKAM study in 2012, the use of self- help practices (e.g., relaxation techniques, yoga, Qigong, and mediation) and CAM products (e.g., herbal medicine) were defined as CAM [18]. When these CAM modalities were included as CAM, the overall CAM use was 45.3 % [18]. In the general population, a persistent finding is that CAM users are more likely female, have a higher education level, are middle-aged, and report poorer health statuses than non-users [17].

CAM use among IBD patients

In IBD, CAM use has been assessed largely in selected patient populations, such as hospital-based samples or patients from patient self-help organizations. Data from non-selected population studies are rare. From 1995 to 2013, the reported current or past CAM use in North-America and Europe ranged from 21% [100] to 56 % [101]. There is a large variation in the types of services, products, and techniques that are included as CAM. The more CAM modalities included in the questionnaire, the higher the prevalence rates. Some studies include only CAM services (e.g., acupuncturist, homeopath, and healer) [102], some include CAM services and CAM products (e.g., herbal medicine, homeopathic remedies, and dietary supplements) [103-111], and the majority include CAM services, CAM products and CAM self-help practices (e.g., relaxation techniques, yoga, Qigong, and mediation) [101,112-115,100,116-118]. Two studies assessed oral products only [119,120]. Visiting a homeopath is reported more often in European studies than in studies from North America [15]. This may suggest that, although the overall prevalence of CAM use seems to be similar across North America and Europe, the preferred form of CAM varies by region.

A review of CAM use in IBD patients found that the reasons for CAM use fit into two broad categories: 1) *direct disease-related benefits*, indicating concerns regarding conventional treatment, including perceived lack of effectiveness and fear of side-effects; and 2) *indirect non-disease related benefits*, indicating the subjective benefits from CAM therapies and products, the desire to take personal responsibility for treatment, and the hope to gain a greater sense of control over one's own health care [15]. Whether CAM was utilized for IBD

symptoms, or other health problems or well-being was reported in some studies, but not others. The majority of patients used CAM alongside conventional medicine rather than replacing it [15].

The main socio-demographic characteristics associated with CAM use among IBD patients are female gender, younger age, and higher education level. These findings are in accordance with other chronic diseases [121,27,122,123]. Many disease-related factors have been linked to the use of CAM: hospitalization rates, extra-intestinal complications, experience of adverse effects in response to conventional IBD medications, immunosuppressant use, systemic steroid intake, comorbid chronic conditions, disease severity, and disease duration [110,111,101,104,115,102,113,118]. Three studies have assessed the relationship between CAM use and HRQOL. One reported that CAM users had lower scores on emotional and social dimensions compared to non-users [108], whereas no difference between CAM users and non-users was found in the two other studies [103,101]. An overview of the main studies that have evaluated IBD patients CAM use and the factors associated with CAM use are depicted in Appendix.

4.3.2 Fatigue among IBD patients

Fatigue has gained increased attention in IBD research over the last decade, and two systematic reviews have been published [21,7]. Several questionnaires have been used to assess fatigue prevalence in the IBD population. Fatigue has been conceptualized as a multidimensional phenomenon, and most of the studies refer to different dimensions of fatigue, including physical, cognitive, emotional and functional axes [7]. In addition, one study examined chronic fatigue [23]. The prevalence of fatigue among IBD patients in remission varies between 22 %–41 % and in moderate to active disease between 44 %– 86 % [7]. The association between severity of fatigue and severity of disease symptoms has been reported in several studies, but the association between fatigue and factors, such as gender, disease duration, anemia, and sleep quality has shown conflicting results [7]. Chronic fatigue has been found to be associated with impaired HRQOL and increased disease-related worrying [25,20]. One qualitative study used focus group interviews to explore the experience of fatigue among IBD patients and how they managed their fatigue in everyday life [124]. The patients experienced fatigue as a disabling effect on their social and emotional well-being,

which limited their employment opportunities. However, the experience of fatigue interference with daily living has not been systematically measured in an IBD population.

4.3.3 Sense of coherence and self-efficacy in IBD patients

Personal factors, such as SOC and self-efficacy, have not gained much attention in IBD research. A few studies have assessed SOC in IBD patients [125-129]. Oxelmark et al. [125] included the SOC questionnaire as an outcome variable to evaluate a medical and psychosocial group-based educational intervention program with the aim of strengthening the coping ability of IBD patients. No significant increases in SOC scores were seen when comparing the intervention group before and after completion of the program, after 6 or and 12 months. In another study by Oxelmark, SOC was evaluated in UC patients taking part in a cancer surveillance program. The results showed that the UC patients' SOC scores were comparable with healthy controls [129]. The General Self-Efficacy scale was included in a study with the aim of assessing the role and impact of stigma in IBD. Perceived stigma was found to be a significant predictor for decreased self-efficacy [130]. Keefer et al. [131] developed *the IBD self-efficacy scale*, which assesses four disease-related domains: managing stress and emotions, managing medical care, managing symptoms and disease, and maintaining remission. The psychometric test of the scale showed high reliability and validity.

5 Material and methods

5.1 Research design

The studies included in this thesis have a cross-sectional and descriptive design. Two different patient populations are included: one population-based sample and one outpatient - based sample. The reason for including two patient populations was two-fold. *First*, no studies had reported CAM use in a population-based IBD cohort, and the frequency of CAM use among IBD patients in Norway was not known. The Inflammatory Bowel South Eastern Norway (IBSEN) study included a few questions about CAM use in the ten-year follow up (Paper I). *Secondly*, because the IBSEN study had few, and no standardized questions about CAM use, a new cross-sectional study was designed to more extensively evaluate CAM use in Norwegian IBD patients. In addition, we wanted to assess psychosocial factors, such as fatigue interference, SOC and self-efficacy (Papers II, III, and IV).

5.2 Study populations

5.2.1 The population-based sample

The Inflammatory Bowel South Eastern Norway (IBSEN) study is a prospective, population-based inception cohort. Between 1 January 1990 and 31 December 1993, all newly diagnosed cases of IBD in the south-eastern Norway (the counties of Oslo, Østfold, Telemark and Aust Agder) were registered in the inception cohort. On January 1, 1992, the total study population in these areas was 966, 427. The organization of the study included collaboration between 15 hospitals and 1,236 general practitioners. All the participating hospitals followed strict guidelines for case definitions which followed internationally accepted criteria [34,132]. Endoscopy was the main instrument of diagnosis and determination of the extent of disease. A total of 843 patients were included in the original cohort. Further details about the organization of the cohort are described by Moum et al. [133].

Prescheduled follow-ups were performed at one, five, and ten years after enrollment in the cohort. At each follow-up visit, the patients underwent a clinical interview and a clinical examination by a gastroenterologist. In addition, blood samples were collected, and a

colonoscopy was performed upon patient consent. At the five- and ten-year visits, a patient-reported questionnaire was included, and in the ten-year visit, questions about the use of alternative therapies for their IBD were included in the questionnaire. The patients completed the questionnaire at the hospital, prior to the clinical interview.

In paper I, we used cross-sectional data from the ten-year follow up. The collection of data for the ten-year follow up took place from 1 January 2000 to 31 December 2004.

Socio-demographic data

The included socio-demographic variables were age (continuous variable), gender, and highest completed education (dichotomized as ≤ 12 years; maximum upper secondary school vs. >12 years; college/university degree).

Clinical data

Disease location and disease behavior in CD patients were classified according to the Vienna classification system [47]. There was no classification system for CD when the IBSEN study was started; therefore, this classification was performed retrospectively. At the ten-year follow up, the Vienna classification was the standard classification system, and the patients were classified prospectively. UC patients were classified into three subgroups by disease extent: proctitis (inflammatory changes up to 15 cm from the anus); left-sided colitis (inflammatory changes up to the splenic flexure); extensive (inflammation above the splenic flexure).

Relapse was defined as an aggravation of symptoms resulting in more aggressive medical treatment or surgery. Surgery was defined as any intra-abdominal procedure for the treatment of active CD and was recorded as yes/no from diagnosis to the relevant follow-up visit. However, incisions and drainage of perianal abscesses and simple perianal fistulectomies did not qualify as surgery in this outcome definition. Colectomy status was recorded consecutively for UC patients.

Medical therapies included the use of 5-ASA, azathioprine, and systemic steroids. The study was initiated before immunomodulators were widely used as maintenance therapy for UC and before anti-TNF therapy were generally introduced to IBD patients.

Clinical course of the disease

The patients were asked to categorize the clinical course of their disease from the time of diagnosis to the present ten-year follow up according to four predefined curves, each reflecting a different disease pattern in terms of the severity of bowel symptoms: 1) remission or mild severity of intestinal symptoms after initial high activity, 2) increase in the severity of intestinal symptoms after initial low activity, 3) chronic continuous activity or 4) chronic intermittent activity.

Questions regarding CAM use

Questions regarding CAM were included in the patient reported questionnaire at the ten-year follow up. The questions were restricted to the use of CAM for IBD symptoms and included any of three therapies listed: 1) homeopathy, 2) acupuncture and 3) a healer. In addition, patients could specify other therapies they had used in a comment field. CAM use was defined as: 1) ever used CAM (any use of CAM in the ten years since diagnosis); 2) recently used CAM (any use of CAM during the six months prior to follow up); and 3) regular use of CAM (the use of CAM more than four times or regularly in the previous six months). The patients were also asked to assess their satisfaction with the CAM treatment they had used by providing one out of four possible scores: not at all satisfied, somewhat satisfied, mostly satisfied, and very satisfied.

5.2.2 The outpatient-based sample

The outpatient-based sample was collected by inviting 14 outpatient clinics at 9 hospitals from the counties of Rogaland, Vest-Agder, Aust-Agder, Telemark, Oslo, Østfold, Hedmark, Oppland and Hordaland including eastern, western, and southern Norway. The patients were recruited during a regular visit to the outpatient clinic. Patients aged ≥ 18 years old with a previously verified diagnosis of CD or UC that was confirmed clinically, endoscopically and histologically were eligible for inclusion in the study. The recruitment period was between 1 October 2009 and 31 June 2011.

A booklet was made to collect both clinical and self-reported data. At each hospital, either a study nurse or a gastroenterologist was in charge of the study protocol. Clinical data were obtained from medical records by the health professional responsible for the enrollment and included diagnosis, classification of disease location and behavior, disease duration, current

medical therapy, and previous surgery for IBD. The disease activity scores (HBAI and SCCAI) were completed under clinical consultation. Self-reported data included socio-demographic status, any experience with adverse drug reactions to IBD medication, comorbidities, CAM use, the five-item Fatigue Severity Scale, the General Self-Efficacy Scale, and the 13-item Sense of Coherence questionnaire. The booklet was completed at the hospital, but patients were also given the option to complete the questionnaires at home and return the booklet in a stamped addressed envelope.

Socio-demographic data

Socio-demographic data included *age* (continuous variable), *gender*, *educational level* (12 years education or less [secondary] vs. more than 12 years [college/university education]); *civil status* (married or cohabitant vs. single, divorced, or partnered but living separately), *work status* (working including being a student vs. not working, including pensioner and work disabled); *income* (<25, 000 €/year, 25,000-45, 000€/year, 45,000-65,000 €/year, or >65,000 €/year); *place of residence* (city vs. rural area) and *smoking status* (yes, defined as once or more daily vs. no).

Clinical data

The Montreal classification was used to classify disease location and behavior in CD [48]. Previous surgery included all types of surgery related to IBD. A pre-defined list of comorbidities was presented for the respondents and included cardiovascular disease, diabetes, arthritis, arthralgia, asthma, dermatological disease, and cancer. In addition, the respondents could add comorbidities not queried. In addition, the patients were asked to state yes/no if they had experienced adverse drug reactions to conventional IBD medication in the past or currently. A pre-defined list was presented and included nausea, abdominal pain, diarrhea, headache, fever, weight gain, mood changes, joint pain, sleep disturbance, and skin itch. In addition, the respondents could add adverse drug reactions not queried.

Disease activity was measured with the Harvey-Bradshaw activity index (HBAI) in CD patients [134] and with the simple clinical colitis activity index (SCCAI) in UC patients [135]. HBAI measures clinical symptoms over the last 24 hours based on five items: general well-being (scale range 0-4), abdominal pain (scale range 0-3), number of liquid stools per day, abdominal mass (scale range 0-3), and complications, including: arthralgia, uveitis, erythema nodosum, aphthous ulcers, pyoderma gangrenosum, anal fissure, new fistula, and

abscess (score one per item). SCCAI measures clinical symptoms over the last 24 hours and consists of scores for five criteria: bowel frequency (day) (score range 0-3), bowel frequency (night) (score range 0-2), urgency of defecation (score range 0-3), blood in stool (score range 0-3), general well-being (score 0-4), and extra colonic features (score one per manifestation).

International CAM Questionnaire

The International CAM Questionnaire (I-CAM-Q) was used to assess CAM use [70]. I-CAM-Q is a self-reported questionnaire and includes four main questions and a number of sub-questions. In this study, we report the results from the four main questions: (1) visiting health care providers offering alternative therapies (physician, chiropractor, homeopath, acupuncturist, spiritual healer, reflexologist, kinesiologist, laser treatment, or other not queried), (2) complementary treatments received from physicians (MDs') (manipulation, homeopathy, acupuncture, herbs, spiritual healer, or other not queried); (3) use of herbal medicine and dietary supplements (vitamins/minerals, homeopathic remedies, and other supplements) and, (4); use of self-help practices (meditation, yoga, Qigong, Tai Chi, relaxation techniques, visualization, attending healing ceremonies, pray for your own health, or other not queried). Respondents were asked to indicate whether they used a particular provider/health care product or self-help practice within the previous 12 months.

Definition of a CAM user

In this study, a CAM user was defined as someone who had visited an alternative health care provider and/or used CAM products and/or used self-help practices at least one time within the previous 12 months. In the I-CAM-Q questionnaire, the use of vitamins and minerals was queried. Vitamins and minerals are often recommended by physicians as a part of the treatment regimen for IBD patients. We did not ask if the vitamins and minerals were recommended by a physician. In Norway, the use of fish oils is recommended by Norwegian health authorities [136]. Consequently, in this study, patients who reported their CAM use to consist exclusively of vitamins/minerals or fish oil supplements were defined as non-users. Following the recommendations of Harris et al. [99], we reported estimated overall CAM use, estimated use of each CAM modality, and estimated use of the three CAM categories: *CAM services* (including visiting an alternative health care provider or alternative treatments received from physicians (MDs), *CAM products* and *CAM self-help practices*.

In our study, the respondents were asked to provide information if they used CAM *alongside with* (response option yes/no) or *instead of* conventional medicine (response option yes/no). Additionally, we asked the respondents to provide information about their sources of information regarding CAM: friend, newspaper, relatives, health care workers, internet, health food store, TV, or a CAM practitioner.

The five-item Fatigue Severity Scale

The five-item Fatigue Severity Scale (FSS-5) assesses the experience of fatigue interference with daily living [137,138]. Each item is rated on a 7-point Likert-type scale ranging from 1 (disagree) to 7 (fully agree). The mean of the five item scores represents a continuous variable with values from 1.0 (no fatigue interference) to 7.0 (maximum fatigue interference). A higher score indicates higher fatigue interference. Mean scores ≥ 5 are considered indicative of severe fatigue interference [139]. The internal consistency for the FSS-5 is shown in Table I.

The Sense of Coherence Questionnaire

The 13-item version of the Sense of Coherence Scale (SOC-13) was used [28]. The SOC instrument has been translated into 33 languages in 32 countries and is regarded as applicable to all cultures [140]. SOC-13 measures the degree to which an individual views the world as comprehensible (5 items), manageable (4 items), and meaningful (4 items). The item scores are summed up by means of a 7-point Likert-type scale. The total score is the sum of the items, ranging from 13 to 91, and the sub-dimensions range from 5-35 (comprehensibility) and 4-28 (manageability and meaningfulness). Higher scores reflect a stronger SOC. The SOC-13 scale is reported to be a reliable and valid instrument [140,141], with reported internal consistency (Cronbach's α) of 0.70 to 0.92. The internal consistency of the scale is shown in Table I.

General Self-Efficacy Scale

The General Self-Efficacy Scale (GSE) [142] measures the strength of an individual's belief in their ability to cope with difficult demands in life. In particular, it explicitly refers to personal agency, i.e. the belief that one's actions are responsible for successful outcomes. The GSE consists of 10 statements to which the respondent rates from 1 "completely agree" to 4 "completely disagree". The GSE total score is calculated by summing each individual score

(range 10 to 40). A higher score indicates a stronger self-efficacy. The GSE has been translated into several languages, including Norwegian [143]. The Cronbach's α value is shown in Table I.

Table I. Description and reliability of the FSS-5, the 13-item SOC questionnaire and the GSE

Instruments	Article	Scales/dimensions	Response Scale	Items	Range	Cronbach's alpha		
						All	UC	CD
5-item Fatigue Severity Scale (FSS-5)	III and IV	-	7 point Scale	5	5-35	0.89	0.90	0.88
Sense of Coherence (SOC)	IV	SOC total		13	13-91	0.85	0.86	0.85
		Comprehensibility	7 point Scale	5	5-35	0.72	0.74	0.71
		Manageability		4	4-28	0.61	0.62	0.61
General Self-Efficacy Scale (GSE)	IV	-	4 point Scale	10	10-40	0.90	0.90	0.90
		Meaningfulness		4	4-28	0.72	0.69	0.73

5.3 Data analysis and statistical methods

Univariate descriptive analyses were performed to assess the characteristics of the two study samples. Continuous variables with normal distributions were described with means and standard deviations. When the continuous variables had skewed distributions, they were described with medians and ranges. Crude differences between groups were assessed with the Chi-square (χ^2) test for categorical data and independent samples t -test for continuous variables with normal distribution and the non-parametric Mann-Whitney U test for variables with skewed distributions. In paper 4, Pearson's correlation coefficients were calculated to identify the strength and direction of the relationships between the SOC total and the three SOC sub-dimensions (dependent variables) and age, disease activity, disease duration, fatigue interference and self-efficacy (independent variables). The strength of the correlations was interpreted according to Cohen's guidelines: a small association is $r = 0.1$ to 0.29 , a moderate association is $r = 0.3$ to 0.49 and a large association is $r = 0.50$ to 1.0 [144].

In papers I, II, and III, we used logistic regression analyses to assess possible associations between the dependent variables: CAM users *vs.* non-CAM users (papers I and II); severe fatigue interference (FSS-5 ≥ 5) *vs.* no severe fatigue interference (FSS-5 < 5) (paper III) and

socio-demographic and clinical variables. In paper I, the variables that differed (p -value <0.15) between CAM users and non-CAM users were considered for inclusion in the multivariate analysis. In paper II and III, the inclusion criteria for multivariate analysis was set to p -value <0.10 between CAM users and non-CAM users (paper II) and between those with and without severe fatigue interference (paper III). The strength of the association was expressed as an odds ratio (OR) with the 95% confidence interval. The significance level was set to 5%.

In paper IV, multiple linear regression analyses were used to determine the associations between relevant socio-demographic variables, clinical variables, GSE, FSS-5 (independent variables) and SOC and its sub-dimensions (dependent variables). Variables with p -value <0.10 in bivariate analyses were entered into the multiple linear regression models. Socio-demographic variables were included in step 1, clinical variables in step 2, fatigue interference in step 3, and self-efficacy in step 4. To compare the included variables, the strength of their association with the dependent variable was expressed with the standardized beta coefficient. Age and gender were considered as possible confounders, and were consequently included in all multiple regression analyses. Because of multiple testing, the significance level was set to 1%. Cronbach's alpha was used to assess the internal consistency of the instruments. A coefficient >0.70 is considered acceptable, >0.80 is good and >0.90 is excellent [145]. All analyses were performed using SPSS for Windows version 20.0 [146].

Missing items in I-CAM-Q, FSS-5, 13-item SOC questionnaire and GSE

In I-CAM-Q, all 430 respondents answered yes or no for some of the CAM modalities listed in the questionnaire. If the respondents ticked yes at one or more CAM modalities listed and left the rest blank, the blank answer was recorded as no. These respondents were included in the CAM user group. If the respondents ticked no for one or more of the CAM categories but did not tick yes for any of the other CAM modalities, they were included in the non-CAM user group. Some respondents left a CAM category completely open. In these cases, a missing value was recorded when the respondent did not tick either yes or no for any of the CAM modalities listed in that particular CAM category.

Respondents with more than 50 % missing in the FSS-5, SOC-13, and GSE were excluded from the analyses. With less than 50 % missing items, the values were replaced by means of the items with valid responses.

5.4 Ethical issues

The IBSEN study was approved by the Regional Committees for Medical and Health Research Ethics in Norway and the Norwegian data inspectorate.

The outpatient-based study was approved by the Regional Committees for Medical and Health Research Ethics in Norway (reference number: S-00858b) and the internal data protection officer at Oslo University Hospital.

The studies were conducted in accordance with the Helsinki declaration [147]. All patients received verbal and written information about the objective of the studies and their right to withdraw or restrict their data from analysis at any stage. They signed a written informed consent prior to being enrolled in the studies.

6 Results

6.1 Study populations and flow charts

Paper I present data from the IBSEN study. The study sample is depicted in Figure 1. Papers II, III, and IV presents data from a selected sample of patients attending outpatient clinics at Norwegian hospitals. The study samples are depicted in Figure 2.

Figure1. The population-based sample

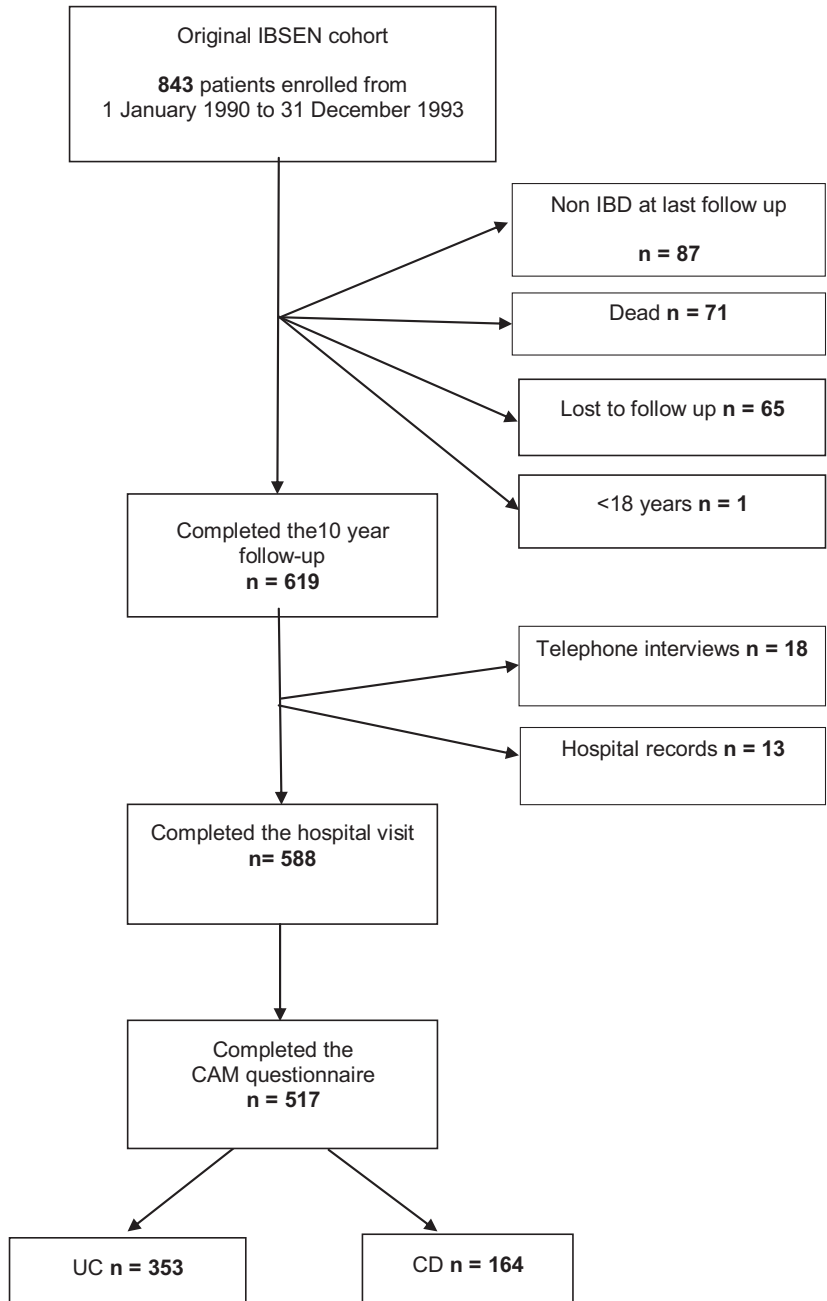
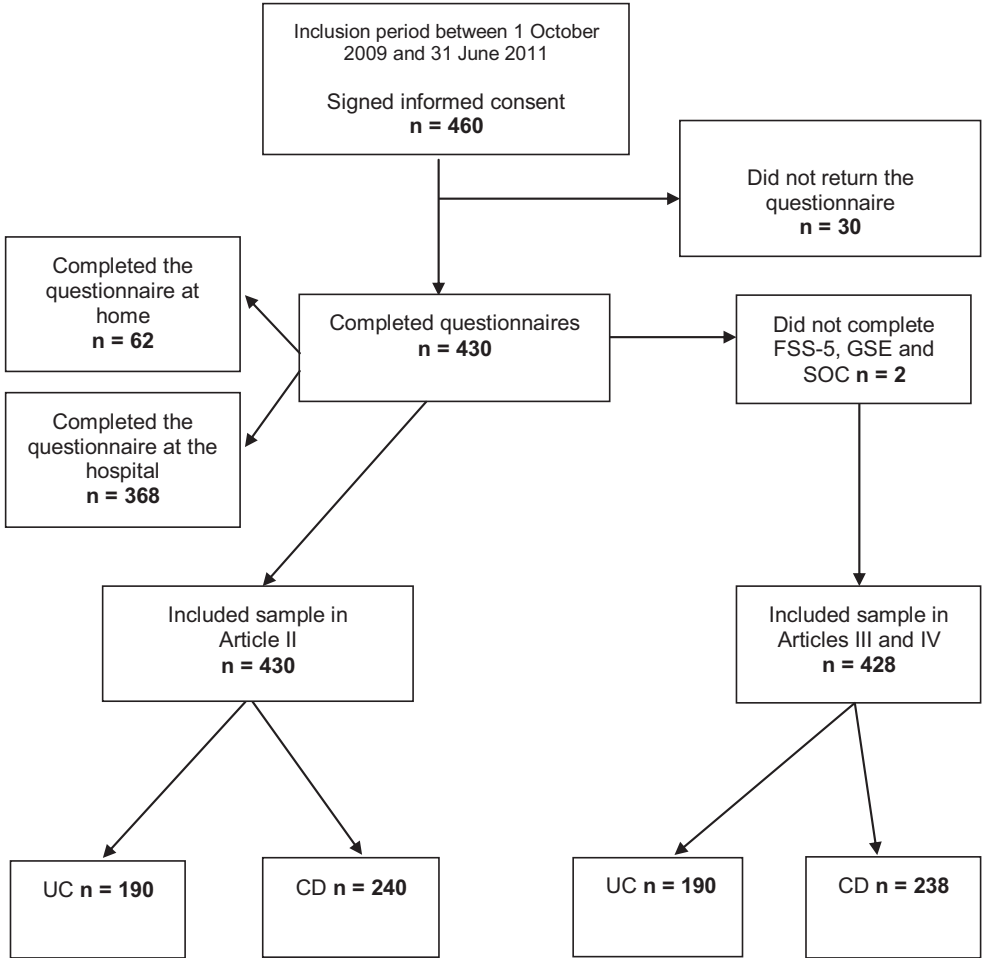


Figure 2. The outpatient-based sample



6.2 Summary of results (papers I-IV)

Paper I

Background: The aims of paper I were to determine the proportions of CAM use in a population-based cohort of IBD patients followed for ten years and to describe the associations between CAM use and socio-demographic and disease-related factors.

Results: Thirty percent of the IBD patients reported that they had used CAM for their IBD at some point in the ten-year period since the initial diagnosis, 7.5% reported current CAM use, and 3.1% reported regular use. A higher proportion of CD patients compared to UC patients reported CAM use (38% vs. 27%, respectively; $p=0.01$). The most frequently used CAM therapy was homeopathy (64% of the CAM users).

The multivariate analyses revealed that younger age was independently associated with CAM use in both disease groups (CD, adjusted OR [adjOR] 0.96, 95% CI: 0.93-0.99 and UC, adjOR 0.95, 95% CI: 0.95-1.00), and it was the only factor independently related to CAM use in the CD group. In the UC group, female gender (adjOR 2.14, 95% CI: 1.23-3.73) and higher education level (adjOR 1.95, 95% CI: 1.12-3.37) were also independently associated with CAM use. Further, CAM users were mostly satisfied or very satisfied with the treatment.

Conclusion: One third of the IBD patients had seen a CAM provider in the ten-year period since diagnosis, although very few used these modalities currently and regularly. Because only three CAM modalities were assessed, there is a possibility that our results are underestimated. Younger age was independently associated with CAM use in both UC patients and CD patients. Disease-related variables were not associated with CAM use.

Paper II

Background: To determine the overall and specific use of CAM among IBD patients attending outpatient clinics in Norway and to describe associations between CAM use and socio-demographic and disease-related factors.

Results: Of the 430 patients with evaluable questionnaires, forty-nine percent (95% CI: 44-54) had used some type of CAM within the past 12 months. Twenty-seven percent (95% CI: 23-31) had used CAM services (seeing a CAM provider). The most common single CAM service was acupuncture. Twenty-one percent (95% CI: 16-23) used CAM products, and 28% (95% CI: 23-31) used CAM self-help practices (relaxation techniques and praying for own health were the most frequently reported techniques). The most common pattern of CAM use involved a combination of CAM services and CAM products.

A significantly higher proportion of UC patients reported CAM use compared to CD patients (55% versus 44%, respectively; $p = 0.03$). Among CD patients, the strongest factor independently associated with CAM use was experiencing adverse drug reactions from IBD medications (adjOR 3.23, 95% CI: 1.73-6.06). In addition, the socio-demographic factors of female gender (adjOR 2.43, 95% CI: 1.27-4.64), being aged 31-50 years (adjOR 2.32, 95% CI: 1.09-4.96), and having a higher education level (adjOR 2.11, 95% CI: 1.08-4.14) were independently associated with CAM use. Among UC patients, only the presence of at least one comorbid condition was independently associated with CAM use (adjOR 2.36, 95% CI: 1.18-4.72).

Conclusion: CAM use was common among IBD patients attending outpatient clinics at hospitals in Norway. Both demographic and disease-related variables were associated with CAM use among CD patients, while only disease-related variables were associated with CAM use among UC patients.

Paper III

The aims of paper III were to examine fatigue interference with daily living in IBD patients and to explore relationships between severe fatigue interference, socio-demographic and disease-related variables, as well as use of CAM.

Results: Patients attending outpatient clinics at Norwegian hospitals were invited to participate. Of the 428 patients with evaluable questionnaires (response rate 93%), severe fatigue interference was reported by 39 % of the total sample. CD patients (n=238) were more likely than UC patients (n=190) to report severe fatigue interference (43% and 33%, respectively; $p=0.003$). Patients reporting severe fatigue interference were more likely to have active disease than patients without severe fatigue interference ($p<0.001$ for both diagnoses). A significantly higher proportion of CAM users reported severe fatigue interference compared to non-users among UC patients with active disease.

Multivariate regression analyses revealed that factors independently associated with severe fatigue interference in the UC group were disease activity (adjOR 4.32, 95% CI: 1.87 to 10.02) and CAM use (adjOR 2.20, 95% CI: 1.09 to 4.44), while in the CD group, disease activity (adjOR 3.59, 95% CI: 1.81 to 7.13) and current smoking (adjOR 1.62, 95% CI: 0.83 to 3.16) were independently associated with fatigue interference.

Conclusion: Similar to other studies assessing fatigue in IBD populations, active disease was strongly associated with severe fatigue interference. CAM use was independently associated with severe fatigue interference among UC patients but not among CD patients.

Paper IV

Background: The aim of paper IV was to explore associations between SOC and socio-demographic, disease-related, and personal characteristics in a sample of patients with inflammatory bowel disease.

Results: A total of 428 patients attending outpatient clinics (ulcerative colitis, n=190; Crohn's disease, n=238) completed the questionnaires (response rate 93%). The overall mean SOC total score was 66.25 (SD 11.47). No significant differences were found in the SOC total or sub-dimension scores between UC patients and CD patients. In both disease groups, higher self-efficacy was positively associated with SOC, and fatigue interference was negatively associated with SOC. Socio-demographic and disease-related variables were not significantly associated with SOC after controlling for fatigue interference and self-efficacy in multiple regression analyses.

Conclusion: Fatigue interference and self-efficacy contributed more to the variance in SOC than socio-demographic and disease-related variables. Longitudinal studies are warranted to investigate the value of SOC as a predictor of disability, medication adherence, coping behavior, and health-related quality of life.

7 Discussion

7.1 Methodological considerations

7.1.1 Generalizability

The ability to generalize findings to a larger population contributes to the *external validity* of a study [148]. Representativeness is important for consideration of external validity.

The population-based sample

The main aim in paper I was to describe the proportion of CAM use in Norwegian IBD patients. The IBSEN study represents an unselected population-based IBD cohort. A non-selected population is preferable because it is not biased by including the most ill patients, those who seek care through conventional medical providers, and those who are most comfortable within the framework of conventional medicine [15,106]. The IBSEN study has a prospective design, strict case ascertainment criteria, and the patients were included from four well-defined geographical counties in south eastern Norway with a uniform health care system. The ten-year follow-up rate was high, and the completion rate of the questionnaire was acceptable (83.5%). There were no significant differences with regard to age, gender, or type of diagnosis between the responders and the non-respondents. Thus, we may assume that the sample is representative of the general Norwegian IBD population.

The outpatient-based sample

The main aim of the cross-sectional descriptive study was to assess CAM use in a broader manner than was possible in the IBSEN study (paper II). In addition, we wanted to explore psychosocial factors related to patient management of their disease (papers III and IV). An outpatient-based IBD sample was chosen because the majority of the IBD patients are followed up at outpatient clinics at Norwegian hospitals. Further, we can approach the patients it is in clinical practice. The Norwegian health care system is divided into four health regions to provide specialized health services to the whole population [149]. To assure heterogeneity of the IBD sample, we recruited patients from small local hospitals, regional hospitals, and university hospitals in the two health regions covering southern, eastern, and

western Norway. Thus, the sample is representative of IBD patients attending outpatient clinics at hospitals in Norway.

Four hundred and sixty patients provided their informed consent and were included in the study. Of these, thirty patients did not return the questionnaire after one reminder. Responders and non-responders were comparable with regard to their age, gender, disease duration, and type of diagnosis. A response rate of 93 % is considered high. However, the patients were included under a regular visit at their hospital. Only eight out of 14 hospitals included patients consecutively. The reason given for not including consecutive patients was lack of time under the consultations to introduce the questionnaire. In addition, no data were collected from the individuals who were approached but who chose not to participate. Further, a high proportion of the patients were currently treated with TNF- α inhibitors (60 % of the CD patients and 44% of the UC patients), which corresponds well to the fact that a high proportion had severe disease. There is no data available of the proportion of patients on anti-TNF therapy in Norway, but this high use of anti-TNF therapy is likely not representative of the Norwegian IBD patients attending outpatient clinics. We assume that the reason for this selection bias is due to convenience; infliximab is administered intravenously over one to two hours and thus, these patients had the available time to complete the questionnaire. Convenience samples may be biased in that those who are included differ from those who were not approached or those who declined to participate. However, the study sample had a higher proportion of CD patients than UC patients, corresponding well to the fact that more CD patients require regular medical care than UC patients. With the relatively large sample sizes, (N = 430 for paper II / and N = 428 for papers III and IV), we believe that the description of the phenomena and the relationships between the dependent and independent variables at fixed points of time are representative of IBD patients attending outpatient clinics at Norwegian hospitals.

Different methods of administering the questionnaire may also impact the results, as the patients choosing to complete the questionnaire at home may differ from those who complete the questionnaire at the hospital. A significantly higher proportion of patients undergoing TNF- α therapy completed the questionnaire at the hospital compared to those who completed the questionnaire at home ($p=0.003$ for the difference), in accordance with the observation that the high use of TNF- α therapy was associated with logistical convenience at the hospitals. The patients who completed the questionnaire at home were comparable with those

who completed the questionnaire at the hospital in regard to gender, age, education level, diagnosis, CAM use, fatigue interference, GSE scores, and SOC scores.

The northern part of Norway is not represented in the two samples. It may be possible that this demographic area differs from southern Norway regarding CAM use, especially with regard to folk medicine, which is more commonly used in northern Norway.

Cross-sectional design

In both studies, we used a cross-sectional design. In a cross-sectional design, the measurements of exposure and outcome are made at the same time. This makes it difficult to assess direction of the associations observed. However, cross-sectional studies indicate associations that may exist and are therefore useful in generating hypotheses for future research.

7.1.2 Internal validity

Internal validity refers to whether the conclusions drawn from the study population are valid [148]. Concerns of the internal validity in the present studies will be discussed.

Information bias

When recall time is long, information bias can occur. In the IBSEN study we asked about CAM use during the 10-year period since the initial diagnosis. It is highly possible that the patients used some form of CAM without remembering 10 years later. Consequently, we may have underestimated CAM use in this study. In the outpatient-based sample, the recall time was 12 months, thus it may have been easier to remember. However, when several CAM modalities are pre-defined for the patients, it may lead to false memories of using a modality one has used or think one has used. Hence, this may have led to an overestimation of CAM use in the outpatient-based sample. In addition, it is possible that questions of CAM use in a clinical setting, in which attitudes toward CAM may be unfavorable, may have caused bias towards an underestimation of true CAM use.

Confounding

A threat to the validity of associations in observational studies is referred to as confounding, i.e., when an association between two variables is fully or partly caused by a third factor [148]. One way to address this is to correct for possible confounding variables by

multivariable statistical analysis. We chose to correct for gender and age in the multivariate analyses in all four studies. It is known from earlier studies in IBD populations that anxiety, depression, sleep disturbance, and anemia are associated with fatigue severity. We could not control for the possible confounding role of these factors in our study (paper III).

Multicollinearity occurs when independent variables in a regression are so highly correlated that it becomes difficult to distinguish their individual effects on the dependent variable. Thus, multicollinearity can be viewed as a case of confounding, when the same variable is essentially entered into a regression model twice or when a variable contains exactly the same information as another variable. In paper IV, we assessed factors associated with SOC. None of the independent variables included in the final analyses were highly correlated (defined by Pearson correlation coefficient >0.7) with any other possible covariate.

Reliability

Reliability refers to the degree to which a questionnaire is free from errors of measurement and the consistency with which it obtains the same value at repeated measures [148].

In the population-based study, the questions about CAM use were not standardized or validated. In the outpatient-based study, we used several questionnaires. The reliability of the questionnaires is discussed below.

I-CAM-Q was developed by CAM researchers and practitioners brought together in an international workshop sponsored by the NAFKAM of the University of Tromsø, Norway [70]. Consensus regarding the definitions and international comparability between the questionnaires used to measure CAM are a much needed methodological improvements in the field of CAM research. I-CAM-Q was developed to provide an opportunity for researchers to gather comparable data in studies conducted in different populations, thus facilitating comparisons between studies [70]. When we carried out our study from 2009- 2011, no psychometric test of the I-CAM-Q had been conducted. Later, Eardley et al. [150] conducted a pilot feasibility study of I-CAM-Q in five European countries to assess the item wording and the design of the questionnaire [151]. The pilot study revealed problems with the layout, the terminology, and the response options. Respondents from all countries found the questionnaire hard to read and understand. This resulted in a high missing rate. Eardley et al. concluded that I-CAM-Q had low face validity indicating that it failed to subjectively cover the concept it purportedly measured [145]. Additionally, a validation study of the I-CAM-Q

among breast cancer patients compared with the general population in Germany was conducted. The results from this study supported the low face validity and also found a high rate of missing. The highest missing rates were found in the questions regarding the frequency of use, reasons for use, and helpfulness of a CAM modality [151].

The pilot study by Eardley et al. and the German validation study sum up the problems we faced with I-CAM-Q. The rates of missing data in the questionnaire concerning the frequency of use, reasons for use, and helpfulness of health care service and self-help practice were substantial in our study, in accordance with the results from the two studies mentioned. We therefore decided to not use these data.

With regard to the questions we used in the I-CAM-Q, the main limitation was due to terminology. I-CAM-Q provides no definitions of the CAM modalities queried. Therefore, the respondents had to know about a particular CAM modality to give a valid answer. We had to assume that respondents declared themselves as non-users of a particular CAM modality if they were not familiar with it. In addition, I-CAM-Q included physicians (MD) as health care providers. This option was included with the aim of comparing conventional health care use with CAM use. Our respondents were patients at regular hospital visits, and failure to include physicians (MD) would not be valid information in our study. Further, I-CAM-Q did not have questions on CAM use specifically related to a disease, and thus, we do not have data on how many patients used CAM specifically for IBD. In conclusion, further validation of I-CAM-Q is needed before it can be used in future research. The results from our study should be interpreted in light of these limitations.

The disease activity measurements SCCAI and the HBAI do not adequately evaluate disease activity in patients with a stoma, and the majority of studies choose to exclude this patient group when assessing disease activity scores with these disease activity indices. In our study, five UC patients and 20 CD patients had a stoma. The stoma patients in the UC group had a median SCCAI score of 6.5 (range 2-8). However, the median SCCAI score was 4 (range 0-15), regardless of the inclusion of those with a stoma. The median HBAI score in the CD patients with a stoma was 6 (range 1-21), and the median HBAI score was 5 (range 0-15) regardless of the inclusion of those with a stoma. Therefore, we decided to include the stoma patients when assessing disease activity scores.

A short version of the original Fatigue Severity Scale (FSS) was used to assess fatigue interference. The choice of using the FSS-5 was based on results from studies using modern test theory (Rasch analysis). These studies showed inconsistent responses in the FSS, and they demonstrated that a five-item version of the FSS had better psychometric properties than the original nine-item version [137,138]. The five items query how fatigue interferes with daily living. In the introduction to the FSS-5, fatigue was defined as “being tired and weary and having lack of energy” [139]. Using classical test theory, the original FSS demonstrated good psychometric properties [152,153,83], and it has been validated in the Norwegian general population [139]. However, FSS-5 has not been validated in the Norwegian general population or in an IBD population. In our study, the reliability of the FSS-5 was measured in terms of internal consistency, which was found to be satisfactory (Cronbach’s α 0.89) [145]. No other studies of FSS-5 have reported a Cronbach’s α value. Further validation of the FSS-5 should be performed before further use in studies.

The General Self-Efficacy Scale was used to assess the IBD patients self-beliefs in coping with demands in life [142]. The internal consistency of the scale in our study was high (Cronbach’s α 0.90), which is considered excellent [145] and corresponds well with other Norwegian studies [154,155].

The 13-item Sense of Coherence Scale was used to measure an individual’s orientation to life. The internal consistency of the total SOC score was satisfactory [145] (Cronbach’s α 0.85) and corresponded well with other Norwegian studies [156,157]. We also assessed the SOC sub-dimensions. A coefficient above 0.70 is regarded as acceptable. In our study, the internal consistency at the sub-dimensions was 0.61-0.74. The Cronbach’s α value is a function of both the average inter-item correlation and the number of items in a scale, and it increases as either of these increases [145]. Thus, the lower values of the subscales may be because the scales consist of 4 and 5 items.

7.2 General discussion of the results

7.2.1 CAM use

The results from our studies revealed that CAM use was common among Norwegian IBD patients. Our results are congruent with results from previous IBD research, from other chronic illness groups as well as in the general population [17,15,16,18,122,123,26,158,159]. The CAM modalities measured in the two samples differed. In the IBSEN study, only three types of CAM modalities were predefined for the patients: homeopathy, acupuncture, and spiritual healer. In the outpatient-based study, CAM use included both CAM services, CAM products and CAM self-help practices. In addition, the IBSEN study asked for CAM use related to IBD symptoms, whereas this was not a question in the I-CAM-Q. Because of different CAM definitions and different time-frames (CAM use since diagnosis *vs.* the last 12 months), the proportion of CAM use cannot be compared between the two study samples in this thesis. This methodological difficulty is reported to be a common problem in CAM research and leads to great variation in prevalence rates. This is demonstrated in a systematic review of the prevalence of CAM use among general populations in Europe [16] reporting prevalence rates from 0.3 % to 86 %. Furthermore, due to the heterogeneity of the CAM modalities included, the data could not be pooled in a meta-analysis.

CAM use in the population-based sample

In the IBSEN study one third of the patients reported CAM use at some point since diagnosis. The prevalence of current or past CAM use among IBD patients varies from 21 % to 56 % [100,113,111,112,108,106,107,115,105,101]. However, CAM use among IBD patients has rarely been reported in an unselected IBD sample, thus there are no direct comparable IBD studies. CAM use was more common among CD patients compared to UC patients in this population-based study. This finding is in contrast to other IBD studies, where comparable rates between the diagnoses are most often reported (Appendix). One possible explanation is that this is a population-based study, and CAM use specific to IBD symptoms was investigated.

Even though one third of the IBD patients had seen a CAM provider in the 10-year period since diagnosis, only 3.1 % had used CAM regularly during the previous six months. This may indicate that, despite the relative high use, consistent use is uncommon. This assumption is supported by a longitudinal study that measured CAM use among IBD patients over a 4.5 year period: the overall CAM use was high (49 %), but only 14% used CAM consistently at every time point [103].

CAM use in the outpatient-based sample

In the outpatient-based sample, one third of IBD patients reported the use of CAM services at least once the last 12 months and acupuncture was most frequently used (10 %). Despite the limitations to I-CAM-Q described above, our results are in accordance with the reported use of CAM services in the Norwegian general population, reported by NAFKAM in 2012 [18]. In Norway, acupuncture is the most frequently reported modality both inside and outside the government-funded health care system [96], and it is offered at 50 % of Norwegian hospitals [72]. Eight percent of patients had been seeing a chiropractor. A chiropractor is defined as a CAM service in several international IBD studies [15,103] and was one of the modalities listed in the I-CAM-Q. Despite the fact that chiropractors are authorized health personnel in Norway, we included chiropractors in the CAM services in our study. The use of CAM products and self-help practices was reported by 21 % and 28 % of the IBD patients in our study, respectively. Our results are higher than reported numbers in the Norwegian general population, where 11 % had used CAM products and 13 % had used self-help-practices within the last 12 months [18]. The differences found between the studies may be because a higher number of self-help practices were predefined in I-CAM-Q compared to the NAFKAM study. For example, prayer for one's own health was included as a CAM modality in I-CAM-Q, but not in the NAFKAM study. There is no common agreement on whether to classify prayer as CAM [160]. There is also a lack of a clear definition of the CAM modalities queried in both I-CAM-Q and the NAFKAM study [150]. Ten percent reported prayer in our study, and together with relaxation techniques this was the most common self-help practice. In a qualitative study, patients with chronic diseases were interviewed about their decision to use CAM [161]. The study revealed that many of the participants considered spiritual approaches to be an important element addressing the emotional effects of having a chronic disease. They claimed it helped to make sense of the world and gain a sense of control when faced with a

challenge such as chronic illness. Religious belief has also been found to be an important aspect of psychosocial needs in patients with cancer [162].

The most common types of CAM services used by the IBD patients in both IBD study samples in this thesis, (homeopathy, acupuncture, chiropractic) also reflect the pattern of CAM services used in Europe, where the top five CAM modalities are herbal medicine, homeopathy, chiropractic, acupuncture and reflexology [16]. In this regard, patients appear to use CAM that is available and common in their culture. With the growth of more complex and culturally diverse societies, therapeutic options are likely to increase in number [163] and slowly integrate into the culture, although they may not be accepted as therapies in the formal health care system. The regional and cultural variation in CAM services, products, and practices worldwide suggests that a uniform profile of CAM use is unlikely.

Factors associated with CAM use

Female gender, a higher education level and younger and middle age were independently associated with CAM use in both the population-based sample and the outpatient-based sample. These socio-demographic variables have been found to be related to CAM use independent of the population studied (general populations or disease-specific populations) and the CAM definition used [17,164,16,165,102,15,119,122,123,166,158,97,121]. In general, women seek health care more often than men [167]. To our knowledge, no studies have further assessed the gender differences in CAM use among IBD patients. Several studies have shown that women report worse HRQoL scores compared to men in IBD populations [9,8,168]. There are contrasting findings between HRQoL and CAM use [108,103,101]. Compared to older patients, younger patients may be more likely to perceive the diagnosis as a threat to their future plans and may therefore be more willing to seek out available treatment options, including CAM. People with higher education are more resourceful in seeking out additional support for their illness and are more likely to be able to pay out-of-pocket for their health care [165,166]. However, income was not an independent factor associated with CAM use in our study. This may be due to relatively low levels of socio-economic inequality in Norway.

In the outpatient-based sample, we found that disease-related factors were associated with CAM use. The presence of comorbidities was associated with CAM use among UC patients.

It is known from studies in the general population that those who use CAM more often have chronic health problems compared to those who do not use CAM [169,170]. Experiencing an adverse drug reaction to IBD medication was associated with CAM use in CD patients. Our finding is in line with that perceived lack of effectiveness of treatment and seeking help with adverse drug reactions to conventional medicine are of the most frequently stated reasons for seeking CAM among IBD patients [171]. The association between CAM use and comorbidities and adverse drug reactions to IBD medications may suggest the IBD patients seek alternative therapies when conventional medicine not has a therapeutic option. In this case, CAM use is a self-management strategy for chronic illness [102]. Questions about comorbidity and adverse effects from IBD medication were not included in the IBSEN study hence we could not assess this relationship in the population-based sample.

We may assume that a patient seeing a CAM provider differs from a patient who practices self-care, such as the use of CAM products and self-help practices. We did not ask why the patients used CAM nor did we ask for their health beliefs. This information is interesting because it is reasonable to assume that health beliefs and health care preferences will provide important information as to why they use or do not use CAM. Li et.al. [171] found that commonly stated reasons for CAM use among IBD patients were the subjective benefits experienced from CAM therapies and products (well-being), the wish to take personal responsibility for treatment, and the desire to gain a greater sense of control over their own health care. In contrast, those who found that conventional health care was successfully treating their disease and those who did not believe CAM to be effective did not use CAM. This may indicate that IBD patients seek CAM to promote health following their health beliefs. Health is an important and positive value in the modern western society [172]. To be concerned with and care for your own health has become the norm and may also be seen as a duty [172]. In addition to conventional medicine, there are many stakeholders, such as CAM providers, that help to improve health. Thus, it is possible to be pragmatic in the choice of health care [96]. The pragmatic health care user utilizes both conventional and alternative medicine in the management of health problems [173]. One reason IBD patients in Norway may be pragmatic in their search for health care, is that they can afford to pay for it. Norway provides health care services for all based on need and regardless of personal income. A cross-cultural comparison between Norway and the United States, a country with low government expenditure on health showed that utilization of CAM practitioners was higher in

Norway compared to the United States [174].

7.2.2 **Fatigue interference**

Several studies have identified fatigue as a common concern for IBD patients [175-178,11]. Our interest was to explore if fatigue interfered with physical functioning and with work, family, and social life. We found that 39 % of the IBD patient reported fatigue to severely interfere with daily living. Disease activity was the strongest independent factor related to severe fatigue interference. A strong association between fatigue and disease activity is common finding in IBD research [179,23,24,22,7], and it is assumed that inflammation processes play a role in the physiological etiology of fatigue [21]. Elevated disease activity is often associated with increased bowel movement, decreased general well-being, and stomach pain. Therefore, it is reasonable to assume that this may affect the patients' energy capacity and interfere with their physical and social function. In addition, when fatigue is addressed in the clinical consultations, it is most often assessed in relation to physical aspects, such as anemia, which are assumed to contribute to fatigue in IBD [7]. If this is not the case, there are few therapeutic options for fatigued patients. The relatively large proportion of the IBD patients reporting fatigue to severely interfere with daily living indicates that fatigue may be best understood from a bio-psychosocial perspective. Depression and anxiety, sleep-disturbance, malnutrition, and side effects from medical treatments, such as thiopurines, in part explain the variance in fatigue in IBD [7]. In addition, psychosocial distress may be an important contributor to fatigue severity in chronic diseases such as IBD [180,22]. Except from the impact of thiopurines, these associations could not be elucidated in our study.

We found an association between CAM use and fatigue interference in UC patients with active disease. Considering that many of the CAM services and practices have an underlying assumption that illness is a disturbance of an individual's energy balance, it is perhaps not surprising that fatigued patients use these services and practices to try to improve energy levels. Elsenbruch et al., [181] found that UC patients in remission who participated in a ten week course that included mind-body therapies and diet showed significantly greater improvement in HRQOL scores (SF-36 and IBDQ) compared to a control group that got standard care. However, a systematic review of CAM interventions for management of

cancer-related fatigue found no support for their effectiveness, mainly due to poor quality research, heterogeneity in CAM modalities assessed, and a variety of outcome measures [182]. A challenge in conducting interventional studies regarding CAM is how to understand the outcome concept. To measure only direct biomedical outcomes (e.g., disease activity) has been criticized for being too narrow when evaluating complex interventions such as CAM [183]. The experience of fatigue is related to one's perceived energy capacity. Hence, the choice of outcome measures in relation to fatigue must be able to detect health-related changes, including subjective experienced energy and well-being [184].

In other disease groups, such as cancer, multiple sclerosis and rheumatoid arthritis psychosocial interventions (counseling, stress management, and coping strategies) have been found to be potentially beneficial in reducing fatigue levels [185,186]. In IBD, one newly published intervention trial which used a health promoting perspective (focusing on coping abilities of the patients rather than their problems), was effective at reducing fatigue and improving HRQOL in IBD patients with quiescent disease [187]. However, while a significant effect was observed after 3 months, the effect diminished after 9 months. Hence, a prolonged intervention period was proposed [187].

7.2.3 Sense of coherence

The socio-cognitive concept SOC is shown to be useful to evaluate the patient's resources to cope with stressful situations such as chronic illness [91]. SOC has not been well evaluated in an IBD population. Therefore, to explore associations between SOC and socio-demographic, disease-related, and personal variables in an IBD population was an important first step. We found a strong association between SOC and general self-efficacy. Due to the cross-sectional design, we were unable to identify the direction of the association observed. Nevertheless, the results suggest that positive feelings, thoughts, and expectations (self-efficacy) contribute to a high SOC. Both SOC and self-efficacy have been found to be positively related to mental health and HRQOL in the general population and in other chronic diseases [86,155,90,156]. Fatigue interference was associated with significantly lower SOC scores. The FSS-5 measures the intensity of fatigue interference with daily activities. We found that the higher the intensity the lower the SOC scores. The experience of fatigue is related not only to disease processes and physical conditions but also to general life circumstances [188]. A study of patients with chronic heart failure found a negative association between mental fatigue and

SOC [189]. The authors suggested that patients with a limited ability to understand and manage their situation may be more vulnerable and affected by mental fatigue. In our study, we were unable to identify the direction of the association observed due to the cross-sectional design.

In addition to the SOC total score, the SOC sub-dimensions were explored in our study. Antonovsky's intention was to use the SOC questionnaire as a measure of the whole and not to examine the three sub-dimensions separately [140]. However, there is an ongoing debate about the factor construction of the questionnaire. Factor analysis has confirmed the one-factor solution proposed by Antonovsky in some studies, while other studies indicate between two and four sub-categories depending on the age of the studied population [140,190]. To evaluate the factor construction of SOC in an IBD population, a population-based IBD sample would be the most appropriate.

Antonovsky assumed that a person's SOC develops from life experience during childhood and young adulthood and to stabilize around the age of 30. After that time, the SOC is relatively resistant to change [28]. However, a large body of research has demonstrated that the development of SOC is a life-long process, and consequently, the highest mean SOC values are seen among the elderly [140]. In our study, age ranged from 18- 70 years, but we did not find support for increasing SOC scores with increasing age. However, our study included a selected sample of IBD patients. A population-based sample may be more appropriate to evaluate the association between age and SOC scores in IBD patients.

Significant changes in SOC scores and improved coping as a result of interventions based on salutogenic treatment principles have been reported among patients with chronic illness [91,191]. One study found that manageability was most affected by intervention in people with mental health problems [91]. In another study, all SOC sub-dimensions changed significantly between baseline and a 12 month follow-up after a patient education course for people with morbid obesity [192]. SOC was used as an outcome measure to evaluate an integrated medical and psychological/psychosocial group-based intervention program for IBD patients. No significant increase in SOC was observed after completion of the intervention, or after six and twelve months [125]. The SOC scores in the IBD group were significantly higher

compared with the mental illness group and the obesity group [91,192]. Thus, the high mean SOC scores at baseline may be one reason no increase in SOC was observed in the IBD study. However, results from the intervention studies mentioned above indicate that SOC may improve with therapy, education, and social support.

7.2.4 Illness perception

CAM use was common among IBD patients independent of the study sample or CAM definition used. IBD patients reported that fatigue severely interfered with daily living, including physical functioning, work, family, and social life. The experience of fatigue was negatively associated with SOC in both the UC and CD patients. These findings underscore that living with a chronic disease with an unpredictable course is challenging and patients need to find ways to adjust and maintain well-being and quality of life despite their illness. Unsuccessful adjustment may result in an experience of an uncontrollable situation and in enduring distress. In our study, we found some differences between UC and CD patients. For example, factors associated with CAM use differed, more CD patients reported severe fatigue interference, and CAM use was associated with fatigue interference only in the UC group with active disease. However, the UC and CD patients had comparable scores for SOC and self-efficacy. Hence, they did not differ with regard to personal recourses. To elaborate these observations further, knowledge about how IBD patients perceive their illness and its consequences may be important in order to understand how they relate to their illness and their health behavior. An individual's illness perception form personal meaning to symptoms and disease and have been found to be important for the self-management of chronic illness [193]. Health professionals contribute to illness perception, as in cases where a medical diagnosis and its consequences are explained, but the interpretation of this information is highly individual [193]. Questionnaires that measure illness perceptions are available, such as the Illness Perception Questionnaire [194]. Studies assessing IBD patients' illness perceptions have shown that low personal control over illness and believing in that IBD has serious consequences predicted psychological stress, poorer quality of life and reduced functional independence [195-197]. Longitudinal studies in other chronic diseases have shown that illness perceptions can change over time and are modifiable with education and psychosocial support [193]. Over time, living with a chronic disease can change the perception of consequences, emotional response, and control in light of the patient's experience with chronic disease. Moreover, interventions, such as medical and psychological education

courses and psychosocial support, can give new insight into illness perceptions [198]. Thus, studies of UC and CD patients' illness perceptions may provide important knowledge to use in health education courses aimed of improving coping and adaption to the symptoms and disease progression.

8 Summary

8.1 Conclusions

- In the population-based sample one third of the IBD patients had used CAM at some point in the ten-year period since initial diagnosis, although few reported CAM use currently and regularly. The most frequently used CAM providers was homeopathy.
- Among UC patients, younger age, female gender, and higher education level were independently associated with CAM use, whereas the only variable independently associated with CAM use among CD patients was younger age.
- In the outpatient-based sample, one out of two IBD patients had used some type of CAM the last 12 months. One third had used CAM services, one out of five had used CAM products, and one third had used CAM self-help practices. Acupuncture, herbal remedies, relaxation techniques, and prayer were the most frequently reported CAM modalities.
- Disease-related factors were associated with CAM use in both UC and CD.
- Severe fatigue interference was common among IBD patients. Disease activity was the strongest independent factor related to severe fatigue interference in both the UC group and the CD group.
- CAM use was associated with severe fatigue interference among patients with the UC, but not among those with CD.
- The mean total SOC score among IBD patients was comparable to estimated rates in general populations. In both UC and CD patients, self-efficacy was positively associated with SOC while fatigue interference was negatively associated with SOC.

8.2 Future perspectives

CAM use seems to be a part of the IBD patients' self-management. The quality of doctor-patient communication is important for allowing the patients to discuss their CAM use. Incorporation of CAM-related courses at nursing schools and in medical education will enhance the ability of these health care professionals to evaluate CAM.

Population-based studies assessing CAM use are rare. The IBSEN 20 year follow-up has included several questions regarding CAM use, including reasons for use. The results may give a more comprehensive picture of CAM use in the IBD population. The results regarding the relationship between CAM use and HRQOL in IBD are inconclusive, and this needs to be further addressed in subsequent studies. Knowledge about why patients use CAM may provide important information about health beliefs, values, and patient expectations and will be important guidelines to understand self-management strategies [199,171].

The usefulness of mind-body therapies aimed at reducing fatigue should be further investigated, preferable as a longitudinal intervention study.

The value of SOC as an assessment of patient's recourses to deal with stressors should be evaluated further. This could be achieved through an intervention study using salutogenetic principles with the aim of maintaining and stimulating the adjustment to illness. To further investigate the complex relationship between SOC, disease symptoms, and HRQOL, longitudinal studies are needed.

Improving self-efficacy is addressed as one important goal of educational interventions for patients with chronic diseases [154]. In IBD, the IBD Self-Efficacy Scale [131] is recommended because it relates directly to self-management requirements unique for IBD patients. Therefore, the scale may be a useful tool in both clinical and research settings assessing the impact of personal resources in the management of IBD. Longitudinal studies are also warranted to investigate the value of SOC and self-efficacy as predictors of disability, medication adherence, HRQoL, and coping behavior in IBD patients.

9 References

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10 Papers I-IV

11 Appendix

1. Studies investigating prevalence and user characteristics of CAM in patients with Inflammatory Bowel Disease from 1995 to 2013

2. International CAM Questionnaire

3. The five-item Fatigue Severity Scale

4. The Sense of Coherence Questionnaire

5. General Self-Efficacy Scale

Studies investigating prevalence and user characteristics of CAM in patients with Inflammatory Bowel Disease from 1995 to 2013

Author/year of publication (ref)	Study design	Study sample	n	Frequency of CAM use	Most common CAM modality	Factors associated with CAM use*
Koning et al., 2013 (119)	Case-control	Population-based	IBD 1370 Control subjects 598	<i>The last 12 months:</i> IBD 44 % Control subject 42 %	Vitamins**	<i>In IBD:</i> female gender, younger age, higher education, higher income, being a vegetarian, middle class at birth. <i>In control subjects:</i> female gender, higher education, diagnosis of asthma.
Fernandez et al., 2012 (111)	Cross-sectional	Hospital-based	IBD 705 UC/CD	<i>Current or past:</i> IBD 23% Comparable rates between UC and CD	Herbal remedies	Extra intestinal manifestations, disease duration
Weizman et al., 2012 (101)	Cross-sectional	Hospital-based	IBD 380 UC/CD/IBD unclassified	<i>Current or past:</i> Total sample 56 % Comparable rates between UC and CD	Probiotics	Experiencing adverse effects of conventional IBD medications, Comfortable discussing CAM with their physician
Rawsthorne et al., 2012 (103)	Longitudinal	Population-based	IBD 309 UC/CD	<i>Over a 4.5 year period:</i> 74% <i>The last 12 months:</i> 49% Consistently at every time point 14% Comparable rates between UC and CD	Massage	Female gender
Bertomoro et al. 2010 (112)	Cross-sectional	Hospital-based	IBD 1996 UC/CD/IBD unclassified	<i>Current or past:</i> IBD 24% Comparable rates between UC and CD	Dietary supplements	A need for frequent checkups
Lakatos et al., 2010 (104)	Cross-sectional	Hospital-based	IBD 655 UC/CD	<i>The last 12 months:</i> In both UC and CD 33 %	Herbal tea	CD: younger age, use of 5-ASA UC: younger age, urban residency, use of immunosuppressant, psychological therapy
Sirois 2008 (102)	Cross-sectional	Internet-based	N=365 (arthritis, IBD, mixed chr. illness) IBD 110	<i>Previous 6 months:</i> Overall 38 % IBD 32 %	Massage	Higher education level, female gender, comorbid chronic condition present, perceived control over health, proactive health beliefs, a higher use of conventional health care.

Author/year of publication (ref)	Study design	Study sample	n	Frequency of CAM use	Most common CAM modality	Factors associated with CAM use*
D'inca et al., 2007 (113)	Cross-sectional	Hospital-based	IBD 552 UC/CD	<i>Current or past:</i> IBD 28 % Comparable rates between UC and CD	Homeopathy	Noncompliance with conventional drugs, frequently relapses, and curiosity regarding novel therapies
Joos et al., 2006 (105)	Cross-sectional	Crohn's and Colitis Association	IBD 413 UC/CD	<i>Current or past:</i> IBD 52 % Comparable rates between UC and CD	Homeopathy	No significant factors were found
Bensoussan et al., 2006*** (100)	Cross-sectional	Hospital-based	IBD 325 UC/CD/IBD unclassified	<i>Current or past:</i> IBD 21 % Comparable rates between UC and CD	Homeopathy	Female gender, low level of confidence in physician, having looked for complementary information about their disease
Langhorst et al., 2005 *** (115)	Cross-sectional	Crohn's and Colitis Association	IBD 671 UC/CD/IBD unclassified	<i>Current or past:</i> UC 51 % UC 60 % CD 48%	Homeopathy and herbal medicine	Younger age, higher education level, UC diagnosis, prolonged or intensive steroid treatment, had psychotherapy, Normal body weight, diet with whole grain, use of relaxation techniques
Kong et al., 2005 *** (120)	Cross-sectional	Hospital-based Control group: Customers at local supermarkets	IBD 311 IBS 281 General GI 340 Control group 477	<i>Current:</i> IBD 50 % IBS 51% General GI disorders 20 % Controls 27 %	Multivitamins**	Female gender
Burgman et al., 2004*** (116)	Cross-sectional	Hospital-based	IBD 150	<i>The last 12 months:</i> IBD 60 %	Diet	Not evaluated in multivariate analysis
Hilsden et al., 2003*** (106)	Cross-sectional	Crohn's and colitis Association	IBD 2828 UC/CD/IBD unclassified	<i>Current or past:</i> IBD 47 % <i>Past use for IBD: 24 % Present use for IBD: 24 %</i>	Herbal medicine	Not evaluated in multivariate analysis

Author/year of publication (ref)	Study design	Study sample	n	Frequency of CAM use	Most common CAM modality	Factors associated with CAM use*
Quattropani et al., 2003 (107)	Cross-sectional	Hospital-based and Gastroenterological private practices	IBD 144 UC/CD	<i>Current or past:</i> IBD 47% Comparable rates between UC and CD	Homeopathy	No factors were significantly associated with CAM use
Langmead et al., 2002*** (108)	Cross-sectional	Hospital-based	IBD 101 Non IBD 138	<i>Current or past:</i> IBD 28 % Comparable rates between IBD and non-IBD	Herbal remedies	Younger age, IBS diagnosis, IBD patients: lower scores at the fatigue dimension in IBDQ
Rawsthorne et al., 1999*** (117)	Cross-sectional	Hospital-based Multi-county	IBD 289 UC/CD	<i>The last 12 months:</i> All IBD 51 % Cork: 31 % LA 68 % Stockholm 32 % Winnipeg 57 % Comparable rates between UC and CD	Exercise	Being single, being a Los Angeles or Winnipeg patient, an increase in CAM use for every MD visit
Hilsden et al., 1999*** (109)	Cross-sectional	Internet-based sample	IBD 263 UC/CD/IBD unclassified	<i>The previous 2 years:</i> All 46 % Currently 34 % Comparable rates between UC and CD	Vitamins and herbal products	A history of never had used oral steroid
Hilsden et al., 1998*** (110)	Cross-sectional	University of Calgary Inflammatory Bowel Disease database	IBD 134 UC/CD/IBD unclassified	<i>Previous 2 years:</i> IBD 51 % UC 16 % CD 39 %	Vitamins and herbal products	Disease duration >10 years, history of hospitalization
Moser et al., 1995 (118)	Cross-sectional	Hospital-based	IBD 105 UC/CD	IBD 47 % UC n= 16 CD n= 33 <i>Timeframe not stated</i>	Homeopathy	Disease duration

*Factors associated with CAM use after controlling for other relevant factors in multivariate analyses.

**CAM = oral products only

***included in the review of Hilsden et al. 2011 (ref)

Internasjonalt spørreskjema om bruk av komplementær og alternativ medisin (I-CAM-Q)

Denne delen av spørreskjemaet omhandler din *bruk og nytte* av ulike komplementære og alternative behandlinger (KAM).

Det er flere spørsmål knyttet til hver type behandlingsform.

- Kryss av i listen over behandlinger, **Ja** for dem du har benyttet og **Nei** for dem du ikke har benyttet (sett kryss for hver behandling).
- Hvis du svarer **Ja**: fyll ut *hovedårsaken* til at du oppsøkte behandleren eller benyttet behandlingsformen, og hvilken *nytte* du har hatt av dette.
- Svarer du Nei, går du videre til neste behandlingsform.
- I siste rute skriver du inn de komplementære og alternative behandlingsformene som du har benyttet, men som ikke er på listen.

NAFKAMs internasjonale KAM-spørreskjema (I-CAM-Q):

1. Besøk hos behandlere: Forskjellige alternative behandlere og ansatte innen skolemedisin kan ta seg av helseproblemer.

Har du vært hos en eller flere av følgende behandlere de siste 12 månedene?	Nei Ja Antall ganger du var hos denne behandleren de siste 3 månedene?	Angi <u>hoved</u> årsaken til at du <u>sist</u> gikk til behandleren (Kun ett kryss).				Hvor nyttig var det for deg å gå til denne behandleren? (Kun ett kryss)
		For en akutt sykdom/tilstand med varighet kortere enn én måned.	For å behandle et langvarig helseproblem (varighet lenger enn én måned) eller symptomer knyttet til dette	For økt velvære	Annet (Vennligst spesifiser den andre årsaken)	
Lege	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Kiropraktor	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Homøopat	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Akupunktør	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Healer	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Kinesiolog	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Soneterapeut	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Laser-behandler	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Annen (skriv hvilken) _____	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

2. Alternative behandlinger mottatt fra leger

Hvis du **ikke** har vært til lege de siste 12 måneder, gå til spørsmål 3.

Noen leger gir både alternativ og skolemedisinsk behandling

Har du fått noen av følgende alternative/ komplementære behandlingsformer av en lege de siste 12 månedene?	Nei Ja Antall ganger du fikk denne behandlingen de siste 3 månedene	Angi <u>hovedårsaken</u> til at du <u>sist</u> fikk denne behandlingen (Kun ett kryss)				Hvor nyttig var det å få denne behandlingen fra legen? (kun ett kryss)
		For en akutt sykdom/tilstand med varighet kortere enn én måned	For å behandle et langvarig helseproblem (varighet lenger enn én måned) eller symptomer knyttet til dette	For økt velvære	Annet (Vennligst spesifiser den andre årsaken)	
Manipulasjon	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Homøopati	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Akupunktur	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Urter	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Healing	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Annen (skriv hvilken): _____	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

3. Bruk av urtemedisin og kosttilskudd, inkludert tabletter, kapsler og flytende midler.

For hver kategori nedenfor, skriv opp til tre produkter som du har brukt de siste 12 månedene.	Bruker du disse produktene nå?		Angi <u>hoved</u> årsaken til at du <u>sist</u> brukte dette produktet. (Kun ett kryss).				Hvor nyttig var dette produktet for deg? (Kun ett kryss)			
	Ja	Nei	For en akutt sykdom/tilstand med varighet kortere enn én måned	For å behandle et langvarig helseproblem (varighet lenger enn én måned) eller symptomer knyttet til dette	For økt velvære	Annet (Vennligst spesifiser)	Veldig nyttig	Litt nyttig	Ikke nyttig	Vet ikke
Urter/urtemedisin										
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Vitaminer/mineraler										
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Homøopatiske midler										
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Andre tilskudd										
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

INTERNASJONALT KAM-SPØRRESKJEMA

4. Selvhjelpsteknikker

Har du brukt noen av følgende selvhjelpsteknikker de siste 12 månedene?	Nei Ja Antall ganger du har brukt denne teknikken de siste 3 månedene?	Angi <u>hovedårsaken</u> til at du <u>sist</u> brukte denne selvhjelpsteknikken. (Kun ett kryss)				Hvor nyttig var denne selvhjelpsteknikken for deg? (Kun ett kryss)
		For en akutt sykdom/tilstand med varighet kortere enn én måned	For å behandle et langvarig helseproblem (varighet lenger enn én måned) eller symptomer knyttet til dette	For økt velvære	Annet (Vennligst spesifiser den andre årsaken)	
Meditasjon	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Yoga	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Qigong	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Tai Chi	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Avspennings-teknikker	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Visualisering	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Deltakelse i tradisjonell helbredelses-seremoni	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Bønn for egen helse	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Annen (Skriv hvilken): _____	<input type="checkbox"/> <input type="checkbox"/> ____	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	_____	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

FATIGUE – FSS-5

Skala for gradering av det å være sliten, uopplagt og ha mangel på overskudd.

Instruksjon: Velg et tall fra 1 til 7 som angir i hvor stor grad du er enig med hvert enkelt utsagn, der 1 angir at du er helt uenig og 7 at du er helt enig. **Sett ring rundt ett tall for hvert utsagn.**

	Helt uenig				Helt enig			
1	Jeg blir fort sliten og uopplagt.	1	2	3	4	5	6	7
2	Det at jeg er sliten og uopplagt, virker inn på hvordan jeg fungerer fysisk.	1	2	3	4	5	6	7
3	Det at jeg er sliten og uopplagt, skaper ofte vanskeligheter for meg.	1	2	3	4	5	6	7
4	Det at jeg er sliten og uopplagt, virker inn på evnen til å utføre visse oppgaver og plikter	1	2	3	4	5	6	7
5	Det at jeg er sliten og uopplagt, virker inn på mitt arbeid, mitt familieliv eller min omgang med venner og kjente.	1	2	3	4	5	6	7

Opplevelse av sammenheng (OAS)

1. Har du følelsen av at du egentlig ikke bryr deg om det som foregår rundt deg?

Svært sjelden eller aldri 1 2 3 4 5 6 7 Svært ofte

2. Har du noen gang blitt overrasket over oppførselen til folk du trodde du kjente godt?

Aldri Skjedd 1 2 3 4 5 6 7 Alltid skjedd

3. Har det skjedd at mennesker du stolte på har skuffet deg?

Aldri skjedd 1 2 3 4 5 6 7 Alltid skjedd

4. Hittil har ditt liv vært preget av

Ingen klare mål og mening i det hele tatt 1 2 3 4 5 6 7 Svært klare mål og mening

5. Har du følelsen av å ha blitt urettferdig behandlet?

Svært ofte 1 2 3 4 5 6 7 Aldri

6. Har du følelsen av å være i en ukjent situasjon og ikke vite hva du skal gjøre?

Svært ofte 1 2 3 4 5 6 7 Svært sjelden eller aldri

7. Dine daglige gjøremål er

En kilde til dyp glede og tilfredsstillelse	1	2	3	4	5	6	7	En kilde til smerte og kjedsomhet
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8. Har du svært blandede følelser og ideer?

Svært ofte	1	2	3	4	5	6	7	Svært sjelden eller aldri
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9. Hender det at du har følelser du helst ikke ville hatt?

Svært ofte	1	2	3	4	5	6	7	Svært sjelden eller aldri
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10. Mange mennesker, selv de med sterk personlighet, føler seg noen ganger som "tapere" i visse situasjoner. Hvor ofte har du følt deg slik?

Aldri	1	2	3	4	5	6	7	Svært ofte
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11. Når noe har skjedd, har du stort sett følt at

Du har overvurdert eller undervurdert viktigheten av det	1	2	3	4	5	6	7	Du vurderte tingene på riktig måte
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12. Hvor ofte føler du at dine daglige gjøremål har liten mening?

Svært ofte	1	2	3	4	5	6	7	Svært sjelden eller aldri
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13. Hvor ofte har du følelser du ikke er sikker på om du kan kontrollere?

Svært ofte	1	2	3	4	5	6	7	Svært sjelden eller aldri
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Mestringsforventning (GSE)

Vennligst sett kryss ved de svarene som passer best for deg.
(Ett kryss for hvert spørsmål)

	Ikke riktig ▼	Litt riktig ▼	Nokså riktig ▼	Helt riktig ▼
1. Jeg klarer alltid å løse vanskelige problemer hvis jeg prøver hardt nok	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Hvis noen motarbeider meg, så kan jeg finne måter og veier for å få det som jeg vil.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. Det er lett for meg å holde fast på planene mine og nå målene mine.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Jeg føler meg trygg på at jeg vil kunne takle uventede hendelser på en effektiv måte.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Takket være ressursene mine så vet jeg hvordan jeg skal takle uventede situasjoner.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Jeg kan løse de fleste problemer hvis jeg går tilstrekkelig inn for det.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Jeg beholder roen når jeg møter vanskeligheter fordi jeg stoler på mestringsveien min.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. Når jeg møter et problem, så finner jeg vanligvis flere løsninger på det.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Hvis jeg er i knipe, så finner jeg vanligvis veien ut.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Samme hva som hender så er jeg vanligvis i stand til å takle det.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>