

Inflammatory bowel disease and complementary and alternative medicine – The perspectives of patients and healthcare professionals



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**INFLAMMATORY BOWEL DISEASE AND
COMPLEMENTARY AND ALTERNATIVE MEDICINE –
THE PERSPECTIVES OF PATIENTS AND HEALTHCARE
PROFESSIONALS**

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Inflammatory bowel disease and complementary and
alternative medicine - the perspectives of patients and
healthcare professionals
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Till eftertanke

*Om jag vill lyckas med att föra en
människa mot ett bestämt mål måste jag
först finna henne där hon är och börja just där.*

*Den som inte kan det lurar sig själv när
hon tror hon kan hjälpa andra.*

*För att hjälpa någon måste jag visserligen
förstå mer än vad han gör men först och
främst förstå det han förstår.*

*Om jag inte kan det så hjälper det inte att
jag kan mer och vet mer.*

*Vill jag ändå visa hur mycket jag kan så
beror det på att jag är fåfäng och
högmodig och egentligen vill bli beundrad
av den andre i stället för att hjälpa honom.*

*All äkta hjälpsamhet börjar med
ödmjukhet inför den jag vill hjälpa och
därmed måste jag förstå att detta med att
hjälpa inte är att vilja härska utan att vilja tjäna.
Kan jag inte detta så kan jag heller inte hjälpa.*

Søren Kierkegaard

Synspunktet for min Forfatter-Virksomhed

ABSTRACT

Background: Inflammatory bowel disease (IBD) is a term that covers ulcerative colitis (UC) and Crohn's disease (CD). The causes of IBD are unknown and the incidence is increasing. IBD is a lifelong disease with severe symptoms that affect daily life and Health Related Quality of Life (HRQOL). The medical treatment for IBD is complex and many patients suffer from side effects of medication. Complementary and Alternative Medicine (CAM) encompasses methods that are not a part of conventional healthcare and not generally provided by the Swedish healthcare system. The use of CAM is increasing, especially in chronic diseases.

Aim: The overall aim of this thesis was to investigate the use of CAM in patients with IBD and to explore attitudes to and experiences of CAM in patients with IBD and healthcare professionals (HCPs). An additional aim was to investigate IBD patients' worries and disease related concerns in relation to CAM use.

Study I was a controlled cross-sectional and multicentre study. The study enrolled 648 patients with IBD from 12 IBD clinics in Sweden. The control group comprised 440 individuals selected from Statens Personadressregister (SPAR). Data were collected by means of questionnaire. The results revealed that 48.5% (n = 313) of the IBD patients had used some form of CAM in the past year, compared with 53.5% (n = 235) in the control group. The most common CAM methods used by IBD patients compared to the control group were massage 21,3% vs 31,4%, herbal remedies 18,7% vs 21,3%, relaxation 10,5% vs 11,6%, yoga 8% vs 9,6%, acupuncture 7,6% vs 8,9%, counselling 7,3% vs. 6,2 and chiropractic 5,4 vs 5,7%.

Study II was an interview study in which HCPs were asked to describe their experiences and attitudes to CAM. The participants were 16 physicians and nurses who had worked with IBD patients for 1-42 years. The results demonstrated that IBD nurses and physicians had confidence in and a positive attitude to CAM, especially when used as a complement to conventional medicine. The participants were of the opinion that patients considered and tested various CAM methods. They stated that CAM has a role in healthcare, which indicates acceptance. However, attitudes that constituted an obstacle to CAM were also reported, such as lack of evidence. Some participants had a restrictive approach and considered CAM unnecessary, while a few were sceptical.

Study III comprised interviews in which 15 IBD patients described their experiences of CAM both alone and in combination with conventional medical treatment. It was found that patients with IBD wished to be consulted and have a discussion about CAM. They felt disparaged and not taken seriously when they wanted to discuss CAM. HCPs need to be aware of this issue in order to meet and understand IBD patients' needs. The IBD patients considered it easier to discuss CAM with nurses than with physicians, which underlines IBD nurses' important role in communicating with and monitoring IBD patients' use of CAM.

HCPs should be aware that IBD patients consider dietary changes an important CAM treatment.

Study IV was a controlled, cross-sectional and multicentre study. Data from 12 IBD clinics in Sweden were collected by means of questionnaires. A total of 645 IBD patients were enrolled and asked to answer two questionnaires; a studyspecific questionnaire concerning CAM use, disease and demographic data and the Rating Form of Inflammatory Bowel Disease Patients' Concerns (RFIPC) questionnaire. The RFIPC consists of 25 questions to which patients respond by indicating how worried they are about a particular aspect on a VAS scale from 0-100. The questionnaire also contains an open question "Is there anything more that concerns you?", which the patients answer in their own words. Of the participants, 313 used CAM and expressed more concerns in 15 of the 25 RFIPC items compared to patients who did not do so/non-users. CAM use was related to younger age and female gender. The open question revealed that IBD had a major impact on everyday life and that IBD patients' worry concerned: The family and self, the burden of disease and associated factors.

Conclusion: Patients with IBD used CAM in an attempt to achieve improvement and well-being. They considered dietary changes an important CAM treatment with positive effects on their condition. HCPs attitudes to CAM were mainly positive, although a problematic aspect was lack of knowledge and evidence. The HCPs acknowledged their need for education and respected the patients' decision to use CAM. However, patients with IBD reported reluctance on the part of HCPs, being treated in a disparaging manner and not taken seriously when wishing to discuss CAM. They wanted to be asked about their CAM use and start a dialogue, but found it easier to discuss CAM treatment with nurses than physicians. Patients using CAM generally had more disease-related concerns compared to those who did not do so. IBD affects the whole of everyday life, especially the family and the self.

LIST OF SCIENTIFIC PAPERS

- I. Oxelmark L, Lindberg A, Löfberg R, Almer S, Sternby B, Eriksson A, Fossum B, Broström O, Karlén P, Tysk C. Complementary and alternative medicine in patients with inflammatory bowel disease.
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- IV. Lindberg A, Fossum B, Karlen P, Broström O, Oxelmark L. The relationship between complementary and alternative medicine and disease related concerns in patients with inflammatory bowel disease: a mixed methods approach.
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LIST OF ABBREVIATIONS

BMI	Body Mass Index
CAM	Complementary and Alternative Medicine
CD	Crohn's Disease
HCPs	Health Care Professionals
HRQOL	Health-Related Quality of Life
IBD	Inflammatory Bowel Disease
IPAA	Ileal Pouch-Anal Anastomosis
IRA	Ileo Rectal Anastomosis
MPA	Medical Products Agency
MRI	Magnetic Resonance Imaging
NCCAM	National Center for Complementary and Alternative Medicine
N-ECCO	Nurses' - European Crohn's and Colitis Organisation
NSAID	Nonsteroidal Anti-Inflammatory Drugs
RCT	Randomized Clinical Trial
RFIP	Rating Form of Inflammatory Bowel Disease Patient Concerns
TCM	Traditional Chinese Medicine
TM	Traditional Medicine
TNF α	Tumor Necrosis Factor alpha
UC	Ulcerative colitis
WHO	World Health Organization

1 INTRODUCTION

There is a growing interest in Complementary and Alternative Medicine (CAM) in patients with chronic diseases; which also applies to those with inflammatory bowel disease (IBD). IBD is a lifelong condition with severely disabling symptoms that impact on everyday life [1-4]. The side effects of medical treatment and surgery can also affect the patient's ability to live a normal life. There is no cure for IBD and the cause is unknown. During my work as a nurse with IBD patients I have observed that some patients turn to CAM as they seem to be attracted by the holistic approach, which they appear to miss in conventional care. However, education about and knowledge of CAM in the healthcare system appears to be poor. For example, many healthcare professionals (HCPs) are not aware that, according to the Medical Products Agency (MPA), they should treat approved herbal medicinal products in the same manner as conventional medicines. There is a growing need for education about CAM in Sweden. It is necessary to illuminate both IBD patients' experiences of and HCPs attitude towards CAM in order to meet the needs and wishes of these patients.

2 BACKGROUND

2.1 THEORETICAL FRAMEWORK

The theoretical framework in this thesis comprises chronic disease and self-care.

2.1.1 Chronic disease

When living with a lifelong disease, one can be overwhelmed by feelings of powerlessness and of one's social and personal identity being threatened. Worries about no longer being able to rely on one's body or know what is happening to it are also common. The above can give rise to feelings of insecurity and disrupted identity [5]. Patients with chronic diseases make self-care decisions on a daily basis, are experts about their own life and thus responsible for managing their own conditions and solving health in partnership with HCPs [6]

2.1.2 Self-care

There are several definitions of self-care that emphasise disease prevention and changes in lifestyle behaviour. The terms "self-care", "self-management" and "self-help" tend to be used interchangeably. Self-help, describe support and help provided by self-help groups, often supported by health care [7]. Self-management can be defined as how patients take responsibility for their own behaviour and well-being in the long term. It concerns the individual's ability to manage, while self-care refers to activities taken by individuals [8, 9].

Dorothea Orem defined self-care as:

"The practice of activities that individuals initiate and perform on their own behalf in maintaining life, health and wellbeing" (p 117) [10]

Orem holds that a person is an active and free human being who is reflective of both her/his surroundings and her/himself, with the ability to express her/himself by means of symbols. A human being can achieve wellness through self-care. The culture and social group to which an individual belongs affect how self-care actions take place. Individuals have a great responsibility to develop good habits and thus promote health [10]. The most recent definition of self-care from the World Health Organization (WHO) 2009 is:

"Self-care is the ability of individuals, families and communities to promote health, prevent disease, and maintain health and to cope with illness and disability with or without the support from health-care provider"[11].

According to existing definitions, many activities can be considered self-care. There are specific self-care activities for most conditions, which differ from one individual to another. Self-care in a chronic disease is of great value with beneficial effects on well-being [8]. Research has also demonstrated the benefits of a self-management programme in a heterogeneous group of chronic diseases, such as improved health behaviours, better health status and fewer hospitalizations [12].

2.2 INFLAMMATORY BOWEL DISEASES (IBD)

Ulcerative colitis (UC) and Crohn's disease (CD) are chronic relapsing inflammatory bowel diseases (IBD) of the gastrointestinal tract [13, 14]. CD can affect the whole gastrointestinal tract from mouth to anus, but the most common locations are the last part of the small intestine and the colon, while UC is only present in the colon [14-16]. In UC only the innermost lining of the colon is inflamed, while CD affects the entire thickness of the bowel wall. IBD is lifelong and to date there is no cure.

2.2.1 Etiology and epidemiology

IBD is often diagnosed before the age of 30 years. The peak age of onset is between 15 and 30 years, although it can occur at any age [13]. The causes of IBD are not fully understood [16, 17] and the etiology is believed to be multifactorial [13, 16, 18]. Associated factors related are barrier dysfunction, gut microbiome immune dysregulation and genetic predisposition [13, 16, 19, 20]. There are also environmental risk factors, such as smoking, appendectomy, diet, infections, nonsteroidal anti-inflammatory drugs (NSAID) and antibiotics. However, findings related to these factors are inconsistent [21, 22]. The highest prevalence and incidence of IBD is in the western nations with peak incidence rates in Canada and Northern Europe [15, 23]. Asia has a lower prevalence, but research revealed that when an individual emigrate from a low-to a high-incidence country, the risk of developing IBD is the same as that of the population of the high-incidence country. Furthermore, first generation children of immigrants seem to have a higher incidence of IBD than first nation persons [24]. About one million people in the US suffer from IBD [25] and the incidence rates are 9-20 cases/100,000 inhabitants for CD and 10-20 cases/100,000 inhabitants for UC [26, 27]. In the Nordic countries the incidence of CD is 5-8 cases/100,000 and of UC 12-14 cases/100,000 [28]. In Sweden, about 61,200 individuals live with UC and CD and the prevalence increases with age [29].

2.2.2 Symptoms and diagnosis

UC and CD are characterised by similar symptoms and usually the course of both diseases comprises periods of increased activity (flare) alternating with periods without inflammation (remission) but inflammation is sometimes chronic and continuously active. The symptoms include diarrhoea, often with blood or mucus, abdominal pain, malabsorption, weight loss and fatigue [30, 31]. Patients with UC tend to have more pain in the lower left part of the abdomen as well as diarrhoea with blood while CD patients experience pain in the lower right part of the abdomen and less frequent bleeding [30]. About one third of IBD patients develop additional extra intestinal symptoms that involve organs other than the gastrointestinal tract, the most common occurring in the skin, mouth, joints, hepatobiliary tract and eyes [32]. IBD is diagnosed by medical anamnesis and physical examination in addition to other techniques, the most common of which is colon - ileoscopy with biopsies of the tissues, which are used to confirm the diagnosis. Colonoscopy is an endoscopic examination of the large bowel, often combined with endoscopy of the distal part of the small bowel, called ileo colonoscopy. As the small intestine is more difficult to investigate, sometime magnetic resonance imaging

(MRI) and small bowel endoscopy with special instruments are sometimes used to confirm the diagnosis. Additionally, capsule endoscopy can be employed to confirm CD in the small gut. The patient swallows a capsule containing a camera that takes images of the inner layer of the gastrointestinal tract, which are transmitted to a computer. Moreover, lab test on blood and stool are also performed [30].

2.2.3 Treatment and care

The complexity of medical treatment has increased, and the use of new biological therapies is escalating [33]. Corticosteroids are one of the most common therapies in IBD, but as they are associated with a high risk of side-effects, because of that one goal is to reduce the corticosteroid dose by replacing them with other medications such as aminosalicylates, thiopurines, methotrexate, antibiotics, tumour necrosis factor alpha inhibitor (TNF- α) and other biological treatments [34]. However, TNF- α is also associated with a risk of side-effects including non-Hodgkin's lymphoma [35], serious infections [36] such as opportunistic infections [37] and neurological events [38]. Another goal of the treatment is to reduce the inflammatory activity and help maintain remission [30]. During recent years IBD care has changed from a medical to a bio-psychosocial model [39]. The development of European guidelines has contributed to this [40].

Sometimes the medical treatment fails and surgical treatment is required. The risks involved in surgery for IBD patients have decreased over the past six decades [41]. Surgery is a complement to medical treatment and can prevent complications as well as improve quality of life [42, 43]. The reasons for surgery in UC are acute colitis resistant to the medical treatment, continuous chronic activity inflammation, dysplasia and/or cancer of the colon and reconstruction after a previous colectomy. Primary surgery for UC usually involves removal of the large intestine (colectomy), closure of the remaining part of the rectum and ileostomy. This is usually followed by reconstruction with an ileal pouch-anal anastomosis (IPAA), ileorectal anastomosis (IRA) or a permanent ileostomy [44]. The indications for surgery in CD include resection of the inflamed bowel and inadequate response to medical treatment as well as the need to correct complications caused by the disease such as stenosis and fistula. The surgery in CD is focused to save as much bowel as possible through limited resections and stricture plastic [45].

2.2.4 The role of the IBD nurse

In 2011, the Nurses-European Crohn's & Colitis Organisation (N-ECCO) agreed on the need for a consensus statement on the nurse's role in IBD care, thus the first N-NECCO consensus statements on European nurses' role in caring for patients with Crohn's disease or ulcerative colitis were published in 2013 [40]. Specialist IBD nurses play an important role in the coordination and management of patient care and are often the first point of contact for IBD patients, but the patients also need support from a multidisciplinary team [46, 47]. IBD nurses also provide advice, counselling and support, resulting in better compliance. Their

interventions could lead to reduced costs for the health service due to fewer hospital admissions [48].

In Sweden the patient's position in healthcare has been strengthened by a new law (SFS 2014:821) that highlights the concept of person-centred care. In person-centred care the patient is considered a partner in the relationship with HCPs and plays a more active role in participation and decision-making [49, 50]. It is important for HCPs to be aware that the patient's perception of care may differ from their own [46]. Person-centred IBD care is essential for positive outcomes and should include clear long-term planning and goal setting by the patient and multidisciplinary team [51].

2.3 COMPLEMENTARY AND ALTERNATIVE MEDICINE-CAM

2.3.1 What is CAM?

There are many terms for Complementary and Alternative Medicine (CAM), making the concept difficult to define. The definition can differ from one country to another. The World Health Organization (WHO) definition is one of the most commonly used:

"CAM refer to a broad set of health care practices that are not part of that country's own tradition and are not integrated into the dominant health care system. They are used interchangeably with traditional medicine in some countries." [52] p. 15.

There are also differences between complementary and alternative medicine. The latter refers to the use of CAM instead of conventional medicine, while the former implies utilizing both CAM and conventional medicine. There is also Traditional Medicine (TM), which has been practised for a very long time in many countries. The WHO definition of TM is:

"the sum total of knowledge, skills and practices based on the theories, beliefs and experiences indigenous to different cultures, whether explicable or not, used in the maintenance of health as well as in prevention, diagnosis, improvement or treatment of physical and mental illness." [52]p.15

Integrative medicine is the development and integration of evidence based, systematically follow- ups and evaluated knowledge from various forms of TM/CAM. The National Center for Complementary and Alternative Medicine (NCCAM), which is part of the National Institute for Health (NIH) in the US, defines integrative medicine as follows:

"It combines treatments from conventional medicine and TM/CAM for which there is some high-qualitative scientific evidence of safety and effectiveness" [53].

The NCCAM groups CAM into five domains [53]:

Whole medical systems: Theories and practices such as homeopathic medicine, Traditional Chinese Medicine and Traditional Indian Ayurveda Medicine.

Mind-body interventions: Strengthen communication between the mind and body, for example meditation, prayer and healing.

Biologically-based therapies: Substances found in nature, including dietary supplements and herbal products.

Manipulative and body-based methods: Employs human touch to move or manipulate a specific part of the body, for example, chiropractic therapy and massage.

Energy therapies: Use energy fields in the body to promote health and healing, for example qi gong, tai chi and magnet therapy.

2.3.2 CAM in Sweden

The popularity of CAM in Sweden is increasing and a research report on CAM use in the county of Stockholm revealed an increasing from 22 % to 49 % between 1980 and 2001 [54]. The Swedish Council for Working Life and Social research (FAS) has emphasized the importance of determining CAM use in Sweden and the great need for advanced research in this area [55]. CAM is generally not provided within the Swedish healthcare system [56] and HCPs are not permitted to prescribe CAM treatments, except the herbal medicinal products approved by the MPA [57, 58]. The WHO has called for countries to take an integrative approach to CAM, which Sweden has not adopted, in contrast to several other countries including Norway, the UK, Germany and Australia. Although the WHO also states that access to CAM is a human right [59], there is no national CAM policy in Sweden and CAM is not officially approved in healthcare or within the education system, thus policy development is essential [60].

2.3.3 CAM/TM internationally

The interest in CAM among HCPs is high [61]. CAM use is increasing in the Western industrialized countries; in the US 42 % of the population use CAM, in Australia 48%, Canada 70 % and France 75 % [59]. However, many countries are struggling with questions concerning safety, quality, efficacy and research in this area [59]. The WHO is working towards the safe use of TM/CAM treatment through regulation, promotion of research and appropriate integration of TM/CAM products in the national health system. The organization has also recommended that member states should create a knowledge base, formulate national policies and strengthen their efforts in the areas of quality, safety and efficacy of TM/CAM [52]. The CAMbrella project was a European research network that developed a research strategy for CAM between 2010 and 2012. The research strategy covered six areas and identified important knowledge gaps [62]. The six areas are:

- CAM prevalence
- Needs and attitudes of citizens and providers
- CAM safety
- Comparative effectiveness research

- Effects of context and meaning
- Models of CAM integration

The results of the CAMbrella project indicated that there is a high demand for CAM in Europe but that regulation and education vary. With the exception of Norway, the UK and Switzerland, European countries have not examined the healthcare field in a thorough manner. CAMbrella recommends that a centre should be established in Europe in order to promote knowledge, research and development about CAM [63].

2.3.4 CAM and IBD

Evidence of CAM use in IBD is rare and randomized controlled trials (RCTs) are necessary. Nevertheless, some evidence of CAM treatment in IBD exists [64]. Probiotics are live microbial dietary supplements and most data on their efficacy in IBD concern UC. VSL#3, a mix of four different probiotics, has been found to increase the clinical response and remission rate in mild to moderate UC [65, 66] and was effective in the prevention of pouchitis [67]. Ayurveda is the traditional Indian healing culture and has been practised for 3000-4000 years. In Ayurveda health is based on the balance between food intake, physical activity and nature. Ayurveda medications are sold as dietary supplements and in a survey, it was found that several contain toxic metals, such as mercury and arsenic [68]. About 200 different plants are used to treat various chronic diseases, some of which have an anti-inflammatory effect [69], but there is no evidence of their effectiveness in IBD [64]. Traditional Chinese Medicine (TCM) is a combination of individualized herbal treatment and acupuncture but is mainly associated with the latter. There are few RCT studies of acupuncture in IBD, although, in two studies, one of CD and the other of UC, the Health Related Quality of Life (HRQOL) and disease activity scores improved markedly [70, 71]. Wormwood [72, 73], Aloe vera gel [74], wheat grass juice [75] and Bilberry [76] are other CAM methods tested for IBD, but controlled trials are still lacking [64]. Mind and body therapies are also CAM methods that have been studied in IBD. A Cochrane analysis of 21 studies of a psychological intervention comprising relaxation techniques, patient education and psychotherapy revealed that psychotherapy had no effect on disease activity, HRQOL or emotional status [77]. On the other hand, hypnotherapy seemed to reduce stress and inflammatory reaction in IBD patients, leading to improved HRQOL, steroid- sparing effects and a reduction of the relapse rate [78-82].

Patients with chronic diseases in general use CAM [83-85] as do patients with IBD [86-88]. The prevalence of CAM use in IBD patients over the last 20 years varied from 21% -74 % (Table 1).

Table 1 Prevalence of CAM use in patients with IBD

Author	Year	N	Country	CAM use	When was CAM used?
Verhoef et al. [89]	1990	395	Canada	27 %	Current or past
Hilsden et al. [90]	1998	263	Canada	51 %	Last 2 years
Hilsden et al. [91]	1999	263	International	46 %	Last 2 years
Rawsthorne et al. [92]	1999	289	US/Canada/Sweden /Ireland	51 %	Current or past
Langmead et al. [93]	2002	239	UK	26 %	Current
Hilsden et al. [94]	2003	2828	Canada	47 %	Current or past
Burgmann et al. [95]	2004	150	Canada	60 %	Current or past
Kong et al. [96]	2005	311	UK	50 %	Current or past
Langhorst et al. [97]	2005	671	Germany	51 %	Current or past
Bensoussan et al. [98]	2006	325	France	21 %	Current or past
D'Inca et al. [99]	2007	552	Italy	28 %	Current or past
Bertomoro et al. [100]	2010	2011	Italy	24 %	Current or past
Lakatos et al. [101]	2010	655	Hungary	31 %	Current or past
Weizman et al. [102]	2011	380	Canada	56 %	Current or past
Fernandez et al. [88]	2012	705	Spain	23 %	Current or past
Opheim et al. [103]	2012	430	Norway	49 %	Last 12 months
Rawsthorne et al. [87]	2012	309	Canada	74 %	Last 4-5 years
Koning et al. [86]	2013	1291	New Zealand	44 %	Last 12 months

There are methodological limitations in prevalence studies of CAM in IBD, which makes comparisons of the prevalence in various countries problematic. One difficulty is that researcher use different definitions of CAM. For example, Burgmann et al. [95] include prayer and exercise in their CAM definition, while not all studies specify whether CAM was used for IBD or other health problems. In order to address that kind of problems, a group of international researchers have developed the International Questionnaire to Measure Use of Complementary and Alternative Medicine (I-CAM-Q) [104] which may contribute to comparable data from different countries for the epidemiology of CAM. IBD patients may turn to CAM because of poor quality of life [93], lack of efficacy of conventional IBD therapy [102], side-effects of steroid treatment [97], stress and the wish for a holistic approach or to gain greater control over the disease [105]. It is important to be aware that CAM use in IBD patients may be associated with non-adherence of conventional medicine [101], while other predictors are female gender [86, 87], younger age [86, 101, 106], high educational level [86, 103], higher disease activity [88, 106] and psychological distress [93].

2.4 HEALTH-RELATED QUALITY OF LIFE (HRQOL)

2.4.1 QOL and HRQOL

Quality of life (QOL) is a broad and complex measure of the individual's own evaluation of her/his physical, mental and social well-being. It also involves the perception of her/his position in life in the context of prevailing culture, norms and value systems in which she/he lives as well as her/his goals, expectations, standard, concerns, objectives, expectations, values and interests [107]. QOL can mean different things to different people and takes on different meanings according to the area of application [108, 109].

In 2006 the US Food and Drug Administration introduced the concept of Patient-Reported Outcome Measures (PROM) [110], which provides information from the patients about their experience of illness and health after treatment or other interventions and includes HRQOL as a measure of physical, mental and social well-being. Validated HRQOL questionnaires can be both disease-specific and generic. Generic questionnaires allow comparisons between different diseases and patient groups [111, 112], whereas disease-specific questionnaires capture important aspects of a particular disease or patient population [113].

2.4.2 HRQOL and IBD

There are several disease-specific instruments available for IBD [114]. The chronic nature and unpredictable course of IBD in addition to the fact that the peak age of onset is 15-30 years lead to impaired HRQOL [1-4]. In a large European survey (n=5,576) as many as 76% of the IBD patients reported that symptoms affected their ability to enjoy leisure activities and 70% felt that symptoms affected their ability to perform at work [4]. The strongest predictors of HRQOL impairment were disease activity [1, 3, 115], stress, anxiety depression [3, 116]

and fatigue [2, 117]. HRQOL is not only influenced by disease activity and its medical management but also by insufficient efficacy and the side effects of medical treatment [118, 119]. Corticosteroids are one of the most common forms of treatments in IBD and can lead to a number of side effects such as osteoporosis, osteonecrosis, cataracts, glaucoma, striae, diabetes mellitus, hypertension and psychological stress [120, 121]. About two-thirds of IBD patients will receive corticosteroid treatment within the first ten years and one third will be exposed to corticosteroids within one year of diagnosis. Heavy corticosteroid treatment during the first year of IBD is a strong predictor of surgery [34]. Immunomodulating treatment with tumour necrosis factor alpha inhibitor can cause serious side effects such as opportunistic infections [37], peripheral neuropathy as well as central nervous system and/or spinal cord demyelination [38].

2.4.3 Worries and concerns

Many IBD patients suffer from psychological distress and disease related worries can affect HRQOL in IBD patients. The highest rated worries are undergoing surgery and having an ostomy [122, 123]. Factors that seem to increase worry in CD patients are active disease, female gender and high body mass index (BMI) [122] and in UC ongoing relapse [123, 124]. Women with IBD report more intense concerns than men [125, 126] and, in addition, depression and coping are predictors of disease related concerns in IBD [126] as well as referral to a psychiatrist for counselling [127].

2.4.4 Stress and IBD

Psychological disorders in IBD are more frequent than in the general population [128, 129] and psychological stress is one of them. It is difficult to define stress, because the experience of stress may differ for each individual and can be both negative and positive [130]. Negative stress could be seen as a threat that starts a reaction in the brain, triggering the body's stress response [131]. No study has found that stress is a cause of IBD [132] but it can be immunosuppressive [131] and affect disease activity and risk of relapse [133-135]. The way IBD patients deal with stress can affect their HRQOL [136]. Common coping strategies for stress in IBD are emotion focused [116], optimistic, self-reliant and confronted [137].

2.5 ENCOUNTERS IN HEALTHCARE

2.5.1 Positive and negative encounters

Healthcare encounters can be both positive and negative. In negative encounters the patients experience that HCPs treat them in a disrespectful and unhelpful manner. It has been revealed that patients find them rude, aggressive or arrogant due to being ignored, lack of empathy and that their personal integrity is not respected [138]. Positive encounters are person-centred, characterised by a perception of the HCPs' sensitivity and empathy, during which the patient is given the opportunity to ask questions and is allowed to express her/his feelings [139]. Communication barriers between physicians and IBD patients regarding CAM have been identified [98, 140]. Few physicians routinely initiated discussions about CAM with

patients, the reason for which could be lack of time, discomfort with and lack of knowledge about CAM on the part of the physician [140, 141]. IBD patients want to discuss CAM with physicians and would like open communication including information and support [142]. Some IBD patients were unwilling to speak openly about their CAM use, which may be due to the quality of the patient-physician relationship, failure of the physician to ask about it and fear of a negative response from the physician [98, 140]. The IBD patients had the same experience of poor communication when it came to HRQOL and reported that physicians did not ask about the impact of the symptoms on their HRQOL [4]. This indicates a desire for emphasis on the personal context and not just focusing on the disease [142]

2.5.2 Interview extracts

The following text is an example of a young woman's experience of a negative and a positive healthcare encounter.

Gosh, we didn't know what Crohn's disease was. We had never heard of it and not many people had it. Then he sits down, and firstly he doesn't manage to make eye contact, he wasn't that kind of person. He didn't like looking people in the eyes when talking to them. So he was always looking somewhere else. And he starts... the worst possible scenario. Immediately "then we will remove the intestines, we put a bag on the stomach, then we do this and that etc. And this is more or less what the rest of your life will be like and you shouldn't think that it will be any better."

As cold as ice and it was horrible, completely insane. And then just "The nurses will be here if you need anything." Then he gets up and leaves. I remember that mum and I just looked at each other and cried and cried and cried, until a nurse came into the room to check how we were. She found us crying and asking "What is this? We don't understand a thing, what kind of disease is this?"

After a lot of ifs and buts I was moved to the adult ward. I was very ill with a high temperature, I had developed fistulas. Just beside the anus. At that time I had abscesses there that had to be drained, on two or three occasions, and the operations were not any fun, that's for sure. Especially when you run to the loo 20 times per day and you have to keep the area clean because you have recently been operated on. It really was hell. I was very very ill. I was admitted to the adult ward and encountered a new doctor and for me it was like the gates of heaven opened when I met him because this was a human being compared to the machine I had had to deal with before. The first thing he did was to go to me and give me a hug. And I thought "What's this?". He dared touch me. He looked at me and mum and said "I will help you, just relax and I will take care of you."

It was so good to be told something like that at last, because all I had heard was “you have to get used to it, this is your life, it’s what you must get used to!”

3 AIM

The overall aim of this thesis was to investigate the use of CAM in patients with IBD and to explore attitudes to and experiences of CAM in patients with IBD and in HCPs. A further aim was to investigate IBD patient's worries and disease related concerns in relation to CAM use.

Specific aims:

- Study I.** To identify the extent of and reason for CAM use in patients with IBD in Sweden, as well as the types of CAM, perceived effects compared with a control group.

- Study II.** To explore IBD professionals' attitudes to and experience of CAM.

- Study III.** To describe experiences of CAM in the healthcare context reported by patients with IBD.

- Study IV.** To explore the correlation between disease related concerns and CAM use in IBD patients.

4 ETHICAL CONSIDERATIONS

Ethical approval for all studies was obtained from the Regional Ethical Review Board in Stockholm with reference numbers: 2008/4:6, 2009/852-32. All studies included in the thesis were conducted in accordance with the ethical principles for medical research involving human subjects contained in the World Medical Association Declaration of Helsinki, a central research ethics guideline. While not legally binding, it has nevertheless had a major impact on national legislation. One of the basic points of the declaration is that care should always come before scientific interests [143].

All participants were provided with information about the study before being asked to provide informed consent. They were assured of confidentiality, for their personal information and that individuals would not be identified, that participation was voluntary and that they could withdraw at any time.

In studies I and IV each patient received a questionnaire, which was numbered to ensure confidentiality. The code for each patient's identity was kept in a safe place separately from the completed questionnaires.

In studies II and III the researchers endeavoured to ensure that the methodology and findings facilitate for discussion and peer review.

In all four studies the researchers did their utmost to protect the participants from distress, indignity, physical discomfort, personal embarrassment and psychological or other harm.

5 METHODS AND PATIENTS

Different designs and methods were used depending on the aim of the study.

Table 2. Overview of designs and methods

Study	Design	Data collection method	No. of participants	Method of analysis
I	Quantitative cross sectional multi-centre controlled	Study specific questionnaire	648	Fishers exact test, Mantel-Haenszel Chi square, Mann-Whitney U-test, Bivariate logistics regression
II	Descriptive qualitative	Semi-structured interviews	16	Manifest content analysis
III	Descriptive qualitative	Semi-structured interviews	15	Manifest/latent content analysis
IV	Mixed methods, quantitative cross sectional multi-centre and descriptive qualitative	Study specific questionnaire, RFIPC questionnaire and one open ended question	645	Mann-Whitney test, Chi-2 test, Hierarchical clustering and Manifest/latent content analysis

5.1.1 Study design

In **study I**, a quantitative cross sectional controlled design was used with a study specific questionnaire.

In **studies II and III**, a descriptive qualitative design with interviews was employed. The interviews were analysed by means of content analysis.

In **study IV**, a mixed methods approach with quantitative cross sectional design and a qualitative questionnaire was used.

5.1.2 Participants

In **study I**, 854 patients with IBD from 12 different hospitals in Sweden were invited to participate of which 648 were included, given a response rate of 76%. The patients came from both rural and urban areas. Data were collected by means of a study-specific questionnaire. A control group comprising general population was recruited through a postal survey to persons

and matched for age, gender, urban, rural and geographic location. The controls were selected from the Statens Personadressregister (SPAR), which includes all persons registered as resident in Sweden. The data collection in study I and IV started in August 2008 and ended in June 2009.

In **study II** all requested participants agreed to take part in the study. The participants were 16 nurses and physicians aged between 26 and 70 years old, who had worked with IBD patients for 1-42 years. They were recruited from four IBD clinics in two metropolitan areas. Purposeful sampling was used to obtain as much variation as possible in terms of experience and to achieve insight into IBD professionals' attitudes to and experience of CAM. The variables on which the purposeful sampling was based were profession, gender, age and years in IBD care. The interviews were performed from April to October 2009.

In **study III** the participants comprised 15 patients with IBD, eight with CD and seven with UC. The nine women and six men were recruited from two out-patient IBD clinics in one urban area of Sweden and ranged in age from 20-80 years (mean 45 years), with a disease duration of 2-34 years. All those invited to participate in the study accepted. Purposeful sampling based on the variables; diagnosis, gender, age and disease duration was employed to achieve as much variation as possible in terms of experience as well as insight into the phenomenon of CAM from the perspective of patients with IBD. The interviews took place from November 2011 to October 2012.

Study IV had the same population as study I. In total, 854 patients with IBD from 12 IBD clinics in Sweden were invited to participate. Of these, 163 did not respond, 41 declined and 5 were excluded due to incomplete questionnaires, thus 645 patients were included (response rate 76 %), of whom 317 had CD, 323 UC and 5 indeterminate colitis. Their mean age was 43 years (18-89).

5.1.3 Data collection

In **study I** the patients were approached at 12 IBD clinics by an IBD nurse or physician who provided oral and written information about the study. If the patients agreed to participate they filled out the questionnaires either at the clinic or brought them home together with a stamped addressed reply envelope. At two of the centres the questionnaires were sent by post to participants. Two reminders were made by letter or telephone. The completed questionnaires were considered as informed consent.

Demographic data such as age, gender, marital status, employment status, annual income and urban or rural residence and lifestyle habits were collected by the self-administered study specific questionnaire. On a list of 24 different CAM methods the participants were asked to indicate type and frequency of CAM use, reason for use, perceived effects of the CAM and whether their physician was informed about it. There was a space for noting "others" if the CAM used was not listed. Further questions included type of inflammatory disease (Crohn's disease, ulcerative colitis, indeterminate colitis), current symptoms, year of diagnosis, conventional medication and perceived side effects

In **study II** nurses and physicians were contacted directly at the IBD clinics. Sixteen HCPs were recruited in accordance with the sampling framework (15-20 persons). All those invited agreed to participate. The interviews were conducted using a semi-structured interview guide with open-ended questions to fulfil the aim of the study [39]. Participants were invited to talk about their attitudes to and experience of CAM from their own perspective. No definition of CAM was given before the interviews. Probing questions were added during the interview (What do you mean? Could you explain?) A test interview was performed to assess the validity of the interview guide [39]. An audit trial of this interview was conducted by an external research group, which confirmed credibility. The first author (AL), who has 15 years' of experience as an IBD nurse, performed all interviews with the exception of two, which were conducted by the last author (LO) to ensure credibility and avoid bias [40]. The interviews, each of which lasted from 15-50 minutes, were conducted in a quiet private room at the participant's IBD clinic. Before the interview the participants gave their informed consent.

In **study III** the patients were approached from two out-patient IBD clinics and all those invited agreed to participate. All interviews were conducted in a quiet, private room at the out-patient clinic. Before the interview the participants provided their written informed consent. All interviews were conducted by the first author and a semi-structured interview guide with open-ended questions was used to fulfil the aim of the study. Probing questions were added in the same way as in study II. The interviewees lasted from 15-50 minutes.

Study IV had the same data collection as study I. The patients were approached at their IBD clinic by a nurse or physician who provided oral and written information about the study. If the patients agreed to participate they filled out the questionnaires either at the clinic or brought them home together with a stamped addressed reply envelope. At two of the centres the questionnaires were sent by post to participants. Two reminders were made by letter or telephone. The completed questionnaires were considered as informed consent. Data on CAM use were derived from the study specific questionnaire. Data on patients worries and concerns were collected by the RFIPC which is a self-administered questionnaire for IBD patients [144, 145]. The RFIPC comprise 25 items, all of which begin with "Because of your condition how concerned are you about..?". Each item is rated from 0-100 (0=Not at all, 100=A great deal) on a visual analogue scale. A total score (sum score) is calculated as the mean of the 25 items. The RFIPC has been validated in Sweden and found to be reliable for both UC and CD patients [122, 146]. It was supplemented by an open ended question with a request for additional concerns.

5.1.4 Data analysis

In **study I**, groups were compared by means of Fisher's exact test for dichotomous variables, the Mantel-Haenszel Chi Square tests for ordered categorical variables and the Mann-Whitney U-test for continuous variables. Bivariate logistic regression was performed to predict the use of CAM. P-values < 0.05 were considered to indicate significant relationship. The IBM SPSS 22 Statistics software was used.

In **study II**, qualitative content analysis was employed. This is a research technique for analysing relatively unstructured data in order to arrive at replicable and valid conclusions from texts in their context [147, 148]. Krippendorff's manifest qualitative content analysis method was applied, as it is appropriate for analysing text that focuses on communication and experiences [148]. A core feature of qualitative content analysis is the development of categories on the basis of similarities and differences at various logical levels. The interviews were recorded and transcribed verbatim. In the first step, the authors read the entire text several times in order to become familiar and gain a sense of the whole. Two domains were recognized: description of attitudes and description of experiences. In the next step, meaning units corresponding to the two domains were extracted and coded. Sentences and phrases containing information relevant to the aim were understood as meaning units. Each meaning unit was condensed, labelled, organised into groups and coded according to domain. This was followed by classifying and abstracting the meaning units into sub-categories and categories to highlight the content. During the analysis efforts were made to remain close to the interview text. Sub-categories and categories were identified by moving back and forth between categories, meaning units, domains and text. Data were analysed by the researchers and the outcomes discussed to ensure reliability. Disagreements were debated until consensus was reached. The researchers jointly discussed the validity to ensure that the sub-categories and categories were mutually exclusive and exhaustive.

In **study III**, the qualitative content analysis method inspired by Krippendorff was employed [148] and the transcripts analysed by manifest and latent content analysis. NVivo 10 qualitative software [149] was used for coding and analysis. The authors extracted, coded and grouped meaning units that corresponded to the aim of the study into sub-categories, categories and the theme. For the purpose of strengthening credibility, the analysis was conducted independently by all the authors, after which they discussed and reached consensus about the findings.

In **study IV**, a mixed methods approach was used with both quantitative and qualitative methods. Quantitative data were analysed by means of the statistical analysis system R, version 3.1.0 [150]. The Mann-Whitney test was employed to assess differences between CAM users and non-CAM users as well as between continuous variables, e.g. age, disease duration and RFIPC. The Chi-2 test was applied to evaluate the difference between categorical variables, e.g. gender and disease. Hierarchical clustering was employed to identify groups with a high total RFIPC score. Statistical significance was set at $p < 0.05$.

The qualitative data were analysed by qualitative content analysis in accordance to Krippendorff [148]. The transcripts of the replies to the open ended question were analysed using manifest and latent content analysis. The former refers to the obvious meaning of the text while the latter comprises interpretive reading in order to capture the deep structural meaning [147]. One hundred and forty five participants (95 women and 50 men), 86 of whom used CAM, commented on the open ended question: "Is there anything more that concerns

you?” The replies provided data comprising the meaning units, which were grouped into sub-categories, categories and a theme.

6 RESULTS

6.1.1 CAM use in patients with IBD

Study I

In study I the aim was to identify the extent of CAM use in IBD patients in Sweden, the most frequently used types of CAM and the reason for use in comparison with a control group. A total of 854 IBD patients were invited to participate, of whom 163 did not respond, 41 declined and two were excluded due to incomplete questionnaires. The study population thus comprised 648 patients (response rate 76%). The questionnaire was sent as a postal survey to 1420 persons to form the control group. Thirty-three questionnaires were returned due to unknown address and in one case the person had died. Two reminders were sent by ordinary post and 440 persons responded, giving a response rate of 32%.

Socio-demographic and disease data

Of the 648 patients with IBD included in the study 324 (50%) had UC, 319 (49.2%) had CD and 5 (0.8%) of the patients had indeterminate colitis. Mean disease duration was 13.3 years (range 1-56 years). The overall, mean age of the IBD patients was 42.7 years (range 13-89 years). The individuals in the control group were significantly older than patients with IBD, mean age 45.9 years ($p = 0.0004$). In the IBD group 48.3% of the patients were female, and 58.1% of the controls ($p=0.002$). Significantly more of the controls lived together compared with IBD patients ($p=0.004$). IBD patients lived significantly more often in urban areas ($p=0.001$) compared to controls. Normal diet was significantly more common among controls compared to IBD patients ($p<0.0001$). Differences between IBD patients and controls were adjusted for when comparing CAM use between groups. Level of education was similar in IBD patients and control group, 43% of the IBD patients had higher education and 45.9% of the controls, showing no statistically significant difference. Likewise there were no differences between IBD patients and controls concerning occupation. Twenty-eight per cent of the IBD patients were active tobacco users, 13.6 % of them smoked and 14.8% used other tobacco, e.g. snuff smokers. Current alcohol use was significantly higher in the control group (83.8%) compared with IBD patients (75.8%) ($p=0.005$). No other significant differences were observed between IBD and controls.

Conventional medication, adverse effects

Five hundred and eighty two (90.8%) of the patients with IBD reported that they had been prescribed medication for IBD and 43% reported the experience of an adverse event from this conventional medicine.

UC vs CD

A significantly higher proportion of patients with UC were working (71.2%) compared to patients with CD (62.7%) ($p=0.03$), and the CD patients had a higher percentage of sick leave (17.2%) compared to patients with UC (7.4%). The smoking rate was higher among patients with CD (16.8%) than among those with UC (10.4%) but this was not statistically significant. No other significant differences were observed between UC and CD patients.

CAM use

Patients with IBD and controls had tried various kinds of CAM, see Table 3. A total of 48.3% of the IBD patients had availed of some form of CAM during the past year compared with 53.5% of the control group, which revealed no statistically significant difference. However, when adjusted for age, gender, residence and diet, a statistically significant difference was found ($p=0.02$). The most common CAM in IBD patients was massage, which was used by 21.3% compared with 31.4% of the controls (adjusted $p=0.0003$). The second most common CAM was herbal remedies, taken by 18.7% of the IBD patients compared with 22.3% of the controls (adjusted $p=0.02$). The IBD patients employed CAM on their own initiative. They obtained information from friends and relatives, the media, Internet and literature as well as being referred to CAM practitioners or recommended CAM by their HCP.

Table 3. Kind of CAM used by patients with IBD within the last year, comparison between groups.

Kind of CAM used	IBD, n=648 n (%)	UC, n=324 n (%)	CD, n=319 n (%)	Controls, n=440 n (%)	IBD vs Controls p-value	Adjusted p-value *
Any CAM	313 (48.3)	147 (45.5)	163 (51.1)	235 (53.5)	NS	0.02
Massage	138 (21.3)	58 (18.0)	79 (24.8)	138 (31.4)	0.0002	0.0003
Herbal remedy	121 (18.7)	51 (15.8)	68 (21.3)	98 (22.3)	NS	0.018
Relaxation	68 (10.5)	29 (9.0)	38 (11.9)	51 (11.6)	NS	NS
Yoga	52 (8.0)	30 (9.3)	22 (6.9)	42 (9.6)	NS	0.06
Acupuncture	49 (7.6)	21 (6.5)	26 (8.2)	39 (8.9)	NS	NS
Counselling	47 (7.3)	24 (7.4)	22 (6.9)	27 (6.2)	NS	NS
Chiropractic	35 (5.4)	16 (5.0)	19 (6.0)	25 (5.7)	NS	NS
Meditation	31 (4.8)	14 (4.3)	17 (5.3)	21 (4.8)	NS	NS
Naprapathy	24 (3.7)	15 (4.6)	8 (2.5)	29 (6.6)	0.04	0.005
Religion	23 (3.6)	10 (3.1)	13 (4.1)	20 (4.6)	NS	NS
Homeopathy	15 (2.3)	8 (2.5)	6 (1.9)	7 (1.6)	NS	NS
Qi gong	13 (2.0)	6 (1.9)	7 (2.2)	15 (3.4)	NS	NS
Dietary change	12 (1.9)	6 (1.9)	6 (1.9)	2 (0.5)	NS	NS
Reflexology	11 (1.7)	4 (1.2)	5 (1.6)	15 (3.4)	NS	0.02
Self-helping group	9 (1.4)	8 (2.5)	1 (0.3)	1 (0.2)	NS	
Acupressure	8 (1.2)	2 (0.6)	5 (1.6)	8 (1.8)	NS	NS
Healing	7 (1.1)	3 (0.9)	4 (1.3)	14 (3.2)	0.02	0.002
TCM	6 (0.9)	5 (1.5)	1 (0.3)	4 (0.9)	NS	NS
Hypnosis	4 (0.6)	3 (0.9)	1 (0.3)	1 (0.2)	NS	
Anthroposophy	3 (0.5)	1 (0.3)	2 (0.6)	5 (1.1)	NS	
Shiatsu	3 (0.5)	1 (0.3)	1 (0.3)	5 (1.1)	NS	NS
Aromatherapy	2 (0.3)	1 (0.3)	1 (0.3)	5 (1.1)	NS	NS
Ayurveda	2 (0.3)	2 (0.6)	0 (0.0)	4 (0.9)	NS	
Rosen Method Bodywork	1 (0.2)	0 (0.0)	1 (0.3)	2 (0.5)	NS	NS

For categorical values n (%) are presented. For pairwise comparisons between groups, Fisher's exact test was used for dichotomous variables. *Adjusted for age, gender, residence, diet using logistic regression TCM, Traditional Chinese Medicine

Effect of CAM experienced by IBD patients

Eighty-three per cent of the 313 IBD patients who had used any CAM during the past year perceived the CAM as a positive experience, whilst 14.4% of them had experienced negative effect(s) from the CAM treatment. Massage was used by 138 IBD patients, from which 77.5% experienced this CAM as positive, i.e. relaxing, pain relief and well-being, and 5.8% experienced a negative effect; pain, unease or ill-being. Herbal remedies were used by 121 IBD patients and 66.1% of those perceived a positive effect from this CAM, i.e. to improve disease symptoms and well-being but also a general improvement. There was no negative experience of relaxation. Yoga was experienced as to achieve well-being, relaxation, and improve mobility. IBD patients who used acupuncture experienced pain relief, well-being and improved disease symptoms.

6.1.2 CAM use in IBD patients from the perspective of HCPs

Study II

In Study II the aim was to explore IBD professionals' attitudes to and experience of CAM. All participants had experience of IBD patients who had used CAM in an attempt to achieve improvement and well-being. Attitudes to CAM were mainly positive, although a problematic aspect was lack of knowledge and evidence. Implementing CAM education in nursing and medical school would allow HCPs to gain an understanding of therapies widely used by patients with IBD. In clinical practice, a standard questionnaire about CAM would enable HCPs to better understand their patients' wishes and current CAM use.

Sixteen IBD professionals (seven physicians and nine nurses) were interviewed. Their mean age was 49 years (range 26–70), 11 were women and five were men. Their mean clinical experience in the IBD area was 20 years (range 1–42). The results are presented in two domains; **Attitudes and Experiences**, each of which generated four categories; *Creating trust and a good relationship with the patient*, *Wishing for knowledge and understanding*, *Trust in CAM and Attitudes that constitute a barrier*, each with two to six sub-categories. The sub-categories are strengthened by quotations from the participants.

Attitudes

Category I. Creating trust and a good relationship with the patient

This category included three sub-categories; Strategies for the encounter with patients, Searching for information on the patients' behalf and A positive attitude to CAM.

The participants emphasised the importance of treating patients with respect when they told about their CAM use. They also stressed the importance of creating trust and a good relationship with patients as well as maintaining contact and assisting them in searching for information about CAM. Several expressed a positive attitude towards CAM in addition to curiosity about and an interest in different CAM methods.

“You have to be very careful not to have a superior attitude towards the patient and not say that it's nonsense and to stop taking it. That would be very dangerous and can ruin the relationship with the patient.”

Category II. Wishing for knowledge and understanding

This category generated the sub-categories; Willingness to learn about CAM, Searching for relevant education and Raising the level of awareness about and concretizing patients' CAM use.

It was clear that the participants wanted additional knowledge about CAM, stating that it would be interesting as well as stimulating to learn more and be able to support patients when they had questions about CAM treatment. They expressed a wish for relevant education in the form of lectures and dialogue rather than written information via e-mail or letter. They stated

that they wanted factual and evidence based knowledge that they could communicate to their patients.

“When considering our patients and their problems, it would be very interesting to learn more.”

Category III. Trust in CAM

This category generated the sub-categories; Acceptance of CAM, CAM as a complement to conventional treatment, Untapped resource, The right time for CAM and Confidence in manual therapies.

The level of acceptance of CAM varied among IBD professionals and became higher when CAM was used as a complement to conventional medication. CAM was considered an untapped resource that had a place within healthcare. Some participants were of the opinion that conventional healthcare was inadequate, arguing that CAM fulfilled a function from a psychological perspective. Others claimed that interest in CAM had increased in society and that it was the right time for it. Some expressed confidence in manual therapies, as they believed that touch could induce well-being in patients

“I definitely believe in touch, if you feel taken care of, you will feel better.”

Category IV. Attitudes that constitute a barrier

This category generated the following sub-categories; Restrictive approach, Distanced view, No need of or interest in CAM, Personal definition of CAM and Reticence about CAM.

Several participants had a distanced view of CAM, being uncertain about what attitude or approach to adopt and tried to remain neutral. Only a few were skeptical although many had a restrictive attitude to herbal remedies and over-the-counter products due to experiences of side-effects. These IBD professionals considered that CAM was unnecessary, in light of the number of effective medications available for IBD treatment. Few believed that CAM could help patients with IBD and only one participant expressed a specific interest in CAM. The IBD professionals found it difficult to define the concept of CAM and one claimed that the terms complementary and alternative were synonymous. The concept was regarded as diffuse and some were of the opinion that CAM is not provided in today’s healthcare system.

“I’m a bit concerned about the risk involved in using CAM in place of traditional medication.”

Experiences

Category I. Motives for CAM use

This category generated the sub-categories; Concern about side-effects of conventional medication, Patients’ wish to avoid conventional medication, Disease course, Interest, The influences from the surrounding environment and CAM provides a holistic perspective.

The participants reported that in many cases long-term disease, a complicated disease course and worries about the side-effects of conventional medication were the reasons why IBD patients tried CAM methods. They also perceived that patients with a chronic condition were more likely to try CAM to ensure that they had done everything possible in order to regain health. In their view, some of these patients were interested in CAM, which influenced them to start using it.

“I think that a lot of them are very open, especially those who are ill as they try out all avenues in order to regain their health.”

Some participants reported lacking the holistic perspective that takes account of patients’ perceptions and is a characteristic of CAM but missing in conventional healthcare. They considered that the surrounding environment such as the media and financial aspects influenced CAM use. Other factors perceived to influence CAM use were traditional and cultural differences.

“CAM embodies much that has been lost in patient care today, namely care of the whole patient.”

Category II. Perceiving patients’ quest for improvement and well-being

This category generated the following sub-categories: the patient is searching, the patient believes in the efficacy of CAM and the patient informs about her/his CAM use.

The IBD professionals perceived that many patients expressed a specific interest in and asked for CAM treatment. They believed that patients did everything in their power to regain health and would try CAM sooner or later. They also stated that patients were very interested in CAM, believed in its efficacy and frequently asked health professionals about it. The majority perceived the patients as honest in terms of informing them, although a few considered that the patients might have forgotten to mention their CAM use or believed that they were not truthful due to fear of being disparaged. Furthermore, they were of the opinion that patients had too much trust in CAM, believing it to be harmless and without side-effects.

“Many patients believe that herbal remedies are something natural, not real medications, and good for the body and non-toxic, which I can understand.”

Category III. Problematic aspects

This category generated the sub-categories; Limited knowledge/education and Safety and efficacy.

The IBD professionals found it difficult to obtain knowledge about CAM due to the large number of CAM methods and the fact that CAM is not included in their basic education. One participant was of the opinion that no CAM education was necessary. However, the majority reported that they lacked knowledge about CAM. CAM was perceived as a limited area and the participants would like impartial information about safety and data on efficacy. They

stressed the need for a system to control CAM methods and the importance of designing randomised control studies. One important aspect mentioned by several of the participants was that CAM methods must not interact with patients' ordinary medication for treatment of an acute onset.

"CAM must not interfere, interact with essential acute treatment or delay a treatment of an underlying or a diagnosed illness."

Category IV. Differing CAM experiences

This category generated the following sub-categories; Personal experiences of CAM, Influence of patients' narratives about CAM, Experiences of friends/relatives and Professional experiences of CAM.

The participants had varying experiences of CAM. Many had a positive personal experience of manual therapies, others had relatives who had tried CAM, while a few had no personal experience of CAM. However, all were familiar with patients who had employed various CAM methods with both positive and negative outcomes.

"I have met many over the years who attended the anthroposophic clinic. "

6.1.3 CAM from IBD patients' perspective

Study III

Study III focused IBD patients' experiences of CAM in the context of healthcare. Our results revealed that the patients found it easier to discuss CAM with nurses than physicians and wished to be asked about CAM as a means of starting a dialogue. The patients perceived that HCPs were unwilling to discuss CAM, treated them in a disparaging manner and did not take them seriously.

The analysis revealed the theme **Knowledge and communication lead to participation in the area of CAM** based on the following three categories; *CAM use, Communication and Self-care* in addition to fourteen sub-categories. The latter are strengthened by quotations from the interviews.

Category I. CAM use

This category consisted of the sub-categories: Changed dietary habits, Factors that influence CAM use, Experience of CAM, Trust in CAM, No need for CAM, Doubtful about CAM as well as Science and safety.

Some of the participants considered changed dietary habits, such as excluding gluten, lactose, dairy products, sugar, flour, E-numbers, raw meat and reducing calorie intake, an important CAM. They reported an improvement in their IBD as a result of dietary changes but stated that they had received inadequate support from HCPs.

“I have been told that it doesn’t matter what you eat, which sounds quite absurd to someone who suffers from bowel disease.”

The participants mentioned several reasons that influenced them to start using CAM, such as side effects or failure of conventional treatment. They were against the use of corticosteroids and perceived taking many conventional medications as traumatic, although they were prepared to try everything, in the hope that it would have a positive effect.

“Anything that will make me better is OK”

The majority of the participants had tried CAM in the form of dietary change in an effort to alleviate the disease. For example, they no longer consumed carbohydrates, sugar or products containing solanine, such as potatoes, paprika and tomatoes. They boiled Chinese herbs to make a tea and some tried Probiotics with varying results. Several found massage and yoga beneficial for alleviating IBD symptoms, reducing stress and increasing energy levels.

“I don’t know if it was [probiotics] but I think so. It was really strong and I experienced a great difference at the beginning.”

The participants trusted CAM, deeming it valuable and that it had a place in healthcare. Some of them experienced CAM as positive in that it reduced stress. However, others were ambivalent, sceptical and not interested in using CAM, while a few expressed doubt about herbal treatment. The participants would feel safer trying CAM if it was provided by the health services. However, they respected the fact that HCPs have to work with evidence-based methods, stating that they would be positive about using CAM when research based evidence is available.

“Then there are things that I haven’t tried, herbal medicines and such, I don’t trust them as much, because I have too little knowledge about them. My gut feeling is that there’s too much humbug in that area and a lot of desperation.”

Category II. Communication

This category comprised the following sub-categories: Perception of doctors’ and nurses’ attitude to CAM, Relationship with the doctor, Revealing CAM use and Wishing for a dialogue about CAM.

According to the participants, doctors and nurses lacked knowledge and were reluctant to talk about CAM, leading to inadequate care. They reported receiving no support from the healthcare service regarding CAM use and that HCPs rarely discussed CAM.

“HCPs don’t talk about CAM of their own accord.”

Some mentioned not being taken seriously and treated in a disparaging manner when trying to discuss CAM. They were also critical with the dietary advice received and suggested that HCPs should discuss diet on a regular basis with patients suffering from IBD. The participants wished for a dialogue about CAM, as they were open to discussing it and wanted

to obtain support for CAM treatment. Some only told nurses about their CAM use, as they considered nurses to have a more relaxed attitude towards CAM and found it easier to discuss with them than with doctors.

“But nurses are a bit more open to it [CAM]. It was easier to have a dialogue with them about it.”

On the issue of whether to reveal their CAM use, some did while others did not. Reasons for the latter were feeling ashamed, being aware that their doctor did not believe in CAM, respect for the doctor and the fact that CAM is not a part of healthcare. They did not mention it unless asked about it by HCPs.

“You feel ashamed, perhaps you have done something that is not quite OK or you don’t know what the doctor will think about it, maybe out of respect for the doctor.”

Category III. Self-care

This category comprised the following sub-categories: Making own choices, Living as normally as possible and Searching for and obtaining CAM knowledge.

The participants considered that making one’s own choices, being allowed to have influence and doing something oneself were important, which was why some turned to CAM.

“I think having an opportunity to influence one’s own situation makes people feel good. Take dietary change as an example, I think it makes a difference that you can sort of control it yourself.”

They searched for and obtained CAM knowledge via the Internet when they needed it. Some talked to other patients in order to share experiences.

“You try to talk to other patients to find out their experiences.”

6.1.4 CAM use and IBD patients’ health related concerns

Study IV

In study IV the aim was to explore the association between disease related concerns and CAM use in IBD patients.

The quantitative results

Relationship between the demographic data of CAM users and non-CAM users

Statistically significant differences between CAM users and non-CAM users were found in relation to age ($p=0.0002$) and gender ($p=0.000$), but there were no differences in terms of diagnosis, disease duration and symptoms.

Relationship between CAM use and disease-related concerns

There was a statistically significant difference between CAM users and non-CAM users, the former exhibiting more concerns in 15 of the RFIPC items and having a higher total RFIPC score ($p=0.003$). The three highest rated concerns reported by patients using CAM were having an ostomy bag, loss of bowel control and reduced energy levels.

Table 4 IBD patients' RFIPC items and CAM use or non-use. The statistical significance was $p < 0.05$.

Rank		CAM use (N=310) Mean (SD)	Non CAM use (N=326) Mean (SD)	Total (N=637) Mean (SD)	P-value
1	Having an ostomy bag	51.4 (36.6)	48.0 (36.8)	49.7 (36.7)	0.25
2	Loss of bowel control	49.3 (34.4)	41.8 (34.0)	45.5 (34.3)	0.006
3	Energy level	47.3 (32.7)	38.5 (30.6)	42.9 (32.0)	0.001
4	Having surgery	43.3 (34.0)	40.8 (33.7)	42.1 (33.7)	0.37
5	Effects of medication	43.2 (30.4)	36.0 (30.0)	39.5 (30.3)	0.001
6	Uncertain nature of my disease	42.4 (32.3)	35.2 (30.8)	38.8 (31.8)	0.003
7	Being a burden on others	41.8 (34.4)	35.5 (32.6)	38.7 (33.6)	0.04
8	Developing cancer	41.8 (32.7)	36.4 (31.9)	39.0 (32.4)	0.05
9	Ability to achieve full potential	41.1 (32.3)	34.8 (30.9)	37.9 (31.8)	0.009
10	Pain or suffering	36.9 (29.3)	30.0 (27.9)	33.5 (28.8)	0.002
11	Dying early	36.5 (32.7)	33.0 (31.2)	34.7 (32.0)	0.23
12	Producing unpleasant odors	35.0 (34.9)	32.0 (34.3)	33.5 (34.7)	0.21
13	Feelings about my body	34.4 (31.0)	28.9 (28.8)	31.6 (30.0)	0.016
14	Attractiveness	33.2 (29.8)	31.3 (31.3)	32.3 (30.6)	0.02
15	Financial difficulties	33.2 (33.2)	25.3 (29.9)	29.2 (31.8)	0.004
16	Having access to quality medical care	31.9 (32.1)	25.8 (29.2)	28.9 (30.9)	0.03
17	Feeling out of control	31.8 (30.7)	26.7 (29.1)	29.3 (30.0)	0.02
18	Loss of sexual drive	30.9 (31.7)	28.4 (31.3)	29.7 (31.6)	0.16
19	Intimacy	29.8 (31.6)	26.4 (30.2)	28.2 (31.0)	0.08
20	Passing the disease to others	28.9 (34.0)	21.0 (29.2)	24.8 (31.8)	0.007
21	Feeling alone	29.6 (29.5)	27.2 (29.7)	28.4 (29.6)	0.19
22	Ability to perform sexually	26.8 (29.0)	25.8 (29.7)	26.4 (29.4)	0.28
23	Feeling "dirty" or "smelly"	25.4 (30.4)	20.9 (27.3)	23.2 (29.1)	0.07
24	Ability to have children	22.8 (30.5)	15.4 (25.2)	19.0 (28.1)	0.006
25	Being treated as different	21.4 (25.7)	16.7 (23.6)	19.0 (24.7)	0.003
	RFIPC total sum score	35.6 (21.9)	30.5 (21.3)	33.0 (21.8)	0.004

One patient did not respond to the question about CAM use and eight patients did not complete the RFIPC. Five patients with indeterminate colitis were excluded from the analysis and 60 patients did not state their IBD symptoms.

Hierarchical clustering

Some of the patients had a high RFIPC total score ($n=118$, mean 67), which means that they rated their concern strongly on all items. To identify this group of patients we employed hierarchical clustering analysis to detect responses with high disease related concern in all 25 items. There is no exact answer as to how many groups are needed in a hierarchical clustering analysis. However, we used four groups developed through a dendrogram based on the

Euclidean distance between the individuals in the material (n=637). To further test the differences in the characteristics of the four groups, they were compared in terms of age, gender, disease symptoms, disease duration and CAM use or non-CAM use. One of the groups (n= 118) had a total mean score of 67 for the RFIPC. Its characteristics were 62 % women and 61% CAM users with shorter disease duration (mean 12 years).

Qualitative results

The analysis of the open ended question with a request for additional disease related concerns revealed the theme: **Inflammatory bowel disease affects the whole of everyday life** based on three categories; *Family and the self*, *Disease burden and Associated factors* as well as sixteen sub-categories.

The category Family and the self comprised the following sub-categories: Family members' concern, Work, Stress caused by uncertainty, The future, Hereditary factors, Never experiencing health and Influence on everyday life

Category I. Family and the self

Some of the participants were concerned due to their family members worrying about them, how the disease impacted on the family and how the children were affected by having an ill parent. Some participants were worried about the children having to give extra consideration to the fact that one parent had a chronic disease.

“How my children are affected by having an ill mother.”

Work related concerns were expressed such as not being part of working life and fear of losing one's job. Some of the participants worried about lost career opportunities and a small pension as well as finding it difficult to accept being unable to work as much as they wished. They also worried about not feeling useful, which led to depressed mood. Concerns about the future emerged in relation to work, their financial situation and the family as well as their children's future and not finding a partner.

“My future. How can anyone be strong enough to love me when I'm ill and with all the complications involved?”

The participants were concerned about heredity and transferring the disease to their children. They also worried that the disease would have an effect on pregnancy. Several mentioned that their doctor had not given them any clear answers with regard to heredity and worried about the effect of medication on fertility.

“I'm scared to death of transmitting the disease to future children, especially as my partner also suffers from ulcerative colitis.”

They were concerned about the fact that IBD is chronic and about never experiencing health. IBD had a major impact on their life such as inability to take care of their children or being unable to go abroad. They perceived that the symptoms ruled their life, making it difficult to

lead a normal existence. The bowel symptoms appeared suddenly and unexpectedly, causing a stressful situation. One participant claimed that the disease had a negative impact on his attitude to adversity in general.

“The fact that my stomach does not function puts me in a bad mood. I get annoyed and tetchy towards others because my bowels cause me trouble.”

Category II. Disease burden

The category Disease burden comprised the sub-categories: Unable to reach a toilet in time, Fatigue, Pain, Ostomy, Fear of complications and Diet.

A concern expressed by the participants was the fear of being unable to reach a toilet in time and inability to control the bowel. This was especially pronounced when travelling by public transport, which sometimes made them choose not to leave their home.

“Being unable to control the bowel and that it suddenly soils my pants when among people.”

Fatigue was a concern, as experiencing that the body let them down was difficult. The fatigue was perceived as considerable, restricting their working life, social life and studies.

“That my body lets me down so ruthlessly that it affects the entire everyday life of both myself and my family members.”

The participants feared pain, a symptom perceived as becoming more severe with age. It was regarded as a vicious circle, where stress increased the pain and pain caused even more stress. A concern reported by the participants was fear of an ostomy. Some had previously had one and definitely did not want another, especially as they were concerned about deterioration in the quality of the bags.

“My worst scenario is getting a stoma bag on my stomach. Should that happen it would feel as if life was over.”

Major concerns were complications such as primary sclerosing colitis (PSC), fistulas, arthritis, osteoporosis, incontinence and cancer, the side effects of cortisone, Imurel and Remicade as well as the potential long-term bodily impact of various medications.

“I’m afraid of side effects that won’t go away, such as fistulas and arthritis.”

Another concern was diet, for example, being careful about food intake and fear of eating the wrong type of food.

Category III. Associated factors

The category Associated factors comprised the sub-categories: Financial worries, Healthcare encounters and experiences as well as Holistic perspective in conventional care.

The participants were concerned about their financial situation and found it difficult to deal with the Social Insurance Agency, as the sickness benefit application process was perceived as awkward and taking a long time. Another concern was the way in which they were encountered and their healthcare experiences. Some participants worried about not having access to a specialist physician, while several had lost confidence in physicians, expressing that they had not been encountered with respect. There was a fear of ending up in the wrong hospital as well as a wish to be treated by the same physician and having annual check-ups. Some were disappointed that research had not resulted in better treatment options and that too little effort was devoted to research.

“That so many doctors who I encountered lacked empathy and did not take my questions and reflections seriously.”

The participants were concerned about the absence of a holistic perspective in conventional care. One of them stated that physicians only focus on the strictly medical aspects as opposed to the whole human being. Some mentioned a lack of social workers in the care services as well as perceiving contact with them as something one did not talk about.

“You can’t get psychological help in hospitals today as they don’t treat the whole human being.”

7 DISCUSSION

7.1 METHODOLOGICAL CONSIDERATIONS

A strength of this thesis is the use of both qualitative and quantitative methods. Qualitative research was previously criticized for being unscientific and subjective. However, in the past decade it has become an important mode of inquiry for social sciences [151]. A combination of quantitative and qualitative methods provides an expanded understanding of research problems compared to either approach alone and opens the way for synergy effects [152].

In Study I the strength was that it was a multicentre, controlled study with different geographic locations, which increases generalizability. The drop out in the control group was larger than in the IBD group, but no difference was found when the data were adjusted for in terms of CAM use. Another methodological issue was that two of the centres chose to post the questionnaires to the participants, resulting in fewer participants.

Studies II, III and part of IV had a qualitative design. The qualitative research method allowed the participants to talk or write freely about CAM and their disease related concerns. The qualitative analysis revealed their experiences by means of their own words and statements. A methodological issue in qualitative research is the researchers' pre-understanding, which could affect objectivity. The first author (A L) has worked with IBD patients for 15 years, but was not involved in the care of the participants. To avoid bias all authors independently read and analysed the text, after which lack of agreement was discussed until consensus was achieved. Qualitative studies are often judged on the basis of trustworthiness, which concerns transferability, credibility, confirmability and dependability [153].

Transferability was ensured by the rich descriptions of the phenomenon, even in the shortest interview, which lasted for 15 minutes. The participants in studies II, III and IV all came from IBD care, i.e. the same context, which also enhances transferability.

In study II **credibility** was strengthened by the selection of participants of different ages, gender, disease duration, a diagnosis of UC or CD and with various experiences of CAM use and in study III **credibility** was enhanced by the inclusion of participants of different ages, gender and professional IBD experience.

Conformability implies that the researcher should remain objective. The first author (AL) who conducted the interviews in studies II and III is an IBD nurse who worked with such patients for 15 years. To prevent bias due to pre-understanding, all authors independently read and analysed the text, after which they discussed any disagreements until consensus was reached. However, the credibility of the researcher is of critical importance in qualitative studies. As the present authors' pre-understanding ensured knowledge and comprehension of the context, it can be considered a strength.

Dependability was achieved by the researchers becoming familiar with the text and continuously returning to it to ensure that the emerging categories and sub-categories covered all relevant aspects. It was also enhanced by a description of the research design and analysis process.

In **Study IV** a mixed methods approach was used. A combination of quantitative and qualitative methods provides a greater understanding of the research problems compared to either approach alone [152]. An additional strength was the multicentre design, with patients from 12 different geographic locations in Sweden, which increases generalizability.

7.2 GENERAL DISCUSSION

The four studies in this thesis highlight IBD patients' CAM use and disease-related concerns associated with CAM in addition to the attitudes to and experiences of CAM on the part of IBD patients and HCPs.

The main findings in this thesis were that CAM use is common among Swedish IBD patients, especially massage and herbal remedies. IBD patients found it easier to discuss CAM with nurses than with physicians. Furthermore, they wanted to be asked about their CAM use in order to start a dialogue but felt that HCPs treated them in a disparaging manner, which contradicted what the HCPs expressed. The HCPs emphasized the importance of treating patients with respect when they informed about their CAM use. In general, IBD patients who availed of CAM had more disease related concerns compared with those who did not use CAM and also reported that they missed a holistic approach in conventional healthcare.

7.2.1 CAM and healthcare

The result of study IV shows that in general, IBD patients who used CAM had more disease related concerns compared with non-users and expressed concerns about the absence of a holistic perspective in conventional care. This is supported by the result of study II, where the HCPs emphasized that one reason patients with IBD turned to CAM was the wish for a holistic approach. Thus it appears that something is lacking in conventional healthcare and we must start thinking about how we treat our patients in terms of involving and developing the whole person, both physically and psychologically. One barrier is the absence of a national CAM policy in Sweden. We need an integrative approach to CAM in line with the WHO recommendation that countries should formulate national policies and increase efforts in the areas of quality, safety and efficacy of CAM [60].

There is a lack of evidence about dietary interventions in IBD patients and dietary changes are not included in the WHO's definition of CAM. However, almost all of the participants in study III expressed that dietary changes were/are an important part of CAM and were of the opinion that such changes may have been beneficial for them. They also stated that HCPs were not supportive when it came to implementing dietary changes. HCPs should be aware that dietary changes are essential for many IBD patients, which is in line with Zallot et al. [154] who found that as many as 58 % of their participants believed that food played a role in

relapse. It is important for HCPs to start a dialogue with patients about diet and studies of dietary changes in IBD are urgently required.

7.2.2 Consequences for the patient

The result of study I revealed that herbal remedies are a common form of CAM among IBD patients. However, herbal remedies can cause liver toxicity and IBD itself is associated with disorders of the liver and biliary tract. Thus, knowledge of CAM use will enable HCPs to better monitor patients and their response to treatment. Patients with a chronic disease who use CAM do not reject conventional medicine, nor do they have an unrealistic hope of a cure, but generally consider it a component of self-care [155]. In studies III and IV, IBD patients expressed concerns about the uncertain nature of their disease and wanted to have personal control over it [156]. The encounters between IBD patients and HCPs during which CAM was discussed indicate a need for change. A good encounter should be person-centred with sensitivity and empathy on the part of the HCP, allowing the patient an opportunity to ask questions and express emotion [139]. This was underlined by the IBD patients in study III who wished to be asked about CAM in order to start a dialogue. HCPs must be aware of this to meet the patient's needs and create a good encounter. The introduction of CAM education in nursing and medical school would improve this situation.

Study III demonstrated that IBD patients felt that HCPs treated them in a disparaging manner and did not take them seriously when they wanted to discuss CAM. Interestingly, this finding contradicts the result of study II, where HCPs emphasized the importance of treating IBD patients with respect when they spoke about their CAM use. This indicates a communication gap between HCPs and IBD patients, leading to uncertainty that could be interpreted by the patients as a disparaging manner. Another reason for the communication gap could be that in Sweden, patients frequently report being encountered in a wrong or disrespectful manner [138]. Furthermore, in an international survey of eleven countries Sweden was found to have the most problems in terms of patient-centred care, access and coordination [157]. Swedish healthcare has substantial potential for improvement, although the patient's position has recently been strengthened by a new law that highlights the concept of person-centred care. Following the implementation of the "Being open" policy in UK [158] there has been a reduction in the number of complaints and litigation. However, the reaction of patients in encounters is not always predictable, thus HCPs need guidance, training and support to cope with these challenges [159].

7.2.3 Implications for clinical practice

Patients with IBD should be asked about their CAM use and a standard questionnaire could be a valuable instrument for assisting HCPs to initiate a dialogue. Nurses have an essential role in communicating about and monitoring CAM use in patients with IBD. HCPs need education and training to communicate about CAM, answer patients' questions and recommend safe and effective CAM methods. IBD patients' experiences of CAM could

enhance HCPs' awareness of and improve communication about CAM, leading to a good HCP - patient relationship.

7.2.4 Further research

This thesis has provided new ideas for future research on IBD and CAM.

- Create and evaluate a standard questionnaire regarding IBD patients' CAM use.
- Perform research on dietary changes in patients with IBD.
- Investigate the sub-group of patients who had high scores in all RFIPC items in study IV. Why did these patients score so high on disease related concerns?
- Conduct research on patients with IBD by means of an integrative approach.

8 CONCLUSIONS

- Patients with IBD use CAM in an attempt to achieve improvement and well-being.
- HCPs' attitudes to CAM were mainly positive, although a problematic aspect was their lack of knowledge and evidence. They required education about CAM.
- HCPs respected the decision of patients with IBD to use CAM.
- Patients with IBD stated that HCPs were reluctant to discuss CAM, although they wished to be asked about CAM use and start a dialogue.
- Patients with IBD perceived being treated in a disparaging manner and not taken seriously when wishing to discuss CAM. They found it easier to discuss CAM treatment with nurses than physicians.
- Patients with IBD considered dietary changes an important CAM treatment with positive effects on their condition and sought knowledge about CAM because they wanted to make their own choices and live a normal life.
- Patients using CAM generally had more disease related concerns compared with non-users.
- IBD affects the whole of everyday life, especially the family and the self.

9 SUMMARY IN SWEDISH

Bakgrund

Ulcerös kolit (UC) och Crohns sjukdom (CD) är inflammatoriska tarmsjukdomar (Inflammatory Bowel Disease=IBD) som drabbar mag-tarmkanalen och förlöper med perioder av ökad aktivitet (skov) växlande med perioder utan inflammation (remission). De är livslånga sjukdomar med symtom som i hög utsträckning påverkar det dagliga livet. I Sverige är knappt 61,200 personer drabbade av UC och CD. De flesta insjuknar mellan 15-30 år men alla åldrar kan drabbas med en jämn fördelning mellan könen. Komplementära och alternativa metoder (KAM) som till exempel homeopati, kinesisk medicin, meditation, hypnos, naturläkemedel och kiropraktik ingår inte i den konventionella hälso- och sjukvården. Det är vanligt att patienter med kroniska sjukdomar såsom IBD använder KAM. Forskningsrådet för Arbetsliv och Socialvetenskap uppmanar till forskning om KAM. Goda kunskaper ökar patienternas trygghet, och en ökad medvetenhet om KAM kan leda till en förbättrad kommunikation mellan IBD patienter och sjukvårdspersonal som i sin tur leder till en förbättrad vårdkvalitet.

Syfte

Syfte med avhandlingen var att undersöka användning och förekomst av KAM hos patienter med IBD, samt att undersöka attityder till och erfarenheter av KAM hos patienter, läkare och sjuksköterskor. Vidare avsågs att undersöka IBD patienters sjukdomsspecifika oro relaterat till KAM användning.

Studie I var en kontrollerad tvärsnitts- och multicenterstudie. Data från patienter vid 12 IBD kliniker i Sverige insamlades med hjälp av frågeformulär. Syftet var att studera i vilken omfattning patienter med IBD i Sverige använder KAM i jämförelse med en normalpopulation, vilka typer av KAM som används samt anledningen.

I studien deltog 648 patienter med IBD. Av dessa IBD-patienter hade 48.3% använt någon form av KAM under det senaste året jämfört med 53.5% av personerna i kontrollgruppen. De vanligaste använda KAM metoderna hos IBD patienter jämfört med kontrollgruppen var massage som användes av 21.3% jämfört med 31.4% i kontroll gruppen, naturläkemedel användes av 18.7% av IBD patienterna jämfört med 21.3% i kontrollgruppen, för avslappning var motsvarande siffror 10.5% och 11.6% och yoga 8% och 9.6%, akupunktur 7.6% och 8.9% och samtalsterapi 7.3% jämfört med 6.2, kiropraktik användes av 5.4% respektive 5.7%.

Studie II var en intervjustudie där sjukvårdspersonal fick beskriva sina erfarenheter och sin inställning till KAM. I studien deltog 16 läkare och sjuksköterskor, som arbetade med IBD patienter. Resultatet visade att IBD sjuksköterskor och läkare hade förtroende för och en positiv inställning till KAM, särskilt när KAM användes som komplement till konventionell medicin. De intervjuade upplevde att patienter sökte och testade olika KAM metoder. Deltagarna uppgav att de ansåg att KAM hade en plats inom hälso- och sjukvården, vilket

indikerar en acceptans för KAM. Men även attityder som utgjorde ett hinder för KAM rapporterades, såsom avsaknad av evidens. Några av de intervjuade uppvisade en restriktiv hållning och ansåg KAM vara onödigt, medan ett fåtal var skeptiska.

Studie III var en intervjustudie där 15 IBD patienter tillfrågades om sina erfarenheter av KAM och hur de upplevde sjukvårdens bemötande i samband med användandet. Resultatet visade att patienter med IBD vill bli tillfrågade och vill ha en dialog om KAM. De kände sig ibland hånade och upplevde sig inte bli tagna på allvar när de ville diskutera KAM. Hälso- och sjukvårdspersonal behöver bli medveten om detta för att kunna bemöta och förstå IBD patientens behov. IBD patienterna upplevde att det var lättare att diskutera KAM med sjuksköterskor jämfört med läkare. Detta resultat understryker IBD sjuksköterskans viktiga roll i att kommunicera och monitorera IBD patienternas KAM användande. Hälso- och sjukvårdspersonal bör bli medveten om att IBD patienterna betraktar kostförändringar som en viktig KAM behandling.

Studie IV var en kontrollerad tvärsnitts- och multicenterstudie. Data från 645 IBD patienter vid 12 IBD kliniker i Sverige insamlades med hjälp av frågeformulär. Syftet var att undersöka IBD patienters sjukdomsspecifika oro relaterat till KAM. Patienterna besvarade ett studiespecifikt frågeformulär med frågor om KAM, sociodemografiska och sjukdomspecifika data, samt frågeformuläret Rating Form of Inflammatory Bowel Disease Patients Concerns (RFIPC). RFIPC består av 25 frågor som patienten besvarar på en VAS skala från 0-100 angående hur oroliga de är gällande en viss aspekt. I frågeformuläret fanns även en öppen fråga "Är det något mer som bekymrar dig?" vilken patienter fick svara på med egna ord. Av de som deltog använde 313 patienter KAM och de uttryckte mer oro avseende 15 av de 25 frågorna i RFIPC frågeformuläret jämfört med de patienter som ej använde KAM. KAM användandet var relaterat till yngre ålder och kvinnligt kön. Via den öppna frågan framkom att inflammatorisk tarmsjukdom påverkar hela livet och att IBD patienterna upplevde oro för: familjen och jaget, sjukdomsördan och omkringliggande faktorer

Slutsatser

KAM är vanligt förekommande hos svenska patienter med IBD och de använde KAM för att uppnå förbättring och välbefinnande. Hälso- och sjukvårdspersonalens attityder för KAM var i huvudsak positiva men de upplevde att de saknade utbildning och kunskap om KAM. Hälso- och sjukvårdspersonalen respekterade att patienterna använde KAM men IBD patienterna upplevde att personalen ibland var ovillig att diskutera KAM. Patienterna menade att de behandlades på ett nedsättande sätt och inte togs på allvar när de ville diskutera KAM. IBD patienterna ansåg att kostförändringar var en viktig KAM behandling med positiv effekt på deras tarmsjukdom. KAM användare bland IBD patienter hade generellt högre sjukdomsrelaterad oro jämfört med de som inte använde KAM och IBD påverkade det dagliga livet, speciellt familjen och jaget.

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