Quality of Life and Coping with Ulcerative colitis and Crohn's disease

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Dissertation presented at Uppsala University to be publicly examined in Sal IX, Universitetbyggnaden, Övre Slottsgatan 2, Uppsala, Friday, November 30, 2007 at 13:00 for the degree of Doctor of Philosophy. The examination will be conducted in Swedish.

Abstract

The aim of this thesis was to investigate health-related quality of life (HRQoL) and coping strategies for individuals with ulcerative colitis (UC) or Crohn’s disease (CD), and to study the effect of a group-based patient information on anxiety/depression and HRQoL. HRQoL and anxiety/depression were investigated (n=492) (Study I). In Study II, anxiety/depression, HRQoL, satisfaction with information and evaluation of the patient information were studied (n=49). Coping with disease activity was investigated in 166 patients reporting current exacerbation (Study III). Fifteen patients were interviewed about disease-related stress, how this is managed and the need of support from the health care (Study IV). Patients with UC reported better HRQoL and less anxiety/depression than did patients with CD during both remission and exacerbation. Satisfaction with information had increased at follow-up 6 months after patient information. The information and the possibility to discuss with lecturers and group members were valued as most important. No change was found in anxiety/depression or HRQoL at follow-up. Both problem-focused and emotion-focused strategies were employed to cope with disease activity, with no difference between patients with UC or CD. The urgent need of toilet availability and stress associated to social situations were the major disease-related stressors. This stress was managed by finding out the location of toilets, bringing toilet paper and extra underwear and emptying bowel before an activity. The patients wanted information and possibilities to talk to experienced staff and to other patients about how to live with the disease. This thesis shows that HRQoL for some patients with UC, and primarily for patients with CD, is impaired. Thus medical staff should be observant of the psychosocial well-being of patients with CD and also of patients with relapse. Methods to identify and support patients with anxiety/depression and poor HRQoL need to be developed. Interventions should target the patient’s specific problems and at appropriate times.

Keywords: anxiety, coping, Crohn's disease, depression, exacerbation, health-related quality of life, ulcerative colitis

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ISSN 1652-9030
urn:nbn:se:uu:diva-8277 (http://urn.kb.se/resolve?urn=urn:nbn:se:uu:diva-8277)
FÖR ATT MAN SKA KUNNA FLYGA

För att man ska kunna flyga
måste skalet klyvas
och den ömtåliga kroppen blottas.

För att man ska kunna flyga
måste man gå högst upp på strået
fastän det böjer sig
och svindeln kommer.

För att man ska kunna flyga
måste modet vara aningen större
än rädslan
- och en gynnsam vind råda.

ur Instruktion för skalbaggar av Margareta Ekström
(förmedlad av Gudrun Tevell)
List of original papers

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


III Larsson K, Lööf L, Rönnblom A, Nordin K. Quality of life for patients with exacerbation in inflammatory bowel disease and how they cope with disease activity. (Accepted for publication in Journal of Psychosomatic Research)

IV Larsson K, Lööf L, Nordin K. Experiences of stress and coping, and need of support for patients with inflammatory bowel disease: A qualitative interview study. (Submitted for publication in Scandinavian Journal of Caring Sciences)

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Contents

Introduction ................................................................................................... 11
  Ulcerative colitis and Crohn’s disease ..................................................... 12
    Clinical manifestations ........................................................................ 13
    Treatments ......................................................................................... 13
    Incidence and prevalence rates ......................................................... 14
    Causes and risk factors .................................................................... 14
  Health-related quality of life (HRQoL) .................................................... 15
    Inflammatory bowel disease and HRQoL ........................................... 17
    Inflammatory bowel disease and psychosocial factors ....................... 18
  Coping .................................................................................................... 19
    Coping with inflammatory bowel disease ........................................ 19
  Information and support ..................................................................... 20
  Short summary .................................................................................... 20
  Aims ....................................................................................................... 21

Method ........................................................................................................ 22
  Design .................................................................................................... 22
  Subjects ................................................................................................. 22
    Studies I–II ....................................................................................... 24
    Studies III–IV .................................................................................. 25
  Data collection ....................................................................................... 26
    Coping ............................................................................................... 26
    Demographic data ............................................................................. 27
    Disease-related data ......................................................................... 27
    Evaluation of information ................................................................ 28
    Evaluation of value of intervention ................................................ 28
    Psychological distress .................................................................... 28
    HRQoL – generic questionnaire ..................................................... 29
    HRQoL – disease-specific questionnaire ......................................... 29
    Stress, coping and need of support ................................................. 30
  Procedures ............................................................................................. 30
    Studies I–II ....................................................................................... 30
    Studies III–IV .................................................................................. 31
  Statistical analyses .............................................................................. 31
  Analyses of qualitative data ............................................................... 33
Results...........................................................................................................35
Health-related quality of life .................................................................35
Anxiety and depression .................................................................37
Effects of group-based patient information.................................39
Coping.........................................................................................39
Disease-related stress – qualitative data .......................................41
Coping with disease-related stress – qualitative data .................43
Need of help or support – qualitative data ....................................44

Discussion.....................................................................................................47
Health-related quality of life (HRQoL)..................................................47
Anxiety and depression .......................................................................48
Group-based patient information......................................................49
Coping.................................................................................................50
Discussion according to the bio-psycho-social model .....................51
Methodological considerations..........................................................53
Conclusions and clinical implications .............................................54
  Conclusions ..................................................................................54
  Clinical implications and suggestions for further research ......55

Sammanfattning på svenska..........................................................................57
Acknowledgement ..................................................................................59
References.....................................................................................................61
## Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Full Form</th>
</tr>
</thead>
<tbody>
<tr>
<td>CD</td>
<td>Crohn’s disease</td>
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<tr>
<td>HADS</td>
<td>Hospital Anxiety and Depression Scale</td>
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<td>HRQOL</td>
<td>Health-related quality of life</td>
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<td>IBD</td>
<td>Inflammatory bowel disease</td>
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<td>IBDQ</td>
<td>Inflammatory Bowel Disease Questionnaire</td>
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<td>JCS</td>
<td>Jalowiec Coping Scale</td>
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<tr>
<td>RFIPC</td>
<td>Rating Form of IBD Patients Concerns</td>
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<td>SF-36</td>
<td>Short Form-36 Health Survey</td>
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<tr>
<td>SHS</td>
<td>Short Health Scale</td>
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<tr>
<td>UC</td>
<td>Ulcerative colitis</td>
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Introduction

The origin of this thesis was a number of clinical questions about patients with inflammatory bowel disease. One question was about patients’ needs of information, and if they would be helped in their management of the disease if they were well-informed in disease and disease-related themes. Another question was how the patients felt, about their well-being and how they perceived their life with a disease. We started in May 1999 with a questionnaire, in order to study the patients’ quality of life and emotional well-being, and also to ask for their interest to participate in a "patient school". The results are presented in Study I. From the findings in Study I, we developed group-based patient information and invited patients with possible anxiety to participate. The interventions were run from January 2000 to May 2001, and the results are presented in Study II. These two studies generated questions about how patients with inflammatory bowel disease cope with the disease and its symptoms. We used a new questionnaire to investigate both coping and quality of life and asked the patients how they coped with a known stressing situation: exacerbation of their disease. This study was performed from November 2005 to February 2006 and is presented in Study III. Study III gave answers to some of our questions about coping with disease. However, there was still a dearth of more specific knowledge about what patients perceived as disease-related stressful, and their specific coping strategies to manage this stress. We also wanted to know about patients’ needs in terms of help and support from the health care system, and chose interviews as method to gain knowledge about these questions. The interviews were performed from September to December 2006 and the result is presented in Study IV.

There is an immense amount of research in the area of inflammatory bowel disease and its’ relation to quality of life and emotional well-being. However, to our knowledge very little is published about Swedish patients, and especially about patients with Crohn’s disease, which is one of the common inflammatory bowel diseases. Thus, we chose to include a large sample of patients and employed well validated and widely used instruments to be able to investigate patients’ quality of life and to make comparisons between subgroups of Swedish patients with Crohn’s disease and ulcerative colitis (which is another common inflammatory bowel disease).

The evaluation dearth of interventions developed for these patients - as well as studies about how patients cope with symptoms of disease and their
own perception of stress, coping and patients’ requests of support from the health care system - substantiates the need of the last three studies.

A bio-psycho-social model to increase the understanding of the determinants of disease was suggested by Engel (Engel 1980), and applied for gastrointestinal diseases by Drossman (Drossman 1998). The bio-psycho-social model is used as a framework for the understanding of earlier research and the findings of this thesis (see Figure 1). The model presumes that both biological and psychological predispositions contribute to the expression of disease and illness. Furthermore, environmental exposures and psychosocial variables affect the clinical expression of the condition and the outcome (e.g., quality of life) in a reciprocal fashion. Thus, a biological event such as an onset of inflammatory bowel disease caused by e.g. a gastrointestinal infection can affect organ function (the bowel), the individual and their family, and, ultimately, the quality of life. Reciprocally, a change at the psychosocial level - as depression or psychological stress - can affect psychological status and quality of life and may activate disease through biological effects on systemic immune and inflammatory function (Drossman 1998; Maunder 2005; Mawdsley et al. 2005).

![Figure 1. Schematic representation of the bio-psycho-social model. (Figure from Drossman 1998, p. 260)](image)

**Ulcerative colitis and Crohn’s disease**

Ulcerative colitis (UC) and Crohn’s disease (CD) are the two main types of intestinal disorders which are denominated inflammatory bowel diseases (IBD). They are chronic conditions with diverse manifestations and courses (Feagan et al. 2003). Ulcerative colitis was first described by the British physician Sir Samuel Wilks in 1859 (Wilks 1859). Crohn’s disease was
named after the American physician Burril B. Crohn who published a clinical description of the disease in 1932 (Crohn et al. 1932).

Clinical manifestations

In UC, the inflammation is located to parts of or the whole large intestine (the colon). The presentation of the disease varies in distribution, severity and duration of inflammatory activity. Common symptoms are bloody diarrhoea, pus, abdominal cramps, and weight loss (Lennard-Jones 1993).

In CD, the inflammation can be extensive and comprise part of or the whole of the digestive system from the mouth to the rectum. Complications as fistulas and abscess formation are prevalent in CD. Sometimes perianal fistulas can lead to fecal incontinence. Common symptoms are diarrhoea, rectal bleeding, fatigue, abdominal pain, and weight loss (Lennard-Jones 1993).

UC as well as CD is characterized by periods of remission and shorter or longer periods of active disease. Life-threatening complications can appear, as bowel perforation, ileus and the development of cancer (Brezezinski et al. 1997; Selby 1997).

Treatments

Medical and surgical treatments are used to reduce symptoms, maintain remission, decrease disease-related complications and improve the quality of life. Medical treatments for induction of remission in deterioration of disease activity, as well as for maintenance treatment to prevent relapses, comprise anti-inflammatory therapy (e.g., salicylates or corticosteroids) and immunomodulatory treatment (e.g., azathioprine or anti-TNFα preparations (Srinivasan et al. 2003, 2003). There has been a substantial development of new, effective drugs during the last decades, and drug treatment is normally the primary option before surgery is considered. However, removal of the whole or parts of the large intestine is performed when there is a substantial risk of cancer development or when medical therapy fails e.g. an acute, severe inflammation does not respond to pharmacological intervention. If the large intestine and/or rectum are surgically removed in patients with ulcerative colitis, the patient will receive an ileo-rectal anastomosis, an ileo-anal anastomosis, or an ileostomy. In CD, surgical interventions are generally more complicated and can involve partial removal of the large or small intestine or surgery for fistulas (Black et al. 2003; Poritz et al. 2003). Malnutrition and weight loss is common among patients with inflammatory bowel disease due to reduced food intake secondary to nausea and diarrhoea. Thus, nutritional support with, e.g., liquid dietary supplements may help patients who are unable to consume sufficient energy (Buchman et al. 2003).
Incidence and prevalence rates

The age of onset of IBD is primarily during adolescence and young adulthood with a smaller peak of onset in individuals at the age of 50 to 80 years old (Feagan et al. 2003).

For UC, the incidence rate (i.e., number of new cases per year) ranges from 3 to 15 per 100,000 inhabitants in northern Europe and North America (Feagan et al. 2003; Vind et al. 2006; Baumgart et al. 2007). In a study from 1992, incidence rates up to 14.9 per 100,000 inhabitants were reported in a Swedish county (Tysk et al. 1992). The prevalence rate of UC (i.e., the number of individuals with a given condition at a specific time) is 150 to 250 per 100,000 inhabitants in northern Europe and North America, and about 225 per 100,000 inhabitants in Sweden (Tysk et al. 1992; Feagan et al. 2003; Baumgart et al. 2007).

For CD, the incidence rate ranges from 2 to 15 per 100,000 inhabitants in northern Europe and North America (Feagan et al. 2003; Vind et al. 2006; Baumgart et al. 2007). The incidence rate has increased from 4.6 per 100,000 inhabitants in the Stockholm county during 1955–1989 to 8.3 per 100,000 inhabitants during 1990–2001 (Lapidus et al. 1997; Lapidus 2006). The prevalence rate of CD is about 100 to 200 per 100,000 inhabitants in northern Europe and North America, and 213 per 100,000 inhabitants in the Stockholm county, Sweden (Feagan et al. 2003; Lapidus 2006; Baumgart et al. 2007).

Western countries like northern Europe, the UK, Canada and North America are high-incidence and prevalence areas. Low-incidence areas are South America, south-east Asia, Africa (except South Africa) and Australia. The low incidence areas could indicate variations in access to, and quality of, health care. However, other environmental factors may be more important in order to explain the differences in incidence rates worldwide. Increasing incidence rates among immigrants who have moved from low-incidence areas to developed countries support this hypothesis (Feagan et al. 2003; Baumgart et al. 2007).

Causes and risk factors

There is no consensus of the causes of UC and CD, but the most common hypothesis is that the diseases are consequences of an interaction between environmental and genetic factors (Baumgart et al. 2007). UC patients have a first-degree relative with UC in 5–22 % of the cases, and CD patients have a first-degree relative with CD in 2–16 % of the cases (Baumgart et al. 2007).

UC was considered a psychosomatic disease for many years (Engel 1955). However, investigations of personality characteristics as risk factors for IBD rendered contradictory results. No significant associations between
disease and personality were found in some studies (Helzer et al. 1982; North et al. 1990; Addolorato et al. 1996; Addolorato et al. 1997), while other studies reported significant associations between characteristics like neuroticism, perfectionism, obsessional or phobic symptoms and IBD (Helzer et al. 1984; Robertson et al. 1989; Magni et al. 1991; Moreno-Jiménez et al. 2007). Personality characteristics are no longer seen as the primary cause of IBD. However, as in most chronic diseases, personality variables and emotional states are known both to influence and to be influenced by the course of the disease (Olbrisch et al. 1982).

Cigarette smoking as a risk factor for IBD has been studied. For UC, smoking is associated with less frequent exacerbations and current smokers have a decreased risk of developing the disease (Feagan et al. 2003; Cosnes 2004). Trials of the effect of nicotine patch in patients with active colitis and the effect of passive smoking have, however, shown contradictory results (Feagan et al. 2003; Cosnes 2004; McGrath et al. 2004). In CD, smoking worsens the clinical course of the disease. It promotes fistulas, increases the rates of exacerbations, and accelerates the need for surgery after surgically induced remission (Feagan et al. 2003; Cosnes 2004). Furthermore, smokers run a higher risk of developing the disease than do ex-smokers (Feagan et al. 2003).

Other environmental factors such as oral contraceptives, diet, appendectomy, vaccines, and gastrointestinal infections have been discussed as risk factors for IBD (Feagan et al. 2003). IBD is more common after gastrointestinal infections caused by contaminated food or water (Feagan et al. 2003; Garcia Rodriguez et al. 2006).

High intake of sugar, fat and carbohydrates, as well as the role played by fish, fruits, vegetables and coffee for the development of IBD or as the benefit of protection against the development of IBD has been studied. There is no consensus of diet as a risk factor or protective factor for IBD. However, hospitalized IBD patients, especially CD patients, are reported to be malnourished (Buchman et al. 2003; Feagan et al. 2003; Baumgart et al. 2007). Appendectomy may protect for UC. For CD, appendectomy is associated to an increased risk of developing the disease (Radford-Smith et al. 2002; Andersson et al. 2003).

Health-related quality of life (HRQoL)

During the last decades, the concepts of quality of life (QoL) and health-related quality of life (HRQoL) have grown in importance in the research of chronic disease. Studies of QoL and HRQoL in patients with chronic diseases can improve the knowledge and understanding of the patients’ perception of the impact of their disease, the outcome of a medical intervention, or the need for support (Slevin 1992).
There is no general consensus as to the definition of QoL, but the World Health Organisation (WHO) defines QoL as the “individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standard and concerns” (WHO 1991). QoL is a broad concept which consists of dimensions of physical health, psychological state, personal beliefs and social relationships. Thus, a perception of being satisfied with life - including aspects of daily life like family, work, social activities and friends - is included in QoL.

The concept of HRQoL refers to the extent to which the individual’s physical, social and psychological well-being and function are influenced by a medical condition or its treatment (Nordenfelt 1995). HRQoL is appraised by the individual’s subjective perception. Emotional reactions to a specific health problem and the individual’s role functions are part of the appraisal of HRQoL. HRQoL is multidimensional and contains components of physical well-being (e.g., disease symptoms and treatment side effects), functional well-being (e.g., taking part in everyday life and activities inside and outside the home), emotional well-being (e.g., reflecting both a positive feeling as well-being, and negative feeling as distress) and social well-being (e.g., social support and family functioning) (Wiklund 1990; Cella 1992).

HRQoL is dynamic and can be altered over time and by condition. The concept response shift, introduced by Sprangers and Schwartz (1999), illustrates this. Response shift refers to a change in the meaning of one’s self-evaluation resulting from changes in one’s internal standards of measurement (what is satisfactory health), a change in one’s values (the importance of health), or changes in one’s definition of the construct (being healthy) which plays an important role in assimilating illness (Sprangers et al. 1999).

A number of questionnaires have been developed which have provided standardised measures of patients’ subjective appraisal of HRQoL. The questionnaires are of different types and the generic, disease-specific and dimension specific questionnaires are common (Guyatt et al. 1993; Garratt et al. 2002). A widely spread generic questionnaire is the SF-36 Health Survey (Ware et al. 1992). Two disease-specific questionnaires developed for IBD patients are the Inflammatory Bowel Disease Questionnaire (Guyatt et al. 1989; Guyatt et al. 1993) and the Short Health Scale (Hjortswang et al. 2006). The Hospital Anxiety and Depression Scale (Zigmond et al. 1983) is a widely spread dimension specific questionnaire. Assessment of HRQoL in individuals with chronic diseases with remission and relapses can produce different results depending on when in the course of the disease the assessment is performed. This does not imply that the result is less true whenever it is performed, since it is the individual’s subjective perception that is assessed. This perception can vary over time and be due to condition and the individuals’ reaction to the assessment (Irvine 1995).
Inflammatory bowel disease and HRQoL

An interest for psychosocial aspects in relation to chronic diseases has grown during the last decades. To solely assess disease activity has been considered insufficient in order to explain the patient’s experience of the disease and the results of a treatment. Other factors than disease activity - such as psychological well-being, the extent of social support, the patient’s opinion of health-related well-being, the physical and psychosocial function in daily life, as well as psychiatric and medical co-morbidity - may influence the patient’s health status (Garrett et al. 1990; Hjortswang et al. 2003; Janke et al. 2005). Disease-specific measures have been developed as means to assist a better understanding of how patients with IBD perceive their HRQoL. The Inflammatory Bowel Disease Questionnaire (IBDQ) (Guyatt et al. 1989) and The Rating Form of IBD Patient Concerns (RFIPC) (Drossman et al. 1989) are examples of two widely used disease-specific questionnaires. The Short Health Scale (SHS) (Hjortswang et al. 2006) is a more recently developed health scale to assess subjectively perceived health.

Several studies have found that patients with IBD frequently report bowel symptoms (e.g., loose stools and abdominal pain) and emotional problems (e.g., irritability and anger), but more seldom social problems (Mitchell et al. 1988; Guyatt et al. 1989; Irvine 1997; de Boer et al. 1998). This could indicate that IBD has a moderate influence on social function and that most patients adapt to the disease and have a productive life with work and family. However, other studies which used generic instruments to assess HRQoL found deteriorations primarily in social and psychological dimensions, and to a lower degree in physical dimensions (Drossman et al. 1989; Drossman et al. 1991; Hjortswang et al. 1998).

Comparative studies found poorer HRQoL in IBD patients compared to a general population (Irvine 1993; Petrak et al. 2001; Bernklev et al. 2005; Janke et al. 2005) and in CD patients compared to UC patients (Drossman et al. 1989; Farmer et al. 1992; Irvine 1997). Furthermore, patients with exacerbation in disease report poorer HRQoL compared to patients in remission (de Boer et al. 1995; Hjortswang et al. 1998; Bernklev et al. 2005; Casellas et al. 2005). Janke et al (2005) suggest that disease activity predicts poor HRQoL, primarily for UC patients. Psychiatric and medical co-morbidity in combination with disease activity is suggested to be risk factors for poor HRQoL for CD patients (Janke et al. 2005). These findings may support the suggestions in the bio-psycho-social model that biologic/psychologic predispositions in combination with disease influence clinical outcome, e. g., quality of life (see Figure 1).
Inflammatory bowel disease and psychosocial factors

As suggested in the bio-psycho-social model, recent research has focused on the association between IBD and psychosocial aspects. IBD patients experience worries and concerns related to the risk of undergoing surgery, lack of energy and body-related worries (Drossman et al. 1989). UC patients are primarily worried about the need of an ileostomy, the risk of developing cancer (Drossman et al. 1991), and loss of bowel control (Moser et al. 1995). These worries and concerns are elevated in UC patients in relapse (Hjortswang et al. 1998). CD patients are concerned with the unpredictability of the disease and lack of energy (Drossman et al. 1991).

Increased levels of anxiety have been found in IBD patients compared to general populations (Addolorato et al. 1997; Kurina et al. 2001), and in patients in relapse (including both UC and CD) compared to patients in remission (Porcelli et al. 1996; Casellas et al. 2005). The presence of anxiety and/or depression contributes to poor HRQoL for IBD patients (Guthrie et al. 2002). In these studies, anxiety and depression may be viewed as the psychosocial modifiers included in the bio-psycho-social model and may have a mediating role between the disease (as independent variable) and the outcome variable, e.g., quality of life.

A number of reviews of the importance of psychosocial factors and IBD have been published. The authors conclude that a) daily hassles are associated to exacerbation of symptoms, b) increased disease activity may influence mood which is demonstrated in the intensity of anxiety and depression, c) factors as gender, socioeconomic status, ethnicity and perceived stress are important to perceptions of quality of life and d) most studies demonstrate high frequencies of depression and/or anxiety in IBD patients (Searle et al. 2001; Sainsbury et al. 2005; Mikocka-Walus et al. 2007). The reviewed studies are criticized for being cross-sectional, for not including control groups, for using quality of life instruments that may not be sensitive to clinical significant changes or for using instruments which include items that may be influenced by disease rather than psychological distress.

However, a number of prospective, longitudinal studies have recently been performed. Bitton et al (2003) followed 60 UC patients for 1 year and found that recent, stressful events are associated to earlier times of relapse in disease (Bitton et al. 2003). Mardini et al (2004) followed 18 CD patients for 2 years and found that depression and disease activity were associated; worsening or improving depression moved in the same direction as did disease activity in the following clinic visit 8-12 weeks later (Mardini et al. 2004). Finally, Mittermaier et al (2004) followed 60 IBD patients (47 CD and 13 UC) during 18 months. They found that depressive mood associated with anxiety and impaired HRQoL may influence the course of disease and may be a risk factor for relapse and for more active disease (Mittermaier et al. 2004). The authors suggest that depressive symptoms may have an impact.
on the course of IBD and that routine screening of psychological distress 
may identify patients at risk for relapse. The above- presented studies illus-
trate the reciprocal fashion of the bio-psycho-social model (see Figure 1) 
with the psychosocial modifiers influencing the disease, which ultimately 
influence the quality of life.

Coping
Coping is one factor in the adjustment to chronic disease (Lazarus et al. 
1984; Folkman et al. 2004). In the theory of stress and coping developed by 
Lazarus and Folkman (1984), stress is defined as external or internal de-
mands that are appraised as taxing or exceeding the resources of a person. 
Coping is defined as constantly changing cognitive and behavioural efforts 
that vary over time and situation, to manage stress (Lazarus 1993). The cop-
ing process involves primary appraisal to assess a potentially stressing situa-
tion as threat, harm/loss or challenge, and secondary appraisal to assess pos-
sible strategies for handling the situation (Lazarus et al. 1984). Coping 
strategies are mainly problem-focused (aiming at managing or altering the 
stressful situation by taking action against problems) or emotion-focused 
(aiming at reducing or managing the emotional distress or changing the 
meaning of the situation) (Lazarus et al. 1984; Lazarus 1993). A third coping 
style, meaning-based coping, is developed by Folkman (Folkman 1997). The 
concept of meaning-based coping refers to the searching for and finding of 
positive meaning in chronic, stressful situations. Employing meaning-based 
coping leads to positive affects (Folkman 1997; Folkman et al. 2000).

Coping with inflammatory bowel disease
A few investigations of coping and IBD have been published. Coping is 
primarily assessed by checklists as the Jalowiec Coping Scale (Jalowiec 
1991) and the Freiburg Questionnaire of Coping with Disease (Muthny 
1989). Problem-focused coping is found to be used more frequently than 
emotion-focused coping in order to manage stressors defined as “IBD” 
(Kinash et al. 1993) and “ileostomy” (Carlsson et al. 2003). The most fre-
cently used separate coping strategy is trying to maintain control over the 
situation (Kinash et al. 1993; Carlsson et al. 2003). Furthermore, optimistic 
coping strategies (e.g., thinking positively) are reported to be most fre-
cently used to cope with the stressor “IBD”, but supportant coping (e.g., 
using supportive resources) is rated as the most effective coping method 
(Smolen et al. 1998). In a study of how patients with IBD cope with surgery, 
high HRQoL after surgery is found to be associated with less frequent use of 
maladaptive coping (e.g., self-control, self-blame and escape) before surgery 
(Moskovitz et al. 2000). Finally, depressive coping (e.g., social withdrawal
and pessimistic thinking) is found to be associated with psychological distress (Petrak et al. 2001; Mussell et al. 2004) and a predictor of concerns related to IBD and to somatic complains.

Information and support

Contradictory results have been reported of the possible correlation between HRQoL and disease-related information in patients with IBD. In two recent studies, no correlations were found between patients’ disease-related knowledge and HRQoL or between a need for information and HRQoL (Verma et al. 2001; Hjortswang et al. 2003). However, in a previous study, a perceived, low information level was found to correlate to more worries and concerns for IBD patients (Moser et al. 1995).

In individualised information-based interventions, IBD patients report increased disease-related knowledge after receiving a compact disc based information (Schreiber et al. 1999), educational pamphlets (Borgaonkar et al. 1999) and patient-centred guidebooks (Kennedy et al. 2003). These interventions did not increase HRQoL. On the contrary, patients reported worse HRQoL scores after receiving educational pamphlets (Borgaonkar et al. 1999). However, Schreiber (1999) reported increased compliance with treatment regimen after patients received compact disc based information (Schreiber et al. 1999).

Although participants highly appreciated a group-based patient intervention that integrated disease-related information with psychological/psychosocial therapy, it did not influence HRQoL. However, significantly increased scores of HRQoL were found in patients with a disease duration of less than 3 years (Oxelmark et al. 2007).

In one of the rare studies aiming at identifying patients’ need for information and support, IBD patients reported a need for information about the influence of disease on pregnancy and family life. They also asked for childcare when they were ill or hospitalised, opportunities to meet other families with IBD, and health-staff’s better understanding of the difficulties involved in IBD (Mukherjee et al. 2002).

Short summary

The two chronic intestinal diseases, ulcerative colitis (UC) and Crohn’s disease (CD), influence the individual’s HRQoL. On one hand, disease activity and symptoms of disease may predict the psychosocial distress (e.g., anxiety and depression) found among patients. On the other hand, severe stress, anxiety and depression may contribute to a risk of relapse in disease. Problem-focused coping strategies are utilized to manage the broad stressor
“IBD” and educational interventions result in patients who are satisfied with the information but do, however, not influence HRQoL.

Although there are an immense amount of studies concerning the quality of life for IBD patients, results are sometimes contradictory, the samples are small and there is a great variability in measures employed to assess the outcome variables (e.g., HRQoL). Studies on HRQoL in Swedish IBD patients are rare, especially for CD patients. So, including a large sample of Swedish UC and CD patients, and using well validated and widely used instruments would increase the knowledge of these patients’ quality of life. It would also give opportunities to compare aspects of life with chronic disease between subgroups of patients.

Studies evaluating information-based group interventions for IBD patients are rare. So are studies on how patients manage symptoms of disease, as well as studies on the patients’ own perception of stress, coping and need of support from the health care system. This thesis seeks to add new knowledge about the conditions of a life with IBD. The bio-psycho-social model is used as a theoretical framework to increase the understanding of the complex mechanisms involved in life with a chronic disease.

Aims

The overall aim of this thesis was to investigate health-related quality of life (HRQoL) and coping strategies for Swedish women and men with ulcerative colitis (UC) or Crohn’s disease (CD). An additional aim was to study the effect of a group-based patient information program on emotional distress in IBD patients. Specific aims were:

1. To study differences in HRQoL, anxiety and depression between UC and CD patients (Study I).
2. To study the relationship between disease severity, HRQoL and emotional distress (Study I).
3. To study the effect on emotional distress and HRQoL for UC and CD patients who had been screened for anxiety and who had participated in a group-based patient information program (Study II).
4. To study HRQoL, coping strategies and associations between HRQoL and coping during exacerbation in disease in UC and CD patients (Study III).
5. To explore what specific stress women and men with UC or CD experience in relation to the disease, and how they cope with this stress (Study IV).
6. To identify the patients’ needs of support from the health care system (Study IV).
Method

Design
In Studies I–III a letter informing about the study - that participation was voluntarily, that confidentiality was guaranteed and that the informants could withdraw from the study at any time - was sent together with the questionnaires. In Study IV, the information letter was complemented with oral information by telephone call. In Study I and Study III, returned questionnaires were interpreted as informed consent. In Study II and Study IV, each patient gave their informed consent before participation in intervention and in interviews. As the interview questions in Study IV could be sensitive for the informants, only patients who had volunteered for additional studies were invited to participate. The local ethics committee at the Faculty of Medicine approved the studies. Table 1 presents an overview of study design and data collection methods.

Table 1. Study design and data collection methods used in studies I-IV

<table>
<thead>
<tr>
<th>Study</th>
<th>Design</th>
<th>Data collection methods</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>Cross-sectional design</td>
<td>Questionnaires</td>
</tr>
<tr>
<td>II</td>
<td>Randomized study with intervention and waiting-list controls</td>
<td>Questionnaires, two data collection points</td>
</tr>
<tr>
<td>III</td>
<td>Cross-sectional design</td>
<td>Questionnaires</td>
</tr>
<tr>
<td>IV</td>
<td>Qualitative design</td>
<td>Individual interviews with open-ended questions</td>
</tr>
</tbody>
</table>

Subjects
Patients’ characteristics (e.g., gender, age, diagnosis, illness duration) and number of subjects included in Studies I–IV are presented in Table 2. The participants in Study II are a sample from Study I, and participants in Study IV are a sample from Study III.
Table 2. Patient characteristics and number of participants in Studies I-IV

<table>
<thead>
<tr>
<th>Study</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Completers</td>
<td>Total</td>
<td>Exacerbation</td>
<td>Remission</td>
</tr>
<tr>
<td>Number of subjects n</td>
<td>492</td>
<td>26</td>
<td>49</td>
<td>166</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female n (%)</td>
<td>266 (54)</td>
<td>18 (69)</td>
<td>32 (65)</td>
<td>100 (60)</td>
</tr>
<tr>
<td>Male n (%)</td>
<td>226 (46)</td>
<td>8 (31)</td>
<td>17 (35)</td>
<td>66 (40)</td>
</tr>
<tr>
<td>Age mean (range)</td>
<td>46 (19–70)</td>
<td>46 (25–65)</td>
<td>44 (21–65)</td>
<td>46 (18–65)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>UC n (%)</td>
<td>331 (67)</td>
<td>13 (50)</td>
<td>23 (47)</td>
<td>103 (62)</td>
</tr>
<tr>
<td>CD n (%)</td>
<td>161 (33)</td>
<td>13 (50)</td>
<td>26 (53)</td>
<td>63 (38)</td>
</tr>
<tr>
<td>Illness duration mean years (range)</td>
<td>16 (0–48)</td>
<td>20 (3–37)</td>
<td>19 (1–41)</td>
<td>16 (2–42)</td>
</tr>
</tbody>
</table>
Studies I–II

Patients with ulcerative colitis (UC) and Crohn’s disease (CD), 18–70 years old, and residents in the county of Uppsala, were invited to participate (n = 710). The patients were identified by a registry (see below in the Data collection section) consisting of patients with inflammatory bowel diseases (IBD) at the Gastroenterology department at Uppsala University Hospital. After two reminders, 492 patients (70 %) had returned a completed questionnaire. The non-responders were slightly younger than the responders (Study I).

Of the participants in Study I, 143 patients were screened as possible or probable cases of anxiety (score 8-21) in agreement with the cut-off levels of the Hospital Anxiety and Depression Scale (see below in the Data collection section). From these patients, 135 were invited to a group-based patient information program. Eight patients were excluded because they had taken part in a previous patient information intervention. A total of 49 patients accepted to participate and were included after informed consent. No significant differences were found in anxiety among patients that accepted participation and patients that declined participation (m=10.8, sd=2.8 and m=11.5, sd=3.6 respectively, t=1.5, p=0.14). Nor were any differences in depression found among the two groups (m=6.7, sd=3.1 and m=6.4, sd=3.6 respectively, t=0.36, p=0.71). Twenty-six patients (53 %) adhered to the treatment protocol which meant participation in 5 or more sessions and completed questionnaires at base-line and follow-up. There were no differences in the demographic or clinical data between the completers and the drop-outs. Seventeen patients completed the questionnaires as controls: 9 with UC and 8 with CD. Table 3 presents an overview of Study II.
Table 3. Overview of participation and compliance through recruitment, randomization, intervention and 6 months follow-up

<table>
<thead>
<tr>
<th>Inclusion</th>
<th>Intervention</th>
<th>Waiting-list controls</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients scoring 8-21(^a)</td>
<td>143</td>
<td></td>
</tr>
<tr>
<td>Excluded</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Declined participation</td>
<td>86</td>
<td></td>
</tr>
<tr>
<td>Randomised to period of participation 2000-2001</td>
<td>49</td>
<td></td>
</tr>
<tr>
<td>Assessment 1 (baseline)</td>
<td>49</td>
<td>35</td>
</tr>
<tr>
<td>Declined participation</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Did not show up</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Participated in 1-4 sessions</td>
<td>7</td>
<td></td>
</tr>
<tr>
<td>Assessment 2 (6 month follow-up)</td>
<td>33</td>
<td>35</td>
</tr>
<tr>
<td>Non-responders</td>
<td>7</td>
<td>18</td>
</tr>
<tr>
<td>Completers</td>
<td>26</td>
<td>17</td>
</tr>
</tbody>
</table>

\(^a\) Scores 8-10 indicate “possible cases” and 11-21 “probable cases” of anxiety in the Hospital Anxiety and Depression Scale (HADS)

Studies III–IV

UC and CD patients who had attended the Departments of Gastroenterology or Surgery at Uppsala University Hospital from 1999 to 2003 were invited to participate in Study III (n = 1099). Inclusion criteria were diagnosis of IBD, age 18–65 years and habitation in the hospital catchment area at the time of the study. After the return of 56 questionnaires due to incorrect mailing address and after the use of two reminders, 742 completed questionnaires were returned (71 %). The non-responders were slightly younger than the responders. A total of 166 patients reported increased disease activity when responding to the questionnaire and 554 patients reported being in remission. Twenty-two patients did not respond to the question about disease activity. As Study III investigates coping during exacerbation of disease, data from patients who reported current increased disease activity at the time when they responded to the questionnaire was used in the study. Data from patients who reported being in remission was used only for comparisons of HRQoL, emotional well-being, and coping between patients in exacerbation and in remission.

A sample of 24 individuals who had volunteered to participate in additional investigations was invited to study IV. Six information letters were returned due to incorrect mailing address; three women (one with UC and two with CD) and three men (two with UC and one with CD). Three men were not available by telephone during the study period (two with UC and
one with CD). The study is based on interviews with 15 informants: nine women (five with UC and four with CD) and six men (two with UC and four with CD.

Data collection

The data in the present thesis is collected by self-administered postal questionnaires or individual interviews using open-ended questions. An overview of data collection methods used in Studies I–IV is presented in Table 4.

Table 2. Data collection methods in Studies I-IV

<table>
<thead>
<tr>
<th>Questionnaires</th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Coping: Jalowiec Coping Scale (JCS)</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Demographic data: study-specific questionnaires</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disease-related data: IBD registry</td>
<td>X</td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Evaluation of information</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>Evaluation of value of intervention</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Psychological distress: Hospital Anxiety and Depression Scale (HADS)</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HRQoL (generic questionnaire): Short Form-36 (SF-36) Health Survey</td>
<td></td>
<td>X</td>
<td></td>
<td></td>
</tr>
<tr>
<td>HRQoL (disease-specific questionnaire): Inflammatory Bowel Disease Questionnaire (IBDQ)</td>
<td></td>
<td>X</td>
<td></td>
<td>X</td>
</tr>
<tr>
<td>HRQoL (disease-specific questionnaire): Short Health Scale (SHS)</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

Individual interviews about

<table>
<thead>
<tr>
<th></th>
<th>I</th>
<th>II</th>
<th>III</th>
<th>IV</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disease-related stress</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Coping with stress</td>
<td></td>
<td></td>
<td>X</td>
<td></td>
</tr>
<tr>
<td>Need of support or help</td>
<td></td>
<td></td>
<td></td>
<td>X</td>
</tr>
</tbody>
</table>

Coping

The Jalowiec Coping Scale (JCS) is developed to assess strategies to manage stress (use scale) and the effectiveness of these strategies (effectiveness scale) (Jalowiec et al. 1984; Jalowiec 1991). As strong correlations have been found between the use and the effectiveness scales, it seems likely that these scales measure the same aspects of coping (Lindqvist et al. 1998). Thus, only the use scale was employed in Study III.

The JCS consists of 60 items forming eight subscales of coping strategies: confrontive (confront the situation, face up to the problem, constructive problem-solving), evasive (evasive and avoidant activities used in coping
with a situation), optimistic (positive thinking, positive outlook, positive comparisons), fatalistic (pessimism, hopelessness, feeling of little control of the situation), emotive (expressing and releasing emotions, ventilating feelings), palliative (trying to reduce or control distress by making the person feel better), supportant (using support systems as personal, professional and spiritual support) and self-reliant (depending on oneself rather than on others in dealing with the situation). The confrontive and supportant subscales are classified as problem-focused coping behaviours and the other six subscales as emotion-focused coping behaviours (Jalowiec et al. 1984; Jalowiec 1991).

The respondents were asked to rate, on a four-point Likert scale from 0 (never used) to 3 (often used) how often each item was used as a strategy to cope with a stressful situation. In this study the stressful situation meant increased disease activity as experienced by the patients. Examples of what could be included in increased disease activity were given, as diarrhoea, bloody stools and abdominal pain. The JCS is translated into Swedish and has internal consistency (Cronbach alpha) for the problem-oriented coping subscales in an acceptable range (values higher than 0.60) for end-stage renal disease patients and their spouses (Lindqvist et al. 1998). Cronbach’s alphas for the JCS of 0.88-0.94 (Jalowiec 1991) and 0.46-0.85 (Lindqvist et al. 1998) have been reported. Cronbach’s alpha was in this study 0.78 for the entire scale (60 items), and 0.83 for confrontive (10 items), 0.64 for evasive (13 items), 0.76 for optimistic (9 items), 0.29 for fatalistic (4 items), 0.64 for emotive (5 items), 0.53 for palliative (7 items), 0.55 for supportant (5 items), and 0.62 for self-reliant coping (7 items).

Demographic data
A study specific questionnaire was used to gather information on sex, age, education, employment status, diagnosis, illness duration, medical and surgical treatment, hospital admissions, and disease activity.

In Study III the presence of additional stressors than exacerbation in disease were investigated. Patients were asked to answer “yes” or “no” to the following question: “Do you at this moment experience other problems that influence your well-being?” Patients who answered “yes” were asked to give examples of the perceived problems. In addition, patients in Study I were asked if they were willing to participate in a group-based patient information and to give their views on the contents of such an education. In Study III, patients were asked about their willingness to participate in additional studies in the area of quality of life and coping.

Disease-related data
Data of diagnosis, diagnostic investigations, distribution of inflammation, time of diagnosis, current medication and previous surgery were collected
from the IBD registry in Study I. In Study III, disease-related data were collected through a study-specific questionnaire.

To assess disease activity in Study I and Study III, patients were asked to answer “yes” or “no” to the following question: “Are you at this moment experiencing increased disease activity?” Exacerbation was defined as “yes” and remission as “no”. In Study III, patients’ subjective perception of disease activity was supported by the bowel symptom severity item in the Short Health Scale (see the section below for HRQoL – disease specific questionnaire). Patients who perceived themselves being in exacerbation reported more severe symptoms than did patients in remission.

Evaluation of information
A study specific questionnaire was developed in order to assess the patients’ perceived satisfaction with disease-related information. Satisfaction was measured using a visual analogue scale ranging from 0 (maximally dissatisfied) to 100 (maximally satisfied). The items measured were information about: disease, medication, surgery, ileostomy, diet and nutrition, the social security system, stress management, and information from the patient organization.

Evaluation of value of intervention
At the final session of the group-based education, patients received a study specific questionnaire designed to assess the value of the intervention. In open-ended questions, the participants were asked whether they found any topic especially interesting, if they had had any practical or emotional use of the different topics, and the relevance and balance of the contents in the sessions. Space was left for patients’ comments.

Psychological distress
The Hospital Anxiety and Depression Scale (HADS) was developed as a screening tool for psychological distress in somatic out-patients (Zigmond et al. 1983). HADS consists of two subscales measuring anxiety in 7 items (e.g., feeling tense, worrying, and having panic attacks) and depression in 7 items (e.g., taking interest in things as usual, feeling cheerful, and feeling optimistic about the future). The respondents were asked to rate their answers on a 4-point Likert scale ranging from 0 (no distress) to 3 (maximum distress). The items in each subscale were summed up into a dimensional score (for anxiety and depression, respectively). A score of 7 or less on either subscale is suggested as indicating “no cases”, 8–10 as “possible cases” and 11–21 as “probable cases” of anxiety or depression (Zigmond et al. 1983). HADS has been translated to Swedish (Lundqvist et al. 1991).
HRQoL – generic questionnaire

The Short Form-36 (SF-36) Health Survey is one of the most widely used, self-administered questionnaires for generic health status or health-related quality of life (Ware et al. 1992). The SF-36 consists of 35 items divided into eight dimensions and one single item of reported health transition. The dimensions are physical functioning (e.g., limitations in lifting and carrying groceries, climbing stairs and walking moderate distances), role physical function (limitations in work or other daily activities due to health problems), bodily pain (frequency and discomfort of bodily pain), general health perception (subjective perception of general health), vitality (energy level and fatigue), social function (the impact of health problems on social activities), role emotional function (limitations in work or other daily activities because of mental problems), and mental health (anxiety, depression and psychological well-being). The item raw scores are coded and summed up, and transformed into a dimension with a scale score from 0 to 100 with the higher score indicating better health (Sullivan, M et al. 1994). A difference of 5 points is suggested to be clinically and socially relevant (Sullivan, M et al. 2002). The Swedish version of SF-36 is found to be feasible and reliable, and normative values for the general, adult, Swedish population are available (Sullivan, M et al. 1994; Sullivan, M et al. 1995).

HRQoL – disease-specific questionnaire

The Inflammatory Bowel Disease Questionnaire (IBDQ) is a self-administered questionnaire developed to assess health status or health-related quality of life in IBD patients (Guyatt et al. 1989). The IBDQ consists of 32 items with responses graded on a 7-point Likert scale from 1 (very severe problem) to 7 (no problem at all). The items were summed up into four subscales assessing bowel symptoms (e.g., loose stools and abdominal pain), systemic symptoms (fatigue and sleeplessness), emotional functioning (irritability and anger) and social functioning (limitations in social activities, school or work attendance) (Guyatt et al. 1989). The Swedish version of the IBDQ is reliable and sensitive but in need of re-division of items to improve homogeneity and discriminative validity for patients with UC (Hjortswang et al. 2001), and CD (Stjernman et al. 2006).

The Short Health Scale (SHS) is a disease-specific questionnaire consisting of four items measuring four dimensions of health: bowel symptom severity, social functioning in daily life, disease-related worry, and perceptions of general well-being. Items are responded to on a 100 mm visual analogue scale from 0 (no problems/very good well-being) to 100 (severe problems/very low well-being). The SHS has been found to be valid and reliable for Swedish patients with UC (Hjortswang et al. 2006).
Stress, coping and need of support

In Study IV, individual interviews were performed using an interview guide with open-ended questions. To ensure that each informant was asked the same questions in the same way and the same order, the key questions were standardised (Patton 2002). The following key questions were used: 1. Are there anything in relation to the disease that you perceive as stressful? 2. How do you handle this? 3. What did you need/do you need now in terms of help or support from the hospital? Follow-up and elucidating questions were used to stimulate the narrative (Patton 2002).

Procedures

Studies I–II

A postal questionnaire was sent to UC and CD patients identified by a local IBD registry. Information about diagnosis, distribution of inflammation, operation procedures (ileostomy, ileo-anal anastomosis, ileo-rectal anastomosis) and disease duration (time since diagnosis) was collected from the registry. Remaining demographic data were reported by patients in a study specific questionnaire. HRQoL was assessed by SF-36 and IBDQ, and anxiety and depression by HADS. Two reminders were used to enable as complete a data collection as possible (Study I).

Patients who completed the questionnaire in Study I and scored 8 or more on the HADS subscale of anxiety (indicating possible or probable anxiety) were identified (n=149) and invited to participate in a group-based patient information. Eight patients were excluded because of participation in previous group information. Forty-nine patients accepted and were randomly assigned regarding period of participation (the spring of 2000, the autumn of 2000 or the spring of 2001). Patients randomized to participate during the autumn of 2000 and the spring 2001 served as controls during the waiting period. During each period, one group for UC patients and one group for CD patients were run. Immediately before (baseline assessment) and 6 months after the intervention (follow-up assessment) all participants received a questionnaire package containing SF-36, IBDQ, HADS and questions about perceived satisfaction with information on disease-related themes. The same questionnaire package was at the same time sent to the waiting-list controls. Patients who participated in 5 or more sessions and completed the questionnaires at baseline and follow-up were regarded as compliant to the intervention protocol.

The intervention comprised eight sessions, held once a week in the evening for 2 to 3 hours and comprised seven to eight patients in each group. The intervention consisted of medical, pharmacological and surgical information about IBD, information about diet and nutrition, stress and stress
management, the social security system and the patient organization (Swedish Association of People with Stomach and Bowel Diseases). Cooking and computer-based evaluation of nutrient profiles were included. Participants were encouraged to discuss the different topics during the sessions. A gastroenterologist, a surgeon, a psychiatrist, a physiotherapist, a dietician, a specialist nurse of stoma care, a medical social worker and members of the patient organization provided the information and participated in discussions. During the last session, patients were asked to evaluate the value of the intervention through a study-specific questionnaire using open-ended questions and leaving space for each patient’s own comments (Study II).

Studies III–IV
A postal questionnaire package was sent to UC and CD patients who attended the Departments of Gastroenterology and Surgery at Uppsala University Hospital from 1999 to 2003. Demographic and disease-related data were collected by a study-specific questionnaire. Coping was assessed by the JCS, HRQoL by SHS and anxiety and depression by HADS. Two reminders were used to collect as many questionnaires as possible (Study III).

Informants in Study IV were recruited from Study III among participants who volunteered to additional studies in the fields of the quality of life and coping. In qualitative research focus lies in the depth of relatively small samples with information-rich cases that are selected purposefully (Patton 2002). The sample size was considered sufficient to generate depth rather than breadth (Sandelowski 1995; Patton 2002). A purposeful sample of individuals was invited to participate in the study. To guarantee a maximum variation sampling aiming to capture variations in experiences (Patton 2002), the sample included individuals with UC and CD, women and men, varying in age and illness duration. A letter informing about the purpose of the study was sent to the potential participants, followed by a telephone call to ask for their interest to participate. All individuals who were reachable by telephone accepted to participate, and time and place for an interview were set during the telephone call. Two informants chose a face-to-face interview and 13 a telephone interview. The interviews lasted 45–60 minutes and were tape-recorded. All interviews were performed and transcribed verbatim by the author (KL) (Study IV).

Statistical analyses
To prevent data recording bias, data from the questionnaires in Studies I and III were entered in a database by the use of a scanner. Data from Studies I–II are presented as means and standard deviations as this is the most common way of presenting values from these questionnaires. Due to the small sample
in Study II and the fact that data for patients in exacerbation in Study III was not normally distributed, non-parametric statistical methods were used (Hazard Munro 2005). Data in Study III is presented as median and interquartile range (25th–75th percentile). Data was excluded from analysis if dimensional scores could not be calculated because of missing items.

In Study I, independent samples $t$ tests were used for comparisons of group means of the scores from SF-36, IBDQ and HADS. One sample $t$ test was used for comparisons of SF-36 scores with norm data. The Pearson product moment correlation coefficient was used to test for relations between variables. Stepwise regression analyses were performed to determine how much of the variance in HADS was explained by age, gender and disease severity. Comparisons of SF-36 and IBDQ scores between UC and CD patients were performed by analyses of covariance controlling for age and gender, and comparisons of HADS scores between UC and CD patients controlling for age, gender and disease severity.

In Study II, as the same individuals were included in the intervention group and the control group, analyses were performed with within-group analysis with each group separately. The Wilcoxon matched-pairs test was performed to compare scores of SF-36, IBDQ, HADS, and evaluation of information at baseline to the scores at the 6 months follow-up. A one-sample test for proportions was used in calculating the number of patients needed to test the null hypothesis (=no effect). To detect an effect with a power of 0.8, criterion for significance at $p<0.05$ and an effect size of 0.80 a minimum number of patients for randomization were calculated to be 40. Completer analysis was performed and the criteria for compliance were participation at 5 or more sessions and return of completed questionnaire at baseline and follow-up. The patients not fulfilling these criteria were regarded as drop-outs, and their data was not analysed.

In Study III, the chi-square test was used for group comparisons for nominal data (e.g., gender) and the Mann Whitney U-test for ordinal data (e.g., JCS scores). Spearman R statistics were performed to test for associations between a) JCS scores as an independent variable and SHS and HADS scores as dependent variables, and b) gender, diagnosis, current exacerbation, daily use of steroids, disease duration and additional stressors as independent variables, and SHS and HADS scores as dependent variables. Stepwise multiple regression analyses were performed to determine how much of the variance in JCS, SHS and HADS scores were explained by gender (male-female), diagnosis (UC-CD), current exacerbation (yes-no), daily use of steroids (yes-no), disease duration ($\leq5$ years $\rightarrow 5$ years) and additional stressors (yes-no). To cross-validate the stepwise multiple regression, two second analyses were performed by randomly splitting the data set into two halves as recommended (Tabachnick et al. 2001). Only results that were consistent for both analyses were reported.
The significance level was set at p<0.05. The statistical software program Statistica® for Windows was employed for analyses in Studies I–II, and the Statistical Package for the Social Sciences (SPSS) 14.0 for Windows in Study III.

Analyses of qualitative data

The open-ended questions in the evaluation questionnaire in Study II and the interview data in Study IV were analysed by using content analysis. Content analysis is a research method for making valid inferences from text and can be used to code open-ended questions in surveys or to describe attitudinal and behavioural responses to communications (Weber 1990). In this thesis, qualitative data was analysed following the procedure and concepts of a qualitative content analysis suggested by Graneheim and Lundman (2004).

The analyses were performed by the following steps:

1. The interviews were read and reread by the author to capture the message in the data as a whole.
2. Parts of the text that carried information relevant to the key questions were identified and organized in one content area per key question.
3. Meaning units or words and sentences reflecting the central messages were marked, condensed and labelled with a code.
4. Meaning units and codes were compared and grouped together in categories represented by the empirical findings (manifest content)
5. The categories were formulated into central themes reflecting the underlying or summed-up meaning (latent content).

The author and a member of the research group (Annika Lundquist) independently categorised meaning units in categories in the content area of coping. Four meaning units were re-categorised and one category was renamed after discussions between the analysts. The consistency of the classification system in the content areas was discussed in the research group (Annika Lundquist, Karin Nordin and the author) until an agreement was reached of the relevance of the categories and themes. This constituted the final version of the classification system.

In qualitative research, the procedures for achieving trustworthiness are mainly made through credibility (validity) and dependability (reliability) (Patton 2002; Graneheim et al. 2004). Credibility refers to adequate data collection methods and sampling processes, collecting the appropriate amount of data and systematical data analysis. To show representative quotations from the text and to use multiple coders categorizing the data can be ways to approach credibility (Patton 2002; Graneheim et al. 2004).
Dependability concerns practicalities like using effective technical devices in interviews and transcription, but also stability of data over time and alterations in the researchers’ decisions during analysis. Open discussions within the research team about similarities and differences of consistence in content over time may address questions of dependability (Patton 2002; Graneheim et al. 2004).

Whether qualitative findings are transferable (generalizability) to other settings or groups, is decided by the reader. To facilitate transferability, clear and distinct descriptions of selection and characteristics of the participants, data collection and data analysis, as well as appropriate quotations will enhance transferability (Graneheim et al. 2004).
Results

Health-related quality of life

Comparisons of differences in HRQoL between subgroups of patients, and relations between demographic and disease-related variables on one hand and HRQoL on the other hand will be presented in this section.

Table 5 presents an overview of SF-36, IBDQ, SHS and HADS scores reported in Studies I and III. The patients in the last three columns reported disease activity when responding to the questionnaire.

Patients with ulcerative colitis (UC) and Crohn’s disease (CD) reported lower SF-36 scores compared to a general, adult, Swedish population in all subscales except for physical functioning (for UC and CD patients) and bodily pain (for UC patients) (see Study I, Table III for detailed data).

UC patients had higher SF-36 scores, except for the dimension of role emotional functioning, and higher scores in all subscales of the IBDQ than CD patients (see Study I, Table II for detailed data).

Within the UC group, patients with ileostomy had better social functioning than patients with ileo-anal anastomosis. Patients with ileo-anal anastomosis also reported lower scores for bodily pain and mental health than patients without ileo-anal anastomosis (Study I).

Furthermore, patients with subjectively perceived disease activity when responding to the questionnaire, reported poorer HRQoL in all IBDQ subscales (Study I).

The findings in Study III were in accordance with the findings in Study I with respect to differences between patients with increased disease activity and patients in remission. Thus, patients in remission when responding to the questionnaire reported significantly better HRQoL than patients in exacerbation. This was true for all subscales of SF-36 and the four SHS items (see Study III, Table 2 for detailed data).

SF-36 and SHS scores were compared for UC patients and CD patients (both with increased disease activity). Analyses revealed that UC patients reported better HRQoL than CD patients in six of eight subscales of SF-36. In emotional role functioning and mental health, the differences were not significant. UC patients also reported better social functioning and general well-being assessed by SHS (see Study III, Table 3 for detailed data).
<table>
<thead>
<tr>
<th>Scale</th>
<th>Study I</th>
<th>Study III</th>
</tr>
</thead>
<tbody>
<tr>
<td>SF-36</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical functioning</td>
<td>90.8 (16.3)</td>
<td>85.4 (18.8)</td>
</tr>
<tr>
<td>Role physical</td>
<td>77.8 (36.0)</td>
<td>67.0 (42.0)</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>79.0 (26.1)</td>
<td>68.0 (29.4)</td>
</tr>
<tr>
<td>General health</td>
<td>64.4 (24.0)</td>
<td>55.4 (25.5)</td>
</tr>
<tr>
<td>Vitality</td>
<td>61.5 (25.4)</td>
<td>50.9 (24.6)</td>
</tr>
<tr>
<td>Social functioning</td>
<td>85.0 (23.4)</td>
<td>77.3 (23.8)</td>
</tr>
<tr>
<td>Role emotional</td>
<td>81.1 (35.1)</td>
<td>73.0 (39.2)</td>
</tr>
<tr>
<td>Mental health</td>
<td>77.3 (20.0)</td>
<td>69.7 (21.1)</td>
</tr>
<tr>
<td>IBDQ</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bowel</td>
<td>58.8 (9.5)</td>
<td>54.1 (10.5)</td>
</tr>
<tr>
<td>Systemic</td>
<td>26.8 (6.1)</td>
<td>24.5 (6.3)</td>
</tr>
<tr>
<td>Emotional</td>
<td>69.5 (11.8)</td>
<td>64.4 (12.6)</td>
</tr>
<tr>
<td>Social</td>
<td>32.6 (4.2)</td>
<td>31.0 (5.2)</td>
</tr>
<tr>
<td>SHS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Symptom</td>
<td>14 (3-46)</td>
<td>57 (30-71)</td>
</tr>
<tr>
<td>Function</td>
<td>11 (5-50)</td>
<td>58 (28-79)</td>
</tr>
<tr>
<td>Worry</td>
<td>20 (5-50)</td>
<td>53 (27-78)</td>
</tr>
<tr>
<td>Well-being</td>
<td>21 (5-50)</td>
<td>50 (22-68)</td>
</tr>
<tr>
<td>HADS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td>5.2 (4.3)</td>
<td>6.3 (4.4)</td>
</tr>
<tr>
<td>Depression</td>
<td>3.3 (3.2)</td>
<td>4.2 (3.4)</td>
</tr>
</tbody>
</table>

Table 5. Summary of SF-36, IBDQ, SHS and HADS scores from Studies I and III (Study I; mean and sd, Study III; median and iqr)

SF-36 Health Scale: = 0-100 (poor health-optimal health)
Inflammatory Bowel Disease Questionnaire: Bowel = 10-70 (severe problem-no problem), Systemic = 5-35 (severe problem-no problem), Emotional = 12-84 (severe problem-no problem), Social =5-35 (severe problem-no problem)
Short Health Scale = 0-100 (no problem-severe problem)
Hospital Anxiety and Depression Scale = 0-21 (not present-always present)
Stepwise multiple regression analyses exposed the relative importance of the predictor variables included in the analyses. Only variables with significant correlations with the outcome variable (SHS scores) were included in the regression analyses. (Correlations and regression coefficients included in the final significant models are presented in Study III, Table 4.) The regression analyses revealed that disease activity (e.g., current exacerbation), additional stressors and daily use of steroids explained 27.0 % of the variance in the SHS Symptom subscale scores and 25.5 % of the variance in the SHS Function subscales scores. Gender, diagnosis and disease duration were excluded in the final significant model. Current exacerbation was assessed through answering “yes” or “no” to the single question “Are you at this moment experiencing increased disease activity?” Additional stressors were identified through answering “yes” or “no” to the question “Do you at this moment experience other problems that influence your well-being?” Use of prescribed drugs was asked for by indicating “sometimes”, “daily” or “no”.

Current exacerbation and additional stressors explained 21.7 % of the variance in the SHS Worry subscale scores and 26.4 % of the variance in the SHS well-being scores. Gender, diagnosis, disease duration and use of steroids were excluded in the final significant model.

Additional stressors at the time when they responded the questionnaire were experienced by significantly more patients with exacerbation in disease (44 %) than patients in remission (30 %). The patients mentioned stress (n=15), sleeplessness, fatigue and/or dizziness (n=15), depression (n=11), pain (n=10), work or school related problems (n=8), emotional distress (other than depression) (n=7), other diseases (n=5), serious illness or death within family (n=5), conflicts within family (n=4) and financial strain (n=2).

Thus, patients with UC and CD reported impaired HRQoL compared to a general Swedish population. The low scores of HRQoL were mainly found among patients with CD and patients with increased disease activity (including both patients with UC and with CD). Current exacerbation, additional stressors, and (in the SHS symptom and function subscales) daily use of steroids were the strongest explanatory factors for the variance in SHS scores.

Anxiety and depression

This section will present the amount of patients reporting scores indicating possible or probable anxiety and depression, and differences in psychological well-being between subgroups of patients. Furthermore, relations between demographic and disease-related variables on one hand and anxiety and depression on the other hand will be presented.
Table 6 presents an overview of patients in Study I and Study III who reported HADS scores of 8 or higher indicating possible cases (8-10) or probable cases (score 8-21) of anxiety and depression.

Table 6. *Per cent of patients with scores indicating possible cases and probable cases (scores 8-21) of anxiety and depression*

<table>
<thead>
<tr>
<th>Sample</th>
<th>Anxiety</th>
<th>Depression</th>
</tr>
</thead>
<tbody>
<tr>
<td>Study I, total group</td>
<td>29 %</td>
<td>13 %</td>
</tr>
<tr>
<td>Study III, remission</td>
<td>26 %</td>
<td>12 %</td>
</tr>
<tr>
<td>Study III, exacerbation</td>
<td>47 %</td>
<td>23 %</td>
</tr>
<tr>
<td>Study III, UC in exacerbation</td>
<td>39 %</td>
<td>17 %</td>
</tr>
<tr>
<td>Study III, CD in exacerbation</td>
<td>60 %</td>
<td>33 %</td>
</tr>
</tbody>
</table>

In Study I, CD patients reported higher levels of both anxiety and depression (HADS) than did UC patients. These differences were, however, eliminated when controlling for disease severity in the analysis of covariance. This indicates that the higher psychological distress in CD patients may be explained by more current symptoms.

CD patients who perceived themselves being in an active phase of the disease when responding to the questionnaire, reported higher levels of anxiety and depression than did CD patients in remission. However, among UC patients, no differences were found between those in exacerbation and those in remission. Patients with ileo-anal anastomosis (only UC patients) reported more psychological distress than patients without anastomosis (Study I).

In the multiple regression analyses, 41% of the variance in anxiety and 43% of the variance in depression was explained by bowel symptoms. Remaining independent variables tested (age, gender, illness duration, number of exacerbations and current exacerbation) did not contribute significantly to the explanation of the variance in anxiety and depression. (The result of the bivariate correlation analyses preceding the multiple regression analyses is presented in Study I, Table IV.)

In Study III, CD patients and patients with increased disease activity (including both UC and CD patients) reported more anxiety and depression than UC patients and patients in remission (including both UC and CD remissions). The multiple regression analyses revealed that a final model emerged in which additional stressors and current exacerbation in disease explained 16.1 % of the variance in HADS anxiety scores, and additional stressors explained 18.8 % of the variance in HADS depression scores. The variables gender, diagnosis, daily use of steroids, and disease duration did not contribute significantly to the final models. (Correlations and regression coefficients included in the final significant models are presented in Study III, Table 4.)
Effects of group-based patient information

The anxiety level was high both at baseline and follow-up for the intervention group and the anxiety level did not differ at follow-up compared to baseline scores. Fourteen patients remained in the same category (i.e., non-case, possible case and probable case) at follow-up. Five patients improved (changed from case to possible case or from possible case to non-case) and seven patients deteriorated (changed from non-case to possible case, from non-case to probable case or from possible case to probable case).

The SF-36 and IBDQ scores did not change at follow-up compared to baseline for the intervention group.

The waiting-list controls reported decreased anxiety score and increased role-physical functioning at follow-up compared to baseline scores.

Patient satisfaction with the information given in the routine health care system was low at baseline, especially the information about the social security system, stress and stress management, and diet and nutrition. The satisfaction with information was higher in all areas of disease-related information at follow-up compared to baseline for the intervention group.

The patient evaluation of the group-based information revealed that the opportunity to meet and discuss with peers and lecturers was the most important subject for the participants. It was followed in importance by information about diet and nutrition and information about medication and surgery. Most patients were satisfied with the relevance and balance of the intervention. However, 14 patients felt that too little or no attention was given to some themes (e.g., stress management, diet and nutrition or information about diseases) or they wanted more individual counselling in different areas.

When analysing the participants’ comments on the open questions about the value of the intervention, two categories were found to be of equal importance: the actual information that provided the participants with better knowledge and the benefit from discussions with peers.

Thus, despite of the participants’ satisfaction with gaining knowledge in disease-related topics and the benefit of the discussions during the sessions, the intervention showed no effect on scores on HRQoL or anxiety and depression.

Coping

In Study III, no differences in use of coping strategies were found between UC and CD patients, or between patients who perceived themselves being in relapse and patients in remission. Disease activity was assessed by the
patients’ subjective perception and supported by higher scores in the disease-specific Short Health Scale for patients reporting current exacerbation.

The most frequently used coping strategies to handle exacerbation in disease, was the optimistic, self-reliant and confrontive strategies, and the least frequently used strategies were the emotive, supportant and palliative strategies (Figure 2).

Figure 2. Patients’ frequency (never, seldom, sometimes or often) of use of coping strategies assessed by the Jalowiec Coping Scale (JCS) to manage exacerbation of disease activity (n=166), per cent of patients

The separate coping items that were highest ranked in frequency of use were: 1, wishing that the problem would go away (evasive strategy), 2, trying to keep the situation under control (confrontive strategy), 3, hoping that things would get better (optimistic strategy), 4, trying to think positively (optimistic strategy), and 5, trying to keep feelings under control (self-reliant strategy).

The separate items that were lowest ranked in frequency were: taking a drink to make oneself feel better (palliative strategy), taking medications to reduce tension (palliative strategy), praying or putting one’s trust in God.
(supportant strategy), telling oneself that the problem is someone else’s fault (evasive strategy), and doing something impulsive or risky that one would not usually do (emotive strategy).

Six correlations between coping, HRQoL and emotional well-being were significant at p-level 0.05 and two at p-level 0.01. However, the correlations were weak ($r_s=0.16–0.23$) - and three of them concerned the subscales of fatalistic and supportant coping with Cronbach’s alpha values below the acceptable level (detailed values are presented in Study III, Table 6).

Thus, patients were primarily using optimistic, self-reliant and confrontive coping strategies to handle exacerbation in disease. Least used were the emotive, supportant and palliative strategies. This data does not support associations between coping, HRQoL and emotional well-being.

**Disease-related stress – qualitative data**

In Study IV, the aims were to explore disease-related stress, how patients managed this stress, and patients’ needs of support or help from the healthcare system. As a means to a deeper understanding of the studied phenomenon we chose to interview patients. As this area is sparsely covered in previous research and the findings are new and informative, the results from Study IV will to a large extent be presented in this thesis.

Content analysis revealed two themes regarding the specific stress that UC and CD patients experienced, related to the disease: stress associated to the disease and stress associated to relations to others. Themes, categories and characteristics of the categories are presented in Table 7.

The theme of stress associated to disease contains two categories: stress associated to the need of toilet availability and stress associated to disease-related symptoms and worries. Stress related to an urgent need of a toilet was the first answer for most informants to the questions of disease-related stress. Women with UC were especially active in expressing a wide range of stressful situations within this category. Furthermore, all informants expressed various disease-related symptoms and worries. One example of a statement within this theme is from a 29 year old woman suffering from UC for less than 5 years. She shared her feelings about stress associated to the need of toilet availability like this:

“It is so urgent that if you have to wait, you won’t make it. And that... I find that stressful. And that you always have to know where you can find a toilet. If you are going shopping, you go to places where you know there is a free toilet or else you always have to bring a pile of coins. That’s what it’s like even if you’re rather well.”
The second theme focused on stress associated to relations to others and contains two categories: stress associated to social situation and stress associated to reactions from other people. Women with CD expressed a relatively large amount of stress related to social situations. Furthermore, women, to a higher degree than men, expressed fears of other peoples’ reactions and perceived others peoples’ reactions as stressful. An example from a statement is from a 53 year old woman suffering from CD for more than 5 years. She explained her fears of reactions from other people:

“How fun is it to go to a public toilet when there is a long queue waiting outside the door and it is impossible to be secluded … and they can both smell and hear what you are doing? I think that’s why I have chosen to isolate myself.”

Table 7. Themes, categories and category contents of patients’ experiences of stressors related to ulcerative colitis and Crohn’s disease

<table>
<thead>
<tr>
<th>Theme</th>
<th>Category</th>
<th>Characteristics of category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress related to disease</td>
<td>Stress associated to the need of toilet availability</td>
<td>The need to have access to a toilet, bowel urgency, frequent visits to the toilet and fear of loosing bowel control.</td>
</tr>
<tr>
<td></td>
<td>Stress associated to disease-related symptoms and worries</td>
<td>Abdominal pain, bloody stools, fatigue. Fear of deterioration and need of ileostomy. The unpredictable character of the disease and depression during relapses.</td>
</tr>
<tr>
<td>Stress associated to relations</td>
<td>Stress associated to social situation</td>
<td>Difficulties taking part in social activities and being in time for appointments when disease is active. The need to always make plans and be prepared to be able to take part in social activities. To feel unclean and keeping secretive about the disease.</td>
</tr>
<tr>
<td></td>
<td>Stress associated to reactions from other people</td>
<td>Feeling ashamed of or embarrassed by the disease and its symptoms. Fear of reactions from other people on frequent toilet visits or sounds and smells when using public toilets. That the disease is concealed, which results in difficulties to tell others about the disease, and for others to understand the problems living with the disease.</td>
</tr>
</tbody>
</table>
Coping with disease-related stress – qualitative data

In the content analysis of the interviews it became apparent that patients’ experiences of coping with stress in relation to the disease consisted of problem-focused coping strategies and emotion-focused coping strategies, as suggested by (Lazarus et al. 1984). Themes, categories and characteristics of categories are presented in Table 8.

The theme of problem-focused coping strategies consisted of three categories: to act, to plan, prepare and adapt, and to seek help and information. In particular, women with UC expressed a great number of active strategies on how to manage the disease. Furthermore, women in a higher degree than men described how they used strategies to plan, prepare and adapt to manage the disease. Almost exclusively women used strategies to seek help and information. One example of a statement within the category of problem-focused coping is from a 52 year old woman suffering from UC for more than 5 years:

“When I was younger I used to ride a bike everywhere in order to be able to use the first bush I saw if I needed to go. And I knew where to find every toilet in the city. So if I was in the city, I knew exactly where to go. So I have put up a strategy like that. But I always bring spare stuff. I keep it in my locker at work, some extra knickers and that. So I have never had to go home from work. I have never done that. I just have washed up and so, and it has worked out fine.”

The second theme was emotion-focused coping strategies which also consisted of three categories: distraction and positive attitude, acceptance and sharing feelings. Women with UC and men with CD were most active in expressing statements within the category of distraction and positive attitude. Many informants - there was no difference between women and men - expressed the importance of accepting the disease. Furthermore, a few women stressed the importance of getting emotional support by sharing their feelings about disease with family and friends. One example of statement within the theme of emotion-focused coping is from a 38 year old man suffering from CD for more than 5 years:

“I have gained knowledge and experiences during the years gone by. I have learnt how to handle medication. I know that there will be a couple of days when the disease is active but I will get better again, and I don’t have to be so worried any more.”
### Table 8. Themes, categories and category contents of patients’ experiences of strategies to cope with disease-related stressors

<table>
<thead>
<tr>
<th>Theme</th>
<th>Category</th>
<th>Characteristics of category</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Problem-focused coping</strong></td>
<td>To act</td>
<td>Changing meals and work related conditions, such as working hours or workload. To live an ordinary, active life and to inform friends and colleagues about the disease. To rest, take medication or use complementary medicine.</td>
</tr>
<tr>
<td></td>
<td>To plan, prepare and adapt</td>
<td>The need of making plans for toilet availability and be prepared with clean underwear. To avoid eating or to empty bowels before an activity.</td>
</tr>
<tr>
<td></td>
<td>To seek help and information</td>
<td>To seek contact with and help from health care. To seek information in newspapers and web-sites and by talking to other patients.</td>
</tr>
<tr>
<td><strong>Emotion-focused coping</strong></td>
<td>Distraction and positive attitude</td>
<td>Trying to make the best of the situation and have a positive attitude. Making social comparisons. Distraction by engaging in pleasant activities. Experiencing one's own capability to handle stressful situations.</td>
</tr>
<tr>
<td></td>
<td>Acceptance</td>
<td>Accepting the disease. Getting used to it and learning how it works and how to live with it.</td>
</tr>
<tr>
<td></td>
<td>Sharing feelings with others</td>
<td>Sharing their feelings about the disease with others as a means to receive emotional support.</td>
</tr>
</tbody>
</table>

### Need of help or support – qualitative data

In the interviews, all except one informant expressed needs for help or support from the health care. The statements were divided into two themes: instrumental support and emotional support. Themes, categories and characteristics of categories are presented in Table 9.

The theme of instrumental support consisted of the categories information, organization and support at the time of diagnosis. Also help to apply for financial and practical aid was asked for. Especially the women and men with UC asked for information about disease related aspects. Informants
expressed suggestions for the organization of medical care in terms of support and information, as e.g., multi-professional teams and flexibility in providing information. Instrumental support at the time for diagnosis was expressed primarily by women with CD. A 59 year old woman suffering from CD disease for less than 5 years expressed her opinion about how the information could be organized:

“I think they should arrange an open house with news, tests and so on. And I was thinking that there are heart groups and anti stress groups and diabetes groups and classes and so on for the new ones. Could there be a stomach group with a couple of meetings? Even if we have different diseases, we must have a lot in common about how to cope with them.”

The second theme concerned emotional support and was expressed primarily by the female informants. They wanted contact with people who had experience of the disease - e.g., other patients or experienced medical staff - in order to share experiences about how to live with the disease. This need started at the time they got their diagnosis. A 38 year old man suffering from CD for more than 5 years expressed his opinions about the need of support at diagnosis:

“A person who gets this diagnosis has to be asked if there are things that are difficult and also to get information that there are other professionals they can see. One has to be asked more than once, especially during the first 2 years and when the appointments with the doctor become sparse.”
<table>
<thead>
<tr>
<th>Theme</th>
<th>Category</th>
<th>Characteristics of category</th>
</tr>
</thead>
<tbody>
<tr>
<td>Instrumental support</td>
<td>Information</td>
<td>Information about disease and diet. Information and help to apply for financial and practical aid. Information about patient organization, ileostomy and how to live with the disease.</td>
</tr>
<tr>
<td></td>
<td>Organization</td>
<td>Co-operation between medical specialities. To work in multi-professional teams and to arrange open hospital hours and patient group information.</td>
</tr>
<tr>
<td>Emotional support</td>
<td>To talk about the disease</td>
<td>To talk about the disease and how to live with it with people with experience of the disease.</td>
</tr>
<tr>
<td></td>
<td>Support at time of diagnosis</td>
<td>To have contact with a multi-professional team and to talk about how to live with the disease.</td>
</tr>
</tbody>
</table>
Discussion

Health-related quality of life (HRQoL)

Although HRQoL in patients with inflammatory bowel disease (IBD) has been investigated during the last decades, there are few studies published reporting on HRQoL for Swedish patients.

CD patients reported more exacerbations of symptoms and had more surgical interventions performed than UC patients. This underlines that Crohn’s disease is generally a more complicated and serious condition in medical terms. CD patients had poorer HRQoL than UC patients, and patients in exacerbation (including both UC and CD) had a more impaired HRQoL than patients in remission. These findings are consistent with previous research (Drossman et al. 1989; Irvine 1997; Petrak et al. 2001; Bernklev et al. 2005). The differences in HRQoL between UC and CD patients remained during exacerbation in disease; patients with exacerbation in UC reported better HRQoL than patients with exacerbation in CD (Study III).

The use of the SF-36 Health Survey in Study I made it possible to compare patients’ scores of HRQoL to norm values for a general Swedish adult reference population. IBD patients reported equal values in the dimension of physical function, which means that the ability to manage daily activities such as going for a walk, climbing the stairs or running short distances is not impaired. The largest difference compared to the reference population was found in the general health dimension which comprises items concerning the individual’s perception of their state of health and expectations of health deterioration. This dimension can be expected to be influenced in patients with a chronic disease. Using the 5 points difference to detect clinically and socially relevant differences as suggested (Sullivan, M et al. 1994) gives additional information. The differences between UC patients and the reference population can be regarded as clinically and socially relevant in the dimensions of general health (11 points), vitality (7 points) and role physical (5 points). Among CD patients, the difference is between 7 and 20 points in all dimensions except for physical function (see Study I, Table III for detailed data). In a Norwegian study consistent findings are reported except for smaller differences in the dimension of mental health (Bernklev et al. 2005). The differences in SF-36 between the diagnoses indicate that CD patients have more severe problems with work or daily activities as a result of reduced physical health, they suffer more pain, consider themselves as being
more likely to fall ill than other people and consider their vitality to be more impaired than is the case for UC patients.

The symptom burden in CD may explain the low scores in the IBDQ emotional functioning subscale (which includes items of e.g., irritability, anger and depression) reported by CD patients. The conclusion in a review of HRQoL for CD patients is that HRQoL appears to be poorer for CD patients than for healthy controls or for UC patients, but equal to or better than for patients with other medical disorders (as rheumatoid arthritis and chronic obstructive pulmonary disease) (Cohen 2002). Furthermore, HRQoL is worse in CD patients during relapse of disease compared with patients in remission and is correlated to disease activity (Cohen 2002). Disease activity, in combination with experiencing additional stressors and daily use of steroids significantly contributed (to 22-27 %) to the explanation of the variance in scores in the disease-specific health scale SHS in our study (Study III). Gender, diagnosis and disease duration were excluded from the final regression models. As diagnosis did not contribute to the explanation of differences in HRQoL between UC and CD patients, other unknown factors may be of importance. In a study of determinants of life satisfaction in IBD, Janke et al (2005) concluded that disease activity was a predictor for poor HRQoL in UC. However, for CD patients, co-morbidity (both psychiatric and medical) combined with disease activity were suggested as risk factors for poor HRQoL. To increase the understanding of factors involved in HRQoL for IBD patients, possible socio-demographic or psychosocial differences between UC and CD patients need to be investigated.

Having an ileostomy does not seem to influence HRQoL, while having an ileo-anal or ileo-rectal anastomosis appears to do so. This difference could possibly be explained by the bowel control gained by a stoma which is not always accomplished by an anastomosis.

### Anxiety and depression

The high prevalence of psychological distress in CD patients and patients with increased disease activity (including both UC and CD) is consistent with previous findings (Andrews et al. 1987; North et al. 1994; Farrokhhyar et al. 2006). Among the patients in Study III who perceived exacerbation in disease when responding to the questionnaire, 39 % of UC patients and 60 % of CD patients reported scores for possible cases of anxiety (using the cutoff values recommended by Zigmond & Snaith, 1983). The corresponding prevalence for depression was 17 % for UC patients and 33 % for CD patients. Although both possible cases (values 8-10 in HADS) and probably cases (values 11-21) are included in these percentages, the prevalence of anxiety and depression is high, especially for CD patients.
The most important variable explaining the variance in anxiety and depression in Study I was bowel symptoms. In Study III, when additional problems were asked for, disease activity together with current additional stressors explained 16% of the variability in anxiety scores. Additional stressors alone explained 19% of the variance in depression. However, some of the problems reported, as fatigue and pain, may be related to IBD.

The psychological distress found in patients with ileo-anal or ileo-rectal anastomosis may possibly be explained by the burden of repeated surgery or unfavourable functional outcome with high stool frequency, incontinence or urgency which may cause anxiety in social situations. However, a previous report did not find a higher prevalence of psychiatric disorders among patients with ileo-anal anastomosis compared to patients without anastomosis (Häuser et al. 2005).

Group-based patient information

A group-based patient information program was developed as we hypothesized that this intervention could improve disease-related knowledge and sense of control which in turn would reduce anxiety and increase HRQoL. The patients’ satisfaction with disease-related information was increased at 6 months follow-up, and the actual information and discussions with other group members were valued as most important. Some patients wanted stress management or individual counselling included in the intervention, or wanted additional information about diet and disease. However, despite the patients’ satisfaction with the group information, the level of anxiety did not decrease at follow-up. The participants had long disease duration and several patients reported various psychosocial problems and stressful events besides the disease. Thus, the intervention focusing on disease-related information was obviously not sufficient to influence the psychosocial distress experienced by the participants.

Previous studies evaluating educational material, such as booklets, pamphlets and compact disc-based information for patients with IBD, showed no effect on HRQoL and psychological distress (Borgaonkar et al. 1999; Schreiber et al. 1999; Kennedy et al. 2003). The limited number of psychosocial interventions that have been effective in reducing stress in patients with IBD is primarily stress management treatment (e.g., training in stress-management) and cognitive-behavioural approaches (including psycho-education of connections between cognition and emotions of distress, training in adaptive coping strategies to handle stress and muscle relaxation) (Mussell et al. 2003; García-Vega et al. 2004). This indicates that further interventions aiming at reducing psychosocial distress should focus on these aspects.
In a Swedish group-based intervention integrating disease-related information and psychological/psychosocial therapy, significantly increased scores of HRQoL were found in patients with a disease duration for less than 3 years (Oxelmark et al. 2007). At follow-up, 12 months after the intervention, the patients evaluated the group therapy as the best part of the intervention. This implies that information in combination with psychosocial support may be effective for patients if initiated early after the diagnosis.

In Study IV, the informants wanted information about the disease itself and disease-related subjects like diet, financial and practical aid and knowledge about how to live with the disease. Alternative ways to supply this information were suggested: group information and hospital open-houses, but also organizing multi-professional teams in the health care to supply a wider spectrum of information. Despite the expressed need for information, only 49 of the 135 patients invited to our group information were interested to participate. As this kind of intervention calls for considerable efforts in planning and implementing, careful considerations have to be made in order to develop interventions that suit the patients’ needs at appropriate times.

**Coping**

To cope with exacerbation of symptoms in IBD, patients primarily use optimistic, self-reliant and/or confrontive strategies, with no differences between UC and CD patients. Optimistic coping is described as having an optimistic outlook and thinking positively, self-reliant coping as depending on yourself, and confrontive coping as employing constructive problem-solving in dealing with stressful situations (Jalowiec et al. 1984). The use of a wide range of problem-focused and emotion-focused coping behaviour indicates that patients’ coping efforts are directed toward changing both the situation itself and the feelings for the stressor. This coping behaviour is reported elsewhere in patients with other chronic diseases and in a general Swedish population (Mahat 1997; Smolen et al. 1998; Lindqvist et al. 2000; Willoughby et al. 2000; Kristofferzon et al. 2005).

In Study III, we raised the question whether coping and HRQoL were associated, i.e., if patients using specific coping strategies differed with respect to HRQoL. If so, we could encourage patients to use strategies that were related to a good HRQoL. However, the data in Study III did not support associations between coping and HRQoL or emotional well-being. To assess coping with a check-list as the JCS, may not be the best way to investigate this phenomenon. JCS does not give specific information of how IBD patients actually behave in order to manage the different stressors related to IBD. Asking patients in open-ended interviews may render more specific answers of the management of chronic disease.
In Study IV both disease-related stressors and coping strategies were studied in qualitative interviews. The disease-related stressors were specified in patients’ narratives and this study confirmed that symptoms of disease were perceived as major stressors. The primary stressor concerned situations caused by diarrhoea and bowel urgency, i.e., the need for toilet availability and the fear of losing bowel control in social situations. To cope with this stress, patients used specific strategies, as e.g., preparing participation in social activities by finding out where public toilets were to be found, bringing extra underwear and emptying bowel before an activity. To encourage other patients with IBD to use these strategies may be useful. The efficiency of coping strategies were not asked for in the interviews, but, presumably patients use strategies that they consider as efficient as possible. However, some patients coped with stress by, e.g., avoiding eating before a social activity. This is a more doubtful action to recommend, especially as patients with IBD may be malnourished.

Discussion according to the bio-psycho-social model

In the bio-psycho-social model developed by Engel (Engel 1980) and applied on gastrointestinal illness by Drossman (Drossman 1998), psychological and social factors are integrated into the biomedical model of disease.

A suggestion of the bio-psycho-social model applied on UC and CD is presented in Figure 3.

Figure 3. The bio-psycho-social model applied on results of previous research and findings in this thesis
The biologic/psychological predispositions may contribute to the expression of disease and illness. These predispositions may involve genetic heritage with first-grade relatives suffering from UC or CD (Baumgart et al. 2007) as well as psychological characteristics like neurotisicm (Moreno-Jiménez et al. 2007). Furthermore, environmental exposures like gastrointestinal infections (Feagan et al. 2003), cigarette smoking (in CD patients) (Feagan et al. 2003), long-term stress (Levenstein et al. 2000) and stressful events (Bitton et al. 2003) may also contribute to the clinical expression of disease. Psychosocial factors, e.g. worries and concerns (Hjortswang et al. 1998), anxiety and depression (Guthrie et al. 2002; Mittermaier et al. 2004) and coping (Moskovitz et al. 2000; Mussel et al. 2004) may affect both the clinical expression of disease and the clinical outcome (HRQoL) in a reciprocal fashion. Symptoms of the disease (at onset and during relapses) may have an influence on both the psychosocial variables (anxiety and depression during relapse) and the clinical outcome with poor HRQoL (Casellas et al. 2005).

In this thesis, the poor HRQoL for patients in exacerbation compared to patients in remission support the influence of disease activity on outcome (HRQoL). Patients in exacerbation also reported more anxiety and depression than patients in remission. This may support the influence of disease on psychosocial variables (anxiety and depression). Disease activity combined with additional stressors explained parts of the variance in both disease-related variables (SHS) and anxiety and depression. This finding illustrates the reciprocal influence between psychosocial variables (additional stressors), disease (disease activity) and outcome (SHS, and in this case anxiety and depression as outcome).

As shown in the bio-psycho-social model, and revealed in the results of the present study, factors like anxiety and depression may be regarded both as psychosocial variables mediating between the disease and HRQoL, and as outcome variables included as a subscale of psychological distress in HRQoL.

The bio-psycho-social model may support an understanding of the complex relations between disease and the individual, family, society, socioeconomic factors, work and social life included in the life with a chronic disease. Adopting a bio-psycho-social model includes patient’s subjective experience alongside with objective biomedical data and develops a model of causality that is more comprehensive than cause-effect relationships. Furthermore, a clinical practice of this model would strengthen the patient from passive object to power as a subject in the routine health care (Borrell-Carrió et al. 2004)
Methodological considerations

In this thesis, both quantitative and qualitative approaches were combined which presents a more comprehensive representation of the investigated phenomenon. As the aim was primarily to explore the situation for patients with UC and CD focusing on HRQoL and coping with aspects of disease, cross-sectional designs and interviews were employed. However, the cross-sectional design in Study I and Study III allows assessments of HRQoL and coping at one point of time only. Thus, associations between HRQoL and psychosocial factors reflect correlation only, not causality.

The participants in Study I and Study III were residents in the same county. They were recruited from a hospital which manages the vast majority of patients with IBD (in- or out-patients) in the county. The participants were not randomly selected to the studies and some patients participated in more than one study. Although the studies are not strictly population-based, the results may be applicable to other populations of patients with IBD in Sweden. Parts of the results in these studies are consistent with findings reported elsewhere in other populations of IBD patients (Cohen 2002; Bernklev et al. 2005; Farrokhyar et al. 2006).

Most of the measures included in these studies do have good psychometric properties and are used in numerous studies, as the SF-36 for general health assessments and the HADS for anxiety and depression. However, the Swedish version of the IBDQ was not fully validated previous to our study. This was made in recent studies for patients with UC (Hjortswang et al. 2001) and patients with CD (Stjernman et al. 2006). IBDQ was then reliable and sensitive for changes in disease activity, but needed a re-division of items to improve the internal consistency and discriminative validity for patients with UC and CD (Hjortswang et al. 2001; Stjernman et al. 2006). This indicates that further research has to be performed to divide items in dimensions that are appropriate for Swedish patients with IBD. The Cronbach’s alpha values for the Jalowiec Coping Scale (JCS) were low to moderate (Cortina 1993) in six of the eight coping styles. This suggests problems with item homogeneity also in this scale and that all of the eight subscales may not be applicable for Swedish patients with UC and CD. Thus, the conclusion for the studies presented in this thesis is that data concerning the JCS should be interpreted with caution.

The patients participating in the group-based information (Study II) were included both in the intervention-group and the control-group. The reason for this was both the limited number of patients, but also ethical considerations. All patients that were willing to participate were offered participation within the study period. Patients that initially were randomized to control-group, were included in the following intervention group. Thus, only within-group analyses were performed. The problem of mass-significance due to
many statistical analyses was controlled for in Study I by increasing the significance level to $p < 0.01$.

The stressful situation defined in Study III - “increased disease activity” - was chosen to be as narrow as possible (in contrast to the broader stressor “IBD” that previous have been studied) in order to present an understanding of how patients cope with exacerbation of symptoms of disease. Increased disease activity may include everything from slight discomfort to being admitted to hospital because of severe symptoms. Thus, we may not fully understand what each patient is coping with, but patients reporting of increased disease activity also reported more severe bowel symptoms than did patients in remission. The defined stressor brought a possibility for each patient to visualize their own individual perception of disease activity and to value their use of JCS items to cope with what they perceived as exacerbation in disease.

Study IV is limited by the sampling procedure which did not succeed in maximum variations concerning the informants’ age. The mean age of the included informants was relatively high with the youngest informant being 29 years old. Younger informants may have contributed with additional categories in the investigated phenomenon. Considering this limitation, the common pattern in data emerging from the variation in informants is still of interest in capturing the shared experiences of stress and coping in IBD. Most informants chose telephone interviews and there were no obvious differences in length and areas discussed in face-to-face interviews compared to telephone interviews. To strengthen the credibility of the findings, informants were asked the same key questions and data was categorised and discussed by co-analysts until an agreement of the classification system was reached. A person with experience of patients with IBD carried out all interviews, which can facilitate the understanding of the informants’ experiences. However, to avoid prejudice, two co-analysts without experience of these diseases participated in the analyses.

Conclusions and clinical implications

Conclusions

- Patients with ulcerative colitis reported better HRQoL, and less anxiety and depression than patients with Crohn’s disease during both remission and exacerbation in disease.
- Patients with increased disease activity (both UC and CD) reported poorer HRQoL and more anxiety and depression than patients in remission.
• According to HADS, anxiety was found in 26 % - 60 % and depression in 12 % - 33 % among patients with ulcerative colitis and Crohn’s disease.
• Disease severity and additional stressors (in combination with daily use of steroids in some subscales) contributed to the variance in HRQoL, anxiety and depression in patients with ulcerative colitis and Crohn’s disease.
• Participants in group-based patient information were satisfied with the information and the opportunity to discuss disease-related topics with lecturers and other group members. However, the intervention - containing disease-related information and practice-based sessions including cooking and computer-based evaluation of nutrient profiles - did not change HRQoL or anxiety and depression in a 6 months perspective.
• No differences in coping strategies were found between patients with ulcerative colitis and patients with Crohn’s disease or between patients in exacerbation of disease and patients in remission. This study did not support associations between coping strategies and HRQoL or emotional well-being.
• The major disease-related stressors were the urgent need for toilet availability and stress associated to social situations. This stress was managed by specific strategies like preparing participation in social activities by finding out the location of public toilets, taking extra underwear and emptying bowel before an activity. Patients expressed needs of co-operation between medical specialities, organized patient information, and to talk to other patients and multi-professional teams about the disease and how to live with it.

Clinical implications and suggestions for further research
• The most essential measure in the routine health care is to help patients reduce or control symptoms as urgency and diarrhoea.
• Health care staff should be observant on the psychosocial well-being of patients with IBD, especially patients with Crohn’s disease and patients in relapse.
• Screening methods should be developed and used in routine health care to identify patients with impaired HRQoL and psychosocial distress.
• Group-based or individual patient informations need to be developed and planned to target the patients’ specific needs and at appropriate times during the course of the disease.
• Developing multi-professional teams may help to assess and address the varying needs and problems experienced by IBD patients.
• Disease-related and psychosocial stressors should be further investigated and their role in the life with inflammatory bowel disease explored.

• Possible socio-demographic and psychosocial differences between patients with ulcerative colitis and Crohn’s disease should be further explored.

• And, finally, a more holistic theory than the traditional biomedical model in the management of chronic diseases has been suggested since the late 1970s (Engel 1980). The bio-psycho-social model is applicable in IBD and may help to explain the degree and variability to some gastrointestinal symptoms and the understanding of patients’ experience and behaviour related to them (Drossman 1998). In the bio-psycho-social model influences of biomedical, physiological, psychological and socioeconomic factors are included (Brantley et al. 1993; Jones et al. 2002), which may be appropriate also in the routine health care of patients with ulcerative colitis and Crohn’s disease.
Syftet med avhandlingen var att studera livskvalitet och coping hos patienter med ulcerös kolit (UC) eller Crohn’s sjukdom (CD), samt att undersöka om en gruppbaserad patientinformation, s k ”patientskola” kan minska oro/nedstämdhet och förbättra livskvalitet.

Data samlades in genom enkäter (Studier I-III) respektive intervjuer (Studie IV). I en studie kartlades livskvalitet och förekomst av oro/nedstämdhet hos 492 patienter med UC eller CD (Studie I). ”Patientskolan” (n=49 patienter) utvärderades i syfte att studera förändringar avseende grad av oro/nedstämdhet, livskvalitet, tillfredsställelse med sjukdomsrelaterad information samt att kartlägga deltagarnas egen utvärdering av interventionen (Studie II). I en tredje undersökning kartlades copingstrategier i samband med sjukdomsaktivitet hos 166 patienter med UC eller CD (Studie III). Femton patienter med UC eller CD intervjuades om stress i relation till sjukdomen, hur det hanteras samt behov av hjälp eller stöd från sjukvården (Studie IV).

Patienter med UC rapporterade bättre livskvalitet och mindre oro/nedstämdhet än patienter med CD både vid ökad sjukdomsaktivitet och i remission. Efter deltagande i ”Patientskolan” ökade tillfredsställelse med sjukdomsrelaterad information vid uppföljning efter 6 månader. Deltagarna värderade informationen och diskussionen med föreläsarna och övriga gruppmedlemmar som mest värdefull. Däremot hade inte oro/nedstämdhet eller livskvalitet förändrats vid uppföljningen. För att hantera ökad sjukdomsaktivitet använde patienter både problemfokuserade strategier (t ex att försöka kontrollera situationen) och känslofokuserade strategier (t ex att hoppas att det ska bli bättre), utan skillnad mellan patienter med UC och patienter med CD. Det mest stressande var behovet av att snabbt ha tillgång till toalett samt stress relaterat till olika sociala situationer. Detta hanterades genom att planera och förbereda, t ex att ta reda på var det finns toaletter, att ta med toalettpapper och extra underkläder eller att gå på toaletten före en aktivitet. Som önskat stöd från sjukvården angav patienterna information och samtal med erfaren personal och med andra patienter om hur man kan leva med sjukdomen.

Denna avhandling visar att vissa patienter med UC, och främst patienter med CD, har påverkad livskvalitet. Detta innebär att vårdpersonal bör vara lyhörd för patienters psykosociala välbehfinande, speciellt patienter med CD och patienter med skov av sjukdomen. Metoder för att identifiera och
hjälpa patienter med oro/nedstämdhet och låg livskvalitet behöver utvecklas. Interventionerna bör anpassas till patientens specifika problem och till adekvata tidpunkter under sjukdomsförloppet.
I wish to express my sincere gratitude and appreciation to all of you who have supported me and contributed to my graduate studies and this thesis. In particular I would like to thank the following persons:

To all the patients who participated in the studies, for sharing your experiences and feelings.

To Karin Nordin, my supervisor, for positive response to my query for supervision. For generously sharing your scientific knowledge and giving constructive criticism. For patiently reading an endless number of manuscripts and still manage to take an active interest in this work.

To Lars Lööf, my co-supervisor, for all encouragement during the years and for sharing your medical and scientific experience and knowledge. For rapidly responds to my questions and for always being there when I needed you.

To Marianne Carlsson, head of the department for allowing me to pass through the needle’s eye to graduate studies and Per Lindberg, head of the unit, always helpful with all “doctoral-related know-how”.

To Maria Sundberg-Hjelm, friend, co-worker and co-writer, for friendship and for sharing the ups and downs involved in a developmental project.

To my co-writers Lars Påhlman, Urban Karlborn, Ulla-Maria Anderberg and Anders Rönnblom, for your invaluable involvement in the project.

To my role-models, the members of the “Researchers’ network: social work in health and mental health in Sweden”, founded by Mariann Olsson and Birgitta Sandén Eriksson, for inspiration and fruitful discussions and seminars.

To all my former and present friends, colleagues, teachers and administrative staff at Caring Sciences, Uppsala University who during the years have shared your knowledge, support and friendship: Afsaneh R, Anne S, Camilla F, Cilla A, Claudia L, Elisabet M, Elisabet W, Eva D, Eva L, Frida A, Gunn E, Gunilla B, Helena L, Ingrid D, Jeanette W, Josefín W, Kerstin K, Louise
E, Marianne H, Maria M, Maria S, Mathilde H, Susanne L, Sören J and Ulrika P. A special thanks to Maj-Britt S, Rose-Marie M and Catarina O for administrative help. To Annika Lundqvist, for being you, and for generous help in the project. To Kristina Haglund and Pernilla Åsenlöf, for invaluable and constructive criticism on the thesis.

To the former and present head of the Department of Psychosocial work at Uppsala University Hospital, Birgitta Almby and Fatane Salehi, for allowing me to take part in the graduate courses during hours of work.

To Christina Lindholm, Maivor Blixt, Helena Sandin, Susanne Lindström and Tony Wiklund, thank your for your generous assistance in administrating the questionnaires.

To all my other friends, co-workers and colleagues, golfers, neighbours and friends in Husbyborg (in particular Lisbeth Björkelund and Johan de Faire for friendship and encouragement, and Gunnar and Yvonne Gustavsson for caring for my nutrition) and members of “the conference network” (Anita Larsson, Gunnel Pehrsson, Ingrid Claesson and Mia Andersson) for bringing a breeze of the wide world into the narrow world of a graduate student.

To Lena, Thomas, Erik and Moa Hagnefur, for friendship and invaluable help during the final stage of the graduate period.

To my family: Lillemor and Willy, Ola, Tiina and Lowe, Bosse, Anna and Odd, Marcus and Malin, for bad stories, discussions and laughter. Thank you for friendship and for being you.

This thesis was supported by grants from the Departments of Medicine and Surgery, Uppsala University Hospital, the Medical and Pharmaceutical Faculty at Uppsala University and from the Uppsala County Council.
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Acta Universitatis Upsaliensis

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